HOW DO FAMILY CAREGIVERS PROVIDING CARE TO OLDER PEOPLE EXPERIENCE PALLIATIVE/END OF LIFE NURSING CARE IN THE OLD PEOPLE'S HOME SETTING AND DO THEIR EXPERIENCES AFFECT THEIR QUALITY OF LIFE?

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Abstract

This study focuses upon the areas of Bremen and Lower Saxony (Niedersachsen), Germany. It aims to ascertain the nursing care experiences of the family caregivers of older people at the end of life in a nursing home setting. These are family caregivers whose loved ones are faced with chronic life-threatening diseases, including cancer and dementia, and includes family caregivers who have been bereaved within one year of this study. Both structured and semi-structured interviews, including a questionnaire, were used to provide an overview of how family caregivers experience end of life care in nursing homes.

A review of the relevant published research studies, journals and literature reviews was initially undertaken to explore the perspectives of family caregivers providing end of life care in nursing homes. Various experiences were identified, collated and appraised. The use of interviews and questionnaires explored the experiences as narrated by family caregivers in the form of satisfaction/met needs and dissatisfaction/unmet needs with disease management, symptom management of their loved one, including communication, information given, psychoemotional, spiritual and other end of life care in the nursing home. Interviews were tape-recorded, transcribed and subjected to content analysis with permission. Questionnaires were used to supplement this information. Initially, twelve participants were to be interviewed; however, initially only six consented and returned their forms. The others were unable due to their stress and fear of Covid-19, which considerably disrupted the initial study plan and caused delays and frustration. Further participants therefore were added post-Covid-19 to bring the study sample size back up to the desired number of twelve.

Three major experiences emerged from the data: the negative nursing care experiences (met and unmet needs, including a lack of support services from both nurses and institutions) and end of life bereavement support. The family caregivers experienced caregiver burden, lack of access to support services, no pertinent information nor communication, insufficient staff to turn to, no proper advice on what to expect next, a need for improved nursing care at end of life and bereavement support. Some of them complained of areas of unmet end of life nursing needs that affected their experiences and quality of life.

The findings provide the first insight into the experiences of family caregivers of older persons with life-threatening diseases, who are at their end of life in a nursing home. The majority of the family caregivers reported that they had indeed received adequate support in some areas, but that they had a range of unmet needs that resulted in them experiencing negative nursing care. Particular attention to educating professional carers in integrating and supporting family caregivers at end of life and the bereavement period would ensure their quality of life is maintained or enhanced, as well as closing existing gaps in the end of life care of older persons in nursing homes that currently cause negative experiences.

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"*Our greatest weakness lies in giving up.*
The most certain way to succeed is always to try just one more time" - Thomas Edison

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List of Abbreviations

ADLs	Activities of Daily Living
GP	General practitioner
MDK	Medical Service of the Health Insurance Fund in Germany, who are responsible for checking the requirements of the socially defined person for their need of care
MDS	The Medical Service of the Spitzenverband Bund der Krankenkassen E.V.
QD	Qualitative description
SAPV	Specialist Outpatient Palliative Care Doctors
SGB	Social Code Social Long-Term Care Insurance in Geremany
WHO	World Health Organization

Declaration of Ownership of the Study

I hereby declare that I have written this work independently and without unauthorised help.

I have not used any sources or resources other than those indicated and cited.

Any passages taken verbatim or in terms of content from publications used are properly cited. I agree that the dissertation can be examined for plagiarism using qualified software.

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CHAPTER 1: INTRODUCTION

1.1 The Social Relevance of Old Age, Palliative Care and Family Caregivers - Introduction

Palliative care and end of life care are complex subjects because of the many and varied patients, providers and community stakeholders involved (Boucher, 2016). Providing a standardised level of end of life care and care for advanced illness, especially in the older person, is not straightforward. It depends upon health providers and health system responses to many diverse things, including cultural diversity. Palliative/end of life care modalities include symptom management (e.g. pain, shortness of breath, anxiousness, nausea and vomiting), as well as social and spiritual support for both the patient and the family caregivers, and a team-based approach to care delivery that has realistic goals for a said prognosis (see Department of Health & Human Services, 2008). According to some authors, family caregiving does not always end at the nursing home front door (see, for example, McFall & Miller, 1992; Aneshensel *et al.*, 1995). So the transition of an older person to a nursing home signals the beginning of a different but still potentially stressful involvement for both patients and family caregivers[1] (Ade-Ridder & Kaplan, 1993; McCullough & Worthington, 1994; Zarit & Whitlatch, 1993; Dellasega *et al.*, 1995; High & Rowles, 1995; Langley *et al.*, 1996). Family caregivers of older people are the focus of this study, because their experiences are prone to neglect, while the staff concentrate on the dying older person and their needs.

Most studies examining and observing family caregivers' experiences of palliative/end of life care of their older person have focused chiefly on home care settings, hospitals, hospices and palliative care units. However, not many studies have considered the family caregivers of older people at their end of life in the nursing home, based upon their perspectives and experiences. In Great Britain, for example, it has been reported that some 70% of Britons would prefer to die at home, yet 60% are reported as dying in hospital. An increasing number of older people are said to be living at home and cared for by their families for many months of sickness or frailty before transitioning to hospital or nursing home care. Such people who die at home, and their families, can often experience isolation, loneliness and a feeling of being shut out and distanced from communication (Dying Matters, 2009; Brown & Walter, 2013). Even those at their end of life in a nursing home have reportedly faced similar feelings, along with their family caregivers.

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[1] The term 'family caregiver' will be used throughout rather than 'carer' to distinguish between the unpaid and voluntary care provided by a family member to a loved one and the care provided by a professional (usually formally qualified and paid) carer.

The focus of this study is upon extracting from the collected family caregivers' narratives of their experiences in order to fill the current gap in knowledge and publications. This will be achieved through analysis of the collected data in order to assess the level of nursing care that led to positive or negative caregivers' experiences, as these affect patients' well-being and how the family caregivers assess the end of life experience in the nursing home (Recio-Saucedo *et al.* 2018). It is suggested that more effort is needed from health professionals to ensure that, at end of life, older people can die at a place of their choice. Efforts should be made to ensure that both the older person and their family caregivers experience positive nursing care irrespective of where the healthcare setting is (Brown & Walter, 2013).

A single method approach is considered appropriate to elicit more on the significance of this topic. The cooperation of the interdisciplinary team (gerontology, professional nurses and assistants), health insurance personnel and family caregivers of older people at the time of palliative care and/or end of life care in nursing homes will help in giving the necessary information, and this present study will thus succeed in generating new and important insights into some of the family caregivers' experiences of nursing care. The geographical area of this study will be the city of Bremen and Lower Saxony (Niedersachsen), Germany.

1.2 Introduction to the Background of the Study

The number of people aged 65+ worldwide is reported to be on the increase, due to many reasons such as beneficial changes in lifestyle, reduction in alcohol and dangerous drug consumption, improved diet and good infrastructure safety, prevention of accidents as well as improved healthcare as seen in the West. "People tend to live longer but face many health challenges in old age" (Krakowiak, 2020: 8). Similarly, "People are living longer, but what about the end of their lives in this part of the world? Do they have adequate access to good end of life care for a loved elderly patient, and what about their family caregiver's experience? Who cares?" (Mackenbach *et al.*, 2015: 798). Studies in Poland and Eastern Europe have shown that, for many years, end of life care has been predominately dedicated to cancer patients only. They were connected exclusively to oncology, with limited or no cooperation with long-term care and care institutions for the elderly and their family caregivers in local communities (Krakowiak, 2020).

People experience the end of life situation differently depending on culture, religion and background. Death in older people at their end of life may come suddenly, or a person may linger in a near-death state for days, weeks or even months (NIA, 2020). The end of life of an older person is very distressing for the family caregiver, who goes through pains and burdens. Some elderly adults experience body weakness with a clear mind at the end of life, while the majority of those who remain physically strong are frequently cognitively unalert.

What happens when an older person dies and how do family caregivers experience end of life care? Traditionally, end of life care involves a specialist team that collaborates with the family caregivers of the dying person, but is it the case with the present nursing situation in older people's own homes?

Most older people with frailty who move to a care home usually stay there permanently until death (British Geriatrics Society, 2020). However, there can also be short stays in nursing homes for assessment, rehabilitation or care whilst a family are on holiday (termed *Kurzeitpflege* in German) and this serves as part of a temporary care programme for the older person. In European, American and British culture, care homes are not usually the first choice of potential residents and family caregivers. The transition of care for an older person from home care to nursing home care is often associated with a sudden or marked deterioration in physical function, cognition or both. Statistically, in Germany and other Western countries that utilise nursing home care, more than three-quarters of residents reportedly have dementia. More than half are said to have problems with mobility, and up to a third are reported to have incontinence. These are stressful situations for the family caregiver (British Geriatrics Society, 2020).

However, caregivers, families and older people find it difficult to discuss issues surrounding end of life matters, as they are already struggling with so many other overwhelming issues. However, it becomes necessary to clearly assess the need for end of life care, whilst at the same time presenting them with opportunities to plan for such a day. Advanced care planning is deemed vital at the point of admission to a care home, as it makes further decisions for all persons involved much easier. There is evidence from some authors that advanced care planning can work well in care homes, reducing inappropriate escalations of care and improving both the residents' and relatives' satisfaction with the care (British Geriatrics Society, 2020). Advanced care planning, described by Adams & White (2003) as a non-addictive health behaviour, requires difficult decisions to be made. Unfortunately, advance care planning issues are often not fully or properly discussed before or during the admission of an older person into a nursing home due to cultural traditions, while those older people and their family caregivers who had previous knowledge of advance care planning were often willing to engage in end of life planning (NHS, 2021).

Statistically, the average life expectancy of older people living in UK care homes without professional nursing care is approximately 24 months, whilst this reduces to 12 months for older people with more severe problems with professional care. In most cases, where a resident enters a home with one or more rapidly deteriorating medical conditions, the situation becomes more complex. Many older people with complications die shortly after admission, while those without complications are mainly in-residents and live-in groups, who often live in care homes for much longer. All care homes should consider end of life care for their residents and family caregivers, as all are likely to need this special care in the future.

Transitioning into a care home can be complex and devastating for new residents and their families. Imagine the older person giving up their natural habitat and moving away from their lifetime home, leaving families and communities behind. In most cases, they and their family caregivers are also likely to be adjusting to a significant deterioration in health and functional status.

Ageing manifests itself differently in many people and their families (NIA, 2020). People's preferences, needs or choices are not the same. However, most people may prefer to die at home, but the majority die in hospitals or older people's care institutions. No matter where end of life occurs, the wishes of the dying older person are the same, to be surrounded by family members. Many older people were reported to have simply quietly passed away alone. When possible, there are steps that can be taken to increase the likelihood of a peaceful death for an older person and enhance the family caregivers' positive experiences. Hence, it is imperative that everyone should follow their end of life wishes and treat them with respect while dying, family caregivers included.

People who are dying need care in four key areas: physically, mentally, emotionally and spiritually. The family caregivers of the older person should be respected by the care nurses whilst performing their practical tasks to avoid undue emotional distress (NIA, 2020).

The recommendations for optimal palliative care published by the European Association for Palliative Care for People with Dementia include recommendations on meeting the needs of family caregivers and covering their burdens and grief. They need information and support throughout the period of dementia (Van der Steen *et al.*, 2014; Campion *et al.*, 2015; Moore *et al.*, 2017).

Unfortunately, in Germany and elsewhere worldwide, providing appropriate end of life nursing care for older people and their family caregivers within the nursing home setting is challenging for healthcare systems. It has been shown as being the most neglected aspect of healthcare due to traditional beliefs about ageing and dying.

Family caregivers play a pivotal role in providing practical, emotional and psychological support. They are central to ensuring the well-being of older family members, particularly when those individuals become debilitated, dependent or require assistance due to age-related challenges. These caregivers may be spouses, adult children or other relatives who step into this role based on necessity, cultural expectations, or personal commitment.

The caregiving role is multifaceted and dynamic, evolving over time as the needs of the older person change. Family caregivers often act as surrogate decision-makers, managing healthcare, financial decisions and day-to-day activities. Their responsibilities may include assistance with personal care, medication management, transportation and emotional companionship. These roles are taxing and can have profound physical, emotional and financial impacts, particularly for long-term caregivers. The National Study of Caregiving (NSOC) conducted by Kasper *et al.* (2014) shed light upon these issues, but notably excluded family caregivers associated with nursing home residents. This exclusion limits the understanding of caregiving trajectories and transitions, particularly when family caregivers shift their role upon the institutionalisation of their older relatives.

One crucial question is whether the caregiving role ends when an older person transitions to a nursing home. In many cases, family caregivers continue to provide emotional support, advocacy and oversight even after this transition. They often remain involved in care coordination, visitation and ensuring the quality of care provided by the institution. However, the intensity and nature of their involvement may change, allowing family caregivers to step back from physically demanding tasks while maintaining an essential supportive presence.

The timing of entering the caregiving role, its duration and eventual transitions vary widely among families, being influenced by cultural norms, family dynamics and individual capacities. Caregiving trajectories are highly individualistic, reflecting the diverse circumstances and relationships that define each family unit. Some caregivers take on these responsibilities gradually, while others are thrust into the role due to a sudden health crisis arising. Similarly, the duration of caregiving can range from a few months to several decades, with transitions (such as the need for professional care or the passing of the older person) marking significant turning points.

When selecting family caregivers as a sample for research, certain criteria should be considered to ensure a comprehensive understanding of the caregiving experience. These criteria might include the caregiver's relationship to the older person, the duration and intensity of caregiving and whether the caregiving role involves co-residency or is conducted from a distance. Additionally, it is important to explore the diversity of caregiving experiences, including those who continue their involvement after transitioning their relatives to professional care settings.

In conclusion, family caregivers are indispensable to the well-being of older persons, providing a continuum of care that adapts to evolving needs and circumstances. While the caregiving role may shift upon institutionalisation, it seldom ends entirely, reflecting the enduring bonds of family and the multifaceted nature of caregiving. Family caregivers can and indeed want to bring their experience into the nursing home, so as to help their loved ones. Research into family caregivers must account for these complexities, ensuring a holistic understanding of their contributions and challenges.

End of life is defined by many as being when someone approaches the end of their life, irrespective of age and disease status, as with progressive diseases such as cancer, dementia and motor neurone disease, and increasing frailty in old age complicated by heart disease and stroke. Health practitioners often predict that patients will die within one year of end of life diagnosis. However, many people at the end of their lives, even older people, may last just a few more days, weeks or months, or occasionally more than a year. The medicalisation of death and dying in every healthcare setting means that medicine will often fail to predict the exact time of death. So many people, especially older adults with life-threatening diseases, are likely to experience considerable discomfort, including pain, and may require palliative care and/or end of life nursing care to ease the discomfort. Some authors define end of life care as care given to those in the last months of their lives. However, this care given at the end of one's life is not for healing but to somewhat improve the quality of their life, including family caregivers and others relevant to the dying person. Although people have the right to choose where to spend the last days of their lives, this is not always easy for many reasons. Accordingly, for some authors in this field, end of life care may be at home, in hospitals, hospices or even in nursing homes. In whichever setting, family caregivers play a crucial role in the continuity of care at end of life and deserve recognition by professional carers.

In Germany and elsewhere, nursing home care can be the best option for those older people with life-threatening diseases at their end of life, including those with advanced cancer and dementia, who require more than just primary care and whose relatives cannot continue caring for them at home. Older people also face other health challenges at the end stages of their lives, which can be challenging without the support of family caregivers, who take up responsibilities as ageing sets in (Hudson & Payne, 2011). Palliative care would not be able to fulfil their preferences, such as the care in an old people's home, without significant family caregivers' input. Family caregivers often continue their care of the older person even when admitted into a long-term facility for end of life care. There is a need to recognise family caregivers of older people at end of life as hidden patients because, as reported in many studies, they are suffering too, especially when their loved older persons are not adequately cared for or when their condition deteriorates. Many studies on end of life nursing care have focused primarily on cancer cases, while only a few have been published about non-cancer patients' family caregivers' experiences of end of life care in nursing homes. Steele and Davies (2015) define palliative care as being both patient- and family-centred care. Seng Beng *et al.* (2013) explain that caring for a terminally ill family member causes immense strain on the caregivers, as family members still provide considerable amounts of care for an older person even when institutionalised for end of life care.

1.3 The Focus of the Present Work

The author's working for many years in an older people's care setting was the stimulus for this thesis. Through my contact with many family caregivers over the years, it became clear that there was considerable data that could be obtained with regard to clarifying family caregivers' experiences at the end of life of a dying older person within a nursing home setting. Often, care is provided by a spouse, daughter, daughter-in-law or sister, although even grandchildren have been known to provide such care. I decided to focus upon relatives who had consistently taken care of an older person for more than six months.

Family caregivers might find satisfaction and meaning in the caring role of their older person but at the same also experience considerable distress, depression, anxiety and guilt (Pinquart & Sorensen, 2005; Andren & Elmstahl, 2008; Sampson *et al.*, 2011; Moore *et al.*, 2017; Livingston *et al.*, 2020), particularly when they feel that they no longer have sufficient resources to cope (Lazarus & Folkman, 1984). This may be compounded by the conflict between caring and other relationships and/or work roles, leading to a sense of being trapped within the caring role with no way out. Family caregivers' experiences must not continue to go unnoticed within the healthcare sector.

There is no doubt that the palliative nursing care and/or end of life care of dying older persons and their family caregivers within nursing homes face challenges both now and in the future. Unfortunately, Bull's Palliative Care Programmes will never be financially viable without support from other entities (Kamal *et al.*, 2014; Hanson *et al.*, 2014). Hence, it becomes necessary for family caregivers to know which particular older people's home offers a good standard of palliative/end of life care, as this is vital to the quality of nursing and thus the family caregivers' experiences.

Good palliative/end of life nursing care should be made fully available and incorporated within nursing home institutions as part of ageing care, for with old age comes increased morbidities, comorbidities and frailties. The recent pandemic caused by Covid-19 will inevitably adversely affect the palliative/end of life nursing of the dying elderly and their family caregivers' experiences of unmet needs which are tagged as a 'negative experience' within nursing homes. Unfortunately, many diseases are still underrepresented in definitions of multimorbidity. This number increases daily due to the age-altered structure within the Western world, resulting from prolonging and sustaining lives. However, the global effects of Covid-19 or potentially similar pandemics affecting the population, particularly the vulnerable (the elderly formed a significant vulnerable part in the recent Covid-19 pandemic), should also be considered, albeit such consideration will not be looked at further in this thesis.

However, the focus of this study is not limited to family caregivers of older people in end of life nursing care. The analysis is also on family caregivers of older people in palliative care nursing/residential homes and family caregivers whose older persons received end of life nursing care and are deceased within one year of this study. This single approach aims to sensitise family caregivers prone to neglect and those who suffer a high degree of neglect in the nursing home setting at the end of life of their older person. According to this study, a broad thematic approach allows insight into the family caregivers' experiences.

Of course, there are always parallels to the original research projects, especially concerning the methodological approach. The design, data collection and data analysis questions are closely related to previous studies on family caregivers' nursing experiences at end of life in the nursing home. As in many other research studies, time and financial resource limitations led to unique individual aspects remaining unevaluated, despite detailed data collection (Görgen *et al.*, 2010).

In order to generate data from the present study to answer the research question, I sought the cooperation of some older people's nursing care homes/residential homes in Niedersachsen, the palliative centres and hospices in Bremen and more widely in Niedersachsen, the Ministry of Health in Osterholz-Scharmbeck and Bremen, and AOK Health Insurance in Niedersachsen. It is postulated that this study can generate data which, once evaluated and analysed, might improve the knowledge of nurses to improve the family caregiver's palliative care/end of life nursing experience. Hence, this research focuses on the family caregiver's experiences of the nursing care home setting involving the palliative care/end of life stages of an elderly person; for example, good communication and ability to listen, transparency and clear dissemination of information.

1.4 Advance Care Planning Defined

Since the 1970s, living wills have existed in Germany, although these were not very often drawn up nor enacted. In 2003, the Federal Court of Justice confirmed that previously expressed wishes from patients must be respected when they became incapable of making decisions. Informed consent to medical care was reinforced in Germany by the Patient Rights Act (The Federal Statistical Office, 2015; 2020).

The Hospice and Palliative Care Act (as described in the Social Security Code Book '*Sozialgesetzbuch'* [SGB V]) is a legislative framework aimed at improving access to and the quality of hospice and palliative care services in all healthcare settings in Germany

(Kuhlmey *et al.*, 2003). It emphasises holistic, patient-centred care that considers not only medical needs but also psychological, social and spiritual aspects. The Hospice and Palliative Care Act was passed in December 2015 by the German Parliament. It contains detailed requirements with regard to Advance Care Planning (§132g) and its implications for care facilities and the involvement of relatives (§132g SGB V). However, in order to offer Advance Care Planning services, one does not necessarily require any specific qualifications.

Advance Care Planning may also be defined as a comprehensive concept requiring cultural changes at individual, institutional and regional levels, in order to achieve consistent care. It is a structured, voluntary process that supports individuals in planning their future healthcare, particularly when they may no longer be able to make such decisions for themselves. The focus is on aligning medical care with the individual's values, preferences and wishes (Götze *et al.*, 2023).

Advance Care Planning in care facilities is now firmly anchored in Germany. Demographical changes within German society have led to an increase in demand for care services within nursing homes for end of life care (Statistisches Bundesamt, 2015; 2016; 2024). Residents at end of life have significantly benefited from hospice palliative care and the implementation of Advanced Care Planning, although the refinancing of Advanced Care Planning services by statutory health insurance funds has only became possible since 2018 (Berloge *et al*, 2024). According to §132g SGB V, the nursing home reimbursement for Advance Care Planning was to improve end of life care.

Section 132g on Health Care Planning in Germany for the last phase of life was stipulated in the Social Security Code Book (SGB V) as an insurance benefit of statutory health insurance funds (Gesetzliche Krankenversicherung) for certain patient groups, which reflects the Advance Care Planning concept. The Advance Care Planning concept, which is geared towards the structures of the German healthcare system, has become known nationwide as 'Behandlung im Voraus Planen' (BVP) (Stanze & Nauck, 2022). The legislation specifically emphasises the role of care facilities in implementing and supporting Advance Care Planning.

Nursing homes, hospices and other care institutions are required by law to offer Advance Care Planning services to their residents and to their family caregivers. For this purpose, further training which follows the predefined core curriculum of the GKV-Spitzenverband must be successfully completed (Stanze & Nauck, 2022). This ensures that end of life preferences are fully discussed, documented and respected. Facilities must ensure that all of their staff are trained to understand and respect Advance Care Planning directives. Training includes recognising the ethical and legal importance of patient autonomy. For this purpose, further training which follows a predefined core curriculum of the GKV-Spitzenverband must be successfully completed (Stanze & Nauck, 2022).

Family caregivers should be systematically involved in the work of nursing homes, as emphasised in §113 SGB V, to ensure holistic and personalised care for residents. Their involvement fosters better communication between family caregivers and staff, providing valuable insights into the loved one's history, preferences and needs. This collaboration enhances care quality, supports emotional well-being and strengthens trust. Systematic involvement can be achieved through structured family meetings, regular consultations and integration into care planning processes, ensuring a partnership that benefits both the resident and the caregiving team.

The systematic involvement of family caregivers of older people when they are receiving nursing care in Germany can improve the quality of care, provide emotional support for residents and create a collaborative care environment. Strategies which facilitate the integration of family caregivers when going into nursing homes are now discussed below. Whilst family caregivers are not, not ever likely to be, professionals in a nursing home, they often do want to bring their experience into that home. Firstly, in order to establish a partnership model, collaborative care plans should be drawn up which involve family caregivers in the creation and regular updating of individual care plans for residents. This ensures that their insights, preferences and knowledge are thus integrated into the care process. Similarly, joint interdisciplinary care teams which include family members, care staff and healthcare professionals can be set up to discuss and coordinate the care of their loved ones.

Secondly, structured communication channels should be established. This can be achieved through regular meetings with the family caregivers to provide updates on their loved one's health, discuss concerns and plan their upcoming care needs. The use of apps or online platforms can be considered to keep family caregivers informed about daily care routines, medical appointments or activities involving their loved ones. Then, finally, feedback mechanisms should be developed to create opportunities for family caregivers to provide their input on the care quality observed and suggest any improvements.

Thirdly, the notion of education and relevant training for the family caregiver needs to be addressed. This may be achieved through workshops and seminars which would offer training sessions to help family caregivers understand the routines of the care home, the needs of older adults with specific conditions (e.g., dementia) and how to support the nursing staff. Such sessions could also provide manuals or guides tailored to the specific care facility's policies and procedures.

Fourthly, the active participation of the family caregivers can and should be encouraged. Flexible visitation policies that encourage family caregivers to spend meaningful time with residents without disrupting routines can be drawn up. Their active role as volunteers would allow family caregivers to assist in non-clinical activities such as recreational programmes, at meal times or cultural events, thus fostering a sense of contribution.

Fifthly, family caregivers should be provided with psychological and social support by the care homes. The use of counselling services would provide access to the existing psychological support for family caregivers, in order to help them cope with the stress and/or emotional burden of caregiving. The use of peer-support groups, where family caregivers can share experiences, challenges and strategies, could also be set up.

Sixthly, the policy and structural requirements need to be established. Formal agreements should be drafted which outline the roles and responsibilities of family caregivers within the nursing home setting, ensuring mutual clarity. Public policies or insurance models that formally recognise and support the role of family caregivers in nursing homes should be advocated for.

Finally, consideration should be given to cultural and individual preferences, thus recognising the cultural and personal values of family caregivers when involving them in care routines. A tailored engagement could be achieved through the development of individualised plans for family caregiver involvement, considering the availability, skills and emotional readiness of the caregiver.

Through the adoption of such strategies, nursing homes in Germany could systematically integrate family caregivers into the care process, enhancing outcomes for residents and creating a supportive care community.

Informal carers have an essential role to play within every family, especially at the end of life of a loved older person, as the family caregiver will often accompany a relative during sensitive and critical stages that may lead to death (Grande & Ewing, 2009; Buyck *et al.*, 2011). Informal caregivers are mainly family members (Costello, 2017) and it appears that family structure, dynamics and involvement can strongly influence individuals' experiences as death approaches (Peterson, 2019). The law acknowledges the essential role of families and loved ones in end of life care decisions.

Relatives or legally authorised representatives may participate in Advance Care Planning discussions if the patient consents or under certain circumstances when the patient cannot communicate their wishes. Care institutions are encouraged under the Act to provide emotional support and guidance for families, helping them to navigate the complex decisions and to respect the patient's preferences. Families and caregivers are part of the communication network of the care facilities to ensure that the directives are understood and implemented during medical emergencies or end of life care.

With regard to the overall integration with hospice and palliative care services, Advance Care Planning can support a person's treatment and thereby respect their wishes whilst in incapacity, palliation or end of life support. Such planning can identify personal and social wishes and align these with life goals such as place of death (e.g., hospice), housing preferences or desire (or not) for resuscitation (Orlovic *et al.*, 2020). The Act promotes a continuum of care, ensuring that Advance Care Planning is embedded within broader hospice and palliative care strategies, including those of holistic support, access to resources and providing a focus on quality of life. Section 113 (SGB V) states that family caregivers should also be systematically included in the work of the nursing home. Holistic support arises where individual care plans are personalised, integrating physical, emotional and spiritual care. Access to resources ensures that patients and their families have full access to hospice services, the specialised palliative care teams and bereavement support. Finally, through their focus on quality of life, the overarching goal of the Act is to respect patient autonomy while improving their life quality at the end of life.

However, Brooke and Kirk (2014) found that patients receiving palliative care sometimes dismissed Advance Care Planning discussions at times when their disease status became stable or when they were feeling well. Dismissing Advance Care Planning at such times often leads to subsequent conversations triggered by a sudden change or deterioration in health, but with little notice for the careful development of detailed care plans for their end of life (Carr & Luth, 2017). This becomes especially problematic when the patient's mental capacity is then compromised (Wilkin *et al*., 2024).

Healthcare providers and facilities are required to implement Advance Care Planning as per §132g. This requires them to develop protocols, documentation systems, interdisciplinary collaboration and community outreach plans. Thus, they are required to develop and have in place protocols which ensure standardised procedures for offering and conducting Advance Care Planning discussions, documentation systems which securely store advance directives and allow their easy retrieval, interdisciplinary collaboration which enables the engagement of medical, nursing and social work teams in Advance Care Planning and palliative care planning. There should also be a system to outreach into the community, by educating patients and families about their rights and options under the Hospice and Palliative Care Act.

In conclusion, the international concept of Advance Care Planning is a systematic and qualified communication process for people who want to talk about possible disease scenarios and their wishes for medical, nursing, psychosocial and spiritual care, along with treatment for those scenarios, in the presence of their relatives and therapists (Stanze & Nauck, 2022). It may be said that the Hospice and Palliative Care Act, with its emphasis on Advance Care Planning (§132g), has transformed end of life care in Germany by promoting proactive, patient-centred decision-making. By integrating Advance Care Planning into care institutions and involving relatives and/or caregivers, the Act ensures that patients' wishes guide their care, offering dignity and respect during their final phase of life.

1.4.1 Advance Care Planning in Relation to This Study

The present research work is associated with public health nursing research. However, the topic's relevance for this group of people justifies the limitation of the doctoral project to the field of action of long-term care. For the first time in Germany, this present study used a qualitative overview of the experiences of family caregivers of palliative care and/or end of life care in older people's nursing homes to detect ambivalence in the experiences of family caregivers. Many authors have supported the fact that family caregivers supporting an older person in their palliative/end of life care in a nursing home face significant challenges, especially where no advance care planning has taken place (no written will). As medical technology advances, those who work with patients and their family caregivers might find it challenging to provide end of life care measurable to a particular context (Perkins, 2007). Most older persons would prefer to die at home, but unfortunately, less than a fifth have this opportunity (While, 2012). Lynn and Goldstein (2003) state that advance care planning addresses two issues: who will speak on the patient's behalf and the kinds of treatment that should be allowed when in a critical/dying state. Knowing the preferences and wishes of the person helps to abridge the problem. However, sometimes advance care planning can present as being legal, complex documentation, unfamiliar to many staff (Griffiths, 2014). There is a need for staff to receive training in communication and advance care planning skills. Advance care planning enables the older person to discuss complex issues concerning end of life care. It enables them to communicate their wishes concerning their future healthcare in the event of severe illness or a severe accident that may result in invalidity (Shanley & Wall, 2004; Thomas *et al.*, 2011; Boot & Wilson, 2014; Sellars *et al.*, 2015).[2]

There are, though, ethical concerns, mainly arising when no advance care planning exists. In the UK, Germany and other advanced countries, people have been admitted to hospital at the last hour against their wishes because no advance care planning was available (Keogh, 2014). Studies have reported nurses' lack of confidence in suggesting a place of death for patients where no advance care planning exists; this is one psychosocial challenge and an

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[2] The most common predicted causes of death in older people in 2020: ischaemic heart disease; cerebrovascular disease; chronic obstructive pulmonary disease (COPD); and respiratory infections.

aspect of palliative/end of life care (Walshe & Luker, 2010; House of Commons Health Committee, 2015).

In this study, the development of a conceptual basis for palliative/end of life care of the elderly within institutions for long-term care to improve the quality of life for the dying elderly and their family caregivers' experiences is presented. The outcomes of this study will aim to achieve a more balanced partnership among the actors involved in the palliative/end of life care of older persons, and aim to find more appropriate solutions to the growing issue of the long-term care of our ageing society as well as their caregivers' level of satisfaction (Eurofamcare, 2006). The literature review (see Chapter 4) will elucidate and support the choice of this topic for this research study.

1.5 Definition of Terms Used

As medically defined, 'end of life' is the stage of life where a person living with a life-threatening disease is impaired by an eventually fatal condition, even if the prognosis is ambiguous or unknown. Doctors and health specialists normally predict end of life cases to live for up to six months, although some may live beyond one year (Forero *et al.*, 2012).

End of life care, as defined by the WHO (2020), is a kind of care that combines the broad set of health and community services that care for the population at the end of their life. The quality of end of life care increases when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists, support care providers and the community, all working together to meet the needs of the people requiring care. Palliative care is specialised care provided by professionals for all people, young and old, living with and dying from an eventually fatal condition and for whom the primary goal is their quality of life (PCA, 2020; WHO, 2020).

1.6 End of Life Care in Other Countries

There can be many different characteristics of family caregivers at end of life when caring for a loved, dying, older person. Everyone experiences the moment differently when one of his or her family is dying, as death and dying can be very significant in the lives of family members.

In Asian countries, the accepted basic unit of society is not a person but all family members, and this societal belief of a family is why a patient's disease creates visibly high anxiety levels within the whole family system. Additionally, the sickness of a family member affects relationships, roles and communication between family members regarding end of life matters. It thus affects the lives of all family members (Lee, 2001). In Korea, there is no fully implemented hospice system for patients at their end of life, and those limited hospice facilities and care assistants are not adequately supported. Therefore, the involvement and assistance of family members is crucial for the patient requiring end of life care during their stay in the care setting (Lee, 2001; 2005).

This shared end of life care can lead to family dysfunction if family members are not well prepared for such physical, psychological, emotional and financial problems. Some authors consider that the overall quality of life experienced by terminal cancer patients and their caregivers is interrelated; if the former's quality of life improves, the latter's also improves. Some of the problems, including emotional anxiety, fear of impending death, and feelings of loss, which are reportedly what family caregivers experience during the care process, affect both the patient and their family members. As such, it is important that nurses regard family members not only as supportive resources but also as quasi-patients, and thus nurses should identify any family caregivers' problems as part of the family's problems (Gudykunst & Kim, 1992; Kim *et al.*, 2010). Nurses should perceive families in end of life care as essential subjects for care and should take an active role in supporting them emotionally and helping them deal with stress or difficult situations more efficiently (Fox-Wasylyshyn *et al.*, 2005). An end of life stay can mean long-term care and may also include specialised care (Lee, 2001).

1.7 The Importance of Family Care Experiences at End of Life in the Nursing Home

Nurses must endeavour to identify the family caregivers' experiences with the end of life care given to a loved one, as knowledge of these experiences enables nurses to provide proper and satisfying care for the families, and particularly the family caregivers, at end of life. One of the pressing needs of almost all family caregivers is to know what is happening with their loved ones. For example, families want nurses to explain to them the patient's prognosis and the care strategies planned. Unfortunately, nurses often underestimate the families' needs (Verhaeghe *et al.,* 2005). In a separate study by Dockter *et al.* (1988), nurses were often unwilling to allow family caregivers to assist in the care of their loved ones, as they thought that family caregivers did not have enough time for their loved ones. However, although family caregivers often wanted to inquire into the patient's condition, they did not ask due to anxiety or worry. Wagner *et al.* (1996) suggest that family caregivers often better understand their loved one's needs than the nurses. Family members perceive a need for information. The nurses favoured the patient's comfort more than the comfort of the family caregivers. However, seminars and programmes to help such nurses understand and appreciate how family caregivers react at the end of life of their loved ones are widely advocated. In all healthcare settings, nurses should endeavour to recognise the end of life needs and desires of family caregivers and other members. In so doing, this brings about a positive experience response from family caregivers, and hence to the needs and requests of family members to bring about positive responses and increased satisfaction levels (McIntyre, 1997; Eom, 2001).

1.8 The Structure of this Research Work

This section outlines the general structure of this thesis. Throughout each chapter, the legal implications of end of life, the stress on older people, and the stresses on family caregivers are considered regarding the long-term care system for the elderly, with particular reference to Germany.

To better understand family caregivers' experiences of nursing care at end of life in the nursing home (with a focus on Niedersachsen and Bremen in particular), Chapter 2 begins with a presentation of the legal basics. Two essential questions are dealt with in this thematic introduction: (1) under what conditions are family caregivers of older people at their end of life discussed in Germany? and (2) how many family caregivers of older people take advantage of benefits, and what financial benefits or payments are available? This is followed by an assessment of the epidemiology of older people in need of palliative/end of life nursing care in Germany, along with an assessment of long-term palliative/end of life nursing care in a nursing home.

The characteristics of palliative/end of life nursing care arrangements in older people's nursing homes are then considered, along with the role of family caregivers in the palliative/end of life nursing care of an older person within a nursing home.

Following these hard facts and figures, first impressions are then given regarding what is actually happening presently with those family caregivers who have decided to care for a close relative at their end of life in an older people's home. From the author's point of view, it is only against this horizon that the complexity and explosiveness of the end of life and caring families' situations become relevant.

Chapter 3 of this thesis provides a brief conceptual framework of palliative/end of life care for those elderly persons suffering from severe pain resulting from diseases including advanced cancer and dementia, with a brief definition of palliative/end of life care. Three research questions are then posed: (1) When is an older person pronounced as being at their end of life? (2) What is involved in the end of life care of an elderly person in a nursing home? and (3) How do family caregivers experience palliative/end of life care in a nursing home, focusing on Niedersachsen and Bremen in particular?

Following this, an illustration of the types of nursing care available for the dying older person at their end of life is given in Section 3.2. This includes a brief mention of the specific types of palliative care options available for older people in Bremen and more widely in Niedersachsen, which are pivotal to this study. The differences between palliative nursing care and hospice care follows, but not in detail. Necessary actions or omissions within the overall palliative care system affect family caregivers' experiences in a nursing home (structural, individual and personal experiences), and these are discussed in Section 3.2. How does the disease spectrum and discrepancies regarding palliative/end of life care affect family caregivers' experiences in the nursing home today? This is discussed in Section 3.3. Finally, a discussion on family caregivers' ethnicity, religion and cultural experiences and how to tackle deficits in the nursing home follows (Section 3.4) before presenting the chapter summary in section 3.5.

Chapter 4 presents the literature review - the empirical data regarding the palliative/end of life care experiences of the caring relatives surveyed whose older persons are in palliative nursing care/end of life care (in older people's nursing homes). As data sources, surveys of family caregivers of older people in end of life nursing home care or family caregivers whose loved older persons have died within one year of this study will provide information about their experiences. In particular, this makes it possible to uncover incidents around the so-called 'dark field' beyond the notifications to the health insurance company. On this basis, international and national studies will be presented, which analyse the experiences of family caregivers of older people; however, these examinations usually do not consider the healthcare professionals. Subsequently, therefore, further attention will be paid to and presented regarding those worldwide research projects that explicitly deal with negative family caregivers' experiences of older people in the context of nursing homes.

After the extent and manifestations of negative and positive experiences of family caregivers at end of life in nursing homes have been illustrated, Section 4.2 shows under which conditions family caregivers of older people's negative experiences increase. The different theoretical models for explaining a family caregiver's experience are critically examined (see Section 4.3). This serves the purpose of defining an authentic family caregiver's experience of end of life nursing. The summary then identifies existing research gaps from which the central questions of this work emanate.

Examining the current state of research within this chapter will aim to show that analysing a family caregiver's experience of care at end of life in an older people's nursing home is very relevant to this study.

Chapter 5 focuses on the conceptual framewqrk and methodology chosen. The central questions of this study are examined in relation to the current state of research and theoretical embedment. The research questions seek to understand the nursing care experiences of family caregivers of older people at their end of life in a nursing home. Hence, the research questions are: (1) ‘How do family caregivers of an older person experience end of life nursing care in a nursing home?’ (2) ‘How do these experiences affect their emotional well-being?’ and (3) ‘What can be done in future to fill the existing gaps in the family caregiver’s experience of nursing care?’ Appropriate methodology and design were chosen based upon the research topic. However, tensions can also arise between the family caregivers and practising nurses.

This chapter concerns the state of the current research (see earlier, Chapter 4) and the theory embedded from which the central questions of the present work originated. Here, it is necessary to focus on the research subject using a qualitative instrument. At the core of this chapter is the presentation of the concrete methodological approach of the study. The basic theory behind using a single method approach in this study is presented, followed by a brief rationale for using the qualitative approach.

A more detailed description of the selected method is then presented from Section 5.4. The qualitative interview study is then presented. The first step is the problem-centred interview and the individual survey instruments, then the qualitative content analysis and its main features are described. The qualitative content analysis used in this study evaluates the empirical data. However, qualitative content analysis in this study helps explain its main features. The use of field access to collect data for this study is presented, followed by sample descriptions.

The first step is to develop a suitable instrument for the written survey. After presenting the written questions, next are details on the qualitative questionnaire study. Finally, it is essential to clarify the sample’s composition and analyse the data collected. At the end of this chapter, there is a summary of the most critical aspects of the methodological procedure.

Chapter 6 presents the results of the questionnaire study. Detailed descriptions of the twelve family caregivers interviewed are presented. Each person’s socio-demographic characteristics and peculiarities are then established. The differences and similarities in family caregivers’ palliative/end of life nursing care experiences are noted, ready for further analysis in the next chater. The aim is to precisely determine how often the family caregivers encounter negative experiences from the nurses and how often these appeared during the interview.

Chapter 7 then further presents the results of the interview study, providing detailed analysis and discussion. This commences with the introduction (section 7.1), then considers the process of the interviews (section 7.2) and socio-demographics of the interview group (section 7.3). The study critically examines three aspects of older person's family caregivers' experiences at end of life. Firstly, the family caregivers' motives for taking on the care of the elderly person or relative (Section 7.5) followed by their motives for moving to institutionisation (section 7.6) and their experiences of such a move.

Secondly, the experiences of each family caregiver as analysed from the questionnaire study results and how many family caregivers reported a positive experience compared with those with a negative experience of palliative/end of life care. Evidence has shown that subjective stress and negative experiences affect significant problem behaviour and how the family caregivers of older persons deal with bereavement (section 7.7). The chapter then progresses to discuss how the family caregivers' experiences in end of life nursing care were seen in retrospect (Section 7.8). This procedure focuses on individual family caregivers' experiences within the nursing home setting.

In the further course of this chapter, the qualitative aspects of a family caregiver's experience of end of life nursing care are shown to still exist. In this context, family caregivers' experiences are analysed based on the empirical material gathered at the structural level (section 7.9). Pillemer & Lüscher's (2003) model identifies specific family relationship types (see section 7.9.1.3).

The first step is to examine which negative experiences of the family caregivers are discussed in the interview and how often the individual family caregiver mentioned each in the interview. It is important to note that dissatisfaction can be latent or manifest. The consciously perceived everyday experiences, which lead to a feeling of being dissatisfied on the part of the family caregiver, have to be distinguished from unconscious forms, which are assessed through in-depth scientific analyses. In the second step, concerns arose regarding how the structure developed and how the nurses handled these negative complaints. Finally, the third step of the analysis focuses on family caregivers' experiences. The question is to establish which family caregivers suffer more neglect in their older person's palliative/end of life nursing care (sections 7.10 and 7.11). The chapter concludes with a situational description of the experiencs and future hazardous situations which might arise (section 7.12) and finally, a summary of this overall analysis and discussion chapter (section 7.13).

The final chapter is the conclusion to this study. It summarises the qualitative questionnaire and interview study results in detail and subjects them to a critical discussion (Section 8.1). In addition, within this final chapter, the practical relevance of the results is demonstrated, along with the study's limitations (Section 8.2). In particular, the importance of having family caregivers who experience end of life nursing care positively and who feel satisfied at each level of care needs to be emphasised. This study needs to discuss and seek out broader studies that will include more people than the limited number who became available. However, this present research study's limitations can still guide a broader approach to future studies. Sections 8.3 and 8.4 then identify opportunities for further investigations, based on the present study's results, along with recommendations for improvements and actions within the German healthcare system arising from this study, which could potentially be discussed and implemented in routine palliative/end of life nursing care in older people's nursing homes in the near future.

1.9 Chapter Summary

This research study is both a stimulus and an invitation to deal with the existential decisions made in the last stage of life of a dying older person and aims to find ways to improve how nurses in care homes meet the palliative/end of life nursing needs of family caregivers. It focuses specifically on Bremen, in Lower Saxony (Niedersachsen), Germany. Constantly evolving medical and technological advancements have led to prolonging the lives of the elderly. Moreover, at the same time, it has increased the burdens of older persons with morbidities and comorbidities, as old age brings with it frailty and dependency on others to help in their daily activities. Family caregivers are at the centre of the care of an older person, even in nursing home settings. Hence, the need for palliative/end of life nursing care that is both patient- and family-centred is advocated. Unfortunately, family caregivers sometimes see themselves as being left behind in the decision-making process concerning the palliative/end of life nursing care arrangements and care of older persons. Indeed, this research study will aim to contribute to the ongoing efforts to help make a constructive contribution to improving palliative/end of life nursing care of older persons within nursing homes that impact on family caregivers' experiences positively.

Furthermore, those involved in end of life care, including the palliative care team and those working in the nursing care home, should possess academically the skills and tools necessary to dispense their practice and approach in their daily nursing encounters with family caregivers. The shortage of nurses in Germany has more recently been addressed, and this should have reduced tensions that were likely to arise between palliative/end of life nursing professionals and family caregivers. When family caregivers feel involved in caring for their older loved person at the end of their life, the outcome is always very positive.

CHAPTER 2: THE CONCEPT OF PALLIATIVE/END OF LIFE CARE FOR OLDER PERSONS IN NURSING HOMES

2.1 Legal Regulation of Care and Benefits Available in Germany

Benefits are regulated according to the Care Law (Pflegezeitgesetz, 2015 - Care).

2.1.1 Care Provided Through Insurance Benefit Assessment

In order to provide social and financial protection for health risks regarding long-term care, statutory long-term care insurance (GPV) was adopted in 1994 as the 'fifth' pillar of the pay-as-you-go social insurance system in Germany (LCS, 2015), after more than twenty years of discussion. The first stage of home care services, also known as outpatient care, was introduced in 1995, and this was followed in 1996 by the second stage for care in fully inpatient facilities.

Nursing care funds are attached to health insurance companies for the purpose of providing long-term care. Those families affected or their relatives must apply for benefits under the Long-Term Care Insurance Act. Subsequently, specialists and nurses of the Medical Service of the Health Insurance Fund (MDK) are responsible for checking the requirements of the socially defined person for their need of care. The Eleventh Book of the Social Code-Social Long-Term Care Insurance (SGB XI, 1994) refers to those persons who require care.

> "...as those who due to a physical, mental or emotional illness or disability are unable to carry out the usual and regularly recurring activities in the course of daily life on a permanent basis, and probably for a duration of six months or more, to a considerable or greater extent of them needing help" (SGB XI § 14 Abs. 1).

So far, attention has mainly been on hygiene, flexibility, nutrition and domestics (Kuhlmey, 2002: 297). Currently, there are five care levels in long-term care insurance, which apply to both outpatient and inpatient care (see Table 2.1). The criteria for defining the levels depend primarily on the frequency and duration of necessary assistance. Access to the lowest care level for the needy, Care Level 1, is provided by the MDK after assessment to those:

> "Persons who need help with personal hygiene, nutrition or mobility or for at least in 2 activities of daily living or from one or more areas, and requires help for at least once a day and additionally need help with domestic care several times a week" (SGB XI § 15 Abs. 1 Nr. 1).

The prerequisite for Care Level 2 is that the help is needed at least three times a day. Care Levels 3 to 5 are for when people need full-time support. In addition, for the recognition of the last two stages, there must be a need for help with domestic care several times a week (SGB XI § 15 paras. 1-3). However, those needing care at home can choose between being cared for by an informal caregiver, care by a professional carer (benefits in kind) or a combination of both services.

In recent years, the increasing number of older people in our society has earned a wide recognition of palliative care in general and German politics in particular. This change resulted, in 2002, in the voluntary option for physicians to gain a minor specialisation in palliative care. However, in 2007, a legal introduction of specialist outpatient palliative care doctors (SAPV) was implemented following healthcare reformation. The law enabled specialised outpatient palliative care to be provided; this contains specialist medical and nursing services, including the coordination of healthcare delivery. The aim was to provide palliative care and/or end of life care to those in need in their stated place or place of choice. Interestingly, those groups with fatal or life-threatening diseases and those in greater need of help are compulsorily insured. Notwithstanding this, the person in need of care is expected, according to healthcare laws, to have a prescription from a medical practitioner before SAPV is received. Unfortunately, SAPV is only possible within a limited region in Germany, and there are no specified nor legislated standards regarding specialised service requirements and cooperation with others, such as doctors, nurses and family caregivers (Brüeckner *et al.*, 2009).

In light of these policy changes, this chapter will now elaborate upon areas relevant to this study.

Some healthcare providers mention specific recipients and benefits to older people and family caregivers. In 1995, German health insurance policies added long-term care insurance (*pflegeversicherung*) to ensure that every insured person prepares for long-term nursing care, whether due to accident, illness or old age. The MDK follows criteria to measure who needs care and the level of care needed to qualify for a long-term care benefit. For example, an older person in need of care would have statutory health insurance, state or private, and pay the premium. There must be a clear indication for the MDK to prove that those who applied for care genuinely do receive it (*pflegebedürftigkeit*), meaning a person in need of care with a health-related condition, which makes it impossible for him or her to engage or carry out daily activities without the help of others. For this grading of care to be possible, the daily living activities of the person in need of care are assessed by the healthcare insurance personnel to ensure that person needs such care. Each patient/family caregiver is examined and questioned in the setting in which they are at that time. Health insurance personnel (MDK) ask relevant questions about their health condition. When the person in need of care cannot answer the questions adequately or comprehensively, the family caregiver takes it up on their behalf. This thus provides answers relevant to the questions asked by MDK, whose duty it is to access every individual with needs and grade the level of their care needs from Care Level 1 to Care Level 5, reflecting the severity of their condition. This act of grading determines how much care, monetary resource and nursing care is required by that person.

2.1.2 Care Insurance Benefits According to the Care Law (Pflegezeitgesetz, 2015)

The law presents rules for treating the sick and what they should receive when terminally ill, including palliative and end of life care. This Pflegegesetz 2015 is seen as part of the social long-term healthcare policy that health insurance should provide. On the other hand, inpatients in hospices receive financial support through statutory health insurance funds, with only minimal daily rates payable by health insurance providers under section 181 of Book IV (The German Social Code [Social Gesetzbuch IV], 2020).

However, this focus is on the palliative needs of older people and family caregivers' experiences in nursing care. Every individual's care level and degree of financial help depends upon their private money available, including pensions. According to the statutory health insurance status, which was changed by Art 5 G.V 27.03.03.2020 1587 (Social Code [SGB V, fifth book - SGB V, 1994) translated into German: *Socialgesetzbuch* [SGB V, *fundsbuch*],§ 39b SGB V Long-term Care Allowance [*Pflegegeld*]), this is up to 901 euros/month (information correct as at November 2022).

There is also a support allowance (*Entlastungsbetrag*) for every needy individual, of up to 125 euros/month (information correct as at November 2022). There is also a free nursing care service available to support family caregivers and others; care advice (*Pflefeberatung*) for individuals and family caregivers; and long-term care cases, including those in hospices and palliative care in nursing homes. According to section 87b SGB XI, in the new system, people with dementia and others with high levels of care also benefit from long-term inpatient facilities. In this case, the ill person receives a monthly amount of money according to the assessed level of care. Hence, those in need of care can supplement their informal arrangements with help from other nursing services in the form of a care benefit that tallies with Section 36 SGB XI. See Section 38§ SGB XI.

As previously stated, in German social law 38 § SGB XI, when older people in need of care no longer get adequate palliative care from outpatient facilities, the long-term German health insurance covers their expenses for essential medical treatment. Also, in cases of complete inpatient care, this cover is provided up to a fixed amount of the monthly care rate per level of social care (see Table 2.1).

This new concept of long-term care has led to an increased number of insured persons. Those on Care Level 1 have less significant problems, with only existing physical restrictions to a certain extent, and receive only limited funding (see Table 2.1 for monetary benefit assigned to care). The financial help, according to healthcare policy, can only be given to relatives or volunteers if they decide to take over the person's care. If that is the case, family members will also usually receive other additional care benefits. With this new Nursing Strengthening Law, it is now possible for those in need of care to receive adequate financial support. Table 2.1 shows the monthly amount of benefit entitlement paid as a fixed non-income amount, differentiated according to the classification of the care grade or care level assigned by the social law (figures correct as at November 2022).

Table 2.1: Benefit Entitlement According to Classification Level

Degree of Care	Cash Benefit (Out-patient)	Benefits in Kind (Out-patient)	Discharged (Earmarked)	Benefit Amount (Fully In-patient)
Care Level 1	125 Euro	125 Euro	--	--
Care Level 2	316 Euro	689 Euro	125 Euro	770 Euro
Care Level 3	545 Euro	1,298 Euro	125 Euro	1,775 Euro
Care Level 4	728 Euro	1,612 Euro	125 Euro	1,775 Euro
Care Level 5	901 Euro	1,995 Euro	125 Euro	2,005 Euro

Source: Nursing Strengthening Law (*Pflegestärkunggesetzt*), 2017.

The shift, in absolute terms, mainly favours persons with more strongly manifested cognitive impairments, who are at a disadvantage under the current system. Also, the enhancement of long-term care prevention measures in the lower Degrees of Need will be realised.[3]

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[3] In Chapter 7 of SGB XII, people with low incomes and/or assets can also apply for Care Assistance (Acts 61 to 66). In 2009, around 392,000 people received Care Assistance, which is therefore just under 15% (3.3 billion Euro, gross-expenditure) and thus belongs to one of the largest spending sectors of all social assistance expenditures (*Statistisches Bundesamt,* 2016:8). Just under 3 out of every 4 beneficiaries (73%) were given care help solely within institutions.

Out-patient care benefits have been in place since 1 April 1995, while those provided in full-time in-patient care settings entered into effect on 1 July 1996.[4] Additionally, insured persons will be entitled to claim individual care counselling provided by the LTCI (long-term care insurance) funds (§ 7a) (Windeler & Görres, 2008). Disabled persons can apply for benefits from the LTCI funds to be added to the benefits for the disabled (Social Code Book IX) (Schulz, 2010).

2.2 Epidemiology of Older People in Need of Palliative Care

In an ageing society, like that of Germany, the number of older people with life-threatening diseases requiring palliative/end of life care shows a corresponding increase in those who require palliative care (apart from cancer cases). Although the need for care is not limited to the elderly population alone, the probability of the elderly from 70 years being dependent on the help and support of others increases significantly with age, with 83% of those aged 65 or older in need of some degree of care (Statistisches Bundesamt, 2015:7).

In Germany, about 5.1 million people required some degree of care in 2006. Out of this number, Schulz (2010) reported that there were about 2.1 million long-term care insurance (LTCI) beneficiaries. However, the need for care increases with old age. According to Schulz, half of the people receiving such benefits were aged 80 and above. Hence, from the age of 70 years and above, the prevalence of the need for care increases sharply (Schulz, 2010). It is predicted that, in the coming years, the ageing population, particularly with the likely sharp increase of the oldest elderly, will greatly increase the number of older people in need of care.

2.2.1 Demographic Considerations

In the Western world, older people in need of care generally prefer to live in their home environment, surrounded by families and friends, for as long as possible. However, in Germany, about one million people are reportedly receiving informal care cash benefits. Some 500,000 beneficiaries receive benefits for professional care at home. In 2006, a total of 4.4 million older people in need of care received the necessary care and support from the system or through practical help from family caregivers (e.g., domestic and others) within

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[4] Currently, the following services are available (all mentioned in the Social Code Book XI): - Benefits in kind for community care (§ 36) - Benefits in cash for informal care (§ 37) - Combination of benefits in cash and kind (§ 38) - Respite care at home during a vacation or illness of informal carers (§ 39) - Medical equipment and technical aides (§ 40) - Day care and night care (§ 41) - Short-time institutional care (§ 42) - Full-time inpatient care (§ 43) - Long-term care given in institutions for the disabled (§ 43a) - Benefits for social security of informal carers (§ 44) - Benefits for carers who take long-term care leave (§ 44a) - Training courses for family carers and voluntary carers (§ 45) - Additional benefits for people whose competence in coping with everyday life is considerable impaired (§ 45b) - Benefits for a personal budget (§ 17).

the home. Some 90% of all people in need of care and assistance depend upon informal care for help (with and without help from professional home care services). Many who give care to their older loved ones have done it out of love and appreciation. Most family members reported to prefer giving care at home. However, this depends upon the individual circumstances of the informal caregivers in each family, or the personal network available, and upon them being willing to care for an elderly person who has been assessed as being at a specified level of impairment in daily living caused by physiological or mental illnesses and who is not in a position to care for themself. Most authors, including the official Bundes statistics, support the notion that informal caregivers are mainly spouses. Females are more prone to be caregivers than their male counterparts; for example, sisters, daughters-in-law, other members of the family and friends or neighbours may take up the care work in the family (Schneekloth & Leven, 2003). However, according to some authors, married people living in a partnership are likely to jointly receive care at home when they become old and frail. On the other hand, many people living alone tend to move into a nursing home.

The possibility of a person becoming an informal caregiver often depends on whether they are married or not. This also leads to the supply of accommodation for the carer and whether the person in need of care can pay for such accommodation. Other fundamental factors determining a possible informal care situation include employment status, the current living arrangements of potential informal caregivers, and the distance between the place of residence of people in need of care and their potential caregivers.

However, the demographic changes seen in every society, especially in the Western world, have affected the conditions of human coexistence for older people. Ageing societies like those in Germany will need to assess the new political, social and economic challenges and costs caused by an ageing society. In particular, older age has developed as an independent phase of life, and this phase, which is getting more in number and longer than the entire lifespan, can already cover up to 40 years. The increasing number of people over 100 years of age living in Germany who end up needing help is said to have doubled between 2000 and 2010 “from 5,937 to 13,198” (Jopp *et al.*, 2013:9).

However, the welfare state pension system and a wide range of services for the elderly in Germany have significantly contributed to drastically improving their health and material well-being at an older age. Today, ‘age’ in developed Western societies is characterised on the one hand by new biographical designs and forms of social accompaniment, but also on the other hand by illness, frailty and the need for help.

In 2019, the German population aged 65 years and older amounted to 21.8 per cent of the total. This was only a slight increase over the year before but, in general, the older population is increasing year upon year, which is part of a broader worldwide trend.

The proportion of senior citizens in the German population differs from one region to the next. At the end of 2014, the proportion of generation 65+ in the total population was higher in Eastern Germany (24%) than in Western Germany (just under 21%).

In order to describe the demographic development of the age population and the complexity of the ageing process in more detail, the healthy lifespan fell into a third and fourth age (Baltes & Smith, 2002; Laslett, 1995). Usually, retirement describes the beginning of the third age. This group of people, leaving the labour market when 60-67 years of age, is characterised by a degree of debility and failing health. For older people (65+) in Germany and the EU in general, in 2016, the most frequent diagnoses recorded were diseases of the circulatory system, with cardiac insufficiency (heart failure) the leading cause of infirmity and death. The fourth age (defined as 80+ years of age) is characterised by the growing risk of being affected by multimorbidities, dementia and the need for care. For example, 41% of men and 54% of the female population over the age of 85 reportedly suffer from at least five moderate to severe-grade diseases (Steinhagen-Thiessen & Borchelt, 1999) which increase the probability of them relying on the help and support of others to cope with everyday life (Hoffmann & Nachtmann, 2007).

There are many physical and psychological changes experienced when ageing. These changes are not acutely harmful, but bodily function is gradually declining (Pasco-Pinellas, 2013). People now live longer and die more slowly due to degenerative diseases rather than acute infectious ones (Kelle, 2000; Todres *et al*., 2009; Brown & Walter, 2013).

Data from the medical services (The Medical Service of the Spitzenverband Bund der Krankenkassen E.V. [MDS]) indicate that, for older adults, the most frequent nursing-related illnesses fall into three or four diagnostic groups (Wenzel & Paris, 2018). They often suffer from illnesses that do not directly lead to death, but which limit an independent lifestyle and involve the need for long-term palliative nursing care. In men, cognitive impairment is common, at least up to the age of 80 years, with a dominance of circulatory diseases, which increase the risk of death. Circulatory diseases are still the most common cause of death in both men and women. In the case of women who need help and care, recourse to compensation options at home is significantly reduced, in contrast to men, who often are taken care of by their wives or partners. In the case of men, this initially entails the waiver of benefits per the Care Insurance Act (Statistisches Bundesamt, 2015:8). Interestingly, the German Ageing Survey (DEAS) data shows that, overall, women use non-medical health-related services more than men (Wurm *et al.,* 2007, 2010).

Projections on future demographic trends are helpful. They can be used to predict changes in the shift of resources between generations as well as to assess the financial sustainability of long-term care services (Economic Policy Committee and DG ECFIN, 2006). According to projections made by Eurostat (see Figure 2 in ESN, 2008:3), by 2020, there will be only three working-age people per retired person in Europe. This ratio will reduce to just two economically active people per retired person by 2045; that proportion will be reached in Germany and Italy a decade earlier. Like many other OECD member countries, Germany will face a dual demographic challenge in the coming years, having a considerably ageing working population and a shrinking of working-age population numbers. In Germany, people over 50 will likely have increased from 30% to almost 40% of the population by 2020. Subsequently, working-age people will decline from 50 to 40 million by 2050. The only way to reduce the decline projected by the German demographic in the workforce is by allowing 200,000 (young) immigrants into the country every year. However, an influx of immigrants does not significantly influence the ageing pathway (ESN, 2008).

Demographic changes happen differently, at a different pace, in each country. However, different countries react to ageing and dying differently, as many believe in old age, debility and dying being ordinary things that do not require palliation. The highest ageing process occurs in Poland and Romania (ESN, 2008), with both countries currently having a proportion of around five people of working age per retired older person; by 2050, that ratio will reduce to two workers per older person. Hence, dependency ratios in both countries are likely to increase to about 15 times higher than in the other European countries and three times more than in Sweden. This increase in the ageing population is much higher than in the rest of Europe and only partially decelerates by a slight increase in the rest of the population (ESN, 2008).

Around one-third of the population of Poland, Italy, Belgium and Germany will be over 65 years of age by 2050, and Sweden, Belgium and the UK will be 25% more (OECD, 2007). By 2050, the current number of older people in Iceland (about 35,000) will double.

In Germany, about 2.6 million people received benefits from social long-term care insurance or private long-term care insurance in December 2013. This corresponds to an increase of 610,000 or 30.3% in the number of beneficiaries compared with 1999 (Statistisches Bundesamt, 2015:75). Reportedly, the proportion of people in need of long-term care in the total population rose from 2.5% to 3.3% in the 14-year survey period (ibid.), showing the increasing ageing of German society (Statistisches Bundesamt, 2016: 21).

Although the need for care is not solely limited to the elderly population, the probability of being dependent on help and support increases significantly with age. Thus, 83% of those in need of care have reached the age of 65, and 37% have already reached or exceeded 85 (Statistisches Bundesamt, 2015:7).

If people in need of care are considered separately according to age groups and gender, considerable differences emerge. In the later years of life, women and men differ significantly in terms of the need for care (Statistisches Bundesamt, 2016). For example, between the 80th and 84th years of life, women reach a prevalence age of around 23%, increasing to 42% in the following five years. Women aged 90 years and older have the highest need for care.

These figures suggest the importance of age and gender as essential and dominant structural characteristics of long-term care risk. Both sexes have experienced significant care-related cuts in their quality of life from around 80 years of age. Differences exist in the extent and scope of the need for care for both men and women in Germany.

Other causes of the varying degrees of care prevalence already lie in the gender-specific health conditions and clinical pictures of older people (Verbrugge, 1982; Murtagh & Hubert, 2004). German data shows that the most frequent women's diseases are categorised into three or four diagnostic groups (Wenzel & Paris, 2018). The increasing prevalence and incidence in the number of older people with palliative needs is increasing daily, representing a socially relevant topic. Thus, the people affected in Germany represent the most rapidly changing population group, yet still lacking early palliative care options.

Table 2.2 shows the significant increase in multimorbidity with age for both sexes. It provides a classified morbidity index of those older people affected and who require palliative care into gender, age, residence, social class and migration status, and shows that around half of all people living in Germany over 65 years of age have more than three relevant chronic diseases.

Unfortunately, the rising number of aged coupled with a reduced birth rate in Germany is a leading cause of reduced workforce and family caregivers. As the number of older people increases, fewer are available to take up the caring work for the more elderly, particularly in the area of geriatric care. In light of this, there is an increase in demand for qualified nurses in the nursing care setting; the great demand for qualified geriatric nurses is increasing steadily, given this demographic change. By 2050, some 50% of the total German population are likely to be older people in need of care (Statistisches Bundesamt, 2016).

In order to continue to have sufficient nursing staff working in the nursing settings in Germany, nursing training was reformed from 1 January 2020, enabling foreign nurses to come into Germany to work.

Table 2.2: Increase in Multimorbidity with Increasing Age

Sub Group and Age	No morbidities	1-2 morbidities	3-4 morbidities	4+ morbidities
Men (total)	**20.0%**	**58.6%**	**18.8%**	**2.6%**
18-29	27.9%	59.6%	12.5%	0.0%
30-39	24.0%	63.1%	12.4%	0.6%
40-65	16.4%	59.8%	20.7%	3.1%
Over 65	9.4%	45.5%	36.2%	8.9%
Women (total)	**13.8%**	**54.3%**	**25.7%**	**6.2%**
18-29	18.2%	63.7%	17.1%	1.0%
30-39	16.8%	61.7%	19.5%	2.0%
40-65	13.2%	54.5%	26.5%	5.8%
Over 65	7.1%	37.1%	39.3%	16.4%
TOTAL	**16.8%**	**56.4%**	**22.4%**	**4.5%**

Source: Kohler & Ziese (2004).

From Table 2.2, it can be seen that the relationship of age to multiple morbidities, especially after 65 years of age, shows the likely increased risk of numerous diseases and disabilities common in this age group, making them prone to dependency or needing help from the German Government or other sources. For example, an examination of a cohort of 73,000 older BKK-insured persons showed that 13.8% of women and men identified as being chronically ill and in need of care within the context of the '*Sozialgesetzbuch*' (SGB - Code of Social Law X1) (Kuhlmey *et al.*, 2003). Moreover, health-related quality of life decreases with increasing illnesses (Kohler & Ziese, 2004). Unfortunately, this potentially means reducing the quality of care provided to the people, as seen in Germany, the UK, the USA and elsewhere. In 2016, non-communicable disease (NCD) led to mortality and morbidity estimated at 56.9 million global deaths, 71% due to known infectious diseases (WHO, 2018).

According to the calculation model used in the study mentioned above, the number of people in Germany in need of help is likely to rise over the next few decades. Data published by Sachverständigerat (SVR, 2001), the Council of Experts to assess the development in healthcare, shows that the estimates in various forecasts largely agree with this study. By 2030, *status quo* forecasts range from 2.61 to 3.36 million people in need of care, although these figures are based upon predictions rooted in 2005 and 2007. This number, as seen in the above study, is thought to be less than the 3.36 million forecast by SVR, with the Federal Statistical Office estimating 2.95 million people likely to require care. The results in Table 2.2, as predicted by the Council of Experts, estimate 2.93 million people for the year 2050. The *status quo* forecast of the Council of Experts shows the highest projected number of people in need of care at 4.35 million. However, other recent projections show this figure could be up to 4 million, while Dietz *et al*. (2002) speculate that, in an extreme case, over 5 million could need care.

2.3 Use of Types of Care

The criteria for those working in healthcare to measure a person's ability to perform Activities of Daily Living (ADLs) are commonly used as a starting point to help determine their medical status and long-term care needs. So, if an older person cannot engage in a few or all of the ADLs, he or she may need to transit to a nursing home where a team of physicians, nurses and health aides provide ongoing care and supervision, either full-time or through visits. Consequently, the supply and demand of long-term care is determined mainly by the demographic balance between the elderly and the working-age group. This balance between generations, as expressed in the old-age dependency ratio, is the proportion of the older age segment (aged 65 and over) compared with the economically active age group (from 15 to 64) (Economic Policy Committee and DG ECFIN, 2006).

Concerning the type of care existing for older people in Germany, older people in need can choose between care in their own home with or without the support of an outpatient service, or care in a full-service facility (usually an older people's nursing home).

The Federal Statistical Office (2015) figures show the following picture for 2013 regarding the type of care: from 1.86 million people, seven out of ten (70.9%) people in need of care are cared for at home. 1.25 million are supported solely by family members or other private individuals. The remaining 616,000 people in need of care also live in private households.

However, outpatient care services organise their care in part or whole. The healthcare needs of these older people in need of care are classified based on the severity of their cases (see earlier, Section 2.2).

The share of Care Level 1 is highest among those cared for at home, at 63.1%. Around 28.7% are accounted for by Care Level 2 and 8.2% by Care Level 3. This overall high outpatient rate expresses the priority of outpatient care over inpatient care (SGB XI § 3). Three out of ten (29.1%) people in need of care receive full-time care (i.e., care in nursing homes). Some 38.1% of residents are assigned to Care Level 1, 39.6% to Care Level 2 and 20.6% to Care Level 3. 1.8% have not yet been allocated a Care Level (SGB XI § 9).

Over the past 14 years, the share of recipients of pure cash benefits has increased by around 4%. At the same time, the demand for professional help from outpatient care services and inpatient care facilities has increased. This development is directly related to the growing average age of people in need of care. However, this is also associated with the increasing number of older people needing palliative nursing services.

In addition, the proportion of people needing care at Care Level 1 has been rising steadily since 1999 (1999: 30.8%; 2015: 38.1%). One reason for this could be the decreasing possibilities for examination and care in the unique home environment, which often forces those affected to give up an independent lifestyle in the private household. The increasing consideration of dementia patients in assessing applications for care levels may also play a role. Even when a person is at Care Level 1, their need for care may be so great that they can move into an inpatient facility.

There are advantages to nursing care homes. For example, professional caregivers in nursing homes are trained to assist the older people in their care for all of their ADLs, like personal care needs, mobility issues, meals, cleaning and laundry, and they can provide skilled medical care or therapy whenever it is needed. The high quality of services offered in these older people’s nursing care homes enable many families who cannot continue caring for their older persons at home to make decisions about full-time care for the older person. Residents receive many services to maintain their dignity, thus alleviating family caregivers’ stress (George *et al.*, 2020).

2.4 Care Arrangements With a Focus on Long-term Care Facilities

Long-term care, according to the National Institute on Aging, “is the services that help people live independently and ensure the safety of the older person when they can no longer perform the daily activities of living on their own” (NIA, 2020). Long-term care may be formal, informal (often specialised and paid) or informal (often unspecialised and unpaid).

In Thailand, Germany and other countries practising long-term care, most is provided informally by unpaid caregivers, such as family members or relatives. In the past, in most of these countries, healthcare and social support systems for seniors with disabilities provided a limited amount of funds and services, and most long-term care facilities were public foster homes (Sasat *et al.*, 2014).

The concept of a national long-term care programme for the elderly first appeared in 2010, as seen in the second National Health Assembly resolution. The government of Helmut Kohl introduced Social Law XI 1 in January 1995, known as the popular German long-term care insurance. This is an independent part of social security (*Sozialgesetzbuch*), as it made provision for financial risk in the ageing society. Long-term care insurance was introduced in Germany as the fifth pillar of social insurance after health insurance, industrial injuries, pensions and unemployment insurance.

Due to the many challenges faced in providing palliative care in nursing homes, healthcare workers, including clinicians, pay close attention during the arrangement and transfer of older people to the nursing home setting for their future long-term care. Some authors have pointed out that regardless of the care setting, older people who leave hospitals are prone to poor hand-overs from one healthcare setting to another (Boockvar *et al.*, 2004; 2005). Accordingly, this is often worse when the case is complicated with symptoms and a line of treatment. The authors advise that hand-overs of such cases are better when done by one physician to another who takes over the patient’s continued care. In this way, continuity of care is ensured, especially for an older, frailer patient (Hanks *et al.*, 2015). Essential information such as the names of family caregivers and contacts, their wishes for DNR/DNI (resuscitation/ventilation), ADC, name of their doctor, plan of medication, and other essential information needs to be forwarded to the new care provider.

In Germany, various pieces of legislation deal with older people’s home and nursing care arrangements, including nursing care insurance and the Care For Development Act (Schneekloth, 1997). However, nursing home care arrangements can be problematic and time-demanding due to many factors. There are steps to go through once a decision has been made and concluded with the GP, followed by the family caregivers having to arrange to move the patient to an older people’s home for long-term care. The specialist assesses with the insurance company to determine the level of need, such as personal care needs, participation in social living, ability to control activities of daily living, nutrition/food and the safety of the individual. Once considered eligible, the family caregiver must find a suitable home, send applications and do the paperwork, including sorting out how and who takes charge. Nursing homes for older persons have become popular in providing palliative care for residents at their end of life.

Older people living with chronic conditions, including cancer and dementia, pose challenges for both the patients themselves and family caregivers at home and are institutionalised when family caregivers cannot continue care at home. Hence, the decision for end of life care in a long-term care facility may be ideal for the older person and their family caregivers. Unfortunately, most literature studies in this field have focused more on the care of older persons with cancer and their palliative nursing care in the nursing home setting. Few studies have included the palliative nursing care of older people with non-malignant diseases and their family caregivers' needs.

However, in our society, the transition of care may mean moving the older person from one setting to another and between healthcare providers, leading to increased healthcare expenses for both the family and the state (Phelam *et al.*, 2012).

Incidentally, some literature studies have proven that those with dementia have the highest tendency to face the transition of care; how many receive palliative nursing care is unknown. Moreover, the transition of care to an older people's nursing home has implications when done suddenly. Some studies have shown that the transition of care to an older people's nursing home may be done hastily and without due preparations of both parties. When this happens, some studies point out the risk of a lack of good communication, confusion of medication, lack of follow-up, inaccuracies in information exchange, ineffective coordination between care providers and inadequate patient and family caregivers' preparation on what to expect.

Table 2.3: Number of Long-term Care Beds in Nursing Homes in Germany

Year	1995	1996	1997	1998	2000	2001	2002	2003	2004	2005
Beds	301,196	344,732	363,878	363,878	645,456	645,456	674,292	674,292	713,195	757,186

Source: (OECD, 2007).

It becomes essential to understand why most older people's nursing care settings face difficulties when implementing palliative care amongst the elderly at their end of life. In recent times, Western countries, including Germany, have legislatively sorted out ways to improve the process of end of life and how to change the timeline of treatment care for a terminally ill patient, especially the (dying) elderly, when transitioning into long-term palliative care in a nursing home. Hence, family caregivers are vital and play a crucial role in the palliative care of the older person in a nursing home and should also join in the end of life decision-making of the older dying person.

For palliative care to reach all in need of it, every level of government, health insurance funders and community developers are expected to make an effort to support policies that are realistic and sustainable, and which support the development and improvement of existing healthcare laws and social policies. Some publications in this field have shown that mapping out palliative care provision in long-term care facilities shows great diversity within the long-term care facility sector in Europe, with examples of innovative interventions and practices at national, regional and organisational levels. Long-term facilities will remain a significant part of our society's health and social services, especially for the frail elderly and their family caregivers, and the fact that the ageing population is increasing. To be efficient, national policies, funding, regulatory bodies and quality assurance frameworks will need to address some of the challenges facing the inclusion of palliative care for the elderly and family caregivers in long-term care facilities. Hence, appropriate bodies' support to help implement actions that will realise new appropriate policies at both local and organisational level is expected. Moreover, staff at older people's nursing homes are well equipped with knowledge and resources to deliver palliative care at appropriate units for both in- and out-patients (Brazil *et al.*, 2016); this, in turn, prevents discrepancies in meeting the family caregivers' needs.

2.5 Summary

The demographic changes outlined earlier will affect many areas of daily life, particularly the end of life nursing care of the elderly and family caregivers' experiences. A future challenge is to generate a more positive approach to ageing and end of life care. Moreover, the family caregivers' experiences are to be seen as neither just personal treatment nor a collective burden (EESC, 2008). Despite this appeal, the European Economic and Social Committee also stresses that the socio-political debate on the negative experiences of family caregivers of older people must not be neglected.

However, this includes the long-standing taboo topic of end of life care for the elderly in older people's nursing homes, who are aware that most people in need of care receive caring support. There needs to be a broad, professional and open discussion about the end of life care of these older people in the nursing home and their family caregivers, and care relationships together with family caregivers' experiences. Against this background, this present work focuses on the end of life and/or palliative nursing care experiences of family caregivers in the nursing home setting.

Before the third chapter sheds light on the management of palliative / end of life care, this second chapter has discussed several conceptual areas and the definitions of some terms, including the overall construct of family caregivers' end of life and/or palliative nursing care experiences. Moreover, the consideration of what constitutes a good or bad experience for a family caregiver of the end of life care of their older person in a nursing home (Lamura *et al*., 2009).

CHAPTER 3: MANAGEMENT OF PALLIATIVE/ END OF LIFE CARE

3.1 Introduction

The current concept of palliative/end of life care for terminally-ill patients comprises of shifting the goal of treatment from cure to care, providing a 'good death' by ensuring comfort at their end of life (including spiritual and cultural needs), ensuring truth-telling, ensuring a high quality of life until final death, provision of a comfortable place of death, and ensuring support for family caregivers.

However, the basic principles of palliative care for the elderly are similar to those for end of life care, being care not cure, and would thus be part of an ongoing treatment plan. However, the patient's condition and the setting in which the patient finds him/herself may take a long or shorter period to adjust to. The clinical practice guidelines for quality palliative/end of life care by the 'National Consensus for Quality Palliative Care' serves as a guideline for those in palliative management (NCP, 2013; NCHPC, 2018). However, WHO guidelines are also relevant, but this thesis will not be going into any detail on these guidelines. The decision to transit an elderly patient from a cure pathway to palliative care is very complex and can often be devastating for patients and families, depending on the illness trajectories envisaged. This complex decision should be appropriate for both the patient and caregivers. Decisions made around the domain stipulated by the NCP and WHO guidelines depend on the diagnosis, and they should be to maintain the health and dignity of the individual in need. While experts decide on many operable cases, those who may be on solid pain relief are also decided upon based on expert opinion and, in all, their care should, at all times, be holistic. Structures of palliative care (NCHPC, 2018) include (1) processes of care, (2) aspects of the physical care of the patient, (3) psychological and psychiatric care, (4) social care, (5) spiritual, religious and existential care, (6) cultural aspects of care, (7) caring for the patient at the end of life, and (8) ethical and legal aspects of care.

Palliative care may involve complex drug regimens and near-constant symptomatic care, or it may involve only honest, compassionate conversations with family members. Either way, one has acted to ease a patient's transition from life to death (Nurse Key, 2016). However, any skill and proper application of palliative care at the right time when a patient requires it goes a long way to helping the elderly patient and family attain spiritual and physical satisfaction (*ibid.*). However, the public health approach should be acceptable, sustainable and affordable no matter what approach is used. Hence, the WHO Public Health Model, which is:

> “The core components of palliative care include more than assessing and treating of physical and psychological symptoms, also right for everyone irrespective of age. Hence, the identification of and support of those in spiritual distress, those in need for expert communication to benefit from the establishment of goals of care and assist with complex medical decision making, and coordination of care ideally. However, in their opinion, many of these components can and should be provided by primary treating clinicians” (Kelley & Morrison, 2015:747).

When planning palliative/end of life care for patients in need, international collaboration with the WHO is crucial. Its collaborating centres recognise that individuals and beacon services play a significant role in initiating and implementing palliative care. This way, empowering local pioneers through the availability of advocacy tools, teaching curricula, clinical guidelines and policy documents is possible. These are seen as one way of averting reinventing international funding at an early stage, which may cause disruption (Prail & Pahl, 2007; Stjernswald *et al*., 2007b; Pantilat *et al*., 2012; Callaway *et al.*, 2017; Cherny *et al.*, 2021).

It is necessary to assess all the necessary requirements for an ageing patient in need of care. This would include their spiritual needs too, as anticipatory grief may arise at the decision to transfer the patient to an institutional palliative care unit (Cherny *et al*., 2015; Cherny, 2021). Unfortunately, medical teams typically underscore the pain in older people (Scottish Intercollegiate Guidelines Network, 2008), leading to many dying without unmet palliative care. Everyone has a right to enjoy the highest attainable physical and mental health standards, and everyone should take steps towards carrying this out (Human Rights Watch, 2015). This includes all palliative care packages and access to adequate pain management. International drug control conventions state that:

> “…the use of narcotic drugs medically remain[s] indispensable for the treatment and management of symptoms as well serve in the relief of pain and suffering in people with chronic pains. Hence, adequate provision must be made to ensure the availability of narcotic drugs for such purposes” (Human Rights Watch, 2015).

However, palliative care and pain relief are essential health services and components of universal healthcare, and are necessary at end of life (Human Rights Watch, 2015).

Ethically, all people have a right to receive high quality care during severe illness and to a dignified death, free of overwhelming pain and in line with their spiritual and religious needs. According to the history of health in Germany and elsewhere, palliative care was initially for people with cancer. Ethical concerns about fairness, equality and equity required that this standard of care should be offered to other people with similar needs, as in the standard guidelines. There are also significant ethical concerns about how care offered to people fits their choices. People who are very sick and old or cope with chronic severe illness have their own experiences and values, and the same goes for the family caregivers. However, the benefits from healthcare insurance concerning a patient with a terminal illness and their family caregivers, as mentioned previously, and the main criteria as stated by the WHO (2020) for those requiring palliative care, help draw the link to the research subject (see Table 3.1).

3.2 Ethics of Care, Guidelines for Palliative/End of Life Care

Ethics is a code of conduct. In reality, this supports the traditional normative ethics, primarily based on action principles and individual autonomy. The ethics of care, however, consider, in this case, the older person's vulnerability and family caregivers' experiences as the source of context-sensitive, prudential judgment and care. The vulnerability seen in older dying persons is seen not only as a lack of autonomy but also as a way of strengthening the older person's capabilities by healthcare professionals. Hence, autonomy is self-determination which, according to some authors, constitutes and enriches interpersonal relationships. In other words, professional caregivers of old and frail people who are terminally ill or at the end of their lives and the professional workers need to articulate perspectives and open a dialogue space, considering the patient's and their family caregivers' narratives.

The American Geriatrics Society (AGS, 1998; 2009) formulated appropriate treatment guidelines for chronic pain in 1998, updated in 2009. Based upon these AGS guidelines, every treatment in this guideline starts with drugs with low toxic levels and administered at a low dosage, preferably given orally and as a planned dose regimen, in case of pain crisis and having a consideration of rational polypharmacy with drugs of complementary mechanisms of action whenever needed. Elderly persons face chronic pains which are caused by, for example, musculoskeletal disorders such as degenerative spine and arthritic conditions. These are proven in geriatrics as the most typical reason for the excruciating pains in older people. For example, neuropathic pain, ischemic pain and pain due to cancer, as well as its treatment, are seen as playing a role in the chronic pains seen in older persons (Dziechciaż *et al.*, 2013). Some studies have reported a high rate of vertebral compression fractures leading to pain and discomfort in older people. Undoubtedly, most elderly suffer multiple chronic illnesses that affect an adequate assessment of pain and efficient treatment (Dubois, 2001). Unfortunately, family caregivers suffer alongside their loved ones' pain.

3.2.1 Palliative Pain Therapy and End of Life Care for the Dying Elderly in Nursing Homes in Germany

Palliative care in old age may range from involving complex drug regimens and near-constant symptomatic care to just simply honest, compassionate conversations with family members. No wonder it is used alongside care at end of life. The nurse has acted to ease a patient's transition from life to death (Nurse Key, 2016). However, any skill and proper application of palliative care at the right time when a patient requires it goes a long way to helping the elderly patient and family caregivers attain both spiritual and physical satisfaction (Nurse Key, 2016). A public health approach means that no matter what approach is used, it should be holistic, acceptable, sustainable and affordable; hence, the WHO Public Health Model (see Table 3.1 below). Palliative care of older people varies widely and may often include a mixture of medication, nutritional change, relaxation techniques, emotional and/or spiritual support, and the support of family caregivers and their children.

Opioids are potent analgesics and comprise, for example, morphine, hydromorphone, oxycodone, fentanyl and buprenorphine. Some medications fall into the category of weaker opioids; for example, Tapentadol and Tramadol, with their dual actions, have mu-opioid agonists and norepinephrine reuptake inhibitor functions in the body. However, Tramadol is a drug to be taken with caution when prescribed for older people, as it has a sedative effect and can impair cognitive reaction. It also interacts with other drugs (FDA, 2008; Biondi *et al.*, 2015), causing intense serotonin reuptake inhibitory actions that need consideration to avoid serotonin syndrome, a severe drug reaction, as serotonin is produced naturally in the body for the nerve cells and brain to function. Tapentadol, which was approved in 2008 (FDA, 2008), has a weaker effect than Tramadol. It has no active metabolites, but Tapentadol should be prescribed for the elderly with precaution due to the danger of hypotension, suppression of the respiratory centre and drowsiness. Randomised placebo and active-controlled studies in elderly patients (older than 75 years of age) with chronic pain showed similar efficacy between Tapentadol and Oxycodone controlled-release groups. However, more gastrointestinal adverse effects in the Oxycodone group than the Tapentadol group were reported (Biondi *et al.*, 2015). The use of opioids for managing pain in the elderly is thus tapered with caution, due to the many side effects reported.

GPs and specialists in this field tend to use opioid analgesics to manage severe pain or failed responses to other treatments in the elderly with morbidities and co-morbidities, including cancer, dementia and others (Ferrell *et al.*, 2018). However, the use of opioid analgesics in managing chronic pain in the elderly is considered by some to be only for short-term use (German Bundestag Online Services, 2006; Zaki *et al.*, 2023).

Table 3.1: WHO Pain Relief Ladder

STEP 1	Recommended for mild pain, normally with non-opioid analgesics with or without co-analgesics.
STEP 2	Used in cases of moderate pain. This contains weak opioids used in combination with step 1 analgesics.
STEP 3	Used for severe pain, includes strong opioids in combination with step 2 analgesics.

Source: WHO (1986; 1996).

According to the WHO (1996), twelve types of adult diseases qualify for palliative care, and about 19.2 million people require palliative care worldwide (Rojas & Garcia-Vivar, 2015). Overall, 56 million people die each year, with many dying with or from non-communicable diseases, often in older age (Payne, 2015).

Table 3.2: Common Medications Used in Palliative Care

Medication Type	Common Medications Used
NSAIDs	Ibuprofen, Naproxen, Diclofenac, Kerolac, Rofecoxib: co-analgesics used with analgesics to relieve pain
Steroids	Dexamethasone
Antidepressants	Amitriptyline, Clothespin
Anticonvulsants	Carbamazepine, Sodium valproate, Clonazepam, Gabapentin
Antispasmodics	Baclofen, Diazepam, Hyoscine, Butylbomide
Psychotropics	Diazepam, Levoneprozamine
NMDA Receptor Antagonists	Ketamine

Source: Goldstein *et al.* (2014).

These drugs are known to cause some common side-effects such as constipation, which may in their own right cause additional pain, apart from the underlying pain from the disease or illness. Immobility leads to constipation (when bedridden), insufficient oral fluid intake, general malaise, use of opioids and anticholinergic, hypocalcaemia, bowel obstruction (pseudo-obstruction) and spinal cord compression. In the case of constipation, doctors prescribe xanthine syrup.

3.3 Disease Spectrum and Discrepancies Regarding Palliative/End of Life Care

Discrepancies exist regarding which diseases in older persons are for palliative care. Within the German healthcare system's history, primarily patients diagnosed with cancer have gained easy access to palliative care, irrespective of age.

Unfortunately, older patients with other life-threatening diseases are often considered too late for palliative care in the nursing home. For example, GPs in Germany are not quick enough at offering non-malignant cases, including dementia, heart disease and chronic renal failure, into palliative nursing care. This delay leads to a late referral of many older people in need, with many dying with unmet palliative nursing care needs; this is very bitter for the family caregivers. Many older people with other conditions experience acute or chronic pain, including cancer pain, headaches, neuropathic pain, oral and maxillofacial pain, rheumatologic pain, myofascial pain and spinal pain (Goldstein *et al.*, 2014). Some 35% of all the above cases seek consultations to transit to a palliative care unit, with 15% reported as initiating and contacting a palliative home care team. About 46% of the cases with chronic pain qualify for the general assessment for palliative care management (Goldstein *et al.*, 2014).

More than 20% of the adult population in African countries suffer from HIV, with some 25 million dying from HIV in the last decade with no palliative nursing care. Some third-world countries (such as the Middle East and India) have a poor approach to palliative care for older persons; although old age and its complications in every culture are considered normal. Despite the technological advancement within China, there still exist loopholes in how the healthcare system considers older persons with chronic diseases at their end of life.

Everyone can suffer pain from different diseases; degenerations and reduced functions of some vital organs are common in older people and are the leading cause of pain and morbidity in old age. Chronic pain is a recurrent pain lasting longer than 3 months. These chronic pains seen in the older person fall into seven different categories, namely (1) chronic primary pain, (2) chronic cancer pain, (3) chronic posttraumatic and postsurgical pain, (4) chronic neuropathic pain, (5) chronic headache and orofacial pain, (6) chronic visceral pain, and (7) chronic musculoskeletal pain, as further defined by the experts under whom they are assigned (Üstün & Jakob, 2013). See Table 3.3 for the classification of cancer pain, which is also closely related to some pain seen in chronic cases of the older person.

Table 3.3: Classification of Cancer Pain

Type of Pain	Percentage of Pain
Semantic pain, for example, bone/muscle pain	49%
Visceral	21%
Neuropathic	15%
Mixed types of pain	15%
Underlying causes include (as below)	
Chronic pains related to old age and cancer	97%
Acute pain syndromes in the presence of existing cancer	22%
Chronic cancer pain syndrome	4%
Post-operative pain (as below):	
Acute non-surgical pain syndrome	2%
Cancer pain and chronic (non-cancer) pain	4%

Source: WHO (1996).

3.3.1 Provision of Essential Drugs in Bremen, Lower Saxony

The WHO estimates that two billion, one-third of the world's population, have no access to essential drugs (Quick, 2003), claiming this to be due to a mixture of economic, social, educational and legal reasons. Essential drugs satisfy the health needs of people and should be available at all times, under appropriate dosages. Provision of an essential drug list is made available every two years by the WHO, each satisfying its criteria that it should be safe, efficient and its therapeutic qualities well transparent and affordable (WHO, 1977, 2023b). In addition, some 150 countries worldwide are known to have published their own list of drugs.

Germany's drugs for their health systems are listed (WHO, 2012). Some authors report that developing countries face enormous challenges in accessing many of the listed drugs due to poor supply, high cost, possible ineffectiveness, scarcity of facilities and lack of qualified staff. Germany recently introduced 49 new drugs with new active ingredients that have improved their potency. These essential drugs treat severe and life-threatening illnesses like cancer, many severe infections and pulmonary diseases (EMCDDA, 2002; GT&I, 2015). As far as palliative medicines and opioids are concerned, many policies and debated ethics will remain a considerable challenge, both now and in the future. However, the essential drugs concept can be applied at various levels - national, provincial, municipality and in hospitals - in developing countries, as this is one way of prioritising medications and improving treatment. These, however, need to be available at the correct dosage, at a good quality and an affordable price (Doyle *et al*., 2013; Radbruch & De Lima, 2015).

3.3.2 Challenges and Barriers Facing Palliative Care Delivery Worldwide

Many older patients with advanced, life-limiting diseases would fare better with the early introduction of palliative care and good end of life care; unfortunately, only a minority of the population can receive such care. Many older people in Germany and elsewhere suffering from life-threatening diseases are sometimes not considered for palliative care until late in their illness trajectories, and the family caregivers suffer. This is despite the WHO pronouncement that palliative care should include all life-limiting diseases, irrespective of age, including cancer (Coym *et al*., 2020a). Each year over 40 million people require palliative care; of these, 78% live in low or middle-income countries, and half live in Africa. Hence the need to sort out the barriers (WHO, 2020). For example, Uganda is a classic example with full integration of palliative care services (Lynch *et al.*, 2011). However, the WHO (2023a) stress the following as being significant barriers to developing palliative care worldwide: policy, education, medication availability and implementation.

Twelve professional journals devoted to palliative care, various other published literature and numerous books, along with many internet sites, blogs and forums have identified an assortment of barriers to smooth palliative care delivery (Lynch *et al*., 2010). These factors (Clark & Graham, 2011) are cited as being due to geographical setting, economic resources and funding, availability, education and training. Every year around fifty-six million deaths occur, with forty-four million of them occurring in developing countries. It is estimated that some 60% of the dying would benefit from palliative care, but unfortunately a number of barriers exist that prevent delivery of palliative care where it is most needed to relieve suffering (Stjernsward & Clark, 2003).

Globally, not many countries exist that include palliative care content and guidance on the development of appropriate services (Sloan & Gelband, 2007). To this effect, more research is needed (World Health Assembly, 2005; Van der Steen *et al.*, 2014; Moore *et al.*, 2017). According to a UN resolution, all member countries should take steps to prevent the abuse of narcotics while ensuring the availability and affordability of narcotic drugs for medical use (Joranson & Dahl, 1989).

The availability of policies that back palliative care, pain management and national essential drug lists are non-existent in most developing countries. However, in Germany, Niedersachsen and specifically Bremen (the focus of this study), the use of morphine opioid medicines are supervised by a qualified nurse or doctor; who documents, signs and keeps stock of the drugs. Hospital intensive care units (ICUs) are the only place where the full range of palliative drugs may be administered (Rajagopal, 2016). However, palliation for older people in nursing homes is not shared.

Palliative nursing care is very new within Germany's older people's nursing homes. Unfortunately, many laws and regulations prevent the easy use of it (Joranson & Ryan, 2007; Human Rights Watch, 2009). The limited knowledge of palliative care by some nurses and doctors are enormous constraints and challenge the effective administration of opioids in many other health settings, especially nursing homes in Niedersachsen and the city of Bremen. Hence, in Germany and elsewhere, people are usually confronted with palliative care too late, which makes patients and family caregivers associate palliative care with death (Coym *et al.*, 2020b). Insufficient funding for specialised palliative care, inadequate availability of information to the public, GPs and nurses, and a lack of unified care structure remain significant challenges (Papke & Rosenbaum, 2012).

There are also significant ethical concerns about how the care should be administered and the choices people may wish to make. People who are very sick or are coping with chronic severe illness have their own experiences and values. Unfortunately, some of the wishes of older persons, for example, to die at home, are rarely met due to cost and structural arrangements. Again, poor or lack of training of healthcare workers in this field remains a significant constraint in the palliative nursing care of the dying elderly and meeting family caregivers' needs.

Most times, older people being treated by their GPs do not know much about palliative care and this lack of knowledge makes it difficult to prescribe the necessary pain-relieving drugs or to ensure adequate control of the pain. Myths about morphine and opioid analgesics remain a problem and require the education of the public.

3.4 Ethnicity, Religion, Culture and Implications in End of Life Care of Older Persons in the Nursing Care Home

3.4.1 Ethnicity

In Germany and elsewhere, many factors influence people's healthcare policies and preferences at end of life (Coolen, 2012; Cain *et al.*, 2018). These preferences will continue to affect people's healthcare choices at end of life and family caregivers' experiences irrespective of the healthcare setting.

Culture is significant to us all and is within a conceptual framework to transmit information to other generations (Koffman & Calanzani, 2021). Historically, individuals have migrated from their native homes to other countries due to war, political instability, economic reasons and education. In 2010, about 214 million people migrated worldwide, with 70 million settling in Europe and over 50 million in North America (United Nations, 2009). 2020 estimates are for 272 million international migrants globally (or 3.5% of the world's population) (IOM, 2020, Chapter 2). Germany, for example, is still experiencing high immigration rates, with people coming from ethnic groups, bringing with them their culture. 21.2 million people, one-quarter of Germany's 82 million population, have a migrant background, representing about 26% of Germany's total population (The Federal Statistical Office, 2020). In 2040, it is projected that about 35% of Germany's population will have a migrant background or be migrants themselves (German Migration Expert, 2020), meaning Germany will become more diverse (Brucker & Coleman-Jensen, 2017).

3.4.2 Cultural Issues

Health providers in nursing homes are in constant touch with people from different origins, widening their knowledge in cultural skills to deal with the different cultural contexts of patients and their families. Coolen (2012) states that cultural influences affect patients' reactions to death and dying and the end of life scenario in general. In short, people do not just leave their culture behind them when they migrate to another country, because the culture is inborn and should be within the medical school curricula. The concern of this section is how migration affects palliative/end of life care in the nursing home.

Petra Bendel, Chairman of the Expert Council of the German Foundation for Integration and Migration (SVR), said Germany has consistently had one of the world's lowest birth rates since the Second World War. The Statistics of the Federal Republic of Germany (Statistisches Bundesamt, 2016) show an increase in the number of those seeking citizenship in recent years; for example, more than 266 in Niedersachsen compared to previous years. However, the North-Western city-state of Bremen has the highest figures, with 36.5% of its population having a migrant background. By contrast, the Eastern state of Thuringia had only 7.8% (Statistisches Bundesamt, 2016). Generally, this has influenced the culture, religion and spirituality within German healthcare. Cultural diversity in Germany, particularly in Niedersachsen and Bremen, calls for the attention of healthcare providers, including nurses and doctors, to treat every individual with uniqueness. Religion, spirituality, culture and level of education influence their behaviour, attitude, preference and decision-making in end of life matters. Some 247,000 people in Bremen have a migrant background (Reichelt, 2020). The diversity in culture seen in Bremen will continue to be a problem for palliative care in old people's nursing homes, and for hospice nurses, social workers, family practice doctors and other healthcare providers. Hence the need for adequate medical education, as diverse cultures and social contexts affect different values, religious meanings and social norms that deal with interpersonal and family relations, as they affect decisions and preferences at end of life (Huang *et al.*, 2019).

Old peoples' nursing homes in Bremen, Niedersachsen comprise people from different ethnical, religious and social backgrounds. This diversity leads to problems in end of life situations (Brown, 2014). Studies investigating both minority and majority populations suggest a need for clinicians to be aware of cultural issues, particularly the role of spirituality at the end of life decision-making, as well as the interpretations made by individuals (Tulsky *et al.*, 1997). For example, a growing literature has proven an increased demand for life-sustaining treatments by Latinos and Afro-Americans (op. cit.). In a separate study, African Americans presented as wanting everything that will sustain life, with less desire by Caucasians to want to be on ventilators to prolong life (Steinhauser *et al.,* 2000a; 2000b). A good death is interpreted differently between different cultures (Munn *et al.*, 2007; Miyashita *et al.*, 2007, 2008; Sanjo *et al.*, 2007; Yao *et al.*, 2007; Spathias & Booth, 2008; Murakawa & Nihei, 2009; Iranmanesh *et al.*, 2011; Iranmanesh, 2012; Wilches-Gutierrez *et al.*, 2012; Balboni *et al.*, 2013; Lopez-Sierra & Rodriguez-Sanchez, 2015; Busolo & Woodgate, 2015; Rietjens *et al.*, 2017; Huang *et al.*, 2019). All these studies have taken a deeper look at the relationship between religion, spirituality and culture as they affect end of life decision-making and family caregivers' experiences, encouraging palliative healthcare providers to be very sensitive to all these factors at all times of decision-making.

3.4.3 Implications

The cultural background of an individual affects end of life treatment. However, different cultural thoughts about death help to build links to draw closer to others (Hasegawa, 2011). Recent years have shown how terminal (end of life) medical treatment and care have become facility-centred, especially for hospital-centred care. The end of life care of an older person, be it at home or in the nursing home setting, involves the crucial role of a family caregiver, whose warmth and human bond become an essential part of the most important event at the end of life of the older person. A family caregiver's presence and involvement help complete the individual life with dignity (Hasegawa, 2011).

Thus, the topic of death will continue to be perceived differently within different cultures, attached to emotional, social and cultural significance (Cherny *et al.*, 2021). There are reportedly misconceptions about palliative care worldwide. The potential language barrier or post-traumatic fears may compound and confuse some immigrants seeking palliative care in their new host countries (Gavagan & Brodyaga, 1998). In many countries, including Asia, Africa and Europe, decisions on end of life and what nurses tell patients depend mainly on their family caregivers. The patient's autonomy is deemed as being significant in the UK, USA, Canada, Australia and Germany (Brown, 2014).

Dying is an individual matter influenced by one's culture and religious, spiritual and social background. One unique aspect of cultural beliefs, mores, standards and guidelines play significant roles in end of life decision-making. Culture influences us in every way, as it involves sets of rituals and ceremonies. Some of these are helpful in one's inner peace in matters of end of life, for example, the choice of place of death (Allegra Learning Solutions, 2015). In the same way, religion and spiritual beliefs affect decision-making in end of life matters. Alternatively, faith helps one view life differently, as some Christians engage in prayers and meditations. In contrast, others find peace in carrying out rituals customary to their beliefs (a practice seen in many countries). In Niedersachsen, and specifically Bremen, the case is the same and calls have been made for awareness from health workers, stakeholders and healthcare providers to respect and treat every individual case differently.

The patient must honestly communicate their cultural, religious and spiritual needs, in order to enable healthcare workers in their planning strategies to support the dying, and make the journey less painful for all concerned in the end of life matters.

3.5 Chapter Summary

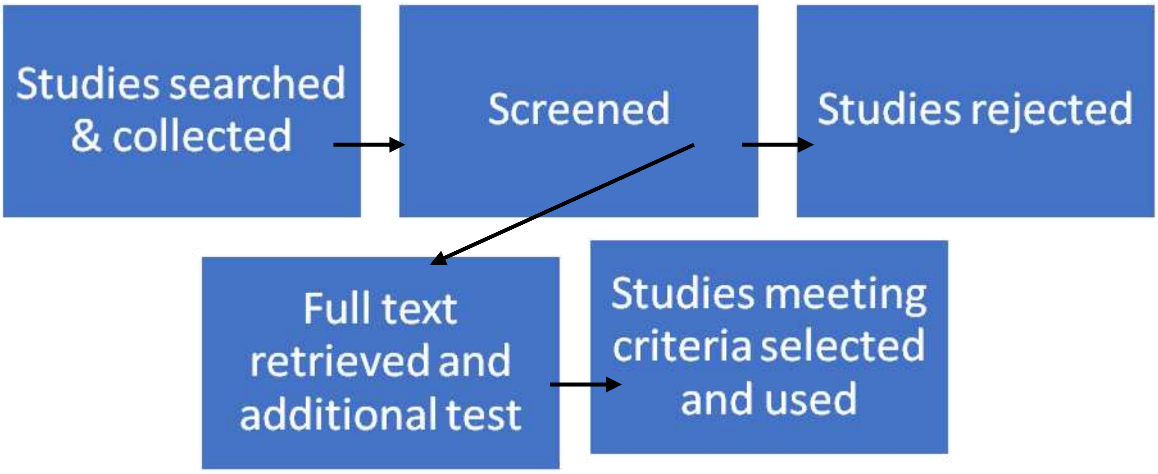
Despite the considerable progress made to integrate palliative care in all settings, especially in nursing homes, palliative nursing care is yet to find its proper place, due to the many reasons mentioned above. Historically, palliative care favours the young and also cancer cases. In order for palliative care to reach all those in need, including older people at end of life and their families, the numerous barriers seen by healthcare professionals and carers need to be addressed. For example, global health policy factors are militating against caring for those in need, particularly at the individual level (status, age and social position). For example, organisational and institutional factors preventing access to appropriate drugs for use in older people's nursing homes have, in most cases, led to a mixture of barriers and unforeseen problems in end of life care of the elderly. Hence, there is a need for quality information about the global state of palliative care, with the further education of nurses and clinicians to understand the importance of including family caregivers in palliative care plans, especially in the nursing home. General practitioners are at the centre of health professionals' palliative care delivery for older people. The professionals in health involve specialised services such as palliative care teams where necessary. Within the German Health Care Reform (Schmidt, 2007), the legal framework created allows for this. As far as its realisation is concerned, the healthcare system must ensure that the spotlight remains on the needs of patients and not on policy conflicts and rivalries between healthcare professionals (Brüeckner *et al*., 2009).

CHAPTER 4: LITERATURE REVIEW

4.1 The Selection Process

This chapter will review the published literature on the current state of research on family caregivers' experiences of palliative/end of life care in the nursing home and the effect on their quality of life, with a focus on long-term care. The literature search was undertaken during the period of May 2021 to June 2022.

Figure 4.1: Literature Selection Process



4.2 Introduction

This chapter will review the published literature from authors, pooling information from previously conducted relevant research work that aligns with this study's topic. Evidence has shown how research papers and journals of other authors have supported previous published and unpublished studies. Hence, the findings from other studies are likely to identify typical relationships between certain concepts and why there should be other identifying relationships and characteristics between certain concepts, along with justifying why a problem or phenomenon exists or is worthy of additional study.

The essence of reviewing the published literature is to make a critical and in-depth analysis of other studies to extract resourceful, scientifically sound and convincing answers and results to support this present study. In other words, the literature review for this study will help to develop the research questions by selecting literature dealing with similar issues. Once selected, these publications will be assessed and analysed, and it is through this process that answers to research questions that align with the current topic of this study might be elucidated (Aromataris, 2014). This chapter will also summarise and present overviews of the knowledge gathered from past and more recent studies in this field.

At the centre of the present research study is the growing interest in the family caregivers of older persons suffering from diseases other than cancer and how they experience palliative and/or end of life care in a nursing home. Families play a significant role in the care of the elderly and when they become dependent, families are there even at the end of life in every healthcare setting.

4.3 Methodology

A systematic search of the literature related to the study topic was undertaken using the Cumulative Index for Nursing and Allied Health Literature (CINAHL) and German Health Research Information from May 2021 to June 2022. A total of 20 studies met the inclusion criteria.

The search entailed selecting the most appropriate keywords and relevant databases for this thesis. The literature search and selection process included previous and current studies in line with this study's research topic: 'observing the experiences of family caregivers of older persons (positive and negative palliative/end of life nursing experiences) in the nursing home and of family caregivers whose older persons are recently deceased'. Selection of the literature to be reviewed was based purely on the inclusion and exclusion criteria. These criteria aimed to enhance the relevance of the articles concerning the topic of study and to assess the answers to the literature review questions that had been raised.

4.3.1 Inclusion and Exclusion Criteria for the Literature Review

After the data search, a further assessment of each study's relevance was made by reviewing articles using inclusion and exclusion criteria. Publications that fell under the inclusion criteria were relevant to the study. These included articles with full-text access, those that answered the research questions, peer-reviewed articles and articles related to the topic of the study. In addition, articles published within the last twenty-five years were favoured, scientifically-based articles and those that used the English and German languages were included. Excluded were studies that were not relevant.

The research literature used in this study was from the State and University Library Bremen (SuUB), the State Library Lilienthal, the National Library of Medicine (PUBMED), as well as literature from the German Centre for Age and Population Issues (GeroLit). The three primary PUBMED databases (Medline, Psych Info and the Social Science Citation Index) were applied in this research to answer some of the questions raised. More than 400 studies, including nursing and health journals were found, with no restrictions on publication dates but favouring recent studies. The articles/literature used in this review went through selection criteria, including a survey of patients, family members, and healthcare providers on different types of end of life issues, along with qualitative studies on labelling diseases and how they affect the care and experiences of the family caregivers of the dying.

Articles published in English, a few in German and carefully selected others were included, with no strict year restrictions. Relevant literature on end of life care of the older person and family caregivers supported by palliative care nurses were selected using keyword searches of the primary bibliographical databases in the clinical, behavioural and social sciences. Multiple keywords including ‘death’, ‘dying’, ‘palliative care’, ‘healthcare’, ‘nursing care home’, ‘healthcare of the elderly’, ‘families’, ‘family healthcare’, ‘caregivers’, ‘patient comfort’, ‘qualitative description’, ‘end of life’, ‘nursing care’, ‘qualitative descriptive design study’, ‘qualitative design’, ‘older people’, ‘family carers’, ‘transition of care’, ‘curative medical care’, ‘rehabilitation’, ‘palliative nursing care’, ‘transitional care’, ‘dying elderly’, ‘end of life decision-making’, ‘LTCs for the elderly’, ‘nursing/medical palliative curriculum’, ‘palliative team’, ‘old age’ and ‘German health institution’ were used in the search. Literature based upon nursing-related research where the authors used ‘QD’ or ‘qualitative description’ were also included.

The authors of the selected literature also identified other relevant authors in their research references and bibliographies.

4.3.2 Summary of the Literature Review Methodology

The theoretical framework of this study opens discussions on the palliative/end of life nursing care experiences of family caregivers of older persons, comparing it with other published cases, including advanced cancer and dementia. However, the transition of care of the elderly at end of life is widespread and affects family caregivers’ experiences, particularly those in older people’s homes.

The data sources provided information about family caregivers’ experiences from different sources and individually. The use of widely differing publications from many authors helps reveal any loopholes and shortcomings as seen in other places from the side of the nurses and complaints from family caregivers, as highlighted through the different literature used, that might not have been otherwise considered. Also, characteristics of family caregivers are prone to neglect and barriers from every level need to be identified in the selection process. Some literature presented positive results on family caregivers’ experiences, others negative.

This study’s attention is towards worldwide research projects that explicitly deal with family caregivers of older people at the end of their life receiving palliative care in a nursing home and their experiences of that nursing (both positive and negative). Since family caregivers have their own exact needs, irrespective of the setting, some examples are drawn from other healthcare settings with similar cases. Family caregivers of persons with advanced cancer tend to dominate the literature, because palliative/end of life care of patients with cancer traditionally dominates studies in this field. However, with this aim in mind, the content of this present work has not deviated.

People who have worked in healthcare and have enjoyed a professional education are more sensitive to family caregivers’ needs. Against this background, the subsequent implementation will focus on research based on the testimony of family caregivers.

Palliative/end of life nursing care of older people with other terminal conditions apart from cancer and the family caregivers’ experiences at end of life in long-term care (within nursing care homes) seem not to be a priority for nurses. Also, many nurses lack adequate palliative/end of life care knowledge which might have been gained from other healthcare settings. They are often under work pressure to attend to those in their care, including the family caregivers.

However, the theoretical assumptions for this present study are based on my own preliminary work from 2019, which served as a theoretical sensitisation to the topic of investigation. Most of the research interest directed at the family caregivers’ experiences at end of life in a nursing home has concentrated mostly on cancer patients and their family caregivers; even cancer cases dominate the media’s attention. However, family caregivers of older people with other medical conditions receiving palliative care in nursing homes have reported more positive experiences than those in the hospital setting. This assumption, gained in the first literature review, is based on the evidence of family caregivers’ experiences of end of life care in nursing homes. Research studies that used qualitative, quantitative and even mixed designs were assessed.

The research results based on the evidence of family caregivers’ experiences of nursing care at end of life are primary sources from the Anglo-American language area, German studies and a few selected others. The contextual background knowledge on long-term care institutions was not strictly limited to the English and German-speaking sectors where specific publications were identified. The results of more recent relevant German studies that were not completely available at the time of the data analysis of the present work are included in the discussion.

Theoretical approaches provided the first assumptions according to which a family caregiver's experience is determined. Various expert discussions, other relevant end of life care and works of literature, exchanges of knowledge with the Nursing Administrator at AOK Health Insurance in Niedersachsen, some family caregivers and nurses in a small number of old people's care homes on the current topic, and the suggestions from my personal supervisor all enabled the academic argument about the chosen topic.

4.4 Findings from the Literature Review

Most studies related to the end of life of older patients; some family caregivers have reported negative experiences in some studies such as: "burdens", "depression", "exhaustion/tiredness" and neutral experiences such as "family needs" at end of life. However, some family caregivers reported positive experiences: "hope", "commitment", "opportunity to show love" to their older relative, and "reflecting on life" were identified in some studies. Most studies on this topic indicate that assessments regarding family experiences and needs should be performed on various aspects carefully, cognitively, continuously and in every healthcare setting. However, many negative experiences analysed in this study were related to a lack of social support. When family members share patient-care duties and the nurses provide enough social support, the families tend to experience nursing at end of life positively and are more satisfied.

Regarding end of life care, healthcare professionals have historically focused more on patients than their family members (Lee, 2001; Main, 2002; Fox-Wasylyshyn *et al.*, 2005). Researchers have also focused on the end of life of patients, with only a few consulting family members surveying their experiences (Sung, 1996). Lee (2001) highlights nurses' potential for assisting patients' family caregivers in end of life care, since families are not passive observers but play an active, vital part at the end of older patients' care and medical treatment by acting as caregivers and decision-makers. Hence, the inability of a family caregiver to cope with the end of life situation of an older patient may lead to family dysfunction that could negatively impact on the patient (Fox-Wasylyshyn *et al.*, 2005). Nurses should understand families' attitudes toward death and dying and feelings such as fear, panic and anxiety within the family, because these can directly affect the older patient's medical progress or condition (Sung, 1996). Therefore, it is crucial to understand what family caregivers experience during the end of life care of their loved ones in order to provide appropriate care for future patients and their families (Verhaeghe *et al.*, 2005).

Some research studies are quick to point out that the illness of a dying older person affects family caregivers psychologically, mentally, physically and even financially. Kristjanson (2004) terms family caregivers as 'hidden patients' who equally deserve attention from professional caregivers of health. Since the 1990s, the growing interest in issues relating to end of life care has increased, and researchers have started to look at patients' families as quasi-patients. The number of studies using various research methods on family caregivers of end of life older patients has been steadily increasing, albeit numbers are still quite low. Only 35 publications relevant to this study were analysed, a small number compared with other similar topics (Verhaeghe *et al.*, 2005; Andershed, 2006). Several of the publications on this topic were Korean studies for Masters or Doctoral theses, which provided only limited data relevant to this study area.

Healthcare providers who view the family as the unit of care can better assess and identify support for those in need of assistance and enhance the family caregivers' experiences. During the palliative/end of life phase of illness (as end of life care), attention to family caregivers who may be psychologically vulnerable, lack resources or have concomitant health issues and concerns constitutes good preventive family care. If we do not care for these family members and know their experiences at this challenging time in their lives, they may well become our patients sooner rather than later. Some studies have looked at nursing homes as settings where end of life care takes place (Bollig *et al.*, 2021). Nursing homes are becoming a common setting where delivering end of life care for older adults is made possible. They often represent the junction between the curative and the palliative phase (Gonella *et al.*, 2019). Family caregivers' experiences tend to be neglected by the nurses at the end of life of the older person. It is necessary to understand the experiences of family caregivers to provide appropriate care for them (Yoo *et al.*, 2008).

A study on the long-term care of bedridden patients in Thailand has been reported by Suriyanrattakorn and Chang (2021). This study investigates whether higher levels of care to patients resulting in their increased satisfaction with long-term care results in greater happiness and satisfaction for their family caregivers. The significant independent variable in this study is 'care-receipt satisfaction' in long-term care, which can be used as the proxy to represent long-term care service quality. Suriyanrattakorn and Chang (2021) mention that patient satisfaction is vital for measuring the healthcare quality of family caregivers' experiences. The link between satisfaction in health services and happiness may vary, depending upon the type of health services involved (Roberts *et al.*, 1983; Matsuguma *et al.*, 2018). Kane & Kane (2001) state that happiness or satisfaction in life is one of the most aspiring long-term care policy goals, while Dolan and Metcalfe (2012) suggest that subjective well-being should be one of the primary outcomes of appraising healthcare policy. Most published research on long-term care's impact on the elderly's physical functioning shows a positive relationship (Sasat *et al.*, 2014; Abruguah *et al.*, 2019). However, only a few studies have analysed the impact of healthcare satisfaction on the elderly's subjective well-being (Roberts *et al.*, 1983; Matsuguma *et al.*, 2018; Abruguah *et al.*, 2019).

Gonella *et al.* (2019), in a mixed-design study, assessed 18 cases that met inclusion criteria to analyse the experience of family caregivers. A 'life crisis' often resulted in a changed need for care, and a patient-centred environment sustained the transition towards palliative care. The family caregivers described good end of life care as being the provision of good nursing care to their older person in the nursing home. They described examples such as 'primary care', 'spiritual support', 'recognising and treating symptoms', 'assuring continuity in care', 'respecting resident's end of life wishes', 'offering environmental, emotional and psychosocial support', 'keeping family informed', 'promoting family understanding', and 'establishing a partnership with family caregivers by involving and guiding them in shared decision-making'. These elements improved the quality of end of life for residents, their families and caregivers, thus suggesting a common ground between good end of life care and palliative care.

Many studies exist that deal with family caregivers' experiences. However, only a few studies exist that specifically identify the experiences and perspectives of family caregivers of older people at end of life in nursing homes. Based on this, more studies are needed to look into family caregivers' experiences, especially in nursing homes; hence nurses need to be more aware of the experiences of family caregivers and their potential needs. Regarding end of life care, healthcare professionals have historically focused more on patients than their family caregivers and other family members (Lee, 2001; Main, 2002; Fox-Wasylyshyn *et al.*, 2005).

Most studies that have dealt with family caregivers' experiences of palliative care and end of life care of older people in nursing homes have been in Western societies. Thus, further studies in diverse regions with an ethnically diverse population range are required to identify what kinds of experiences (positive and negative) are prevalent and how many negative experiences were related to the quality of life of family caregivers at that time (Kim & Yi, 2015).

Scientific studies focused on family caregivers' situations in research studies have been published for more than 20 years. American studies dominated at the beginning (Schneekloth & Wahl, 2008). Schulz and Beach (1999) report on a caregiver health effect study that family caregivers are affected by significantly higher mortality compared to people without family caregiving tasks.

As older adults approach the end of their life, many are faced with complex decisions, including whether to use medical advances to prolong their life. Limited information exists on the priorities of older adults at the end of life and their family caregivers (Lewis *et al.*, 2019). One descriptive qualitative study was conducted utilising three focus group discussions (n = 18) and six in-depth interviews with older adults suffering from a terminal condition and their caregivers in New South Wales, Australia (Connors *et al*., 2020). The data was analysed thematically. Seven major themes were identified: ‘quality as a priority’, ‘sense of control’, ‘life on hold’, ‘need for health system support’, ‘being at home’, ‘talking about death’ and ‘competent and caring health professionals’. An underpinning priority throughout the seven themes was knowing and adhering to the patient’s wishes.

Family caregivers experience the nursing home placement of an older loved person differently, and many have expressed mixed feelings (Kellett, 1999). Kellett (2007) used four family caregivers’ stories of nursing home placement to uncover five shared meanings from the family caregiver’s perspective: ‘experiencing a loss of control’, ‘being disempowered’, ‘feeling guilt, sadness and relief simultaneously’, ‘possessing a sense of failure’ and ‘having to make a forced and negative choice’. No matter the healthcare setting, negative family caregivers’ experiences can bring about threats to the safety and quality of life of the dying elderly person.

Several studies have assessed family caregivers’ experiences in nursing homes. However, these studies have centred on advanced cancer cases in all healthcare settings such as homes, hospitals, hospices and palliative units. Unfortunately, very few research studies exist that have considered the experiences of family caregivers (negative and positive) specifically in the nursing home setting, either in Germany or elsewhere, based upon the perspective of the family caregiver. This lack of studies that include such experiences, either negative or positive, has created difficulties in generalising the results and applying the findings to other countries.

Despite this review including only limited empirical findings, there is enough evidence from the selected studies to demonstrate that older people’s poor nursing care affects the family caregivers’ experiences, including fundamental human needs, which can result in stress, guilt, frustration and even depression. These are very negative experiences and need addressing. However, several studies have investigated family caregivers’ experiences from other perspectives, which are significant in continuing and improving care at end of life. Most of these studies have revealed that positive family caregivers’ experiences are lacking not only in nursing homes but also in the quality of care (Poghosyan & Brooks-Carthon, 2017; Brooks-Carthon *et al*., 2017). Furthermore, the varied reasons for missed care are essential to establish, as these affect the family caregiver’s experience.

Some studies argue that family caregivers’ experiences of palliative/end of life nursing care differ and that their negative experiences of older people at the end of their life in nursing homes results in a poor quality of life (Kim & Yi, 2015). Other studies have suggested that most family caregivers take on their role under sudden circumstances without the appropriate time to prepare for the uncertainties of end of life and face many uncertainties that need support from the nurses in the nursing home care setting. However, these uncertainties result in diverse and multidimensional needs, ranging from informational to physical and psychological. In most studies, the family caregivers' needs were not appropriately met, leading to negative experiences (Hwang *et al*., 2003; Kim *et al*., 2010; Given & Northouse, 2011; Printz, 2011b; Romito *et al*., 2013; Skalla *et al*., 2013).

Although numerous studies have been conducted previously on the needs of cancer patients at the end of their life, there is a lack of studies focused on older patients with non-oncological complex chronic multi-pathologies. Examining these needs/experiences of family caregivers would help to gain a greater understanding of the profile of this specific population within the palliative/end of life care pathway and how the health and care systems can address them. Medina *et al*. (2022) reviewed eighty-one studies demonstrating a great variety of unaddressed needs and negative family caregivers' experiences at end of life. The stress of poor nursing care of older patients affected the family caregivers' experiences and the complexity of detecting these needs and how to refer them to palliative care pathways was noted. This review also suggested a scarcity of tools and narrow pathways for professionals to satisfy the needs of these patients and their families, who often felt ignored by the system. Substantial changes will be needed in health and care systems at the institutional level, providing more specialised palliative and end of life care processes.

A Canadian study examined the perspectives of family members, registered nurses and healthcare aides regarding the last 72 hours of nursing home residents' lives in Canada (Goodridge *et al*., 2005). The study utilised an exploratory, descriptive design using semi-structured interviews. The study's participants consisted of 14 registered nurses, eight healthcare aides who had provided care during the last 72 hours before a resident's death, and four family caregivers who had visited within the same timeframe. Thematic analysis was conducted independently through consensus in this 220-bed nursing home located within a more significant long-term care facility in Canada. They identified themes and sub-themes emerging from the interviews. The caring behaviours of staff were central to the residents' dying process and involved assessment, coordination of care, physical care, family education and nurturing. The participants frequently reported family members' apparent ambivalence about the resident's death and fear of dying alone. Appropriate and timely symptom management and a range of caring behaviours of staff are critical elements in the dying experience of nursing home residents. Additional education and support for personnel caring for this group will enhance end of life care.

Yoo *et al*. (2008) summarised and analysed families' experiences of end of life care by conducting a systematic review of peer-reviewed journals in Korea and abroad. Families play an increasingly important role in care and medical treatment, acting as caregivers or decision-makers rather than just passive observers. It is necessary to understand the experiences of family members in order to provide appropriate care for them. Seventeen studies used a quantitative design, while 18 used qualitative methods. The quantitative studies reported that the family's quality of life was relatively low when the patient required high medical/nursing services. The perceived burden levels were moderately high, and depression levels were high among family caregivers. Various concepts emerged from the 18 qualitative studies, including psychological issues, physical problems, burdens, needs and interpersonal relationships. This study concluded that most previous research findings had focused on negative and neutral experiences, while only a few studies identified positive experiences. Based on these study results, I would suggest that nurses need to be more aware of the experiences of patients' families and their potential needs.

Much of the published research on the experiences of family caregivers has centred chiefly on hospice cases with advanced cancer, in the patients' homes and palliative units in hospitals (Lee & Cha, 2023). Few studies reportedly exist that have centred mainly in nursing homes. Wang *et al.* (2018) report using an assessment tool developed to measure the comprehensive needs of cancer patients' family caregivers, whereby each item measured was assigned a score ranging from 0 if the unmet need (negative experience) was not relevant, not needed or if the caregiver was satisfied with the support, through to a score of 3 if it was very much needed. A higher score thus indicates a more significant amount of unmet needs, amounting to negative experiences. The few studies that reported on family caregivers' experiences of nursing at the end of life of the older person all call for more research in this field (Kim & Yi, 2015).

Wang *et al*. (2018), in a systematic review study, identified the unmet care needs of family caregivers and the associated variables (in most cases, unmet needs were assigned as negative experiences), along with summarising the tools used for the needs assessment. Seven informal caregivers' needs were identified. Family caregivers' most commonly identified unmet needs, as negative experiences, were 'information needs, including illness and treatment information' (26%) and 'care-related information' (21%) (Aoun *et al*., 2010).[5] They investigated unmet needs from the perspectives of the patients or caregivers with a cross-sectional study design incorporating single time-point assessments. The authors identified significant heterogeneity, including differences in study contexts, assessment methods, measurement instruments, needs classification and reporting methods being noted across these studies. Unmet needs of patients with advanced cancer were associated with their physical symptoms, anxiety and quality of life. These, in turn, affected their family caregivers' experiences. The majority of studies included in this present review investigated

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[5] The most commonly used instruments for needs assessment among patients with advanced cancer were the 'Supportive Care Needs Survey' (n = 8) and the 'Problems and Needs in Palliative Care' questionnaire (n = 5).

unmet needs from the perspectives of patients and family caregivers using cross-sectional study designs and single time-point assessments. However, many other studies in this field have worked with valid and reliable instruments to address family caregivers' negative and positive experiences in older people's nursing homes.

The vital thing to note is that most authors understand that informal/family caregivers, no matter the healthcare setting, are usually regarded as fellow sufferers alongside patients (Proot *et al.*, 2002). Family caregivers' problems are linked closely with patients' well-being (Milbury *et al.*, 2013). Moreover, unsolved problems or negative family caregivers' experiences at the end of life of the older person will not only decrease their own quality of life but also affect the patient's end of life experience (Hodgkinson *et al.*, 2007). Informal family caregivers and patients with advanced cancer are considered as being a whole unit in fighting the illness (Lambert *et al.*, 2012; Wang *et al.*, 2018) and deserve attention from the nurses.

Family caregivers looking after patients with cancer, chronic obstructive pulmonary disease or chronic heart failure were purposefully recruited in Belgium, Germany, Hungary, the Netherlands and the United Kingdom (Van der Eerden & Groot, 2016; Ateş *et al.*, 2018). On average, quantitative data showed a moderate study burden, but the qualitative findings indicated that this burden might be underrated. There is evidence that IPC-i[6] with well-developed professional care networks and communication systems relieved family caregivers' burden by direct and indirect interventions (e.g., provision of night shift nurses or psychological support). The needs of family caregivers were similar in all participating countries. However, in all countries, IPC-i mostly offered one-off events for family caregivers, lacking systematic or institutionalised support structures. The data suggests that most IPC-i did not pay enough attention to the needs of the majority of family caregivers and did not offer them proactive care and access to supportive resources (e.g. training, respite care, access to resources). The study recommends recognising family caregivers as part of the unit of care and partners in caregiving to improve their knowledge about and access to available support. This study aimed to identify the experiences of families caring for patients with terminal cancer (Ateş *et al.*, 2018). The question was, "What is the caregiving experience of a family caregiver who has an older member with terminal cancer?" Grounded theory was applied and in-depth interviews with 11 family caregivers undertaken. Interviews were recorded with the interviewees' consent, transcribed and analysed. Participants' relationships with patients were six spouses, four daughters and one mother. The ages of the participants were between 32 and 62, with an average age of 47.5. The study showed "enduring with bonds" as the main category, and the main factor affecting this category was the "patients' diagnosis of terminal cancer." The families' experiences were divided into four stages: 'shock', 'confusion', 'struggle' and 'acceptance'.

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[6] IPC = Infection prevention and control.

Mediating factors were related to the patient, intimacy with the patient, social support, communication and trust. Conclusively, participants underwent internal maturity, and changes occurred in family, social and personal life. The families took care of the patients with responsibility and love and continued the care even when in other healthcare settings.

In a designed systematic review study, a meta-aggregation methodology was utilised. Five electronic databases were used for the study (Gonella *et al.*, 2019). This study presents qualitative studies (mixed-method designs) of end of life care experiences of nursing home family caregivers whose relative had died or was at the end of their life. No language or temporal limits were applied. In all, 18 cases met the inclusion criteria. A 'life crisis' often resulted in a changed need of care, and a 'patient-centred environment' sustained the transition towards palliative care. However, family caregivers described good end of life care as providing patients with primary care and spiritual support, recognising and treating symptoms, assuring continuity in care, respecting the patient's end of life wishes, offering environmental, emotional and psychosocial support, keeping the family informed, promoting family understanding, and establishing a partnership with family caregivers by involving and guiding them in shared decision-making. These elements improved the quality of end of life for both the patients and their families, thus suggesting a common ground between good end of life care and palliative care. The findings concluded by providing a family-driven framework to guide a compassionate transition towards palliative/end of life care in nursing homes.

In the findings of a separate qualitative study, patients and families emphasised the importance of health personnel anticipating illness trajectories and recognising the information and palliation needed (McCloskey *et al.*, 2018). Family members who became proxy decision-makers reported uncertainty and distress when health personnel lacked guidance, worried about staff shortages and emphasised doctor availability. Relatives and health personnel seldom recognised patients' ability to consent and patients' preferences were not consistently recognised.

A more recent study in Sweden involving people with advanced dementia showed that most die in nursing homes (Lundin & Godskesen, 2021). It stressed that there should be resources and strategies available for providing information to family members and involving them in the decision-making process, as they are often unfamiliar with the multitude of considerations involved in decisions such as whether to administer morphine. Nevertheless, end of life experiences for older people with frailty and their families were often seen as being 'poor'.

The philosophy of palliative/end of life care is that the person receiving palliative care and his or her family comprise the unit of care. Supporting the family is, therefore, a crucial part of palliative care. Family caregivers can provide help with personal care along with emotional, social and financial support. They often perform tasks that used to be performed by qualified nurses, such as assessing and managing symptoms and giving medication (Hall *et al.*, 2011).

Both the older person and the family caregiver become involved in the successful management of acute or chronic health problems and significant adverse health-related events (Beach *et al.*, 2020). In every society, nurses represent the largest group of healthcare professionals. Negative experiences related to end of life care demand a closer examination and recognition of these problems. Nursing care needs from the point of view of older people, care receivers in general and even family caregivers are different from those defined from the viewpoint of professionals or systems. Another recent review focused on the individual family caregiver's perspective (Kalankov *et al.*, 2021), whereby the informant or identifier of experiences of nursing care could be the informal caregiver, a family member or a professional.

In a cross-sectional survey study using a random sample of 5,000 inhabitants of Rhineland-Palatinate who had died between 25 May and 24 August 2008, family caregivers of these randomly-drawn persons who had died in a nursing home were interviewed using a written survey (Pinzoin *et al.*, 2010). Results of the study showed that those who had died were professionally cared for by a nurse who possessed professional home care knowledge in the four weeks prior to their death, but only very few persons had used a specialised palliative home care service.

Skilbeck and Payne (2005), in their research study, stated that palliative/end of life care for cancer patients had become the model for most end of life cases. Despite the positive results shown in most research publications, the authors reported that the model used for cancer patients might not be the most effective model for non-cancer cases and the family caregivers of older people with other terminal illnesses. Terminal care for older patients with life-limiting, chronic illness requires illness-specific treatment and the support of family caregivers. Despite being aided by an appropriately trained nurse who can transcend the boundaries between patient/family concerns and the treatment team to provide the best possible service configuration, older people and their family caregivers were deemed to need more positive experiences at end of life.

The WHO (2012) recommends patient- and family-centred care to address the problems of advanced cancer patients and their informal caregivers, including symptom and side-effect management, as well as emotional, psychosocial and spiritual support. All these aspects of support are typically categorised under palliative/end of life care.

Several studies have been made assessing family caregivers of dying older people's experiences globally. However, these studies have centred on advanced cancer cases in all healthcare settings such as homes, hospitals, hospices and palliative units. Unfortunately, not many research studies exist that have considered the unmet palliative nursing needs of family caregivers, specifically in the nursing home setting both in Germany and elsewhere, based on the perspectives of the family caregivers. This lack of studies that include the experiences and unmet palliative needs of family caregivers of dying older persons with other terminal illnesses, has created difficulties in generalising the results and applying the findings in other countries.

Most of the research studies selected in the search reported mainly on the experiences of family caregivers whose loved ones suffered from cancer, with less focus on family caregivers of older people with other diseases and debilities seen with old age in the nursing home. Patient and family care-centred interventions are significant in most palliative care settings. Unfortunately, as mentioned by Davies *et al.* (1995), no research study specifically describes how family caregivers of older persons cope with their experiences of palliative/end of life nursing care in nursing homes.

The study by Coyle and Kirk (2016) looking at transition and change of care at end of life states that this necessitates changes not only in the older persons but also in the family caregivers' lives. Depending upon who is involved in the care, in most cases, some of the literature identified partners (women mostly) or children as likely carers (Dahlin *et al.*, 2016). This may require them to redefine their needs. The authors mentioned some similarities in the needs of family caregivers of old persons in nursing home care receiving palliative/end of life care.

It is natural for older people to move to a nursing home and for their family caregivers to experience physical, mental, social and spiritual losses. However, family caregivers of older people in nursing homes hope to have their palliative nursing needs met by professional nurses at this crucial time. They become sad when nurses neglect their palliative nursing needs. Death may not be imminent in older people receiving palliative nursing care. The truth is that residents of nursing care homes in most developed countries are highly likely to die there, making these settings with palliative care and good end of life care experiences for both the older person and the family caregivers very vital (Garcia *et al.*, 2003; Froggatt & Payne, 2006).

Palliative care and end of life care are essentially synonymous. According to the WHO, palliative care is not to cure; instead, it improves the quality of life of ill persons, their families and friends (WHO, 2020). However, little or nothing about the family caregivers' palliative nursing or end of life care needs and concerns in the nursing home is known compared to the patients' needs (Oechsie, 2019). It is still largely unknown how family caregivers experience integrated palliative care (ibid.), which is why this subject is to be investigated in this current study. However, many studies have demonstrated that the unmet needs of family caregivers of cancer patients are diverse. Hence the high prevalence of unmet family caregivers' needs that result in the negative experiences seen in all settings (Hwang *et al.*, 2003; Kim *et al.*, 2010; Given & Northouse, 2011; Printz, 2011a; Romito *et al.*, 2013).

A study from British Colombia (Gallagher & Krawczyk, 2013) perceived a high level of satisfaction with end of life care by some family caregivers, focusing on the last 48 hours of life, using a validated instrument used in a telephone survey made with bereaved families (n = 90) of patients who had died within an organisation in British Columbia. Some bereaved family members expressed many unmet needs; for example, dissatisfaction with how the information was given to them by the nurses concerning the changing condition of the older person, the process of dying in the older person, symptoms management and what to do at the time of death.

Many authors also expressed that most older people's needs to live a pain-free life remain unmet, which affects their family caregivers (Schonfeld & Quackenbush, 2009). For example, palliative care nurses do not adequately address their emotional support and that of the family caregivers' own emotional needs. It is a known fact that the last place of care of the older person has the most significant effect on all of these variables, with acute care experienced in older ages still having the most unmet palliative care needs. Hospices had the fewest unmet needs, followed by the palliative and intensive care units. This study concludes by offering possible practices that address the end of life needs of family caregivers.

Several studies in this field have supported the notion that family caregivers of older people with life threatening diseases, including cancer, experience negative nursing in the nursing home (Hwang *et al.*, 2003; Kim *et al.*, 2010; Given & Northouse, 2011; Printz, 2011a; Romito *et al.*, 2013).

Some studies identified emotional support, disease-specific knowledge, carer role responsibilities, self-care and general practical support as family caregivers' most commonly expressed needs which are often neglected in healthcare settings. Some unmet needs include access to professional services, formal education opportunities and communication with health professionals. However, family caregivers are concerned and worried when the needs of their dying person are unmet; hence, family caregivers feel satisfied when nurses meet these needs.

A sizeable systematic review analysed the recent literature on unmet palliative care needs of advanced cancer patients' family caregivers (Wang & Molassiotis, 2018). The authors stressed significant heterogeneity in contexts, assessment methods, measurement instruments, classifications and report methods. Most studies on this topic evaluated unmet needs in cross-sectional designs, with most concluding that 'information' was the central theme in most contexts of unmet needs of family caregivers. Information categories were either 'illness or treatment information' (26%) or 'care-related information' (21%).

In order to clarify some unmet needs of family caregivers of patients with advanced cancer, one study aimed to further elucidate how family caregivers' needs are defined (Hwang *et al*., 2003). Their qualitative interview study categorised the needs of family caregivers of advanced cancer patients. For example, 'social needs' (in the form of care, effective communication & financial support), 'cognitive needs' (educational support and support in decision-making) and 'psychological needs' (support for family caregivers in preparing for the imminent death of a loved older one as well as support during bereavement) (ibid.).

Generally, according to some authors, the most frequent needs of family caregivers of neuro-oncological patients during hospitalisation and after discharge are primarily material and informative. Specific needs tend to decrease over time; in particular, the "need for knowledge about the disease" and "information/communication needs" (Kuba & Weißflog, 2017). They analysed the specific needs of patients with haematological cancer and their partners. They could demonstrate that their supportive care needs were lower in the dimensions of "health system/information" and "physical problems/daily living" compared to an advanced cancer patients' validation sample. Partners' supportive care needs were higher in cases perceiving the patient's negative dyadic coping. At the same time, socio-demographic and illness-related factors were only partially associated with the partners' supportive care needs.

Relatives of advanced cancer patients have reported high rates of psychological and existential distress, burden and psychological morbidity during the entire disease trajectory of the patient. In addition, relatives report an alarmingly high number of unmet needs, with information being the central issue. Several authors have supported the argument that patients' unmet palliative needs adversely affect family caregivers' needs and quality of life. Moreover, this is at the core of research interest (Haley *et al*., 2003; Wilkinson, 2010; Collins & Swartz, 2011; Harding *et al*., 2012; Verbakel, 2014; Higginson, 2015).

Caring for a dying older person usually lasts until their death. However, family caregivers interviewed in some studies have expressed onerous burdens caused by the illness of a loved one (Payne & Grande, 2013).

The question of family caregivers' palliative/end of life care experiences should be taken seriously in every setting, as family caregivers feel safe when they know and experience nurses who are understanding and know what is in their best interests. Unfortunately, research has shown that participants, when interviewed, were reluctant to disclose their unmet nursing needs, despite having identifiable physical and psychosocial domains (Ventura, 2014). However, the variables of those family caregivers who are at higher risk of having at least one moderately or highly unmet palliative nursing care need based on relevant socio-demographic factors (e.g. age, gender) and clinical reasons (e.g. type of disease of the older person, phase and pathway of the disease) highlighted and identified the resulting anxiety, sleepless nights, loss of appetite and depression in caregivers.

Nineteen million people are estimated to need palliative care worldwide each year (WHO, 2020), and evidence to help relief from symptoms and offer support to older people in nursing homes and those close to them at the end of their lives is an ongoing priority. One literature review of end of life care in the UK (Neuberger, 2013) expressed severe concerns about a lack of research in this field and the underuse of existing research. Less than 0.3% of the £500 million spent on cancer research went into research on palliative care for cancer cases and their family caregivers' palliative needs (ibid.), with funding for non-cancer conditions and their family caregivers' needs likely to be even less.

Hashemi *et al.* (2018) used semi-structured interviews and purposive sampling to interview the family caregivers of end of life cancer patients. The interviews were recorded, transcribed and analysed using qualitative content analysis. The results investigated and identified unmet social, cognitive and psychological needs. The 'social needs' category comprised the subcategories of 'support for care', 'effective communication' and 'financial support'. The 'cognitive needs' category comprised 'educational support' and 'support in decision-making'. The 'psychological needs' category comprised 'support for psychological trauma', 'preparation to confront the reality of the death of a loved one', and 'support for mourning'. This study concluded that family caregivers of end of life cancer patients take on the responsibility for many aspects of care for their patients, while many of their own needs remain unmet. Nevertheless, the findings of this study, when used for healthcare policy planning and the development of palliative interventions, particularly for the family caregivers of end of life cancer patients irrespective of healthcare settings and the age of the person suffering, improve the models used in nursing homes and places standards that improve family caregivers' experiences (see also Adams *et al.*, 2011).

In a separate study, family caregivers who participated in a study interview reported an alarmingly high number of unmet palliative needs that have affected their nursing experiences at the end of life of their elderly relatives (Wang *et al.*, 2018), with 'information' being the central theme. They identified that further information and support strategies for family caregivers are urgently required. Family caregivers' information needs are significant, as they value good communication with healthcare professionals. Barriers exist on the part of family caregivers seeking information about the end of life of their loved one, which reportedly prevented them from planning their last days. Family caregivers were not well informed of the older person's prognosis, which affects their experience, which has led to the dying process causing emotional unpreparedness for death. Nevertheless, the authors support that when family caregivers become aware of deterioration in health, the family caregiver is well prepared and feels supported.

Family caregivers of dying older people in nursing homes have also complained of inadequate staff presence that can affect caregiver-centred care (Tilden *et al.*, 2012), far from exemplary implementation of the palliative care approach (Frey *et al.*, 2017).

A number of studies have reported poor knowledge of palliative care by nurses working in old people's residential nursing homes. Some studies cite family caregivers who express the failure of nurses to recognise residents who require early palliation and, as such, fail to recommend cases to the GP, suggesting a need to improve education regarding palliative care (Wilson & Daley, 1999; Vohra *et al.*, 2006).

Lithuania and many Central and Eastern European countries employ a palliative care system based on the Semashko model (Groenewegen *et al.*, 2013). Many family caregivers, initially during the Soviet Union years, traditionally played a significant role in the long-term care provision of their elderly relatives (op. cit.). Unfortunately, their palliative nursing experience in nursing homes went unnoticed.

In a separate study in Lithuania, Kontrimiene *et al.* (2021) cite some of the difficulties that family caregivers have experienced. Some professionals from the healthcare system felt that family caregivers' integration into the Lithuanian healthcare system was inadequate. According to the focus group study, family caregivers did not feel like members of the health and social care network, but rather like isolated individuals fighting against the network in all healthcare settings, including older people's nursing homes. They mentioned several hurtful interactions with the healthcare system, which supported their negative experiences.

Most unmet needs of family caregivers constitute negative experiences and, at the same time, have immediate consequences on family caregivers' everyday lives. According to some authors, family caregivers with patients in palliative/end of life care are part of the formal and informal care network and persons in need of support (Ateş *et al.*, 2018). However, studies should exist that encourage family caregivers to voice their palliative/end of life care experiences, especially in older people's nursing homes. This way, family caregivers' experiences would be unveiled and it would be possible to establish plans that integrate family caregivers' experiences into the nursing curriculum.

In a semi-structured interview study conducted in nursing homes in Belgium, Germany, Hungary, the Netherlands and the UK, most palliative teams ignored family caregivers' emotional and information needs and did not offer proactive care and access to supportive resources (Ateş *et al*., 2018). Essentially, the family caregivers' experiences of the older person at end of life goes unnoticed. The authors recommend recognising family caregivers as part of the 'unit of care' and as partners in caregiving to improve their knowledge about, access to and support of patients.

A separate study on the unmet needs of family caregivers of older patients with progressive neurological disease in the Czech Republic, using grounded theory, conceptualise the patterns of unmet needs, including a lack of information about the disease and available support (Buzgova *et al*., 2019). Family caregivers interviewed in this study expected healthcare workers to inform them about the prognosis of the disease and where they could obtain possible help from the health and social welfare services. The study's outcomes show that the unmet needs of family caregivers constitute a negative experience.

Higher numbers of unmet needs of family caregivers have been associated with psychological distress (Janda *et al*., 2008; Hackett *et al*., 2018) and overall burden (Sharpe *et al*., 2005). Needs-related factors negatively impact family caregivers' burdens: a lack of care training, low available support and a large discrepancy between the family caregivers' and patients' reports of unmet patient needs, indicating that managing medical, non-medical and direct patient care activities may be lacking (Mollica *et al*., 2017).

The impact of socio-demographic characteristics of family caregivers on their support seems to be low (Janda *et al*., 2008), but some effects of partnership and financial aspects may be involved (Foreva & Assenova, 2014). Satisfaction with patient care seems essential for perceiving one's own unmet needs (Park *et al*., 2018). Studies suggest that family caregivers whose elder ones are treated in a specialist palliative care setting are more likely to have their palliative nursing needs met (Frindriksdottir *et al*., 2006) and some studies have distinguished specific aspects contributing to potential benefits as well as relevant deficits (Perner *et al*., 2012; Klarare *et al*., 2016; Ateş *et al*., 2018). In line with all the points raised, the impact and experiences of family caregivers being involved with older people's palliative/end of life care in nursing homes remains controversial (Mohammed *et al*., 2018).

As part of an investigation in Auckland, New Zealand (Frey *et al*., 2017), 26 family members involved in the care of residents who had died within the last 12 months were interviewed. The range of responses was in line with Donabedian's (1966) model of the structure, process and outcome regarding their loved one's long-term care. The outcome showed no evidence of a well-managed transition to palliative care, stating that there were unrecognised needs for family caregivers; for example, information gaps and the family caregivers felt 'out of the loop'. Frey *et al.* (2017) identify the implications of not involving family members and relevant healthcare providers to promote patient palliative/end of life care and help in bereavement.

The most frequently used sources of support for family caregivers were informal sources, such as family, friends and funeral providers, with support from professional sources seen as lacking (Aoun *et al.*, 2018). Family caregivers have a relevant impact on the patient's well-being, care situation and quality of life but, at the same time, they are also affected by the patient's situation in terms of their own specific burdens and needs. They tend to forget their needs as long as the needs of their loved ones are met by the nurses and professionals.

A study conducted in Trinidad and Tobago identified the importance of involving family caregivers in palliative/end of life nursing care of cancer patients in their last year of life. This type of study is also generally applicable to the end of life of older persons. This study interviewed fifteen family caregivers (the spouses and children of the deceased). The research findings identified unmet needs of some family caregivers that constituted negative experiences; for example, delayed diagnosis and treatment, poor transition, and a lack of social support and financial aid (Cox-Seignoret & Maharaj, 2020). Similar results were seen in Australia (ABS, 2018), British Columbia (Gallagher & Krawczyk, 2013), Lisbon (Portugal) (Aparicio *et al.*, 2017) and Belgium (Vrijens *et al.*, 2013). Studies conducted in New Zealand (McKinlay *et al.*, 2021) and the United Kingdom (Livingston *et al.*, 2010) critically studied family caregivers engaged in the decision-making for their loved ones at end of life.

Virdun *et al.* (2017) state that many of the supporting family's needs are not met within acute settings and suggest the need to improve this situation to achieve optimal results and better family caregivers' experiences.

Hashemi *et al.* (2018) conducted a qualitative study using 18 family caregivers. They concluded that the family caregivers of end of life cancer patients take on the responsibility of many aspects of care for their loved ones. However, many of their own needs remain unmet. The findings of this study, when used for healthcare policy planning and the development of palliative interventions in nursing, particularly for the family caregivers of end of life cancer patients, help in formulating models that will improve nurse/family caregiver relationships.

In a longitudinal literature study, Ullrich *et al.* (2021) point out that the information about changes in the patient's condition ranks as a high need, also citing the unmet needs of family caregivers relating to information of the situation and the feeling of a lack of hope for the patient. The higher satisfaction of family caregivers' experiences of palliative/end of life nursing care related in the study to better social support care. In conclusion, better information and provision of tailored services might improve family caregivers' situations in the future.

Ullrich *et al.* (2017) acknowledge that providing a suitable environment for terminally ill patients is very important, and their study suggests that this may also be good for family caregivers. Such an environment should consider aesthetics, multi-sensory impressions, a space for privacy and a space for social discussions. Meeting the family's needs will affect meeting the needs of the family caregivers, perceived by families as being supportive.

However, family caregivers interviewed in previous studies have described their experiences in the form of unmet needs of palliative care provisions for their older person (non-cancer cases). For example, inadequate information and unawareness of prognosis and outcome align with previous studies in this field (Goy *et al*., 2008; Hasson *et al*., 2010). In a review study focused on older people who have cancer, the WHO (2020) found that unmet care needs exist mainly in psychological, information and physical domains.

Some of the few literature reviews on family caregivers' experiences of unmet needs of palliative nursing care in the nursing home have shown that most healthcare workers underestimate family caregivers' palliative/end of life nursing experiences. They, therefore, suggest a holistic care plan model that considers the needs of family caregivers in every nursing home setting. Dying older people with life-threatening diseases need pain management, including symptom management (Garcia *et al*., 2003), spiritual care and other needs which professional caregivers fail to meet. This negligence affects the family caregiver's state of mind. Moreover, experiencing the psychosocial and spiritual needs of the dying elderly, as previously mentioned, is vital to family caregivers' satisfaction. For example, involving patients and family caregivers in decision-making (Garcia *et al*., 2003) and promoting dignity in end of life care in older people's homes are essential needs of family caregivers. Nevertheless, care for dying older people in nursing homes and their family caregivers' needs differ from palliative care and must be a part of medical school curricula. Unmet family caregivers' needs are similar in all health settings.

Some selected studies demonstrate very different results, and the values are even more extreme than might be expected. In Belgium, the number of relatives who expressed dissatisfaction because of inadequate communication about the diagnosis of their loved one was considerable (Masefield *et al*., 2019). Astonishingly, the ability to communicate adequately is still lacking in most healthcare settings in the UK, Germany and elsewhere. However, the dimension is particular and depends heavily upon constant updating and better education for nurses and doctors engaged in palliative/end of life care on the palliative needs of family caregivers and how they experience end of life care. Likewise, the wide range of results differed in their methodological approaches and cultural differences when dealing with family caregivers' palliative/end of life needs in the nursing home. Factors such as legislation and the organisation of how palliative/end of life care should be and who gets palliative care also affected the results reported. For the reasons mentioned above, there is a need to better understand how to improve the process of end of life matters and meet the needs of family caregivers'. To do so requires that one needs to understand:

- How nurses are now engaging in end of life decision-making with family members of acutely ill older patients.
- The roles that nurses play and the strategies they use to enact these roles in the nursing home.
- The typical outcomes of their efforts for patients and family caregivers.

It is essential to understand the palliative/end of life nursing needs of family caregivers and the process to improve how nurses meet their needs. The vital purpose of this study is to characterise the family caregivers' roles, challenges and experiences of palliative/end of life care in the nursing home, along with the strategies nurses use to accomplish these needs, and to document how patients and family caregivers respond to these interactions. The outcomes of this research will enhance current practices and hopefully achieve better results, benefiting the dying elderly patients and their family caregivers in the nursing home.

Despite all efforts to incorporate palliative/end of life care in the nursing home, finding effective ways to support family caregivers and understand the experience of palliative/end of life care remain problematic, due to the many reasons mentioned earlier. Increasing numbers of older people within every society means increasing numbers of older people with life-threatening illnesses, palliative needs and more responsibility for family caregivers. Some authors suggest respite care as a strategy for relieving the burden on family caregivers (Stajduhar *et al.*, 2008; Hasson *et al.*, 2010). Notwithstanding the suggestions made by some authors that respite and other resources or services should be offered to family caregivers, each family caregiver must decide upon what will specifically be helpful to them.

4.5 Family Caregivers as an Integral Part of Palliative/End of Life Care in Nursing Homes

The term ‘Family Caregiver’ refers to those individuals who provide care and assistance to a family member, friend or loved one who is unable to fully care for themselves due to illness, disability, injury or aging. Family caregivers are typically unpaid and take on this role out of love, duty or responsibility.

90% of the care provided to older people living at home is undertaken by family caregivers. They often provide round-the-clock 24hrs care and on average spend 39.9 hours a week directly proving care.

Exactly who falls under the term of ‘Family Caregiver(s)’ in this dissertation needs to be defined. The answer is somewhat difficult to exactly define, as the family caregivers came in many forms and everyone was unique. For this study, they can be grouped into five specific categories, as below:

- Spouse caregivers: these people share a family home and provide often complex intimate daily care and emotional support to their spouse, as well as providing other more general support and advice.
- Child caregivers: these are the now adult children caring for their ageing parents. In doing so they all had to undertake a sometimes complex balancing act to both maintain their chosen career as well as provide as much care as they could to the family member requiring their help.
- Parent caregivers: parents caring for their own children.
- Family-related caregivers: siblings, nephews and nieces, sons-in-law and daughters-in-law, including extended family members.
- Close or less-close friends and neighbours, usually unrelated by blood, who feel a civic duty to assist through their past and still present friendship to someone in need of their support.

Many foundation studies have focused on the situation of those who provide most of the care to dependent older people, typically their families, especially spouses and daughters. These studies have sought to systematically document the needs and experiences of family caregivers across the EU in particular and to assess the impact of caring on daily life. Some eleven national studies have examined policy development and initiatives to assist family caregivers, intending to identify what can be done by the state to improve the quality of life for carers and the cared-for. This present study focuses on family caregivers' experiences of palliative/end of life care in the nursing home, focused in Niedersachsen (Lower Saxony) and more specifically Bremen, Germany.

The family caregivers in this context are an integral part of the palliative/end of life nursing care of an older person in a nursing home and are the 'hidden patients' who deserve support from the nurses in old people's homes. Informal caregivers and carers are non-professionals, typically relatives, friends, neighbours or volunteers, who 'take care' of a person with a chronic illness, disability or other long-lasting health conditions in need of support. The cared-for are mainly older people, generally spouses, parents, parents-in-law, grandparents and friends. Informal caregivers provide unpaid long-term support and services at home or elsewhere, without any formalised contract, based upon personal motivations and social norms (Colombo *et al.*, 2011; Barbabella *et al.*, 2018). They provide help in the accomplishment of basic activities of daily living (e.g. going to the toilet, dressing, eating) or of instrumental activities (e.g. preparing meals, housekeeping, transportation) (Eurocarers, 2017).

In the following publications, the authors provided numbers and discussed crucial elements regarding different kinds of informal care found across Europe. Informal care represents a significant part, about 80%, of the total long-term care provision in Europe (Hoffmann & Rodrigues, 2010; Zigante, 2018). However, its weight in the care mix varies from country to country. In 2015, across OECD countries, the share of people aged 50 and over providing care to a dependent relative or friend was 13%, with different intensities found in different countries. Sweden, Switzerland, Denmark and the Netherlands showed the lowest rates, being countries where the formal care sector is well-developed and public coverage comprehensive. According to Eurocarers (2017), 12% of European carers provide care at least weekly to the elderly (aged 75 and over). Verbakel (2018) found that the prevalence rates of informal caregiving are much higher and vary substantially among European countries. She labelled informal caregivers as those who answered affirmatively to whether they spend any time looking after or giving help to family members, friends, neighbours or others because of long-term physical or mental illness, disability or problems related to old age. In Europe, proportions are as low as 20% to as high as 44%. Informal intensive caregiving for those in need of care in Europe needs to be at least 11 hours a week, ranging from 4% to 11% by country. From the geographical point of view, her data showed opposing patterns regarding the prevalence of informal and intensive caregivers, with the Nordic countries having relatively many.

The roles of a family caregiver in the care of an older person are significant, as the family is a resilient and resourceful group connecting us to the past and future in personally meaningful ways. The effect of family on an older person's life rises with age, as the older person needs more support and help as they become frail. During certain ages, when a chronic illness or degenerative crisis sets in, leading to reduced body functions, their demand for help and support from others, including professionals, may even exceed the caregiver's time spent on themselves (Gillen *et al.*, 2003). Family caregivers provide care to an older person, assisting and helping to carry out the variety of physical tasks of daily living, such as bathing, dressing, giving medication, feeding, cleaning and even shopping and doing paperwork for them. However, the umbrella name 'family' is, in most cases, care provided solely by a single person who takes the decisions and is by law recognised as a family caregiver, whereby he/she serves as everything.

Providing primary care to an older person as care provider often includes acting as advocate. This is especially important for older persons with a mental health history, dementia and disabilities, those residing in the nursing home and those in palliative/end of life care. Family caregivers influence the care older people receive when living in nursing homes. The family caregivers are those most concerned; they know their older persons better and ensure the best possible quality care to promote their well-being and dignity in life. Promoting a high quality care for the older person likewise promotes the family caregiver's satisfaction (Frahm & Martin, 2009).

Family caregivers help their older persons for many hours every day (Schneekloth & Wahl, 2008). A European study (Eurofamcare) came up with comparable results (Döhner *et al.*, 2008). Members of the German study group testified that a family caregiver spends an average of 39 hours per week caring for their older person. Interestingly, in a study by the University of Amsterdam, older people who are taken care of at home by their relatives live at least a year longer than older persons in a nursing home (Trouw *et al.*, 2009).

In a US study (based on an analysis of data from 1994 to 1995 from a National Health Policy survey on disability), two-thirds of severely disabled older people rely solely on family caregivers and other informal help, which often puts a lot of stress on family caregivers. The high amount of time spent by family caregivers on older persons often affects their own health, well-being and quality of life. Numerous research papers with similar topics have reported a connection between stress and a family caregiver's quality of life (Pinquart & Sörensen, 2005; Zank *et al.*, 2007). The effects on the family caregiver's social availability, inflexibility on their own time planning and sleep deficit, due to the physical and mental pressures of caregiving, can be severe (Solomon, 2005). Ehrlich *et al.* (2019) cite that women rank highest as family caregivers (usually mothers, daughters, sisters, mothers-in-law, daughters-in-law), which can cause tremendous stress in a family.

Table 4.1: Characteristics of Caregivers

Year	1991	1998	2002	2007
Percentage of Caregivers by Gender				
Female	83%	80%	73%	72%
Male	17%	20%	27%	28%
Age of Caregivers (%)				
Under 55 years	45	43	37	39
55-64 years	26	25	27	26
65-79 years	25	27	26	24
80 years & above	3	5	7	9
Relationship of Caregiver to Cared-for Person (%)				
Mother/father	14/0	11/2	12/1	10/1
Spouse	37	32	28	34
Daughter/son	26/3	23/5	26/10	26/10
Daughter-in-law	9	10	6	8
Other relatives	6	10	7	4
Friends, neighbours & well-wishers	4	7	8	6
Place of Living of Caregiver to Cared-for Person (%)				
Same house	--	73	62	66
Different house	--	27	38	34

Source: Schneekloth & Wahl (2008).

Overall, in contrast to people not involved in nursing care activity for their older persons, family caregivers are attested to a worse state of mental and physical health (Schulze & Drewes, 2004). According to an analysis by Siemens Betriebskrankenkasse (2011), they suffer more often from depression or chronic illnesses and visit their doctors more often than non-caregivers. At the professional level, carers of working age have to reckon with drastic consequences when assuming nursing responsibilities. For example, some give up their work activities altogether (10%) or at least have to limit them (11%). However, a good half of family caregivers are not gainfully employed before the start of care (Schneekloth & Wahl, 2008).

Some end of life care policies and guidance have recently recognised the important roles of family caregivers, and have therefore recommended that family caregivers' needs should be assessed to support them in their caring roles, especially when the older person is receiving palliative care in a nursing home. Unfortunately, to date there are no stipulated rules guiding this. How regular carer assessment is to be achieved in palliative care settings, as there is no known evidence-based tool for directly assessing carers' support needs that is suitable for use in end of life nursing home care practice, is a problem that needs to be addressed (Ewing & Grande, 2013).

4.6 Application of this Study

This study will utilise twelve family caregivers of older people at end of life in residential nursing homes to identify family caregivers' experiences of palliative/end of life nursing. Twelve participants, all above 18 years of age, participated in the study. The prevalence of unmet family caregivers' needs led to different narrations of experience. The interview consisted of mixed questions (using both closed and open-ended questions). In the final analysis, the different unmet needs constituted the experiences of family caregivers and were considered by the author as variables. Findings in the present study seem to align with those of previous studies on family caregivers who were not well supported.

Some negative experiences of family caregivers stemmed from those whose older loved ones were not well cared for by the nurses and/or nursing homes. Conversely, family caregivers whose loved ones were well cared for reported positive experiences and consequently were able to sleep well at night. This meant that they were better able to carry out their everyday functions and found joy in helping the professional carers in the continued care of their loved ones.

One crucial question is whether the caregiving role ends when an older person transitions to a nursing home. In many cases, family caregivers continue to provide emotional support, advocacy and oversight even after this transition. They often remain involved in care coordination, visits and ensuring the quality of care provided by the institution. However, the intensity and nature of their involvement may change, allowing family caregivers to step back from physically demanding tasks while maintaining an essential supportive presence.

Family caregivers play a crucial role even when their loved ones are in a nursing home because their involvement ensures continuity of care, emotional support and advocacy. They provide a personal connection and understanding of the older person's preferences, history and needs that professionals may not fully know or be able to rapidly access. Family caregivers also monitor the quality of care, communicate with staff and address concerns to ensure their loved ones receive personalised and attentive treatment. Their presence helps maintain the older person's emotional well-being, fostering a sense of comfort and security within an unfamiliar environment. Family caregivers continue to play a critical role in nursing homes to ensure that their loved ones receive not just professional care but also personalised, compassionate support that nurtures their well-being holistically. This partnership between family members and professional carers creates a stronger support system that enhances the quality of life for older persons in nursing homes.

In conclusion, family caregivers are indispensable to the well-being of older persons in nursing homes, providing a continuum of care that adapts to evolving needs and circumstances. While the caregiving role may shift upon institutionalisation, it seldom ends entirely, reflecting the enduring bonds of family and the multifaceted nature of caregiving. Research into family caregivers must account for these complexities, ensuring a holistic understanding of their contributions and challenges.

Providing transparent and honest information will save families and care providers from misconceptions and promote positive experiences for family caregivers. However, several studies have elucidated common mistakes often made by treatment teams and, more specifically, nurses. Often healthcare teams (especially the nurses) in the setting do not provide clear information regarding the imminent change in condition, the illness trajectories, how much time is left and so on. This leads to the unpreparedness of family caregivers to deal with impending death and bereavement; this is at most times devastating to family members (Cherny *et al.*, 2021), whose experiences count. Support throughout illness for family caregivers of the patient can also later help the families cope with their bereavement (Dahlin *et al.*, 2016).

This study investigated the family caregivers' experiences of care in older people's nursing homes at end of life. Care needs in the healthcare setting are generally "the requirement of some action or resource in care that is necessary, desirable, or useful to attain optimal wellbeing" (Sanson-Fisher *et al.*, 2000:227). Needs require to be assessed, in order to identify how well and how much these needs have been satisfied or not, as all these constitute towards the family caregivers' experiences (Wang *et al.*, 2018; Kalankova *et al.*, 2021).

Although this study's care needs concern patients directly, they also apply to family caregivers who are anxious to know what happens to their loved ones. Poor care of their loved ones by nurses will result in negative experiences and feelings in family caregivers.

4.6.1 Perceptions of The Family Caregivers Upon Handing Responsibility Over to a Care Home

Family caregivers can, depending upon their circumstances, have a significant role to play even when elderly loved ones are within nursing homes. It is certainly acknowledged that, for some family caregivers, their responsibilities either partially or completely end once professional care begins. Indeed, many family caregivers feel that, at that point, their job is over and they may simply visit the care home and converse with their loved ones or, for some, never visit them again, handing complete responsibility to the care home for all their needs. This is their personal choice and freedom so to do. However, for many family caregivers, the reality is more nuanced, and their involvement remains critical for several reasons, as now detailed below.

Family caregivers may wish to continue to provide emotional support to their loved ones. Elderly people entering a nursing home often experience feelings of loneliness, disorientation and/or stress. Regular visits from their family can provide emotional reassurance, a sense of familiarity, comfort and continuation of care, as well as a sense of connection with their past. Family members understand their emotional and personal preferences better than the staff, especially in the early days within a care home, and they can advocate for things such as favourite meals, routines or hobbies. They can also observe the quality of care provided and address any concerns with the staff if necessary, serving as intermediaries, ensuring the nursing home staff understand the elderly person’s medical history, specific needs and expectations.

Some aspects of personal care, such as grooming or cultural traditions, might be better handled or supplemented by family members who know the individual’s preferences in depth. This can be quite important in multicultural contexts, where family members can help bridge communication gaps or maintain cultural traditions that might not be fully understood by the care home staff. Family caregivers may often engage their loved ones in meaningful conversations, activities or games that are tailored to their interests, but which will also help them to integrate within their new environment, thus preventing isolation. Indeed, regular interaction with their family helps maintain the elderly person’s mental and emotional well-being, which can otherwise decline within institutional settings.

Family caregivers can also play a role in making important medical decisions, staying updated on health conditions and discussing treatment plans with the care home teams. This can become important in more urgent situations, where family caregivers can, when allowed, act as key decision-makers and provide valuable input to the medical staff. It is an inevitable fact of life that nursing homes manage the care of many residents, making it easy for individual identities to become overshadowed and overlooked. The presence of family caregivers on occasion at the location ensures their loved one's unique personality, history and preferences remain acknowledged and respected. Their visits reinforce bonds and remind the elderly person of their place within a loving family network.

To summarise, family caregivers can choose to continue to play a critical role in nursing homes to ensure that their elderly loved ones receive not just professional care but also personalised and compassionate support that holistically nurtures their well-being. This partnership between family caregivers and professionals, when embraced positively, can create an overall stronger support system that enhances the quality of life for older adults in care.

4.7 Chapter Summary

Most studies reviewed have related to the end of life care of older patients. Some family caregivers reported negative experiences termed as 'burdens', 'depression', 'exhaustion/tiredness' and neutral experiences such as 'family needs' at end of life. However, some family caregivers in the literature also reported positive experiences such as 'hope', 'commitment', 'opportunity for showing love', and 'reflecting on life'. Most studies on this topic indicate that assessments regarding family experiences and needs should be performed on various aspects more carefully and cognitively, continuously and in every healthcare setting. Many negative experiences analysed in this study were related to a lack of social support. However, when family members share patient care duties, and the nurses provide enough social support, the family tends to have a positive experience, such as 'recovering relationships', suggesting that efficient interventions to facilitate social support are necessary.

However, family caregivers reported experiencing communication problems with healthcare providers. As reviewed, family needs relating to information about the patient's overall condition and guidance about the family's role, mentioned in many studies, promote a feeling that nurses have a great deal of responsibility in achieving positive outcomes. Nurses should respect and support the patient's family members as caregivers, listen to them open-mindedly and meet their concerns. Nurses should never forget that this essential duty positively influences the end of life care for the patient and the patient's family.

CHAPTER 5: CONCEPTUAL FRAMEWORK AND METHODOLOGY

5.1 Introduction

This chapter outlines the conceptual framework utilised and discusses the methodologies selected and employed. With this background in mind, the discussion enhanced an empirical clinical framework in understanding how family caregivers experience palliative/end of life nursing care of older persons in the nursing home.

This research work focuses on the topic 'the family caregivers' experiences of nursing at end of life of the dying elderly in the nursing home'. This study uses a qualitative approach, which aims to understand family caregivers' experiences from their own perspectives; for example their attitudes, behaviours and reactions. Utilising target groups to study this topic is appropriate in that it helps the researcher to learn about some aspects of the social world and to generate new understandings to be used by that social world (Rossman & Rallis, 2017:5).

There is the presumption that under conditions that require discussion of existential questions in the last phase of life, social interaction and action processes influence action on the issues of family caregivers' experiences of palliative/end of life nursing care in the nursing home. Subjective structures become action-relevant for those involved in the caring process. Accordingly, the research paradigm or theoretical orientation focuses on how family caregivers understand or interpret what they experience. Qualitative social research methods, with their theoretical positioning of symbolic interactionism and phenomenology, are appropriate (Flick, 2009).

Meaningful action is only constituted in observation and interaction to make meaning of our world. The 'social world' constitutes the individual's ability to reflect on one's actions as well as the ability to interpret and define the behaviour of a person and their social environment in the form of the mutual coordination of actions as a process under constantly changing phenomena. However, people experience the world differently. As changes create social action and norms that are shared and maintained (Corbin & Strauss, 1996; 2015; Haller, 2008; Brüeckner *et al.*, 2009), so the qualitative research approach remains the best appropriate method for this study as it helps find answers to the research questions of the 'who', 'how' and 'what' influences family caregivers' experiences at end of life in the nursing home. People differ in how situations in public health are treated. This also implies implications for future health research. Hence, qualitative researchers have taken this charge seriously. We now have powerful techniques for ‘hearing’ data (Rubin & Rubin, 1995) by listening to what people say about things that concern and bother them, in their own words.

The following chapter discusses the preliminary methodological considerations and the chosen approach to analysing the subjective experience of family caregivers of older people at end of life in the nursing home. For this purpose, the investigation’s goal and research questions will be stated and the design and survey instrument discussed. In addition, a description will be presented of the population and the procedures for sampling, along with data collection and analysis. Finally, ethical considerations when carrying out the study will be elaborated upon.

This study is designed in this form to help answer the study question. McCombes’ (2021) step-by-step guide will be employed, as below:

- The overall aims of the study
- The type of research approach and design
- The sampling methods or criteria for selecting subjects for the study
- Data collection methods
- The procedures used in data collection
- Data analysis
- Discussion.

The family caregivers of end of life patients take on the responsibility of many aspects of care for their loved ones, but many of their own needs remain unmet (Hashemi *et al.*, 2018). As discussed in the literature review (Chapter 4), the family caregivers of cancer patients form the greater proportion of available literature. One should not forget this growing and vulnerable population group within our society.

5.2 The Research Aims

According to Longhofer *et al.* (2013:32), the aim of every research study points to the abstract conceptualisation of a project and also draws a boundary around the numerous practices and realities, as well as drawing on realities. Therefore, the aim depends on the methodology used. Hence, the research aims of this study are:

1. To understand some practices, settings, situations, interventions, information and interactions, in this case, in order to understand and identify some of the experiences (negative and positive) of palliative/end of life care of family caregivers in older people’s nursing homes and from their perspectives.

2. To identify, from their point of view, how some of these unmet palliative care needs in older people's nursing homes have supported the notion that palliative nursing care in older people's nursing homes is poor.
3. To identify and describe behaviours and actions that are associated with the education and mediation role of nurses to family caregivers at end of life.
4. To develop a method to assess the quality of palliative/end of life care delivered to dying older people, as this influences family caregivers' experiences in the nursing home. Moreover, to find out from the interviews and questionnaire answers to what extent nursing care of the elderly affects the family caregivers' experiences.
5. To develop a process model of suggestions for assessing role behaviours that nurses use in contributing to helping families at this difficult time.

Collectively, this research aims to define what kind of experience promotes a set of role behaviours from nurses which would enhance the role nurses play. In addition, this study aims to provide a template for self-assessment and third-party assessment of behavioural interventions contributing to meeting some of the family caregivers' palliative/end of life nursing needs that are positive. This is being conducted at a time when it is becoming challenging for health institutions to boast of having adequate professional workers who are experts in palliative/end of life care. The study's results will serve as a model for the end of life process, which can be orientational and used as a guideline for nurses, stakeholders and policy-makers to improve the support service for both the patient and their family.

5.3 The Questions

5.3.1 The Central Question

The central question may often subdivide into broader questions that explore a study's central phenomenon or concept. Nevertheless, the inquirer poses this question, consistent with the emerging methodology that complies with the rules of qualitative research, but as a general issue and not to limit the inquiry. In order to arrive at this question, this study asked, 'What is the broadest question that I can ask in the study using the qualitative method?'. The essence is to explore the complexities of some factors surrounding the central phenomenon and present the varied perspectives or meanings that participants hold (Asmussen & Creswell, 1995; Creswell, 2007; Creswell & Plano Clark, 2017).

5.3.2 The Theory of Research Questions

The questions of the study make concrete empirical connections to the abstract, aiming at targets and exact points where data is the lifeblood of any research. In other words, it is a view from ground level. How do family caregivers experience palliative/end of life nursing, and how would this knowledge help to bridge the gap seen in nursing homes? Family caregivers exist in every family, as they play critical roles in caring for older people at their end of life in every healthcare setting. Unfortunately, many of their roles go unnoticed, nor do they well document their experiences. While they care for the elderly and are worried about the non-improvement, they tend to overlook their own needs. The caregivers are not knowledgeable about recognising what they experience; hence, specific questions must point to producing data. Thus, (1) how do family caregivers experience and talk about their palliative/end of life nursing? (2) what do they think about end of life in the nursing home? and (3) how can nurses do better in future to bridge this gap?

Given the critical assumption about family caregivers' experiences in the nursing home, qualitative methods are appropriate in answering specific questions on family caregivers and practice gaps amongst nurses. The level of nursing neglect registered by family caregivers and the failure of them to document such experiences, especially in areas that affect their lives directly, need to be documented.

The research questions arose from the current state of research (see Chapter 4) and the conceptual framework embedded in the topic of family caregivers and old age at end of life (Chapter 2), and it is from these that the research questions of this research work originate.

5.3.3 The Research Questions

- How do family caregivers of elderly persons experience palliative/end of life nursing in the nursing home?
- What are their primary concerns from their perspectives?
- What impression do they form on palliative/end of life care in the nursing home?
- What are the roles of nurses/institutions in filling these gaps?

The research questions will structure this study's further work, focusing on the family caregivers' experiences of palliative/end of life care in older people's nursing homes. However, the research questions become very important as there is a lack of documentation of the actual number of family caregivers of older people at end of life in nursing homes. It would be interesting to know the actual number of family caregivers with different experiences of palliative/end of life nursing and therefore the implications for future practice.

The aim of this methodology section is to present a comprehensive description of the various survey instruments used to answer the research questions. The study's results will aim to sensitise the healthcare institutions and nurses on the importance of documenting various experiences of family caregivers. In this way, suggestions can be developed to improve nursing care practices at end of life. This, as a process, can be orientational and serve as a guideline for nurses, stakeholders and policy-makers to improve the support service for family caregivers of the dying elderly, at a time when it is becoming very difficult for health institutions to claim to have adequate professional workers who are experts in palliative care.

5.4 The Design and Methodology Utilised

5.4.1 The Overall Structure of the Methodology

In Germany and elsewhere, there is an urgent need to research the older generation's palliative/end of life care in nursing homes and to assess their family caregivers' experiences. As this generation becomes older with age complications and nearing end of life, a nursing home may be the best option left. Family caregivers face challenges, as they face feelings of guilt, uncertainties and anxieties. However, family caregivers go through challenges and face extraordinary difficulties regarding end of life care, especially in nursing homes. Unfortunately, there is a dearth of research studies in this area, making it difficult to know how family caregivers experience end of life care (Lane *et al.*, 2001). Hence, the delicate and challenging subject of investigation in nursing homes makes it necessary to rely on a single methodical approach. The choice of methodology therefore becomes very relevant in finding out more regarding the way caregivers experience end of life care.

However, in healthcare settings, young people with terminal cancer and their family caregivers receiving palliative/end of life nursing care are more favoured. In contrast, older people (non-cancer) and family caregivers in palliative/end of life nursing care suffer in the nursing home. Therefore, it becomes essential to use various qualitative instruments to identify the subjects of this research.

This section presents the robust methodological approach of the present work. At the forefront is the qualitative interview study. However, the first step is the problem-centred interview and the individual survey instruments. The main features of qualitative content analysis, used to evaluate empirical data, are then explained in Section 5.4.

Prior to that, a discussion of field access (Section 5.6.2) and the sample description (Section 5.5) takes place. Subsequently, the explanations concentrate on the qualitative questionnaire study (Section 5.6).

In the beginning, there is the development of a suitable instrument for the written questionnaire. Subsequently, details on the implementation of the questionnaire study are presented. Finally, there is a need to clarify how the sample is composed and how the collected data is analysed. At the end of the chapter, there is a summary of the most critical aspects of the methodological procedure (Section 5.11).

5.4.2 The Single Method Approach

The sensitivity and importance of the topic make it necessary to rely on a single methodological strategy. The aim is to illuminate different perspectives on family caregivers' experiences of palliative/end of life care in the nursing home to gain a complete picture and in-depth knowledge of the research field.

5.4.3 Definition of the Qualitative Method Approach

The qualitative research method differs from quantitative research in many aspects, such as constructing a method, research strategy and data analysis. Qualitative research tends to rely on little theory; as a result, it permits the researcher to employ unstructured and non-sequential conduct with little usage of theory and no hypotheses (Bryman, 1989; Kumar, 2011). Qualitative research frequently starts with defining very general concepts, in contrast to quantitative research, which begins with theories and concepts (Bryman, 1988; Brannen, 1992). Qualitative research is flexible regarding the research strategy because it allows researchers to use different data collection approaches, methodologies and philosophies (McQueen & Knussen, 2002).

For data analysis, qualitative research does not rely on statistics but on context and the interpretation of observations involving individuals' perceptions of situations to capture individual definitions, descriptions and meanings of events (Bryman, 1989; Burns, 2000). Thus, qualitative methods are appropriate to explore the meanings people give to the phenomenon under study in various aspects, such as stories, accounts, individual values, attitudes, beliefs, feelings, perceptions and behaviour (Hakim, 1987; Blaikie, 2000; Burns, 2000; Matthews and Ross, 2010; Kumar, 2011). Qualitative research has many merits. For example, it can help researchers to increasingly understand participants' perspectives or processes of social life by investigating in depth and in detail within a small number of people and cases (Hakim, 1987; Patton, 1990; McQueen and Knussen, 2002). Although qualitative methods decrease generalisability (Patton, 1990), they can explain contexts and inform more compared with quantitative methods. However, qualitative methods have been criticised regarding reliability and validity.

The face-to-face qualitative interview approach, through the collection of dense, information-rich individual case descriptions within the context of the older people's nursing homes end of life care, will be undertaken. The qualitative survey focuses on family relationship dynamics, aiming to uncover deeper patterns of interpretation and action. Hence, from the family caregivers' perspectives, details are analysed, exploring contexts of origin. This is the most natural approach to use when dealing with human experiences, as it involves tools which researchers use to understand phenomena through in-depth exploration of human behaviours, interactions and meanings, unlike the quantitative approach that relies on numerical data and statistical analyses. Because these methods came into their own during the 1970s and have now become mainstream in education, nursing and, increasingly, in psychology, particularly in non-traditional or professional training schools, an extensive history of using these methods has emerged from these approaches (e.g., Elliot *et al*, 1999). Qualitative analysis has the tendency to encourage users of this approach to develop their own individual mix of methods that lend themselves to the topic under investigation and subsequently the researcher's own preferences and styles of collecting and analysing qualitative data (Miles & Huberman, 1994; Elliot *et al*., 1999).

However, there are many different methods currently used in qualitative research, including ethnography, phenomenology, case study approach, narrative approach and grounded theory. Ethnography is used when collecting data in a social and behavioural world (through observations and interviews) (Creswell & Plano Clark, 2017). Phenomenology tends to look more deeply and uses interviews and observation notes in order to understand a phenomenon's universal nature by exploring the views of those who have experienced the question under study. It explores lived experiences to uncover the essence. The case study approach is used to generate an in-depth multi-faceted understanding of a complex issue in its real context, particularly within social sciences, developing theories inductively based on data collected from participants. The narrative approach explores personal stories to understand how people construct and interpret their experiences. It always includes data from individuals and tends to utilise more loosely-structured interviews. Finally, grounded theory is a qualitative research methodology used in developing theories inductively based upon data collected from participants. It is said to be based on theoretical and epistemological concepts, utilising methodological aspects of classical Straussian and constructivist theories (Glaser & Strauss, 1967; Glaser, 2000). Grounded theory covers the entire research process, from data collection (which may be either a single interview or a series of long interviews conducted over a protracted period of time, utilising questionnaires, interviews, focus groups and observation methods) through to analysis and drawn conclusions.

Finally, some of the principal terminologies utilised in qualitative methodology need to be briefly mentioned, in particular thematic analysis, transcription coding, saturation, triangulation, reflexibility, inductive reasoning and the deductive approach. Thematic analysis may be applied to a set of texts, such as from interviews or transcripts. Here, emerging themes are closely examined to identify common themes and patterns of meaning that come up repeatedly. Transcription coding consists of categorising qualitative data into meaningful groups ready for analysis. Saturation is the point at which no new information or themes are observed in the data and thus the point is approached where data gathering may cease. Triangulation involves using multiple methods or data sources to ensure validity and reliability of the data. Reflexibility is the process of acknowledging and addressing the researcher's personal influence(s) upon the study. Inductive reasoning is traditionally associated with qualitative studies. In a qualitative context, an inductive approach is based upon theory building, in which evidence is gathered and analysed to identify patterns and processes. This may or may not lead to the development of hypotheses which may then lead to theory generation (Newby, 2014). Finally, the deductive approach is based upon theory testing, whereby an idea or theory is developed into a hypothesis which is tested by gathering evidence from which logical conclusions are drawn (Elliot *et al.*, 1999).

The strength of the qualitative approach, as utilised in the present study, is the ability to provide a deeper understanding of complex phenomena, as well as helping to capture context, nuances and the participants' experiences of nursing care from their own perspectives. Another displayed strength lies in its flexibility and adaptability to evolving research dynamics. There is no doubt that limitations exist and the results obtained through this approach may not be able to be generalised due to the context-specific nature of their findings. In addition, analysis of such data can be time-consuming and subject to researcher bias.

5.4.4 Study Design

The experiences of family caregivers will be separated into (1) the negative experiences and (2) the positive experiences. The study design selected here was a 'within participants' design, which can assess family caregivers' experiences. Interviews were recorded then transcribed. A coding system was used for the interview data.

5.4.5 Why was the Qualitative Approach Chosen?

A qualitative approach was appropriate in this study because it enabled the researcher to obtain a rich depth of information through interactions with the participants. According to some authors, the qualitative approach is best used in the real natural world since it is very flexible in exploring questions with participants. As mentioned before, this current research topic is currently understudied and hence a qualitative approach is best. The use of instruments such as questionnaires and individual interviews is widespread for this type of research.

Interview questions are developed in a qualitative research study to suit the specific topic, which is one way qualitative methods have helped create flexibility in research studies on social and natural topics. Also, creating flexibility is the main structure of the interview protocol itself. Semi-structured interviews (the most common type of interview used in academic research) allow for ‘probe questions’ between the planned interview questions of each participant. Probe questions allow participants to discuss specific thoughts or experiences during the interview (Qu & Dumay, 2011). Nevertheless, the interview results, in richly detailed responses to questions, contribute valuable insights into the literature on a topic. Revolving around unusual experiences or highly emotional topics, using a qualitative research approach, helps participants express themselves freely and at length through interviews and/or written narratives. This will yield more informative and thorough insights than only giving participants a simple survey.

5.4.6 The Interview Guide and Other Survey Tools Used in Collecting Data

The essential characteristics of the qualitative interview study are presented below. The concept of the problem-centred interview, developed by Witzel (1985) and Witzel and Reiter (2012), serves as a methodological orientation framework for the qualitative interview study. This method has attracted some interest, mainly in German psychology, as this is effective when based on the central principles of problem orientation, object orientation and process orientation (Witzel, 2000). This form of interview uses semi-standardised procedures, which concentrate on the statements and cues of the subjects (Flick, 2009). In particular, the problem-centred interview uses an interview guide with questions and narrative stimuli. The three main criteria are ‘problem centring’ (the researcher’s orientation to problems relevant to the society), ‘object orientation’ (methods are developed or modified concerning an object of research) and finally, ‘process orientation’ in the research process and the understanding of the object of research.

Within the problem-centred interview framework, various data acquisition instruments become relevant. Four instruments for the qualitative interviews were selected for the present work. These are a social data sheet, an interview guide, a summary rating scale and a postscript sheet. All instruments can be found in their text form within the appendices (see Appendices 6, 7, 8 & 9).

Qualitative interview guidelines were planned based on individual needs (meetings to be at an appropriate time and venue), at a chosen setting within Niedersachsen and, where possible, in or close to the city of Bremen.

For the collection of data, two research methods and data locations were used: (a) the qualitative interview and (b) the questionnaire, including the collection of personal data. The different types of data can be compared with each other with regard to specific comparison dimensions and set in relation to each other, where the spectrum of perspectives can be further differentiated, thereby contributing to the development of theories (Flick, 2009). According to the different methods for data collection, evaluation of the data material can also be carried out using different methods. For example, for the analysis of the interview material, a coding method was utilised according to grounded theory (Strauss & Corbin, 1996).

The data collection of this work is based on a single method. However, the delicate nature of this topic makes it very necessary to use qualitative methods. The aim is to shed light on different perspectives of end of life decision-making in the dying elderly and their family caregivers, so as to gain a clearer picture and deeper understanding of the research field being examined. In this study, both the qualitative interviews and the written postal questionnaire of caregiving relatives form the basis of the empirical part of this work.

A standardised written questionnaire captures some problems faced by caregivers, but not necessarily all. Some customisation will be required. Questionnaire studies enable capturing statements of both the family caregivers and the health providers, and enable comparison of variables. Qualitative face-to face interviews are characterised by dense, information-rich descriptions of individual cases in the context of long-term care facilities. The focus of the qualitative observation is on the familial relationships of the dying elderly and how they respond/responded to palliative/end of life care. The aim is to uncover some underlying situations, and analyse answers and reactions from the selected family members. Thus, subjective perspectives are recorded that determine the reactions of each individual.

5.5 Selection of Study Participants

Selection of study participants was problematic for several previously anticipated reasons and for one, unexpected and exceptional, reason - the emergence and devastating effects of the Covid-19 pandemic. As a direct result, the initial study sample, anticipated to yield ideally twelve participants, only produced six. This could not be improved upon at the time due to the rapidly expanding Covid-19 problems encountered not just in Germany of course, but worldwide. Lockdowns, closures of hospitals and care homes to almost everyone except ‘authorised’ persons (often excluding in this ‘authorisation’ the loved ones of dying patients) meant a severe restriction in the conduct of this study and further expansion of participant numbers.

In this unpresidented situation, it was agreed to continue with the six family caregiver participants identified at this time, and to expand the study post-coronavirus back up to the twelve total participants (assuming that would one day become possible, which again was actually unknown at that time).

The choice of sample in every qualitative study is said to be a critical step that significantly influences the depth and quality of the insights generated. Unlike quantitative research, where sampling often seeks statistical representativeness, qualitative sampling focuses on purposive or theoretical selection to capture rich, in-depth information about the phenomena under study. Thus, for this study, the samples were chosen based on their potential to provide detailed and relevant data that addressed the stated research objectives. This approach often involves selecting participants who already possess specific characteristics, experiences or insights related to the research question. For example, in the present study, the researcher aimed to ascertain and understand, at the time of selection, each family carer's experiences of nursing at the end of life in a nursing home, and thus deliberately included people whose older relatives were either diagnosed with a terminal condition and were at the end of life/palliative care stage in a nursing home, or had died within a year of carrying out this research, rather than a random cross-section of the population.

The size of this sample, as for most qualitative studies, was generally smaller than samples utilised in quantitative research, because the aim of this study was to achieve depth rather than breadth of understanding. Researchers in this field may often employ methodologies such as theoretical sampling, where data collection and analysis occur concurrently, thus allowing for the sample to be adjusted as emerging patterns and themes are identified. This iterative process ensures that the sample evolves to address any gaps within understanding and thus refines the study's focus.

The additional six post-Covid-19 participants were selected based more upon recommendations from friends and colleagues who were currently in the nursing field. However, it should be noted and stressed that none of these additional participants were previously known to myself in any way, nor had any connection to myself or my family. The decision to involve some participants from the nursing field was born out of deliberations, advice and the still influencing presence of Covid-19. Covid-19, though not so dramatic in its impact as it had been initially, still influenced and affected most of these family carers. The nursing homes were still very sceptical. The choice to include samples from the nursing field was still influenced by the continuing fact that Covid-19 still made it nearly impossible to get to other target samples, as even after the Covid-19 bans were lifted people were still very afraid of contracting Covid-19.

Interestingly, the concept of saturation played a pivotal role in determining this study's sample size. Saturation is reached when additional data no longer contributes to new insights or themes. This criterion underscores the importance of flexibility in qualitative sampling, as the researcher must remain open to adjusting the sample size and composition as the study progresses. The study also had one ethical obligation regarding the additional six participants who made up the sample, as to whether any prior knowledge could bias the results. This is examined further in section 5.5.3. The truth is that with every approach chosen and consequent study, there is always some element of bias. However, in this case, the six additional participants were thoroughly scrutinised and, in the end, their involvement proved to have added depth and relevance to the study.

In summary, the choice of sample in this qualitative study was driven by the study's purpose, the nature of the phenomenon being researched, and the stated need for rich, contextually-grounded data. It was thus a deliberate and iterative process that prioritised depth of understanding over representativeness, and was guided by principles such as purposive selection and saturation.

5.5.1 The Initial Six Participants

The study sample was selected in a non-randomised way. Stakeholders were involved in a preliminary investigation, which aided the identification of participants and made it easier for the study to proceed. In Bremen, participants were selected based on the recommendations of nurses or colleagues and even family caregivers. Gatekeepers, on the whole, recommend twenty participants (Brouwers, 2016).

The selected settings with fitting cases for the study were approached by telephone and/or in person and asked for support in identifying participants. If the Head Nurse/manager approved the request, a letter with information sheets on the research topic would be posted to them. In addition, the letter had several agreement to participate forms enclosed that could be handed out to potential family caregivers by the service staff (see Appendices 1, 2 & 3). If there was any interest shown in participating in an interview, the nursing staff forwarded the phone numbers after prior written consent and an appointment was made. The researcher thus obtained information about likely older people receiving palliative/end of life care and targeted these persons' family caregivers through interactions with the Head Nurse. The sample was a random sample from the initial data of all palliative/end of life cases in the respective setting. Nurses were also approached to help to identify likely suitable patients on palliative/end of life care, who would be easy to connect with their family caregivers.

Purposive sampling based upon the nurses' recommendations was then applied. The twenty selected participants were of three different races (German, African and Arabic), although in the end the initial six that met every criterion were all Germans. The family members' relationships will be considered, along with their income, education and other factors. Participants had to speak German or English, care for an older patient during the last weeks of the patient's life, and have some experience of the patient's healthcare providers in the last few days and hours. Family caregivers who did not meet the above criteria did not participate in the interview study, nor did those who did not sign and return the consent form and questionnaire.

With the nurses' permission, the potential participants were contacted on the telephone by the researcher, and those who accepted received consent letters. However, following this initial telephone contact, out of the twenty letters sent, only six signed and returned their consent letters and granted the date, time and venue for the interview.

The general criteria for the interview were that the subjects should be adults who must be linguistically and cognitively sound to comprehensively answer the study questions. The study selected just two males and four females; a spousal partner, son and grandson, and daughters (Brouwers, 2016).

Most of the sittings with the nurses and doctors from the respective settings took place in designated rooms, and the purpose was to elicit information from the family caregivers.

Six interviewees took part in the implementation of the qualitative interviews due to the selection process. On one occasion, a joint meeting with participants, where both son and grandson were involved, took place in the run-up to the deployment as part of a training course and during the field phase.

5.5.2 The Additional Participants

Post-pandemic, during 2022, the once critical situation within care homes, hospitals and life in general resolved back towards pre-pandemic normality with, once again, free access and movement allowed throughout the country. People were becoming less scared of the disease and, through the aid of vaccines and medications, were learning to live with Covid-19 lurking in the background, always hopefully at a level which would not cause major disruption again.

At this time, it was agreed that additional participants could now be selected to be added to this study, using the same methodology and selection criteria as described above for the initial participants. It was agreed, through discussions with the researcher and her supervisor and in agreement with other learned individuals, that the two halves of the study could and should be merged to form the originally intended single study. Thus, further suitable family caregivers were selected and interviewed.

5.5.3 The Potential for Bias During Selection

The study also had one ethical obligation regarding the additional six participants who made up the sample, as to whether any prior knowledge could bias the results? The truth is that with every approach chosen and consequent study, there is always some element of bias. The subjective selection of a qualitative sample in this research has both potential for bias and justifiable aspects, depending on the context and goals of the study.

Such subjective selection can introduce significant bias, as it may reflect the researcher's perspectives, assumptions or access to certain groups while excluding others. This can skew findings and reduce their generalisability, particularly in sensitive areas such as COVID-19 and nursing staff, where diverse experiences and viewpoints are critical. To mitigate this, the selection process was transparently documented, explaining the rationale, criteria and context for choosing specific participants. Efforts were also made to ensure a balanced representation of relevant demographics, roles and experiences to provide a more comprehensive understanding of the topic.

However, the proposal and selection of participants by healthcare professionals due to COVID-19 restrictions can be justified by emphasising the practical constraints imposed by the pandemic, such as limited access to facilities, heightened workloads and safety concerns. These factors necessitated a smaller sample size to ensure feasibility while still capturing valuable, firsthand insights. Therefore, although the sample is limited in size, the selection was guided by a focus on individuals with diverse roles or experiences, aiming to provide meaningful perspectives that contribute to understanding the broader impact of COVID-19 on the selected participants.

The subjective selection of a qualitative sample in this research has both the potential for bias and justifiable aspects, depending on the context and goals of the study. A more detailed breakdown is thus provided below, examining the extent of bias from a subjective selection, the justification for a subjective selection and the balancing of bias and justifiability. Finally, an example based upon research both during and immediately after a period of COVID-19 is presented.

The extent of bias from a subjective selection can be considerable. Subjective selection may lead to over- or under-representation of certain groups, thus skewing results and limiting generalisability. For example, during the COVID-19 pandemic, selecting participants from urban areas could miss perspectives from rural areas, where access to healthcare and the impact of the pandemic might differ significantly. Confirmation bias could arise where a researcher consciously or unconsciously selects participants who align with their own expectations or hypotheses, leading to skewed findings. Thus, if a researcher interviewed healthcare workers who had mostly negative pandemic experiences, they might overlook positive coping strategies observed in other workers. Subjective sampling can also miss diverse viewpoints, reducing the richness of qualitative data and making the findings less representative of the broader population. If the sampling process is perceived as overly biased, the study's credibility and validity may be questioned by readers or peer reviewers. In this current study, it was ensured that no prior knowledge of the participants themselves by the researcher, their likely views or experiences (whether positive or negative) arose.

In qualitative research, the goal is often to gain deep, contextualised insights rather than to generalise a population. Purposeful sampling allows researchers to select participants who can provide rich, relevant data. For example, during the COVID-19 pandemic, selecting frontline healthcare workers for interviews was justifiable to understand the unique challenges they faced. During emergencies such as COVID-19, practical constraints (e.g., safety concerns, time and resource limitations) often necessitate subjective selection of accessible participants. Virtual interviews with urban participants may have been easier to arrange than with rural populations during lockdowns. This would include potential limitations to fast internet and modern computer facilities. Qualitative research often uses small samples until no new themes emerge (saturation). Subjective selection can ensure the inclusion of individuals most likely to contribute to this goal, such as those with unique or extreme experiences. In addition, within sensitive contexts, researchers may prioritise participants who are willing and able to share their experiences without suffering harm (ethical considerations). For example, selecting participants with mental health support during COVID-19 research could ensure ethical compliance.

With regard to balancing bias and justifiability, a number of actions can be taken to minimise bias whilst retaining the justifiability of subjective selection. Transparency can be assured by clearly explaining the rationale for sampling choices in the study design, such as focusing on specific subgroups. Diverse sampling can be assured by including, where possible, a range of participants to capture varied perspectives, even if selection is subjective. Researchers should actively reflect upon and disclose their potential biases during sampling and data interpretation. Triangulation through the use of multiple data sources or methods, will assist in corroborating findings and reducing reliance on any one sample group.

Finally, an example based upon research both during and immediately after a period of COVID-19 is now considered. In much COVID-19 research, the subjective selection of participants (e.g., healthcare workers, patients, policy-makers) was often justifiable due to the urgency to generate timely insights for policy and practice, the ethical concerns about burdening severely affected individuals, and the need to focus upon those most impacted by or knowledgeable about the pandemic. However, this approach risks missing broader community perspectives (e.g., younger caregivers, other religious or ethnic groups, non-frontline workers or vulnerable populations) unless explicitly addressed through diverse or supplementary sampling strategies.

However, the focus of this study is not limited to family caregivers of older people in end of life nursing care. The analysis is also on family caregivers of older people in palliative care nursing/residential homes and family caregivers whose older persons received end of life nursing care and are deceased within one year of this study.

In conclusion, while subjective selection in qualitative research inherently introduces potential biases, it can be justified when aligned with the research objectives, ethical considerations and practical constraints. A balanced and transparent approach will help to mitigate bias and enhance a study's credibility.

5.6 Methodology

The objective was to identify target groups based on recommendations and inclusion criteria for the interview (family caregivers of older people receiving palliative/end of life care in a nursing home). In this case, using a qualitative approach helps identify the family caregivers' experiences. Data collected included the two-way interviews and the use of a questionnaire. Each participant's interview was summarised at the end of the interview to reduce the bulk of work. The interview topic was on their experience of the palliative/end of life nursing care of a dying elderly relative or friend in a nursing home.

All interviews were conducted in March 2021 using the native language of the participant. At the interview completion, a postscript was given to each participant to review and comment on. Each interview was then professionally transcribed verbatim and, where necessary, translated into English by a third party. The subsequent analysis was in English.

5.6.1 Qualitative Interview Study (Structured and Unstructured Interview)

To ensure the authenticity and, above all, precise and accurate recording of the communication process along with subsequent robust analysis of the data, an MP3 recorder was used during the interviews and general communications with the selected participants.

The interviewer was thus able to concentrate on the conversation and non-verbal statements. This integrates findings from the current state of research and relevant theories.

5.6.2 Field Access

Field access was initially between May 2020 and November 2021, similarly followed by the second 'batch' post-Covid December 2022 to May 2023. The qualitative, guideline-based questionnaire helped facilitate the interviews. The author was responsible for the planning, managing and implementation of the study interviews in Bremen, Lower Saxony. The selection included the local recruitment of suitable participants along the criteria of the sampling plan. Data analysis was thus based on (translated) transcripts of the interviews from the participants.

All survey instruments for the present study had been pretested in 2020 using sample family caregivers. In contrast to the primary survey, the participants were asked after the interview to assess the appropriateness and formulation of the questions. The newly acquired knowledge flowed directly into the final design of the instrument used.

The target group of the conversations were family members caring for an older person (over 65) at their end of life in the nursing home at the time of contact or whose older person had died in the nursing home within one year of the planned interview. This criterion excluded the participation of older people themselves who were diagnosed to be at the end of their lives. Instead, only the family caregivers who continued caring for their older person qualified for the study.

This study utilised a qualitative/descriptive design to identify sutable past or present family caregivers of dying older people at their end of life in a nursing home. Some of the participants were proposed by the nurses in charge and other participants by their colleagues. The aim was to find out their experiences of palliative/end of life nursing care, whether their experiences were positive or negative, what they described as negative and positive, and how their experiences affected their quality of life. Adams *et al.* (2014) used a similar method (interviews and questionnaires) to investigate a similar case.

In recruiting interview participants for the present study, a combination of different access routes was involved. The selection of nursing homes through an online search provided addresses of older people's nursing settings in the applicable regions - the direct approach to nursing homes in the close area and colleagues working within these nursing homes. In order not to deter potential participants, words like dying, death or impending death were carefully used only when necessary during the interviews; instead, the focus was on their problems or burdens and their broad experiences of nursing homes. The basis for this is to provide a random sample from the address data of all older people's homes in the region.

A letter (see Appendix 2) was provided to potential participants, starting as below:

> "Study on family caregiver: the author looks for a conversation participant who is caring for a family member at end of life in a nursing home. The study investigates how family caregivers of older people experience nursing at end of life in the nursing home, focusing on Bremen and Niedersachsen. The nurses should recognise the problem early enough and in good time. In so doing, it helps improve the family caregiver's experience. More information under [redacted].com".

If caring relatives indicated that they were interested by the letter, they were contacted by email, telephone or through the Head Nurse. In order to bring the background and objectives of the study closer to those interested, a covering letter with a copy of the detailed relevant information sheet was provided to potential participants after the first contact. After a few days, the study participants were contacted again through emails or telephone calls, and a final interview appointment arranged with them at the chosen site.

5.6.3 Data Collection and Covid-19 Limitations

Data collection was planned to take place from November 2021 to May 2022 for the initial six participants at a setting chosen by them (in Bremen and Niedersachsen) using the qualitative interview instrument. The data collection was to be on an appointed day, at an agreed time and venue.

Unfortunately, the participants had to cancel appointments many times due to Covid-19 outbreaks, resulting in delays and frustrations. All the participants expressed the need not to be interviewed in the nursing home setting, due to Covid-19 risks. Thus, three interviews were held in a local bar and three were conducted at their homes. The study participants were informed about the purpose of the study, selection criteria and procedures, including how to fill out the questionnaire. The questionnaire required approximately 20 minutes to complete. The questionnaire contained forty questions sent out to the different participants, and the participants returned only six fully completed. Thus, in the final analysis, six properly filled out and returned questionnaires were used (some family caregivers were excluded from participating in the interview study due to their non-compliance with the questionnaire instructions, which resulted in them returning incomplete questions).

Qualitative interview guidelines were planned based on individual needs (to be conducted at an appropriate time and venue); at a chosen setting within Niedersachsen and specifically in Bremen when possible.

The additional participants (late 2022 - early 2023) were similarly contacted and interviewed, although fortunately no problems due to Covid-19 restrictions were encountered.

5.7 Research Ethics

Ethical research considerations arise in research projects with vulnerable populations such as older people at the end of life and their family caregivers. However, ethical issues concerning palliative/end of life care involve a series of values held by participants; this belief affects, in most cases, decisions made in clinical decision-making. Research and society have a responsibility on both sides to protect the personal rights of vulnerable research groups. Statistically, the number of older people with life-threatening diseases, and the need for good palliative/end of life care in nursing homes, is increasing worldwide.

Ethical considerations have become a vital requirement for research in healthcare, especially in the advanced stages of diseases in old age that require palliative care. On the other hand, people affected by old age and life-threatening diseases, including those not capable of giving consent in medical and healthcare, should be protected legally in research activities. However, this study focuses on family caregivers' experiences of palliative/end of life nursing. The absolute number of family caregivers with different experiences of palliative/end of life care in nursing homes is unknown, as their numbers are not well documented.

Medical research's ethical and legal limits were first defined internationally by the World Medical Association in 1964 in the Helsinki Declaration (WMA, 1964). A recent revision of this document also addressed non-medical researchers (Taupitz, 2001). There is a consensus that the benefits of research are not justifiable in the case of persons unable to give their consent. The controversy continues around those research activities. Although those involved in the investigation are unlikely to benefit personally from the research results, other people with similar problems will do. For the protection of persons who are unable to give consent, the opinion of the Central Ethics Committee at the Federal Medical Association (CECFMA, 1999) for the implementation of clinical research projects generally provides for the written submission of the examination project to the responsible ethics committee. There can be no obligation to provide final information, particularly about risks and the possibility of participating in research activities. Participation in any research is voluntarily based. A prerequisite is the signed informed consent document. In particular, participants selected for any study get helpful information on the topic, its benefits and risks and the possibility of them withdrawing their consent at any time. However, the involvement of persons who cannot consent to a research study appears to be possible, provided additional safety and criteria are adhered to by the interviewer. Again, there are no expressions of intent to go contrary on the part of the persons concerned, and there are no indications on the part of the other proxies against their willingness to participate in the study (Bundesärztkammer, 1997).

The present study investigates the experiences of palliative/end of life nursing of family caregivers who are/have recently been providing care for the vulnerable group of people affected by old age and life-threatening diseases or illnesses, including dementia and advanced cancer, in a long-term care facility (nursing home).

Being focused upon needing to acquire a specific understanding of particular circumstances regarding the health-related care of older people in the advanced stage of their lives, using an alternative group of people was out of the question. However, given the preparations made by the researcher, the cognitive and communicative abilities of the family caregivers were deemed to be fully considered. Reference questions were not directed at the older dying person, since these residents were unable to express their will, provide their consent or give possible answers. As such, the family caregivers answered questions relating to the older resident on their behalf.

One very important point to note was that should any examination-related question or questions lead to any form of irritation or distress, or the family caregivers of affected residents were seen to become uncomfortable, the investigation would be immediately halted. If necessary, the involvement of a proxy for the family caregiver would then be sought, along with their authorised consent to the investigation.

There are ethical obligations when people agree to participate in research, and these must be respected (Rubin & Rubin, 1995:93). The interviewer must make efforts to ensure that all participants selected for the study understand the following:

- possible risks and benefits
- voluntary participation
- confidentiality, assurance and anonymity
- the purpose of the research
- how they were chosen
- data collection procedures
- whom to contact with any questions or worries
- when to withdraw if not comfortable.

As Williamson (1995: 58) suggests, “that there is potential harm to the selected participant of a study, which according to him are not only physical, also psychological, social, economic or professional”. Some families might have hoped to be informed about local offers of support that might be available, or additional help for the study participants. To assist with this, the researcher developed a handout for each potential participant, which summarised the most important contact points in the care field.

An indirect benefit from identifying and assessing the findings of this qualitative study is that the results apply to those affected with the same situation irrespective of the healthcare setting, as well as providing specific conclusions about the correlations in developing preferential sensitive decisions about the palliative/end of life nursing care of older people and family caregivers’ experiences of nursing homes. The selected design for this study made it possible for easy and smooth interactions with selected family caregivers whose older relatives were at the end of their life in nursing homes. There were no risks for this group of people in the research activities of this investigation; instead, solely their assistance and cooperation becomes necessary to answer the research questions.

On the part of family caregivers, the environment involved in palliative/end of life nursing care and the collection of personal data in the nursing, statistical documentation and medical findings, became relevant. Each family caregiver provided their informed consent to the investigation. Because of the characterised vulnerable person in question and the intention of collecting personal data, the favourable vote of the Ethics Committee of the University of Bremen, who approved the topic, was essential (as well as helpful) in this investigation.

The findings of the Ethics Committee’s deliberations indicated that there were no objections to implementing the research plan as presented. However, from a pragmatic perspective of the research ethics, a particular problem was also emerging (Covid-19), according to which a limitation of the time window for the investigation of the family caregivers’ experiences (irrespective of negative or positive experiences) and the effect on the quality of life, could only be determined inaccurately, except through the use of rigorous research. An initially envisaged participatory observation was refrained from due to the outbreak of Covid-19 and consequent associated lockdown procedures, as well as the sensitive locations of the vulnerable older people involved.

The influence on the course dynamics of the palliative caregivers by the researcher in the field cannot be ruled out, and the facility management could not guarantee participation in personal case discussions on the subject of the investigation in the course of the research. The commitment to good scientific practice and the assumption of responsibility for research ethics becomes very necessary when directed at vulnerable family caregivers (as with all related research groups).

The family caregivers, on their part, bear a high decision-making responsibility for the person at end of life and suffer various challenges. The ethical research concerns regarding the initial considerations for a future study design are all connected to the planned qualitative interviews with participants involved in the research process. After all, if the object of investigation is an event within the last phase of life in multimorbid, dying older people with a high degree of personal decision-making considering palliative treatment measures, such constellations would determine both the content and conduct of the interview, as well as the course dynamics in the interview. Ensuring these considerations is, in fact, of help in the study design phase.

Here, an event that has already taken place at the time of the interview, or is about to take place, is the focus of the research interest, whereby a fundamentally ethically harmless research situation can be assumed. The ongoing situation, the family caregiver's experiences as the object of investigation, allows the use of information data material from the participant, and the researcher does not influence the data collected.

As seen in the present work, the selection of the questions stems from preparatory work and the determination of the survey period using already existing data material. However, there is a risk of distortion in the use of the data. For example, the sources which, according to their origin, are not intended for investigation may have gaps or be too unspecific in their significance. In addition, are the problems of rationalisation and the blurring of the temporal dimension in oral questioning of past events under the principle whereby one cannot remember, for example, the precise course of the process. The present study combines existing sources with collecting new specific data in qualitative interviews with family caregivers.

5.8 Limitations to the Data Collection

Efforts made through the relevant advisory bodies, individuals and target institutions to access problematic cases in sometimes difficult settings via one-time counselling, along with some requests from institutions to exclude them from the sample, all require the researcher's time and energy.

The researcher worked closely with settings and individual families/participants who consented to the interview to ensure confidentiality and trust. Such interview partners recruited for this research study actively supported the researcher in this process. On the one hand, these will involve the focus of this study, which will respect all ethical codes and conduct, whereby such interview partners recruited for this research study accept to participate. On the other hand, this relates to the focus group of the selected institution with palliative nursing care patients; conversely, the initiation of conversations also took significantly more time than might have been initially envisaged. The people addressed were initially highly sceptical about getting involved in an interview. The plan for the data collection phase did not provide for this time-consuming initiation for discussion.

In addition, after the study had been conducted, a further two people were reached through the help of colleagues. They consented to take part in the interviews, along with an additional four through recommendations from other family caregivers interviewed during this research and included professional caregivers from the areas of nursing. However, these people’s interviews and opinions were deemed to be outside of this research, and were not added to the prior collected research data, nor will they be part of any further analysis (Görgen *et al.*, 2010).

Excluded were all incomplete questionnaire cases that failed to meet the research study criteria from the total sample. Also excluded were family caregivers who could not complete the interview for any reason and where permission could not be obtained to reach the target persons in some nursing homes. Additionally, not every nursing home was deemed to be suitable for this research.

5.9 Data Collection

On completion of the interviews, the data collected from each participant was filtered, coded, analysed, then the results interpreted and documented. The initial interview process was for a period of six months, with follow-ups and discussions of outcome with each participant. Unfortunately, the initial plan for data collection was considerably disrupted as a result of Covid-19 restrictions and lockdowns, which made people unsure and insecure. As a result, many booked appointments were cancelled, people were afraid to meet, nursing homes cancelled appointments many times, and everything became very frustrating. Eventually, those who returned their consent forms and questionnaires through the post did so with the condition that they chose the date, time, interview venue and any stipulated additional conditions (involving Covid-19 security measures). The additional participants (late 2022-early 2023) were similarly contacted and interviewed, although fortunately no problems or disruptions due to Covid-19 restrictions were encountered.

For the collection of data, two research methods and data locations were used: (1) the qualitative interview and (2) the questionnaire, including the collection of personal data. The different types of data can be compared with each other with regard to specific comparison dimensions and set in relation to each other, whereby the spectrum of perspectives can be further differentiated and contribute to the development of theories (Flick, 2009). According to the different types of methods for data collection, evaluation of the data material can also be carried out using different evaluation methods. For example, analysis of the interview material and coding method according to grounded theory (Strauss & Corbin, 1996).

The data collection of this work was based upon a single method. This study has already outlined the conceptual framework utilised and discussed the methodologies selected and employed. The delicate nature of this topic makes it very necessary to use a qualitative methodology. The aim was to shed light on different perspectives of end of life decision-makings in the dying elderly and their family caregivers, so as to gain a clearer picture and deeper understanding of the research field being examined. As already demonstrated earlier on the epidemiology of those in need of care, part of this project on the dying elderly and palliation (both the qualitative interview studies and the written postal questionnaire of caring relatives) form the basis of the empirical part of this work.

The standardised written questionnaire captured some of the problems faced by the family caregivers. However, the questionnaire also enabled the capturing of statements relative to both the family caregivers and the health providers, enabling a comparison of variables. Qualitative face-to-face interviews are characterised by the collection of dense, information-rich descriptions of individual cases in the context of long-term care facilities. The focus of the qualitative observation was on the familial relationships of the dying elderly and how they responded to palliative/end of life care. The aim was to uncover any underlying situations and analyse answers and reactions from the selected family caregivers. Thus, subjective perspectives were recorded that determine the reactions of each individual participant.

Different literature studies support the idea that family caregivers of older people at end of life in different healthcare settings suffer a variety of different things (Ateş *et al.*, 2018), confirming that such family caregivers not only form a part of the formal and informal care system, but also provide direct care for the person in need. Hence, unmet palliative nursing needs affect the family caregivers' quality of life. In this study, to assess these factors, the questions were broken down into four points of focus:

- positive experiences
- negative experiences
- effects on the quality of their lives (generally)
- support received.

All survey instruments were tested in two pre-test stages during 2021. In contrast to the main survey, the participants were asked after the interview to assess the appropriateness and formulation of the measures. The newly acquired knowledge flowed directly into the final design of the instruments.

Covid-19 played a part in the interviews and data collecting process. In the qualitative interview study, some of the selected family caregivers felt they could no longer participate, and those who participated opted for other venues rather than the nursing environment. Some participants declined to participate in the study interview at the very last minute due to the outbreak of Covid-19 and the strict hygiene rules to protect all involved.

A total of twenty family caregivers whose loved ones were currently on palliative/end of life care and two family caregivers whose older person had received palliative care but had died three months before (four nurses spoken to threw some light on these two cases, but the nurses' reports were not very relevant to the study).

The final initial total of six individual interviews conceals the fact that four geriatric nursing homes were involved. Most eligible other caregivers could not or would not continue with the study research due to their fears of becoming infected with or becoming agents of spreading Covid-19, either for themselves or their loved one, or both. The additional participants (late 2022-early 2023) were similarly contacted and interviewed, although fortunately no problems or disruptions due to Covid-19 restrictions were encountered.

The interview perspectives of the family caregivers included the following key aspects: the family caregivers' 'positive experiences' (satisfied) and 'negative experiences' (dissatisfied), 'information', 'communication', 'transparency', 'prompt attention', 'friendliness', 'holding of hand', 'empathy', and 'good listening acts'.

5.9.1 Conditions for Case Selection

This work focuses on the family caregivers' experiences of palliative/end of life care (focusing more on how they experience nursing care) in the nursing care home, including the family caregivers of patients who had died in the last six months to one year and had received palliative care. There were no restrictions per diagnosis. Included were families of dementia cases at end of life, whose family caregivers had taken care of them for three months or more. All these measures sought to ascertain through questionnaires and in-depth, face-to-face interviews family caregivers who were aggrieved, felt neglected and reported a negative experience, and similarly those who expressed a positive experience. This study seeks to understand family caregivers' experiences of palliative care in the nursing home to see what can collectively be changed for the better.

To paint a complete picture of family caregivers' experiences in the nursing care homes, the perspectives of all family caregivers who consented to this study had their interviews recorded in their own words, analysed and used for further studies.

Table 5.1 summarises the initial six interviewed family caregivers of elderly patients in palliative/end of life nursing care. All six caregivers were analysed.

Table 5.1: Settings for the Initial Interviews

Setting Number	Daughter	Son	Grandchild	Spouse
1		1	1	
2				1 (wife)
3	1			
4	1			
5				
6	1			

5.9.2 Coding

Coding is the process of labelling and organising the qualitative data collected in order to identify different themes and the relationships between them. Qualitative data analysis involves systematically organising, interpreting and making sense of textual or other (often visual) data which has been collected during the period of research. There are two critical steps utilised in this process, those of transcription and coding. Each of these require accurate and intensive attention to detail and methodology. The process can be summarised of follows.

Data is collected from participants (in this case, from spoken text derived from semi-structured audio-taped interviews). After each interview, the text and postscripts were read, the audio recording was replayed and finalised once the researcher felt that all the data had been gathered. Ethical considerations and confidentiality were maintained by anonymising each participant's identity and securely storing the data. Verbatim transcriptions made using 'Amba' transcription software were checked manually to verify their accuracy. Individual interviews were transcribed within 24 hours of collecting the data, while still fresh in the researcher's mind. After the transcription, it was proofread to remove typographical errors. Accuracy of the data was ensured by re-listening to the audio recordings of the raw data, whilst reading the transcripts, and this ensured that any possible errors and/or omissions were ruled out. The grammar was checked, to ensure that the original grammar from the participants had been retained, with any errors being corrected as appropriate. In the process, any unclear sections were re-read for clarity and, where appropriate, marked as inaudible or as unclear sections (e.g., '[inaudible]' or '[unclear]', which also enabled a further review of the section[s]. Fortunately, such inaudible or unclear parts of the transcripts were extremely rare in occurrence. The timestamp served as a marker for key moments, or every few minutes, for reference. Paragraphs and spacing of the transcripts made it more legible.

Before moving to the next stage, coding, the transcripts were reviewed by colleagues for feedback, and re-checked for accuracy and completeness. Finally, the transcripts were securely saved and stored for preservation of the data. Codes were created based upon the research objectives, as the transcription process was a part of the qualitative data analysis. By following these steps, this study ensured the transcription process was accurate, efficient and suitable for qualitative data analysis.

Firstly, all transcribed interviews were roughly coded according to the main categories which developed. A complete sentence or one or more paragraphs were considered coding units for assigning text passages to categories. In rare cases, a group of words was sufficient - the interviewer's questions in the process were coded.

The coding scheme selected was based upon the methods described by Morgan & Kruger (1993) and Mercer (2004). These two schemes both utilise short codes. Mercer (2004) uses qualitative, discourse analytical techniques to identify examples of exploratory sentences during an interview. This method is significant as it allows the identification of words and sentences that need further explanation.

5.9.3 Coding of the Qualitative Data Collected in this Study

The task of coding in this study involved labelling and organising 'chunks' of data which helped to identify emerging patterns, themes or concepts which may (or may not) become pertinent to later data analysis. This step is central to qualitative data analysis and typically follows a systematic approach. Open, axial and selective coding are steps utilised within qualitative data analysis. These steps are seen as cornerstones to grounded theory, although whichever method is selected within the qualitative approach, the principles are the same. In this research a coding framework was selected as being appropriate. The coding framework was inductively developed as it emerged from the data, and it evolved as analysis progressed.

The following process was adopted. An initial familiarisation with the texts occurred, as the transcripts were read and reread, utilising highlighter markers to identify key texts and to mark key quotes. An 'open' coding was adopted, providing line-by-line coding. From this, simple and clear codes were formed, two to three sentences at a time, in order to stay focused and not miss key details. By doing this, the data was broken down and codes were formed to label them - codes that captured the meanings were formed and assigned from the words, details, tones, repetitions and phrasings. Corbin & Strauss (1996; 2015) see it as digging up the concepts and dimensions from within the data. Through reading through the notes, memos were made and utilised to track ideas, comparisons and to identify connections as the research progressed. After every two to four transcripts, the transcripts were reread and rechecked for any overlaps.

Axial coding was utilised to find connections, through using questions like how the identified codes were interrelated, what led to any consequences, the identification of any patterns that arose, in order to start to develop a bigger picture. Conflicting codes, where they occurred, were re-sorted and unified, with similar codes grouped together. Categories were captured that identified links, so that codes could be fixed to categories. ‘Cause and effect’ relationships were sorted, as were common categories that appeared together. The methodology was found to have become very intuitive and flexible. Connections to other codes were found between elements. Constant comparisons went on throughout, through re-reading, going over everything again and asking questions such as “do the new data codes lead to answering the question?”, “is there a need to revisit the data?”, “which code belongs to which category?” (this also aided transparency) and “are there connections between two different categories?”.

The next stage was to use selective coding in order to develop the core concept. It was found that I could identify certain potential categories which were frequently linked together. Different categories were formed and tested to see which fitted better within the hierarchy as it developed and to identify the ones that most related to the data and which also answered the research questions. A powerful insight was thus gained through this continuous comparison. By going back to the data to re-ask questions such as “does it still fit?” continued until no new information that added further insights was identified. Once this point of theoretical saturation was reached, the next step arrived - the ‘wonder moment’ when all the pieces fell into place (Ho & Limpaecher, 2022). Then, to ensure total reliability, everything was checked and re-checked.

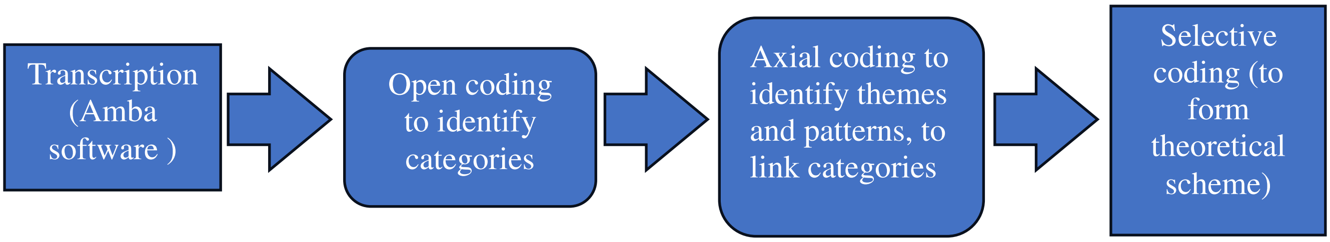

Figure 5.1: The Coding Process

Therefore, to summarise, methodological adaptations and different approaches are available to be adopted (e.g., utilising grounded theory, thematic analysis, content analysis and discourse analysis) which may then lead to being adapted to better suit the transcription and coding procedures. Utilisation of grounded theory encourages constant comparison between the collected data and emerging codes, with emphasis on memo-writing to track theoretical insights. Thematic analysis enables the systematic identification of themes, guided by Braun and Clarke's six-phase approach (2006). Finally, content analysis emphasises quantifying patterns in qualitative data, which often aligns with predefined categories.

While numerous authors have contributed to the field of discourse analysis, two significant figures stand out the most, namely Norman Fairclough and Michel Foucault. Fairclough, the father of critical discourse analysis, in particular stressed upon the importance of language, power and inequality (1985, 2001), whilst Foucault concentrated more upon power and knowledge (Foucault, 1971; Gordon, 1980). In the analysis of my present study, the use of discourse analysis (a qualitative approach that extracts meaning from language in a given context) proved to be the most appropriate. Jones (2012, 2016) has introduced a number of approaches to discourse analysis, focussing upon three specific ways of looking at discourse - as text, action and ideology. Jones (2016) enables the reader to better understand Halliday and Hasan's (1976) notion of cohesion, Gee's (1999) cultural models, Swales' genre and move analysis which bridges the function-form gap, Austin's (1962) theory of speech acts (Urmson & Sbisa, 1975), Grice's (1957, 1975) maxims of cooperative principles (Finch, 2000) and Schleghoff's (1968) conversational analysis (Prevignano & Thibault, 2003). Understanding these shows how strongly text can reflect and reinforce power relationships and ideologies.

There are passages that can be cited from structural linguistics analyses, such as from Zellig Harris (Harris, 1974; Nevin, 1990), Henry Widdowson (1996) and James Paul Gee (2014), that have helped considerably in the present study. The term 'discourse analysis', first used by linguist Zellig Harris (1974), defines discourse as a methodology to be used in analysing connected speech or writing for continuing linguistics beyond the limits of one simple sentence at a time. Discourse analysis (Crosley, 2021) is viewed as verbal and written communication extending beyond individual sentences. It goes beyond simple language, encompassing all linguistic and symbolic units, such as signs. However, discourse analysis extends further by examining the overall meanings conveyed by language in context, encompassing social, cultural, political, and historical backgrounds. Understanding the underlying meanings expressed through language is crucial, as it serves as a tool for prompting social change or achieving specific goals. Hence, language is employed as a means of prompting social change or meeting certain objectives. The analysis draws meaning from the language presented in data, including interviews, focus groups and transcripts. It centres on specific aspects of language, such as sounds and grammar.

Wodak & Krzyzanowski (2008) consider that discourse analysis provides a good general framework for addressing problems. They argue that it is used to research language usage for various social problems which are issues within society negatively affecting individuals. However, Jones (2012) states that discourse analysis is the actual study of language itself, with Halliday (1994) stating that "we represent the world through language". Other writers have different perceptions: Gee (2011) calls it "who is doing what", while Bakhtin calls it "different styles of speaking" (Todorov, 1984). Finally, 'social language' is a term used by Gee (1999) for discourse, although Wu (2010) includes two major "families" in his ideals, these being culturally- or socially-based discursive practices and linguistic-based analysis (e.g., conversation). Aylett and Barnes (2009) further develop the concept of discourse and analysis of language, along with its ability to create new truths and new words. Hence, discourse can be said to be a framework for social action, including mode of thinking, grammar, rationalities and even materials that interpret, represent and create realities.

The Oxford Dictionary (Castree *et al*., 2013) defines discourse analysis in linguistics as a method for analysing the structure of text or utterances longer than one sentence. This analysis considers both linguistic content and sociolinguistic context, and it is applied in linguistics, psychology, sociology, anthropology, communication, education and other fields to construct and maintain social reality. For Ormston *et al*. (2003), discourse analysis originates from the discipline of sociology and is used to examine how knowledge is produced within different discourses and performances, linguistic styles and rhetorical devices. Jankowicz (2005: 229), however, emphasises the relevance of discourse analysis in listening to people's own narratives of a situation, while employing a biographical approach. Respondents draw on differing interpretations of the context in which the interviews take place. Discourse analysis focuses on how language is used in specific settings, aiming to identify context and various interpretative repertoires, then attempting to match them to understand the function from the respondents' points of view regarding the different stories being told.

Thus, the overall purpose of discourse analysis is to investigate language, its functions and how meaning is constructed in different contexts. In this case, data (narrative speeches) are situated in their context, involving background views, reasons for narration, history, participants' contexts, and social and political aspects. In summary, according to the above authors, discourse analysis informs us about power and power imbalances, illustrating how power is developed, maintained and played out in real life (e.g., inequalities arising from power and how language can be used to perpetuate them, examining how someone with power communicates with those having less power, in accordance with Foucault's early work on power [Gordon, 1980]). In light of this knowledge, language has the power, when we speak, to enable a researcher to write down and craft things to suit the moment and situation.

In the coding of participant feedback, the interviewer assigns labels to words and phrases that signify relevant topics. In this way, they are straightforward to remember and organise. So, in the effort to code qualitative research data, common themes are identified as concepts that form a more significant part of thematic analysis. The category system was then further differentiated based on the data material and supplemented by so-called 'sub-categories'. To this end, all text passages within the main category were collected for intensive examination. During the intensive examination of the data material, new, relevant dimensions emerged. For example, the main motives for taking on a caregiving role were differentiated into five sub-categories: 'gratitude', 'biographical fit', 'financial aspects', 'responsibility or feelings of duty', and 'no acceptable alternative'. Then describing the experiences that made them feel either satisfied or unsatisfied; for example, information, communication, support, enough nurses, good knowledge of palliative/end of life care by the nurses, emotional support, spiritual support and psychological support.

With this refined category system, the entire interview material was reviewed and completely gone through again.

5.10 Qualitative Study Questionnaire and its Use

A qualitative form method is a way to increase the depth and breadth of the results from the different perspectives of the research subject.

5.10.1 The Questionnaire

The decision to use a qualitative approach in this study was made as it is a way to increase the quality of the results through identifying the different perspectives of the research subject. The present study focuses more on the family caregivers' experiences rather than the patients and professional carers. Thus, both positive and negative experiences of palliative/end of life nursing as their family caregivers perceive them and how these experiences have affected their public lives are essential for future planning and policies.

The questionnaire is a research device or instrument comprised of a series of closed-ended or open-ended questions. The goal is to collect data relevant to the topic of study from respondents, which can be used for both analysis and to find solutions. When the respondent can give a longer answer it can yield more insights, because they can elaborate upon their thoughts.

As previously mentioned, open-ended questions are free-form and allow respondents to use an open text format to give replies. They can say whatever they want in response to the questions. On the other hand, closed-ended questions are structured and have a preset group of questions a respondent can answer. Although they can refuse to answer all questions, this does not require the family caregiver to inform a decision.

In the development of the qualitative survey instrument, questionnaires were aimed at the caring relatives and were integrated (Görgen *et al.*, 2010), as this survey focuses primarily on the family caregivers and their experiences of palliative/end of life care in nursing homes. For example, the focus is on the caregivers' perceived experiences of dying older persons in the nursing care home, their motivation, support, information, communication and follow-ups. The realisation of impending end of life increases anxiety, tension, fear and anger in some family caregivers, and thus increased holistic care at the end of life is advocated.

Not all variables of the questionnaire were relevant for answering the central questions of this study, and these are characterised in detail as necessary for the presentation of results. Thus, the qualitative questionnaire study only investigates which experiences were pertinent to the study.

The study relied upon Wang *et al.* (2018), who reported on unmet needs, measured with a comprehensive needs assistance tool containing seven domains of unmet needs, and answers used by family caregivers as positive or negative experiences using a four-point Likert scale. Each item was assigned a score ranging from 0 to 5, being zero if it was an unmet need, not relevant or not needed, or if the family caregiver was satisfied and experienced care positively = 5; if it was much needed and led to negative experience = 3.

Self-reported, problematic experiences on the part of family caregivers were noted. Twenty-nine items were marked and noted for the last six months of their experiences. The survey should also address the frequency of the different experiences reported in the last six months. Table 5.2 shows the wording of all items and, at the same time, their origin is listed.

The written postal questionnaire for caring relatives comprised two pages, excluding the title page and information sheet. An additional copy of the two page form was available in cases where more than one eligible participant was present at the time of the survey. In terms of content and theme, six focal points were marked and noted. Each focal point included a number of complex questions. These include personal details (1 to 17), questions about the caregiver and their relatives in need of care (18-23), their negative and positive experiences (24-31) and the effect of these experiences on their quality of life generally. The questionnaire can be found in Appendix 5.

Table 5.2 shows the six types of concerns, as stated by Adams *et al.* (2014), for recording self-reported experiences because generally, when family caregivers perceive older persons as not receiving adequate palliative/end of life nursing care, these concerns affect the family caregivers' satisfaction levels. The items identified in Table 5.2 are part of analysing the family caregivers' perceived positive and negative experiences. However, satisfaction with services is crucial if services are going to continually improve their responsiveness to the needs of those they serve. This can be achieved using the scale of the met versus unmet needs which constitutes the family caregivers' experiences (see FAMCARE tool-2, Aoun *et al.*, 2010).

Table 5.2: Examples of Potential Palliative/End of Life Nursing Care Concerns

Strategy: Give advice that patient/family needs time to rest.	Obtain respondent quotations: Wife of patient - "the nurse asked if I have been able to rest".
Empathy: show concern.	Obtain respondent quotations: Wife of patient describing how the nurse held her hand when she was overwhelmed with emotion.
Psychosocial: take the time to talk and explain everything to the patient and family.	Obtain respondent quotations: how nurse helped family members see when it became necessary to let patient go and transit into palliative care.
Spiritual advice: being able to discuss spiritual needs.	Obtain respondent quotations: how spiritual needs were met or not met.
Professionalism: discharge of professional work, provision of prompt information, provision of support to families regarding end of life decisions.	Obtain respondent quotations: how these needs were met or not met.
Concerns of the nurses: staff shortages.	Obtain respondent quotations: were there always sufficient nurses available to support families at all times?

Source: Adams *et al*. (2014).

The FAMCARE tool-2 can be adapted to reflect inpatient and team-based care within palliative/end of life care services. It is a psychometrically sound valuable instrument for measuring family caregivers' satisfaction with service provision in various palliative care settings (Aoun *et al.*, 2010). They describe how dementia caregivers' needs are currently assessed in the scientific literature to suggest guidelines for enhancing future measurement of caregivers' needs. Factor analysis of FAMCARE tool-2 reveals a 4-factor structure (management of physical symptoms and comfort, provision of information, family support and patient psychological care). This tool is thus a psychometrically sound instrument that measures family caregivers' satisfaction with service provision under various palliative care settings.

On the other hand, the search for factors influencing family caregivers' experiences of palliative/end of life care in the nursing home is at the centre of the questionnaire of my own study reported here. These factors are independent explanatory variables. Through its operationalisation, proven scales are woven into the overall questionnaire of family caregivers' experiences of palliative/end of life nursing needs.

In particular, eight items of the Skala information deficiency are included (Crosswell & Lockwood, 2020). These serve to record stress in everyday care, since the original instrument concentrates on care-related stress experiences, and a modification was necessary for the target group of family caregivers. The developed scale ranges from 1 ('such a thing never happens often') up to 5 ('something like this happens very often'). The analysis of family caregivers' narratives confirms a high value. Though the focus is on end of life care in the nursing home, it could also be appropriate for this research.

5.11 Summary

FAMICARE tool-2 (Aoun *et al.*, 2010) highlights the experience of caring for relatives, as studied in this thesis. The qualitative study in elderly care settings and the written postal survey of caring relatives form the basis of the empirical part of this thesis. In this way, the standardised, written survey captures ostensibly different experiences in the form of unmet needs of family caregivers, which constitute their experiences of nursing care. The questionnaire study thus makes it possible to make statements about the extent of family caregivers' experiences of palliative/end of life care in nursing homes and to examine the interrelationships between different variables.

Qualitative face-to-face interviews comprise dense information with pools of individual case descriptions within the nursing home context. The focus of the qualitative interviews is on the family caregiver's experiences, both good and bad. The aim is to uncover more profound interpretations and reactions. In doing so, the experiences of the family caregivers are detected and analysed in detail. This way, emotional cues are captured which are necessary to compare variables.

Table 5.2 illustrates the process of the subprojects. However, the critical information the author draws upon in this research process is from the FAMICARE study (Aoun *et al*., 2010) and the present work’s contribution. It becomes clear that the research design, data collection and questions about data evaluation are closely related to the examples seen in the FAMICARE projects. The evaluation, in this thesis, is based upon personal questions and their answers.

CHAPTER 6: RESULTS FROM THE QUALITATIVE INTERVIEW STUDY

6.1 Overview of the Chapter

This chapter presents the results of the qualitative interview study, in which a total of twelve family caregivers from four different nursing homes consented to the study interview. It commences with details from the study interview with the selected participants (Section 6.2), later presented in the form of short texts (Section 6.3).

In Section 6.3, each family caregiver's experiences of palliative/end of life nursing in a care home is analysed, based upon the individual's own perspectives. The researcher then examines three aspects in more detail. These are (1) the most everyday mentioned experiences, (2) experiences termed negative by family caregivers and (3) those experiences which reflected positiveness, and the effect on their quality of life. The role of nurses/institutions to fill the identified gaps is then discussed.

The results of the qualitative interview study need to be assessed against the background of the results of the questionnaire study. However, negative complaints/experiences can affect family caregivers' health. At the end of the chapter, it becomes clear how professional nurses are able to fill the missing gaps, termed 'negative experiences'.

Later in this chapter, the focus narrows to the aspects of the family caregivers' negative experiences and how these have affected their quality of life. Three sub-steps are necessary to apply this approach to the empirical material. These will be investigated based upon the narrations of experiences of family caregivers regarding palliative/end of life care. The first step is to examine whether and which experiences led to dissatisfaction, as mentioned by the interviewees. In doing so, attention must be paid to the negative experiences that led to dissatisfaction among the family caregivers, as these can occur either latently or manifest openly. A distinction must be made between consciously perceived everyday experiences, which result in a feeling of being neglected, and unconscious forms, which can only be accessed through in-depth knowledge-based analyses.

In the second step, the question arises of how the nurses dealt with the family caregivers' expressions of negative experiences that led to dissatisfaction (see specific family coping according to the FAMCARE model (Hannon *et al.*, 2021).

Finally, the third analysis step focuses on the family caregivers' palliative/end of life care experiences. Here, it is essential to find out through the interviews which family caregivers had reported having negative experiences with palliative/end of life care in the nursing homes. Neglect in the care of the older person leads to dissatisfaction and complaints.

As the chapter progresses, the focus narrows on key family caregivers' negative experiences. In this context, the question is on how these experiences have shaped their views of the palliative/end of life care of older persons in nursing homes.

At the end of this chapter, the results of the interview study are summarised (section 6.4) and then subjected to a critical discussion in Chapter 7.

6.2 Summary of the Interviews

A descriptive case summary has been written to provide a compact presentation of the main content of each family caregiver's interview. It reflects the common threads of the interviews. To create the short text, the author used the presented situation which was developed in the project context. In addition to the socio-demographic characteristics (age of the interviewees, marital status, number of children, profession, care level required for the older person, experiences [good or bad]), statements will be made about the overall state of health of the person in need of care. The demographical data information will be gathered from the social datasheet and a code tree for the case description formed.

To ensure anonymity of the interviewees, the quotes used in this study do not include the exact geographical location of their place of residence. At the same time, common German names will be randomly assigned to the family caregivers where required, although in the subsequent evaluation they will be simply referred to as FC1, FC2 etc. The names of locations of the care settings involved will not be included.

In every case, the interview consent form was presented, read, understood and signed by each interviewee prior to the interview commencing. Sometimes this was achieved beforehand, by email, or in paper form on the day of the interview.

In order to present the life worlds encountered in a way close to the subject matter, the interviewees will have their say at numerous points within the short family portraits, recorded in the form of concise quotations. In order to improve the flow of reading, total verbatim reproduction of the interviews is omitted (the originals were in German, then translated). All repeated words or filler words (such as 'ehm', 'ah', 'hmm' and similar) will be omitted, provided that this does not distort the context and content of what is said. At the end of this study, the author will retain the original transcripts, ensuring long-term and secure archiving of the research data.

6.3 Summary of the Individual Experiences

A descriptive case summary has been drawn up to provide a compact presentation of the focal points of content for each family caregiver. These twelve small dossier-like summaries reflect the “special features of the case [and] central themes” (Witzel, 2000: Para. 24). To create these, the author was able to use existing examples and motive sketches that were prepared as part of the EUROFAMCARE services to understand the experiences and needs of nurses, not forgetting that family caregivers, as ‘hidden patients’, equally have need of support and understanding from nurses in the nursing homes.

In addition to socio-demographic characteristics (interviewee age, marital status, level of education, occupation, religion, type of care of the older person, etc.), statements are made on the state of health of the elderly relatives in need of care and the people involved in the nursing home. Most of this information comes from the social datasheet and from the code tree for the case description. Notes from the postscripts, such as abnormalities or interruptions in the course of the conversation, are also taken into account in these twelve short dossiers.[7] However, the in-depth knowledge derived from the family caregivers covers different types of experiences, which in turn can help sensitise the settings of family caregivers’ experiences and the needs of nursing care.

To enable an easy reading style for the twelve family caregivers’ stated experiences, the following section will read as being from the anonymised person speaking at interview (i.e., Mr. C reported that he…). However, after this point, the assigned family caregiver number (FC1 through to FC12) will be used in the text where relevant.

6.3.1 Family Caregiver 1 (FC1): ‘Mr. C’

Synopsis: *Experienced frustration, lack of information, poor care of the mother/negligence, lies stated against him and lack of sufficient numbers of professional workers.*

Mr. C was 53 years old at the time of interview. He is German, married with 2 children, self-employed, and was supported by his wife and children to care for his elderly mother (‘Mrs. K) in her own home for nine years before her transfer to a nursing home. His mother had advanced dementia and died on 15 July 2021.

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[7] When specifying the source of a citation, the following should be noted. As a first step, the transcripts of the interviews were imported into Amber Script evaluation software, which formats the entire document according to the speaker. The following citation in brackets corresponds to this principle and refers to the speaker numbering of the texts.

Mr. C reported that he first cared for his sick aged mother (82) in her own home. Mrs. K was divorced and lived 30 km away from him and her other immediate family. Mr. C had power of attorney and received support from external care services who visited her house twice a day. When his mother became very ill after a stroke and through advanced dementia, he said that "*...mother became more dependent on them for help and could not be left alone.*" Caring for his mother in her home became more and more challenging for him and the family after nine years, despite the outside help from visiting nurses. The family also did not cope well due to other private challenges.

A decision was made, in September 2020, after the necessary process in the presence of both the mother and her home doctor, to transfer Mrs. K to a nursing home for professional care (referral was by the general practitioner with the decision taken in her presence). After her MDK assessment, she was assigned Care Level 3 while at home (see Appendix 5, question 26). Unfortunately, Mr. C's brother, in his opinion, did not play an active role in their mother's care, and Mr. C complained that "*his attitude towards our mother* [was] *not good,* [he was] *not interested in mother, never visited her, rather insisted that the family house be sold and money shared.*" Thus, Mr. C not only has the burden of his sick mother, but his brother as well.

In the beginning, Mr. C said "*it was easy at home, but with time I couldn't do it any more. I chose the nursing care facility because it has a large park and a church and both being closer to church and taking her around in her wheelchair or just sitting her close to the window and her seeing the park were very important to my mother, as well as church. And that's how I came to the conclusion to keep her in the nursing home.*"

Initially Mrs. K was in one particular section of the nursing home, where Mr. C had expressed satisfaction on her initial care. As he narrated during the interview, soon after his mother went into the nursing home, her pains became more severe and her condition worsened. She then suffered a stroke. His bad experiences began shortly after this point, when Mrs. K was taken to another section of the nursing home to live in a double room. Mr. C went on to express his total dissatisfaction with what subsequently happened, ranging from staff disrespect towards his mother, communication problems and a lack of information, all of which he complained about (see Appendix 5, questions 33-37). Mr. C detailed exact places and stages of care for Mrs. K that displeased him and how these affected his whole family and quality of life.

His most negative experience was regarding the "*so-called neurological care and drugs*" prescribed for his mother, which he angrily said were at an "*unnecessarily high dosage given to her to knock her off.*" When asked how he made complaints, he said he tried in his way to discuss with the persons in charge about what was going wrong, and suggested how these could be taken care of - in his words, he "*felt disappointed at ways the system solved complaints* [away] *from him*" (see Appendix 5, questions 38-40). He said "*I am so dissatisfied with everything including their way of communication, and disseminating of information. Yes, of course that could be due to all the coronavirus conditions. There were many situations where the nursing staff didn't really know what to do any more. For example, my mother's case at some point became* [very] *bad, she couldn't see well any more and shouted "Hello! when she needed something. And that annoyed the nurses and other people. Instead of worrying and caring for her, that's why she was prescribed neuroleptics to calm her down, for their convenience. And it didn't have to be* [so] *because if they had more nurses to take care of her needs, and kept them busy instead of them just sitting unengaged for hours in the kitchen, leaving* [patients] *staring at each other with no nurses around… this was a bad experience for me and my family.*"

The stroke in the nursing home, Mr. C said, should never have happened, had the nurses been knowledgeable enough, or rather had taken the time to observe the older people properly. They should have reacted better and discussed the matter with the management of the home or called in the doctor. "*It was a clear negligence*", he said. "*Instead, they totally talked their way out of the situation, as if it couldn't have happened. On the morning she went into a coma*", he said. "*But actually I didn't know that the woman who gave my mother the morning medication at half past seven on that fateful morning noticed that she wasn't okay and was now passing into a coma. Unfortunately, nothing was passed on to me, no information and I only found out when I came on my usual visit.*"

Mr. C was so unhappy about the conditions he had witnessed at the nursing home, he was at the point of removing his mother from the placement. However, he was disempowered by his mother's deteriorating condition, as no other facility would have taken his mother in her deteriorating condition. His frustration at the situation is evident from the quotation below. "*There were many things that happened.*" Regarding that time in the nursing home, Mr. C stated "*I should have said that I have to take her to a completely different care facility. You can no longer trust the care here, but that was impossible because due to the dementia, coronavirus, her coma stage, no nursing home would have accepted her. At that time we had no other choice. Yes, that was precisely* [all about] *the stroke that occurred and how it was dealt with. It's just been covered up a lot. Nothing does matter for them… not clearly stated what happened, but I was able to get a clear picture of what actually happened from different people who had a lot to do with my mother. No truth was given to me - it was said, for example, in the night my mother slept on the floor of her room a couple of times,* [but] *all this was kept away from me knowing.*"

During the time his mother was in the nursing home, the waves of coronavirus and consequent restrictions and lockdowns became of great annoyance to him. The lack of freedom to meet with his mother, and the restrictions involved in getting to meet with her when he was allowed by the home to visit, particularly during the time when his mother was quarantined, caused great problems to both Mr. C and confusion and anxiety to his mother. "*Before that and a year before that she was very ill in the care home. It shouldn't have happened like this. In my opinion, the coronavirus regulations caused people to become very isolated because they were not allowed to leave their rooms, and their family could not easily visit them So I was the only one who could visit, by appointment. The reference person was the one who brought the food into the room. What angered me was one time during coronavirus when I visited my mother in this context and it was said that I was sitting on my mother's bed in her room without a mask. That was a lie.*"

The disempowerment suffered by Mr. C, albeit during very trying coronavirus conditions which no-one really properly understood at the time, might have been reduced had staff within the nursing home discussed the situation more comprehensively with Mr. C. Ways to lessen the resulting problems might have been identified and grievances might have been avoided or lessened. He went further to report how his mother was quarantined for no sane reason: "*which is why she was then quarantined again. As a result of this act and the whole thing, a woman working there, a nurse told me that it was when she brought food with a tray into the room where my mother was staying, because she was isolated and that was how she saw my mother on the floor. See the kind of problems she had, being blind and no-one noticed this. And if one of the workers* [a woman] *hadn't lied against me which led to my mother being isolated, maybe it might have been noticed earlier that her condition was deteriorating. Then my mother would have come to the hospital earlier, then the stroke could have been handled to minimise complications. When she was eventually taken to the hospital, it was at least five hours too late. And that weighed down on me"*, he said. "*That weighed on us all. Above all, on me, because my mother didn't even notice that she couldn't see anything any more, because she didn't actually notice it at all due to her condition. She became immobile, of course. The immobility led the circulation of blood in her whole system to reduce, especially in her extremities* [in her legs]. *She had ulcers, which meant that an operation would have to be carried out. And then the doctors found out that the heart wouldn't make it at all. But that's all due to the fact that she couldn't move any more, because she just couldn't see anything any more and one thing led to another. And so it is actually collateral damage from the pandemic and the careless nursing in that setting. And carelessness from the nurses. And if it weren't for the pandemic and the restrictions, it probably would have looked differently today*" he added.

Mr. C went further to narrate that either the nurses lacked formal education on palliative/end of life care of older people, or they were overwhelmed and stressed with so many older people who needed care and the reduced number of nurses then on duty. He stressed the lack of information from the nurses and went further to speak on his mother's last days in the nursing home. “*I realised they were just pumping my mother with drugs, just to make her calm*.” This, he said, was unacceptable. He said, “*I went to visit my mother as I do in the evenings when I return from work*.” On this fateful day, he reported in agony, “*I saw my mother already panting and struggling with breath, with saliva dripping from the side of her mouth*.” The sight of his mother in that helpless state was a painful sight. “*She was suffocating in her saliva, and no nurse was present*.” This he repeated over and over again as a sad incident. “*It was when I came that the nurse told me the palliative doctor had visited and the morphine plaster 100 microgram prescribed. I was shocked*”, he said, “*as no one informed me prior. Now my mother is lying down in her saliva and struggling for breath, no suction machine to relieve her of the saliva*.” He said that he “*wasn't sure if there was any suctioning machine available, if the nurses were trained to operate that*.” When a suctioning machine was finally found and brought to the mother's room, the nurse on duty was “*ignorant of how the machine operates*.” The only thing he had to say that made him feel a bit okay was that he was there when his mother breathed her last. “*I held her hand*s”, he related during the interview and said, “*After all, she did not die alone*.”

ADDITIONAL INFORMATION: Mr. C was eager to narrate his experiences in the 60 minutes of the interview, saying that he longed to be heard. When asked about changes that occurred after the nursing home had taken over the nursing tasks, he describes for a further 20 minutes what he didn't like. For example, the neglect, the lies, the bad information and the coronavirus period. He was extremely happy to speak out on this topic: “*That was the stroke that almost made her blind. Her stroke was overlooked by the staff. I would say intentionally overlooked. And she has shown that she felt everything… Everyone should have seen that something was wrong. But I was told much too late. So if I had known I may not have brought her to this nursing home."* In short, he continued “*this setting is something I would not recommend to anyone, after all the experiences*.”

Mr. J, the Grandson

Mr. J, then aged 22 years, is a grandson of Mrs. K and the son of family caregiver Mr. C. Both were actively involved in the care of Mrs. K. When asked what he thought about the palliative/end of life care of his grandmother, he answered “*thinking about nursing, I was in the middle, feeling just fair*” he said. Asked where he expressed dissatisfaction, he replied that complaints were passed to appropriate quarters, but not much was done. With the palliative/end of life care at the nursing home, he expressed that it was just “*good*” and insisted that more should have to be done to help the dying older people die with dignity. By so doing, they would have assisted the family caregivers to deal with the impending loss and bereavement. He complained bitterly about poor communication, the lack of information and some aspects of nursing and care during the dying process. He had a clear definition of what to expect during the last days for his grandmother. He was a bit sad that the few nurses had so much work and lacked the time to meet the needs of the older people and their family caregivers. He recommended that more nurses be trained to gain further knowledge about palliative and end of life care. He therefore suggested that nursing in old people's homes be made more attractive and rewarding for nurses.

When asked if he would be willing to recommend that particular nursing home to someone else, Mr. J said, "*I would advise they have a good look and think before deciding for that setting*."

6.3.2 Family Caregiver 2 (FC2): 'Mrs. H'

Synopsis: Experienced mixed feelings, both good and bad regarding the care received.

Mrs. H is a mother, 63 years of age at the time of the interview. She is separated, has one child (a son), who is German, and she is currently living alone in a large town. She is educated, had worked in the administrative sector. She was the family caregiver to her mother (born in 1930), who was a 90 year-old widow at the time of her death. "*My mother lived 40 minutes away*" and Mrs. H drove and occasionally walked to visit her. She said she took care of her mother for about eight years, from 2012 to 2020. From January 2020, when her mother's condition deteriorated, she made the decision with the family doctor to transfer her to a nearby nursing home, where she lived until August 2021. She said that after the stroke which her mother suffered and which left her bedridden, there was no way to manage her any longer at home, as she did not have the necessary facilities for her care.

In 2020 she was assessed to receive Care Level 5, which continued from March 2020 in the nursing home. From July 2021, palliative care was started, as her condition worsened. Mrs. H stated that her mother at this time was unable to swallow on her own. After discussions with her personal doctor, Mrs. H said that she was glad that her mother was in the nursing home; not that she wouldn't have liked to have her back home, but rather, as she said in the interview, due to the psychological strain, demands of her private life, and other reasons. Her mother had, according to Mrs. H, arranged a detailed document in law stating how and what should be allowed to be done to her when she no longer was able to decide for herself. During the interview, Mrs. H confirmed that she had the power of attorney to decide when her mother was unable to able to act for herself.

Interview question no.32 received mixed answers, whereby Mrs. H complained of situations where she was misunderstood, there were confusions with some rules, about which she said no-one explained anything to her. Her feelings were mixed, with her general feelings being 50:50 good/bad. She had complained many times, she said. Many times she had spoken with the head nurse, when things were not going as she wanted. Regarding whether she knew anything about palliative or end of life care, she answered "*I must say, I felt left out*." When asked what she understood about palliative care, she said that "*this type of care is meant only for the sick person,* [not] *about the nurses acknowledging my needs as a family caregiver*", and she did not think they were part of the holistic end of life care. She expressed some level of satisfaction with the nursing given, but was dissatisfied with the setting. When asked if she had made the right decision to send the mother to the nursing home she said "*yes*", because she wouldn't have been able to care for her alone at home. She felt bad to see her mother vegetate and not be able to help her.

She said that she did not know much about what was involved with end of life care, as she was not properly educated, although she would have felt better had she received more communication from the nurses. Mrs. H expressed sadness over her mother being in a nursing home, but she was helpless. She said that "*I was always conveying the feelings that I, as a close relative, am taking good care of my mother and would do and arrange everything for her, so that she can feel safe, pain-free and well looked after*, *that was always my wish."*

She said that her mother spent 18 months in the nursing home before passing on. According to Mrs. H, the last six months were terrible. Information was not adequately given to her by the setting regarding a change in her mother's condition and the fact that no doctor could be reached by the nurses quickly when her mother's condition worsened was not good. No-one was answerable directly, and the frustration of not knowing where to get helpful information compounded her experience. This kind of experience continued, she said. She said in a low agonising tone; moreover, that on her mother's dying bed, there was no nurse in the room, and no-one informed her that her mother was at her dying moment. She just came unplanned to see her as usual, and was shocked to see her mother gasping for breath. The fact that she felt her mother was not well cared for affected her general mood, and she said "*I could not understand why no-one informed me that my mother was dying*."

During the interview Mrs. H was calm and able to answer questions relating to her experience. She equally had time for the written questions, which were sent back through the post. These were used to compare with the oral interview answers, for collaboration. It was noted that, during the interview conversation, the anger of Mrs. H towards the nurses was clearly evident.

6.3.3 Family Caregiver 3 (FC3): 'Mrs. J'

Synopsis: Mrs. J, the 55 year old daughter-in-law, was concerned about receiving poor levels of information and lack of spirituality when her mother-in-law and father-in-law were in a nursing home. Married, with three children, Mrs. J had cared for

> *her elderly mother-in-law and father-in-law at their home. Both her mother-in-law and, soon after, her father-in-law had been admitted to a nursing home.*

My initial contact with Mrs. J was through a family member. Contact continued through WhatsApp and emails, then a telephone call on 31 January 2022. An appointment to meet was arranged, and the interview day scheduled for 22 February at a place of her choice. During the interview, Mrs. J was willing to speak regarding both her experiences at the nursing home, where her mother-in-law had spent her last months in 2019 and her father-in-law had been admitted some months later.

Mrs. J's mother-in-law

Mrs. J's mother-in-law was born in December 1933. She raised two children, was evangelical and a farmer. She had been born with spinal bifida and suffered from chronic dementia. As nursing at home became more complicated (being also wheelchair bound and unable to go to the toilet), the family sought a nursing home for her. Collectively, the decision was taken by the family to transfer her to a nursing home where she was to be taken care of 24 hours a day. Consequently, following the initial nursing for three years at her home by Mrs. J and visiting nurses, Mrs. J's mother-in-law was transferred to a nursing home in March 2019 until her death in August 2019. Regarding question number 26 in the questionnaire, Mrs. J stated that her mother-in-law first received Care Level 3, which subsequently increased to level 4 and eventually level 5. They also received some help (Pflege Geld) which was used to supplement the nursing care.

This move to the nursing home seemed to have initially gone well, but during April she developed a decubitus ulcer on one of her right toes. This refused to heal and diabetes was diagnosed, although this information was not initially passed on to the family. Mrs. J's father-in-law would be taken to visit and meet his wife alone in her room, but there was often the smell of urine present.

Mrs. J complained that she would look for a nurse, but often would not find one for quite a while. Her other complaint was that her mother-in-law was a practising Anglican who had been a regular churchgoer. Despite Mrs. J specifically putting it down as a wish for a pastor to visit her mother-in-law, that was neglected until late at the very end of her life. This caused Mrs. J concern, and she questioned this with regard to the nursing of older people and the last days of their lives in the nursing home.

Mrs. J's father-in-law

Mrs. J's father-in-law was born in September 1941. He was married, initially had been very active, having been a tractor and bus driver, and was an evangelical Anglican. He had more recently suffered several falls, due to his liver cirrhosis. His relationship with Mrs. J was not always the best. Mrs. J's mother-in-law was in her 90s, suffered from spinal bifida, and was also being cared for at home. Both were being cared for at home by Mrs. J, and had been for several years past.

At the same time, Mrs. J worked full-time at home at the time of the interview as a housewife, with 3 children and taking care of their farm work, evangelical religion and cooking. Mrs. J loved her garden and all to do with nature. She had one brother who attended school until the 10th class, then trained as a hotel waiter.

She said during the interview that her father-in-law lived in the same area as she did. Her father-in-law had been cared for the past 12 months at home (with the help of visiting nurses) until, in Autumn 2020, he was transferred to a nursing care home very close to them, as a result of his health deterioration, continuous falls at home and loss of weight. He now had no strength due to the liver cirrhosis he was suffering from, which thus made his continued care at home impossible. His wife had earlier been diagnosed with cancer, so looking after both became emotionally draining and caused difficulty when combining this with Mrs. J's work. A nurse from the palliative team visited them at home, explained the need for palliative care, promised that someone from the team would always be easily reachable in any situation, and that one member of the team would visit the nursing home to review his case from time to time.

The decision to transfer him from his home to a nursing home, she said, was a joint decision made by her and her siblings, along with the general practitioner. As she narrated plans that had been made for palliative care due to his condition, she stated that the decision to transfer her father-in-law to a nursing home for intensive 24 hour care was welcomed by all involved in the decision. Her father-in-law was assessed to receive Care Level 4 and there was also a small amount of monetary support from the Nursing Care Fund (Pflege Geld). Her father-in-law, she said, had a signed document expressing his wishes.

In all, she stated that their general experience of the nursing home was good. She said whenever there was a need, she had always requested a meeting and that her queries or complaints were promptly answered and responded to. However, in her words, "*the time of coronavirus was very challenging*", as her father-in-law was isolated with no access to television or telephone, and they only were speaking or getting information indirectly from him, through the nurses. Mrs. J made a complaint regarding this situation. She expressed the need for more qualified nurses to be employed. She directed some of her complaints to the management regarding the politics of the situation, saying the profession should be made more attractive, paying more money and rewards, and employing more trained nurses to enable more time for the needs of the older sick or dying people and their caregivers. However, overall, she expressed a good positive feeling, that her father-in-law got a place at the nursing home; in her words, "*otherwise the entire family would not have coped with the care at home*."

Overall Assessment

Overall, Mrs. J stated that she had mixed experiences of the nursing home. Firstly, she expressed gratitude that the got places for her father-in-law and mother-in-law, and that they were happy with most aspects of life there (but see comments above). The only other area with which she expressed concern was the staff shortage of nurses that made most aspects more difficult. On her overall experiences, Mrs. J stated that communication was good, the nursing care was good, but she was worried about the general conditions within the nursing home.

6.3.4 Family Caregiver 4 (FC4): 'Mrs. N'

Synopsis: *Mrs. N, a 43 year old granddaughter, expressed her mixed feelings. She was particularly concerned about the nursing home nurses who appeared to have only minimal knowledge of end of life care and drug administration, and their poor levels of communicating relevant information to family caregivers. Her interview opinions relate solely to her uncle's end of life situation, not to her grandmother's.*

The family caregiver, Mrs. N, was 43 years at the time of interview. She was now divorced, had one son, and in full-time employment. Her uncle, then aged 70 years, had lived with her grandmother (she used the term 'grandma'), in her grandmother's home, in their later years, and Mrs. N had acted as the family caregiver for both of them.

During the interview, Mrs. N was very relaxed and extremely willing to share her experiences. She was told the ideal duration of the interview, but because she loved the topic she wanted to go on well past the suggested time limit. Mrs. N was very descriptive and precise in her statements and opinions during the interview. Consequently, much of the description presented below is directly from her own transcript.

During the interview, Mrs. N stated: "*Well, my uncle lived with grandma for years, unmarried, no kids, before it became impossible* [for my uncle] *at home after the death of grandma*." She reported that her uncle was a traditional person and very conservative. Her uncle was transferred to a nearby nursing care home for old people when he became very sick, highly dependent and in need of constant care. "*It is OK to talk about him now*", she said, "*He died at a nursing home. My uncle always lived alone at home until three years ago, when he became unable to walk well*."

Prior to the uncle's nursing home admission, "*he often presented himself at home in a wheelchair, but was very resistant to any advice. He just happened to go to the hospital one day, to the university clinic hospital in Essen via the house emergency call,* [a call] *which I eventually persuaded him to do. We then discovered that he already had an intense lot of problems. We had always wondered why the apartment was not well cared for, but he kept on denying his condition* [was deteriorating]."

I asked him "*Uncle, what about you and your health? Please do not be ashamed of me, tell me how you feel and I will help you! I am here to help you. However, it was already too late, and it was also too late before we discovered how serious his condition was. He did not even come home from the university clinic to his apartment anymore. He was transferred directly to a nursing home close to where he lived, because he lives in Essen, and Essen is very near to where I live so I looked for a nursing home for him here where I was living*."

"*However, all I can say is that family caregivers of older people in the nursing home with no end of life/palliative care experience are in a fix. They are absolutely in a fix. Well, I was already in this kind of work, I have experience and knew what to expect during his admissions interview in the nursing home. I first waited for what they would tell me and then, at some point, I presented a few questions like 'now, I am in care work myself'. There were times their answers to my questions were not satisfactory and I would interrupt 'what are you telling me right now?'. I think many helpless relatives, who are powerless and have no idea, are here on the high sea and are afraid it will not go down well with them if they ask too many questions!*"

Mrs. N's uncle later required a strong painkiller (see subsequent paragraph), but she was shocked by the nurses' lack of pharmaceutical knowledge. "*And with the injections. Morphine. What time window, what signs, when the unrest comes back? I am curious to know how nurses managed patients at end of life in the past. I could not believe how* [badly] *they carried out this at the end of one's life. Nevertheless, I hope that through me, through my uncle, they have gotten a different perspective on learning end of life/palliative care in the nursing home*."

The nurses were found lacking in their ability to initiate pain therapy. "*I came to visit my uncle and everything was fine. Nevertheless, then I found it noticeable that he had started to feel pain. Well, I was the one who phoned the doctors. I brought the family doctor on board, and ensured that he was treated with pain therapy at first. I stressed and pressed the button and he was enrolled for palliative care and he got good pain therapy. Then I ensured he got an adapted wheelchair, because he developed massive contractures so that we could not have put him in a standard wheelchair. In the end, he could no longer be mobilised. Every time I put him in the wheelchair, he overreacted - he got sick, stopped eating and drinking,* *that was when I noticed that he cannot and did not want to* [be in the wheelchair] *any more. Then I went to discuss this with the head nurse in charge, but only because I knew it was coming to an end for my uncle and arranged and brought the palliative care service into the nursing home, but also because I had worked in this branch with them every day through my job experience before. Nobody came up with the idea, and I then made sure that the palliative care service had a conversation with the management of the nursing home and did not disregard anything. They did not know that at all. That was for them, where I thought, well, that is how they thought. The care and such, it was all good. I was super happy with it, but they have no idea when it means someone is dying or signals that show one is dying*."

"*I was glad that my sister understood the situation. I mean, really, and she called me on the phone. I drove to the nursing home briefly, then went on and I made sure that he had good end of life care and suitable medication so that he could set out and let go peacefully. And even I, as a relative, had good care. After consultation with the nursing home, I was allowed to do the last care, take the last steps the last time, because that was precisely the last step to let him go in peace*."

"*And nevertheless, I don't know, I can only speak for myself, from experience now, but my father says that if we had not had you with your experience, he would have perished when he needed nursing care*."

Later during her uncle's time in the nursing home, he was found by Mrs. N to be suffering from ulcers, which the nurses had missed. "*It was not even six months after he came to the nursing home. I saw that the nurses in the nursing home had overlooked* [something]. *I saw him one morning. Because I knew him well I recognised immediately that there was something wrong. He had decubitus ulcers.* [But] *the wound material was unavailable. Relatives* [family caregivers] *who have yet to learn are lost. I showed the nurses for the first time the importance of palliative/end of life care in the nursing home and the need for a palliative team from outside*."

Regarding the whole process of dying and the current popular culture around it, Mrs. N had this to say. "*Nevertheless, awareness should be created. Practical education, whether at home, partially, in nursing homes, or in public, will create awareness. I have never seen people sensitised about ageing, dying and the needs of their carer and I have never visited or heard of a seminar for family carers of dying older relatives in a nursing home somewhere. That would be a topic that I would immediately attend because it moves me so much, and I am eager for more awareness to be created. However, dying is not taboo. So, we do not need to repress the topic; it is suppressed and needs to be spoken about so that nurses understand the language of end of life. No matter how much we pretend* [to ignore] *this topic, dying older people and their family carers' needs, the topic will come up again at some point. No, it is present every day. Anything can happen. We can fall on the street every day, needing care. We can be attacked anywhere, needing care! I can fall down the stairs, become suddenly incapacitated, and need help. No, it has not become part of everyday life. It does not belong to our everyday existence, and it does not belong there. We are a death denying society, or those old sayings. 'My God pinches the swaying'. 'It cannot be that bad', but sometimes it is that bad, and sometimes you feel that bad.*"

"*And I think what you are doing is a small stone, but you are making it for a better tomorrow, a good topic for everyone, at least our children today are more aware and truthful about death, that our children no longer see this topic as taboo. I'm so sad: Germany is a rich country, but what do the countries that do not have this opportunity do? All necessary medications are called palliative,* [but] *not available for those in need.*"

Finally, Mrs. N had this to say regarding the current practice of doctors. "*There are many doctors, when they are called for an emergency,* [whereby] *the question that comes from them is 'What do you want from me now?'. Then instead of accessing the actual condition when they eventually come, some dying patients are put on a short infusion, even though they are already in the pre-finals. I think even the doctors should equally be educated on death and dying, so that they are able to recognise and know when to say 'stop'.*"

6.3.5 Family Caregiver 5 (FC5): 'Mrs. M'

Synopsis: *Mrs. M, 57 year-old daughter to her father and former wife to her ex-husband, both of whom had died in a nursing home. Expressed feelings of anger and disappointment.*

Mrs. M was aged 57 at the time of the interview, in full-time employment, divorced, with two children. Despite the prior agreement to talk only about the essentially positive experiences of her father in nursing care, she also was insistent upon talking about her ex-husband, whom she claimed was not treated well in the nursing home. She spoke with anger and disappointment about his care.

Mrs. M had cared for her both her father and her ex-husband. She expressed satisfaction regarding the nursing home where her father was cared for. However, she expressed total dissatisfaction regarding her experiences with the nursing home where her ex-husband had stayed, alleging that nurses had been negligent, were always under pressure, and had no time for the patients. Her answers at interview were full and descriptive, and pertinent sections are reproduced below as spoken.

Experiences Regarding her Father

Mrs. M had been the family caregiver for her father for a number of years prior to his admission into a nursing home. However, her wider family did not agree that her father required additional help or should be admitted to a nursing care home. "[My] *relatives and also my brother refused to use a nursing service or day care or 24-hour service or something like that, and my father had a lot of haematomas all over his body at the time, and also had a bad fall, because he was allowed by his partner who was living with him at that time to take a shower alone and then he had a fall and had several broken ribs. He suffered* [from] *severe Parkinson's disease."*

Unfortunately, she said, when she raised the need for her father to be in a nursing home, she was attacked by her family. "*It was a burden that I was attacked for him being there, because he already had this impairment two years earlier, and when I was still looking for a nursing service, for a nursing care classification, remodelling of the bathroom and other necessary things for his nursing, the other siblings and his partner reacted very negatively. I was bullied. They said I would only want to make work for the others, and avoid taking care of my father. I would feel bad for their reactions. They said I only wanted to make them look bad. All I wanted was for the good of my father.*"

"*We didn't have a specific conversation about palliative medicine. It also happened that the visits weren't that frequent due to the coronavirus period. His partner was often there, and I was very rarely there in person because I* [was] *also constantly in* [contact with] *coronavirus cases at my workplace. I said it doesn't matter, you'll have visitors, but I don't have to walk there now. But we were actually always in there.*"

"*Umm, but we were actually able to come to an agreement on that. He hadn't recovered well after a coronavirus infection in the last few weeks. He got an inflammation of the parotid gland, which also tormented him a lot,* [but] *even then it could be fought back with antibiotics. But you could tell that he became 'a trailer'* [her precise words] *because of his condition, and then it was so understandable that I would come when the family doctor who was treating him, the doctor who looked after the residents, was there.*"

"I personally have had good experiences in the retirement home, and I also know from other relatives, from the relatives of other residents, that even during the coronavirus period, just palliative cases, the visit was also made possible, that under certain circumstances, the rooms have also been swapped so that, for example, relatives can visit their relatives through a patio door and still not endanger the nursing home. Well, a lot has been made possible there and also in such a way that you have time and peace to sit and that you don't have to stick to opening hours."

"Well, there was always someone available, but sometimes, when you notice as a visitor that the employees have a lot to do, you don't like to ask because you don't want to be unpleasant. It would be nice if you had something like a social service in the nursing home for the talks between the home and the relatives, information exchange and exchange about medical matters. That would be desirable."

"Well, it would be very nice if the employees could approach visitors and relatives and say, 'Ms. X, anyway, anyway, they still have a question. Can I explain something to you?' I would have time right now, because then it stays, that's the way it is in practice somewhere at the moment, and then as a relative you don't always have the feeling that you're being a nuisance. When there was an opportunity to talk, I have to say that the nurses really did what they could, but they can't do more than work."

"And if the nurses don't have enough opportunities, don't have enough time and don't have enough support to do their care work well, then they aren't going to be happy either, and you can see that in them. I have seen staff in other nursing homes who were just emotionless in the face towards their residents and just as unhappy, as if there are heavy bags under their eyes, and I would never have put my father in a home like that."

Experiences Regarding her ex-Husband

Mrs. M expressed strong negative views regarding the way her ex-husband had been treated at his nursing home and with respect to the level of nursing care he received. Again, her views were well expressed verbally, thus direct quotations have been used where appropriate.

"In the nursing home where my ex-husband was kept, the bins for used diapers were still in the room when lunch was served, and that's the way it is in most nursing homes. From my ex-husband I found out that despite tube feeding, he only got half the calories that he needed, and no one could understand this. He should have been on high calorie food as prescribed but he was just kept on normal food. Perhaps it was more cost-effective for the nursing home, and if nobody had asked, if nobody had cared, it would continue this way. Perhaps if someone who hadn't experience and didn't ask, but I... found out, but which was narrowed down. On excuses, yes, even with a serious illness like the case of my ex-husband" she said *"high calorie food should have been administered."*

Anonymity of personal information was not observed by nurses and/or administration at the care home, and as such this allegedly became a regulatory issue and investigation for the home. *"My former husband was assigned someone at the time. I described this to the* *caregivers but that was not kept anonymous",* although, she said *"my ex-husband died anyway. I think this nursing home got a ban for two years from the state."*

When asked about the process of a loved one dying, Mrs. M answered *"Yes, the topic about dying relatives is important and the caring. However, some relatives themselves don't understand what this is actually all about, because some adults, up to 30, 40, 50 or older, have no contact with death themselves and dying because that doesn't happen within the family any more, and I come from a rural family of three generations. Well, even as a child I came into contact with death and dying and didn't experience what happened at a distance. Today it is seen* [as being] *in secret houses, as a taboo."*

When asked how her ex-husband died, Mrs. M answered *"He died of an intestinal obstruction, and on a Friday he had severe stomach pains and was taken to the hospital straight away. They immediately suspected* [an] *obstruction and operated on him as an emergency. Unfortunately the operative team also saw immediately that large areas could no longer be treated or repaired and they could not help him any longer. And they told him that on Friday and asked him again on Saturday if he wanted someone to visit him, but he didn't want to see anyone any more. They kept him pain-free and also spent time with him. A nursing sister explained it all to me. She was also on duty with him that Saturday as he fell into a coma in the evening and then died on Sunday morning. She was probably with him. Then she informed me that I was the only relative represented in his files. She was very calm with me, explained everything to me, answered many of my questions. He was still in his room there, and I was able to say goodbye to him while I was still in the intensive care unit and was also allowed to make phone calls there and call my daughters, that is, his daughters, as I described to them what their dad looked like, what happened and that he still has a bit of warmth, and so try to explain the situation to them as well."*

She continued: *"I said to my ex-husband's intensive care doctor at the time* [in hospital, before he died] *that I needed information from him because my husband was in a coma at the time, had very deep eyes, a grey-white face and sunken triangle. And I said to the man, the doctor at the time, I need guidance from you now, but because I have the impression that my ex-husband doesn't look good, just like one with life-threateningly illness, but in my eyes a bit like one dying, and he, the doctor, looked at me quite shocked that I was making this difference. He then told me that my ex-husband was not clearly looking like one dying. But the knowledge of what a serious illness is and what a dying process is, according to doctors, is very little widespread in hospitals, and even more so in nursing homes, because in nursing homes it is more likely that a resident will die, and nurses should be trained to recognise at sight a person dying."*

Regarding access during the coronavirus pandemic, Mrs. M replied *"Um, and that led to an argument. The coronavirus time did not make things easy, both for patients and the family carers. The young people had to take so much negative from coronavirus and were so disadvantaged, as were older people in the nursing homes and their family carers."*

6.3.6 Family Caregiver 6 (FC6): 'Mrs. C'

Synopsis: Mrs. C, 81 years old, long-term caregiver to her 83 year-old husband initially still currently living in a nursing home, who died just before the interview was conducted. Initially, Mrs. C experienced good nursing practices and was content with the nursing care, but this later turned to frustration and anger at the nurses' poor communication and lack of knowledge of coping in the end of life situation.

Initial contact was made through the family. The interviewer then contacted her personally and met her on several occasions. When first met, Mrs. C's husband was still in the nursing home for palliative/end of life care. The interviewer met them severally, observed them and spoke with them. She was quick to give her consent to a formal interview. An appointment was made with her then and she consented to a questionnaire and a face-to-face interview. The date chosen was 11 April 2023. She narrated upon her son and daughter-in-law's support, especially during the time that she had cared for her husband at home, for one and a half years. The 83 year-old husband had been very active in the community until his ill health. "*A business owner, a joiner and a quiet husband*", she said.

Mrs. C, 81 years old at the time of interview, was now widowed with three children. However, two of the children had severed contact with her and her late husband, and this had caused some pain. She was a pensioner and had helped her husband during her working days run and manage two family companies.

During the interview, she broke down many times in tears as she narrated their past bitter experiences with their youngest son and daughter (there was then a long pause). The interviewer gave Mrs. C a tissue to wipe her tears and, after a while, she went on with describing their loss and her husband's condition changes. These experiences must have been harrowing, for these were what, she claimed, made her husband's condition deteriorate.

Mrs. C described how, in 2019, her husband started to behave in a strange way, losing concentration, speaking about one topic then continuing on another, until a level of aggression set in. Their general practitioner consulted her family and made several referrals for her husband. As her husband became incontinent, she said, nurses were arranged from outside to visit morning and evening, clean him up and mobilise him in a wheelchair. She prepared and administered the medications and did all of the house chores, including organising for doctors to visit.

She described her eldest son and his wife as being very helpful, but she was heavily burdened and suffered sleepless nights just watching her husband. Since both her son and his wife were full-time workers, after one of the general practitioner's visits, the discussion turned towards her husband's general condition, "*heart problem and dementia*". The GP recommended and referred him to long-term care (in a nursing home). Eventually, they found a nearby nursing home which could take him and were glad. However, on two occasions, the husband succeeded in leaving the home with no-one taking any notice and managed to find his way back home. She alerted the nursing home, which at first did not realise her husband had left without anyone noticing. The thought of her husband leaving the setting with no-one noticing was a burden for her, "*if it were to be in winter, and he was away without a jacket, what would have happened?"* she asked. She continued uninterrupted, speaking at length.

When asked about the nurses, she said that the family was satisfied with the nursing care in the first six months until her husband's condition changed drastically, so that she could not determine if he still had his cognitive ability. In any case, she complained about poor information and nurse education, the lack of sufficient nurses, lack of knowledge of their own facilities and services available.

At the end of life, no information towards her husband's change in health condition was passed on to her, and there was no practical support provided. "*When morphine was administered to my husband*", she said painfully, "*it was in a high dose, no-one informed me*". With a broken voice, she said that no-one had told her that her husband was gasping for breath. "*Now*", she said, as she added, "*imagine the nurses depriving me of the chance to say goodbye*". She was not present to bid him farewell. The only consolation, she said she had, was that her daughter-in-law came to visit her husband. The following was what she had to say about what her daughter-in-law told her. "*My daughter-in-law said she met my husband at the point of death, eyes fixed, saliva dropping from the side, choking.*" She described, in her own words, struggling, suffocating with saliva, with no nurse present. Eventually, when a nurse came after 30 minutes of searching, she asked for them to use the suction machine to remove the saliva. They started looking for a suction machine, but the one they found was not functioning. She watched her father-in-law suffocate in his own saliva. The whole incident lasted for around two hours. "*What a shame*", she said. In the end, she requested a follow-up discussion with the nursing home so that the same mistake could be averted in future.

Mrs. C broke down many times in tears while talking about her experiences with her husband's care, and regarding the experience of their youngest son and daughter who broke contact with them and made them suffer a feeling of loss for all they had lived for. The death of her husband had broken her and the interview had to be interrupted several times to give her time and to console her. However, in the end, she stated that she was glad to have given the interview.

Some days after the interview had been conducted, Mrs. C requested to attend to hear a replay of the taped interview, and this was undertaken. A transcript was also shown to her. She ended up by confirming she had been glad that she had given the interview and saying that she would wish that "*more qualified nurses are employed to care for the old people.*"

6.3.7 Family Caregiver 7 (FC7): 'Mrs. P'

Synopsis: Mrs. P, 56 years old, was a long-term caregiver to her 83 year-old father, initially still living in a nursing home, but who died just before the interview was conducted. Mrs. P experienced good nursing practices regarding the care of her mother. However, care for her father, in general, was a mixture of experiences - mostly good or satisfactory experiences, but including dissatisfaction. Mrs. P felt that nurses were not always well educated on what to expect (regarding her complaint on wound management and physical neglect of the father).

Family caregiver Mrs. P was 56 years old at the time of the interview. She is educated, divorced, has two children, and is in full-time work. The interviewer had first contact regarding Mrs. P through a friend. Subsequent contact via telephone established that she was willing to assist in this study. Consent was sent and received via email, as well as the supply of the questionnaire. Telephone numbers were also exchanged. She was given the choice to make an appointment at a place and time convenient for her. It was agreed that an on-line interview via FaceTime would be most convenient for Mrs. P, and a time and date fixed (15 March 2023). She said she had a full power of attorney to care and speak on behalf of her parents.

Experiences Regarding her Mother

Mrs. P said that she had taken care of both her mother and father over the past years. She had been happy that her mother had received a place in a nursing home. Her mother died at the age of 76, and she was, to her death, married to her father. They both lived 10 minutes away from where Mrs. P was living with her family. She took care of both of them with the help of external nursing support until she was unable to continue her mother's care at home.

Her parents were both German, lived in their own house, and both suffered from Alzheimer's disease and dementia.

Mrs. P had cared for her mother at her own home for more than two years, but, in 2015, she became very dependent and was transferred to a nursing care home near to them. In 2017, Mrs. P reported that her mother was then suffering from severe Alzheimer's and also a number of organ failures. She was by now receiving Care Level 5. Information, she said, was given to her by her mother's personal doctor and she was duly kept informed by the doctor at every level and of the changes that followed during Care Level 5.

With her experience and knowledge, Mrs. P was able to organise a palliative team for her mother. She mentioned many times that she was satisfied with this situation and stated that "*Maybe* [it was] *because they know I have enough knowledge and understand what to expect. What happens with families and family carers who do not know what to expect and where to get help? This is an open question for nursing today."*

However, Mrs. P stated that her mother suffered from serious decubitus ulcers whilst in the nursing home, which were not, in her opinion, managed properly. This, she felt, was unsatisfactory.

Experiences Regarding her Father

Mrs. P's father, then aged 82 and now a widower, had received care at home for the past two years care from her. Her father had, for the past three years, been suffering from the more severe symptoms of Alzheimer's disease. He had been assessed and was receiving Care Level 3 at that time in 2021. During 2021 he had to be moved into an old people's nursing home due to Mrs. P's work and family commitments.

The experiences regarding her father's treatment within the care home gave rise to her major complaints and were the reasons for her bad experiences. She said she had complained many times because his clothes were not changed regularly. Although they reacted positively, they took a long time to put things right. In all, she now has a positive experience of her father's treatment and said that if she has the choice she would recommend palliative/end of life care for an elderly relative in that nursing home. She is just like any other person, sad about what happened to her parents. She recommended, towards the end of the interview, that nurses should be encouraged to become more educated regarding old age care in cases involving Alzheimer's disease and dementia.

When asked about her experiences, she reported being satisfied in many of the initial areas of her father's care, except up to the point of his wound management. When asked how she experienced nursing she had mixed answers. She was satisfied in some areas, but expressed dissatisfaction in some others.

She reported about one situation that made her unhappy, regarding the physical appearance of her father, when he appeared not to be dressed in accordance with the weather at that time. She said that "*when he's delusional, he dresses himself, and then he just lives in something, and then nobody pays attention to whether it's fresh stuff or something. Yes, and I've* [also] *mentioned this several times now* [to the nurses] *that he wasn't offered enough to drink in his room. Well, if it's empty and I don't come two or three times a week, I always made a note of that on the bottle, but then the bottle was still there. I know he gets a drink at the table, but there is just not enough in the room when he sees that he can do something on his own. But the only thing, as I said, is that I really think it is a pity that the area of dementia and Alzheimer's is not so well received, I think. You can tell when palliative care is needed. Now my dad is lucky that I'm a specialist myself and I'm also very behind it. I can't go there every day, that's why he's there, but I'm always there once or twice a week, and I'm always in control, and I always pay attention and also consult and so on, and I talk also immediately if I had any problems. Of course, this was also quite a while during coronavirus."*

6.3.8 Family Caregiver 8 (FC8): 'Mrs. Marlene'

Synopsis: Mrs. Marlene, 82 years old, was the long-term caregiver to her husband, who had received short-term placements within three different nursing care homes before his death. Mrs. Marlene expressed her concerns regarding a lack of received information, low quality care within the nursing homes, that her complaints were not well received or acted upon, a lack of nurses with experience regarding end of life care, and some personal belongings of her husband had gone missing without a proper explanation, each of which contributed towards her overall negative experiences.

Initial contact with Mrs. Marlene was made through a church member, who gave the interviewer her phone number. On 25 April 2023 an initial telephone chat was made. She was very friendly and stated that she was ready to conduct the interview. An appointment was made, to be held at her home, just two days later, at 10.00 am on the 27th.

On the day of the interview, she was very eager to speak out and narrate what had worried her for years. After the normal greetings and introduction, she offered a glass of water, and was given the consent form which she took time to read and was asked if she was okay with the content. She quickly signed and gave her consent. The interview lasted for 1 hour 45 minutes. She gave answers and elucidated upon all of the questions asked, ranging from her demography and that of her late husband thorough to his final end of life care.

She stated that she had been given the power of attorney to act for her late husband, and was informed regarding the power of this process when her husband was first cared for by her at their home in Münster. Her husband had been diagnosed with Parkinson's disease which was not at a stage which could easily be taken care of at home. This lingered and he was placed in short-term and long-term respite care close to where she lived. When it became more difficult to continue his care at home and after a fall, their house was sold and they moved into rented accommodation, closer to their son. Her husband was initially kept full-time in a nursing home close to where they had lived, and when it became clear where their new permanent address was to be, they relocated him to a nursing home closer to her and their son.

Mrs. Marlene then began to narrate her ordeals and what her experience of nursing care had been. Her complaints ranged from total neglect, bad physical care, the dumping of meals in his room with no-one to help feed him, a lack of changing his clothes, these becoming dirty and unkempt, his dirty finger nails and toe nails, his hair becoming dirty, unwashed and uncombed, a lack of proper information alongside poor communication, the unaccountable loss of some private belongings, and how her complaints were not well handled even when reported to the appropriate quarters.

In her broken voice, she narrated how she felt seeing her husband in that situation and feeling so helpless. What broke her heart, she further narrated, was how her husband suffered during the time of the coronavirus pandemic and how he eventually died alone without her being at his side. She asked "*Can you imagine?*"

She reported that, overall, visiting times were good. "*If there is not any coronavirus reported right now, then the visiting hours are relatively open. Well, in Münster* [an earlier nursing home]*, I could go to* [see] *my husband at any time. And there I could bring him something special that he would like to eat. But that wasn't possible here* [at his final nursing home]. *Once he wanted to have a crab salad, which I brought* [into the nursing home, but] *they threw it away. Apparently the cooling process was interrupted, they said. I got one from the fridge from here… and my husband could have eaten it there, right then. But they didn't allow that. If he becomes ill, it's* [because of] *my salad. Things like that happened often".*

Mrs. Marlene then advised regarding things which could be improved in the future within this nursing care home. She stated that they needed more qualified nurses with better know-how and knowledge regarding the end of life process and family caregivers' needs. In anger, she clearly stated that, if given the choice, she would not recommend that nursing home to anyone. Indeed, she has written down a statement that no-one should take her to a nursing home when she is no longer able to care for herself.

"Yes, of course that's a broad spectrum. Basically, I can only speak from these homes, from the experiences of these three homes where my husband stayed. So, first of all, generally, the environment of nursing homes should be made a little friendlier and nicer. For example, during the Christmas season, in the Advent season, a small Christmas arrangement or a star on the window, at least something that the older persons can notice easily. In their minds they could say, 'Oh!, look, now the best time of the year has come'. Another was hygiene, And yes, the cleanliness in the settings", she said, *"as far as the rooms were concerned, was just fair."* The bed sheets, for example, she said were kept clean, to that effect she said *"I have absolutely nothing to complain about, but the cleaning of the rooms"* she added *"should be better. The food, well..., the food"*, she said, *"they cooked it themselves in the setting, and they had about 50 to 60 people who were looked after there. I mean, one could wish for a little more professional persons* [to be] *on every shift. Unfortunately, it is the same story everywhere."*

Mrs. Marlene did not hide her anger and disappointment regarding the nurses' negligence, that qualified nurses were often lacking and those on duty were overloaded and had little time for the elderly people in their care. *"Well, if someone is in a situation where there is no way out, then maybe a place in a home is the right choice. If there is no other way. But I've decided that I definitely don't want to go to a home if I'm feeling bad or if I fall and I know that's it. I probably wouldn't ask for help either. I would rather wait at home until a stroke or a heart attack ends in such a way that there is no more help. But my son and my grandchildren also know that. They know that too. I decided that for myself. So I don't want to go to a nursing home."*

6.3.9 Family Caregiver 9 (FC9): 'Mrs. Melanie'

Synopsis: Mrs. Melanie, a 46 year-old professional nurse, was the long-term caregiver to her grandmother who was, at the time of the interview, still living in a nursing home. Mrs. Melanie expressed concerns regarding the lack of personal hygiene provision to her grandmother in the nursing home, the lack of privacy and of her grandmother being left alone for extended periods.

My initial contact with this family caregiver was through the church. The first telephone call was on 20 April 2023, with the interview appointment agreed for 28 April at her residence, at around 18.00 hours. She was friendly, offered me a glass of water and pleasantries were exchanged. The interview consent form was presented, read, understood and signed by Mrs.

Melanie. The printed questionnaire was handed over to her, to be returned when she had completed it. The interview lasted for a period of almost exactly one hour.

The interview started by covering some of the socio-demographics of the interviewee and her grandmother (in her words, her ‘grandma’). She said that her grandma, 97 years old at that time, was a Christian who had been very active while in her own home. She was a retired nurse, who always kept her home clean and tidy and who wanted to die at home. However, she suffered from increasingly problematic chronic obstructive pulmonary disease (COPD) that made her continued care at home impossible.

According to Mrs. Melanie, her grandma was now in palliative care. When asked about pain, she answered *“I don’t think pain is a problem for my grandma, so she’s on medication. She gets enough medication, she has had three strokes already, and because of that her left arm is paralysed and she can hardly move it. But she doesn’t really complain about pain as such. She complains more about something else. She’s still very fit in the head. She complains about how some of her needs are dealt with by the nurses there, that no-one takes care of her properly. That the nurses doesn’t actually do the simple things she needs,* [such as] *bathing, taking her out,* [providing] *decent and enriched foods. Almost no nurse has time to listen to her, or even to spend a little time with her. She is set on palliative medication. She’s not in pain like that. She can sleep at night too. That is pretty good.”*

When asked if her grandmother was happy in the nursing home, Mrs. Melanie replied: *“My grandma is losing a lot of her happiness in the nursing home because of the people around her. But it’s not her kind of environment, and she doesn’t like that either. She doesn’t get what she really needs. She now has a very small room, it is very, very small, and she no longer has her surroundings which she knows. And yes, she can’t do things the way she was used to doing anymore either. Well, she actually slept till late in the morning when at home, and then got up late, and now she is woken up very early in the morning. And it is disheartening for her. She is told she has to be mobilised, cleaned and given breakfast, and she lost a lot of weight within a very short time. I mean, she’s been there since the beginning of April, that’s three weeks now. Suddenly she can no longer eat independently and is not able to turn herself any more. So normally she could stand up and then sit in the wheelchair and turn her legs and then sit down anyhow she wanted. She can’t do that any more. So she gets help and she gets fed too. But there are a lot of people in the nursing home, and it’s always loud because a lot of people are either singing, or they’re always dancing around, too. It’s actually not my grandmother’s choice. It’s not for her and I think, at that age, I don’t think she can get involved with any activity that much any more. She is in her own world and would not want to be disturbed.”*

Mrs. Melanie equally complained bitterly about shortage of qualified nurses in the home. *"Well, there is also a shortage of skilled workers in the old people's nursing home. That's just the way it is. My grandma is used to taking a shower every morning. Well, my grandma loves to take a shower, and that's not possible there, and she feels her problems are not considered seriously by the nurses."* According to her narration, she quoted her grandmother as saying that the nurses only took care of most of her needs when any of her family or caregivers were around *"When I'm there, my grandma always says 'yes, they're all really nice', but when she's there alone, she's very vocal about not being taken seriously, that only the washcloth is used by the nurses to clean her face a bit. Well, it's not right, there just isn't enough time to take care of the people who need help. And this is disheartening to us all."*

6.3.10 Family Caregiver 10 (FC10): 'Ms. U'

Synopsis: Ms. U was the 73 year-old daughter and caregiver to her father, who died in 2021 aged 97 in a nursing home. Ms. U paused during her interview on many occasions, and there were several situations she described which she did not wish to be recorded, reported upon and which were given in confidence. Ms. U proposes that a new law should be invoked to favour and promote end of life care in nursing homes. However, she described negative experiences regarding the lack of male nurses in nursing homes, whereby men of an 'older generation' felt uncomfortable describing to young female nurses certain male problems that might arise. Ms. U stated that there were too few nurses in the nursing home to care for too many patients, there was poor dissemination of information, the unnecessary over-prescribing of medications, and the occasional disappearance of prescribed medications within the home.

Ms. U was the family caregiver to her father, caring for him for four years at her own home before he was admitted into long-term care at a nursing home. Ms. U was born in February 1950. She is Anglican, single, has no children, has lived on her own in Germany all her life, attended secondary school, and used to work full-time but is now a pensioner.

The person in need of care was her father, born September 1924. He was a widower, German, who had later in life lived with Ms. U in a common household when he became incapacitated. In 2014, he had a fall on his 90th birthday and shortly after he came home from the hospital, "*that was at the point he decided that I should take care of him. He had a femoral neck fracture, went to the hospital again and then to rehabilitation, and then I cared for him at home*." He continued to be managed at home, with Ms. U being the family caregiver until, in 2015 when he was 91 years old, severe dementia set in, which made it very difficult to continue to manage him at home. The family agreed to put him temporarily into a nursing care home for closer and professional care (for his own security), although he remained in that home off and on from 2019.

Ms. U stated that *"It was when he was back from the hospital the last time, that was in 2019 from the hospital where he was intensively cared for. Then he came home again where I cared for him, but* [he had been there off and on for] *four years. Then I suddenly had to say that it doesn't work this way any more. I came to the point where I said to myself 'now is the time to resign'."*

Ms. U's father died at the end of April 2021. He was in a nursing home full-time for two years. *"Unfortunately, he had always wanted to be brought back home, but he couldn't because I was unable to cope. When his condition became severe, the diarrhoea, there was a major discussion while he was in the hospital concerning palliative care."*

"We also said to each other afterwards, 'yes, because something like palliative care wasn't that common, how should you put it?' - he gets what is ordered, that he should have something to drink or eat, and you have to help him with that [when you are around]."

"Such large containers around a corner in the living room, and then I say, 'why do we have ten or twenty people [working] *here and* [yet] *nobody is there for the people?'."*

"A lot [of medication] *was bought* [and charged to us], *and tablets were also ordered for him about which I did not have any prior information. Which I always paid for myself. But also he had so many drops. When I did the maths, you can only say that if he took all of them, then he would be dead."*

Once, the director of the home was around. Ms. U stated that she and he got along well and it was then he started to receive better care! "*Then, all of a sudden, there were pills on the bill again, and I asked 'why more pills?'. There were 38 different pills on the bill... sometimes there were 52 packs* [on the bill]. *Then we would check the pills and a pack would be missing. I don't know how something like that could happen. But we have to just think and wonder about it. ... this shows how many drugs were ordered for no reason. It's tedious work for me to go through all these* [medications] *every time, you understand. So, I thought to myself, first take it and then ask why later.* [I had to be] *careful not to offend anyone, but that is the truth."*

When asked particularly on her experience of nursing care, she reiterated *"how do you mean that?"*. The question was rephrased and put in this form: *"How was the experience with the nurses?"*. Ms. U answered *"Oh! In general, the care was nice. Everyone who worked there,* *especially the nurses, could only do* [what they could] *within their time. That is just the way it was*" she said. *"I was always there every day until the evenings. Back then, before coronavirus, you could always stay there until he went to bed, which was sometimes regulated internally. Things were better then. When the pandemic, Covid-19, broke out, it made life difficult for patients and family carers. Contacts were severed, you couldn't even visit people at first, which was the most cruel thing for the people who were locked up in my opinion. Well, that was hell for the elderly and for us too. But that was the law and the situation then. We could not do anything about it, it was cruel and it was horrible, but that was the law at the time. We just obeyed the law."*

Ms. U was asked whether there were sufficient nurses present in the nursing home. *"It is assumed that there are enough nurses. But as I said, if they had more people who cared for the older ones intensively, things would be better. People would be better cared for with respect. Unfortunately, people's dignity becomes trampled upon and* [they are] *treated anyhow when they are invalids. This made me sad and worried me."*

Ms. U continued: *"Diseases and health conditions, coupled with old age, cause many older persons to need more attention. But how much attention are they getting in the nursing home where nurses are very few and demands are high. You fight so that the dignity of the elderly is maintained again and again, and as long as you let the people get pumped up with medication to make them quiet early evenings* [even that is okay] *if it is done with good reason. But I've experienced some nursing home situations that make one get angry, but there is no negotiation. It's bad that they then say that he's the one doing wrong thing. Then you have to act immediately but not confront things, even when it isn't right."*

"The dignity of man is denied nowadays, I think. But we have eyes and see everything… You also have to be fair with them. Yet, if you see something you feel is bad, maybe it is because it is your own relative and you see it with completely different eyes [to others]."

When Ms. U was asked what she though of the standard of nursing care in the home, she said that it was not consistently good or bad. *"There is still so much that needs to be done, and more information needs to be provided. Sure, it always depends on who is there. When there are not enough nurses on duty, or even when enough staff were on duty, they were people who were not proficient in the* [German] *language. There was also a lot of staff, who were very nice, who came from another country, but there were some who couldn't speak German very well. You have to say, where the girls came from didn't matter, they had all graduated, but they were gone after a while, once they got other jobs."*

"But, if [patients] have something, a pain or something, maybe something hurts them in their private parts, sometimes they can't find a word to describe it. For men, they would prefer to tell a fellow man or a male nurse, whom they feel understands that more clearly." Ms. U then posed this question: *"Can we all understand our young girls today? In the villages, people sometimes speak with a German dialect, yet some of our older people only speak flat German. And when a male patient says that he has a pain 'here', no old man says that to a young girl - 'downstairs' is used to describe intimate parts. Yes, there are also those who work diligently as nurses, who can also deal wonderfully with old people. But I now hear that some male staff are there, so things are better. But it must be said, it would be nice to include both sexes, hence the management should ensure that there are both male and female nurses available. So I would imagine that the older people would be happy if male nurses take care of older men. But like I said, if I was an old man, I would not like to go up to a young girl and say 'Oh, I have pains downstairs'. But then I tell myself that I would understand it differently to a nurse. When someone like my dad might say that to me, it hurts me and I understand* [his problem] *immediately."*

6.3.11 Family Caregiver 11 (FC11): 'Mrs. G'

Synopsis: *Mrs. G was a 54 year-old professional nurse at the time of the interview, being the family caregiver to her mother-in-law, who died in a nursing home. Whilst having some positive experiences regarding the nursing home, several negative experiences were detailed, particularly regarding staffing levels and the lack of any nurse involvement in the dying process.*

Mrs. G, 54 years old at the time of the interview, was an experienced professional nurse who provided support to her husband's mother. *"Yes, we, I and my husband, supported her at home. It's about my mother-in-law. We didn't* [have to] *take care of her at home. Luckily she took care of herself. She already had Care Level 3, she was visually impaired, but she managed on her own. Of course we went shopping and so on, but she did everything. My mother-in-law last year was getting worse and worse. She couldn't always breathe. She always used an oxygen machine at home, and* [one day] *it was so bad that her oxygen* [level] *was down to 60, and we took her to the hospital, the Bremen Ost Hospital. After a lengthy examination they found out that she wasn't doing well any more. Of course, one could not have guessed earlier that it had deteriorated within such a short time."*

"She was in the hospital for four weeks. She got coronavirus [Covid-19] *there so that we couldn't visit her, and of course she left the hospital in bad shape, but she could still walk a little. But* [while] *in the hospital she couldn't move any more and we talked to her and we suggested that she might go for short-term care at the foundation. Um, she came in October, late October last year, last year, and um, day-by-day you could see that she was getting worse, because she said from the start that if she couldn't do it any more, she didn't want*

any extension measures. Okay, because she is a very positive person and she is very lucky. She always achieved a goal, and we would go for a walk with her or started doing exercises to build up a little muscle. But yes, unfortunately, of course, due to age, many were no longer feasible. The nursing staff did not have time for this, which meant that we had to organise everything. So that it could be done, I, my grandson, her grandchildren, her son [all helped], *and we also organised privately for a woman to visit daily and go for walks with her or* [get her to] *participate in something, every day. But she became worse and she got pains too."*

"Then, after two weeks, she could not get up at all and she already could not go to the toilet, and within four weeks she died. So quickly because she said 'I don't want that, I don't want that', and then she stopped eating. She couldn't eat any more, she kept throwing up, but she said 'I don't want that'. My husband always persuaded her to eat something so she might regain her strength, but then she said 'let me, I want to die. I don't want to live any more'. It was a very difficult time for my husband because he couldn't cope with it like that. Mom is mom, and they were very close, like that, but in the end he understood that and um, we accompanied her to the end. We stayed here for the last three days, we were here for 24 hours [each day] *in the home and in the end, yes, she died. You can say, in our hands, yes, yes. Um, I say it's lucky that we had this opportunity to just be here to think and be with her, because the nurses would never come in, without us she's just going to die alone."*

Regarding how this end of life process had occurred, Mrs. G was asked whether the process was satisfactory. She hypothesised: *"Well, if there had been a diagnosis that it was cancer or a life-threatening illness, when you find out you simply have to become prepared. Your family doctor would say 'Okay, I give referral to palliative care', they come, see that the person is accompanied in the dying process. There might be a caregiver, so in such a situation they have to be called. But in the case of my mother-in-law, the family doctor refused"* this scenario. Mrs. G explained that *"In the end she didn't want that because she only wanted us to come, only us, yes, like that. But of course you expect the nursing staff to come in from time to time. They didn't just come in every hour and look and ask 'is everything okay?', 'do you need anything?'. That didn't happen. If we hadn't been there, then I don't know what would have happened, so it was fortunate that we were there, I say. Fortunately things went quickly for her. She didn't suffer long, fortunately not, and we are nevertheless grateful that she was here and died here.*"

Continuing upon the end of life process within the nursing home, Mrs. G. said that *"I think it would be better in the future that with this* [terminal] *diagnosis, once you found out about it, you have to have a concept and ask yourself these questions: what can it be?, how to proceed with a resident?, what next steps can be made? I think it's good that nursing homes* *must definitely include palliative care in the nursing process. Unfortunately that is not always the case."*

Mrs. G then summed up her thoughts. Her feeling of gratitude yet, at the same time, the experience of such a shortage of nurses, and the fact that they were left to their fate was alarming to her, finding that the nurses were too busy to come checking on them at such a time. Her expression that *"thank God we were there, otherwise she would have died alone"* leaves room for thought regarding future end of life nursing care within this nursing home.

6.3.12 Family Caregiver 12 (FC12): 'Mrs. Hannelore'

Synopsis: Mrs. Hannelore, aged 72, described her husband's final months spent in a nursing home. She had mixed experiences of this time, but recalled the poor care he received and the poor levels of communication she received.

Mrs. Hannelore was 72 years old at the time of her interview. She was a pensioner and now a widow. In her interview she revealed how the diagnosis of her husband was made. *"He was in the hospital, and was diagnosed with a tumour in the head and that he didn't have much longer to live. 'Not with these two kilo blastomas', the professor told me. They would grow to that size within six months and there was nothing that could be done to stop the growth. It was suggested that I should take him to a nursing home right away, but that was out of the question for me at that moment. I then immediately had the bathroom remodelled so that we had the opportunity to care for him here at home. Yes, and then after a few days, that was the second of January after the diagnosis was made, and then he was in the hospital for about ten days and from there he came to the* [nursing?] *home here in front of the rainbow. Umm, rainbow, house, rainbow, I don't even know what that means here in the Luisen Tal. Then he came in and I immediately found a room and he was there for a week or two. In the meantime, the medical service was here to assess him. After that I drove him home, now in a wheelchair, and he was then assessed here in the house and then a short time later we got the classification in Care Class for him."*

Regarding the later days following the Care Class classification he had received, Mrs. Hannelore was asked whether a nursing home had been found for her husband and how she felt about the situation. *"I was happy that I got him a place, but of course he couldn't be taken care of as I would have liked. He was in a ward for dementia patients, and so, tell me, things went wrong somehow. I went every day twice a day, because I just had to bring his food from home, because he did not particularly like what was given to him there. Of course he needed a lot of assistance in everything, and then of course I didn't always see through the medical care so clearly."*

“Then he suddenly was put onto water tablets, but no-one was able to inform me about it and I didn’t know why all of a sudden he couldn’t speak any more. But then, that was the way it was, it became worse from day to day, and then suddenly he became incontinent. No-one took any notice of that and he lost control of his bladder and stools and suddenly everything ran out from under him and nobody bothered about it. He was not cleaned for hours! Imagine the fact that his excretement spread under the chairs and tables and yet he sat in his mess! I-I thought, for heaven’s sake, what is happening? I was horrified when I came to visit him. To be honest, I initially found his care okay overall, but unfortunately that was not what I had hoped for my husband in his [current] *condition.”*

When asked about the perceived levels of staffing at the nursing home, Mrs. Hannelore stated that “*There were also too few staff on duty. I wonder what nursing care of older people with chronic cases has turned out to be in Germany.*”

The interviewer then asked Mrs. Hannelore about what happened after this episode in the nursing home, Mrs. Hannelore was forthright. *“Well, it just didn’t work out as I had hoped and I was glad that I was able to bring him back home. We dismantled everything so that he could lie here, he was cared for. He was able to take a shower, the bathroom was then ready, everything worked out in no time, and anyway, the stay in the nursing home wasn’t nice.”*

Relating her experiences of care within the nursing home, Mrs. Hannelore said “*I don’t have any good memories of that and the care as such. Now, maybe he wasn’t there long enough* [for them] *to really exactly know everything* [regarding] *what needed to be done…”* for him. *“Well, I always pushed forward and reminded the nurses of everything I said to them, my husband have to have new, big pants, he has to put on pants. It was as if everything needed to be said to them.*”

With regard to her husband’s end of life care in their own home, Mrs. Hannelore said “*But I mean, my husband didn’t even notice that any more. He could still walk, but he had a different way of thinking.”* Other people were also involved in her husband’s palliative and later his end of life care. *“Well, I would go for a walk with him in a wheelchair. We also went to the* [rehabilitation?] *house, they were there for memory training or music in the afternoons and stuff like that. I always went there with him. That was, if his condition allowed it. Unfortunately, his health was already too bad, and his care, yes, of course had to involve more pain relievers, very strong ones, because he could no longer do anything on his own.”*

Mrs. Hannelore later informed me that her husband died soon afterwards.

6.4 Interim Summary of the Interview Results

To assist with each interviewee identification, each was assigned a random number, as shown below in Table 6.1.

Table 6.1: Code Given to Each Interviewee

Anonymised Family Caregiver	Assigned Identification Code
Mr. C	FC1
Mrs. H	FC2
Mrs. J	FC3
Mrs. N	FC4
Mrs. M	FC5
Mrs. C	FC6
Mrs. P	FC7
Mrs. Marlene	FC8
Mrs. Melanie	FC9
Ms. U	FC10
Mrs. G	FC11
Mrs. Hannelore	FC12

A full discussion and analysis of these results in detail will now be presented in the next chapter.

CHAPTER 7: ANALYSIS AND DISCUSSION

7.1 Introduction to this Chapter

This chapter will analyse and discuss the results obtained from the twelve in-depth interviews, examining and comparing the rich text data gained. It will describe the interview process with the hindsight of what actually happened, then extract many facets from the data achieved from the interviews.

7.2 The Process of the Interviews

The process by which information about family caregivers' experiences of nursing care of an elderly relation at their end of life within a nursing home was made possible through the following means. Selected family caregivers attended an interview, either in person or by face-to-face means via the Internet, along with answering the written study questions. These commenced with personal data, a short demography, then progressed on to how they each experienced the palliative/end of life care provided by their selected nursing home. The answers to the questionnaire in written form were compared with the audio interview data after transcription, to ensure all aspects were accurately captured and coded. The Canadian Health Care Evaluation method for palliative care evaluation, which aims to measure family caregivers' satisfaction with end of life care was utilised, based upon the 'Never at ease' work by Ateş *et al.* (2018).

Each interview was planned to last around 60 to 90 minutes, but every interview took a different shape, duration and form. Most of the interviews exceeded the planned maximum time of 90 minutes. At the end of each interview, the recording was replayed and postscripts made where necessary. Key words were identified, so as to enable analysis of each individual interview to identify both negative and positive experiences. During the interviews, most of the family caregivers stressed the effect these experiences had had upon them, in particular the negative experiences and how they had affected their quality of life and the bereavement process, with many elucidating upon how these might be addressed for future improved end of life care within nursing homes.

Initial contact was mainly made through colleagues and friends of the researcher, who was also the interviewer. One caregiver was recommended by one of the other participants. Whilst the initial visits made to FC6 and FC9 were while their loved ones were still alive in their nursing home, and the husband of FC12 was still alive at his home, the others were those who had lost their loved ones in a nursing home up to three years previously and who were willing to speak about their experiences of nursing care within the nursing home.

Follow-up of the initial contact was made via the telephone where everything was explained and eventually those who accepted to partake in the study interview were allowed to choose dates and venues suitable for them. Individual participants received a letter of consent to participate in the study for them to read and sign. The signed consent letter was either then returned to the interviewer before the interview or handed over on the day of interview, in accordance with the ethical guidelines for this research study. The printed questionnaire was answered accordingly and followed up through the face-to-face interview, which took place at the appointed time and chosen venue.

Interview guidelines were prepared and shown to each participant prior to commencement. Once each participant had read through and accepted the guidelines, the interview was conducted as planned. Some made one or two changes to the interview guidelines to suit themselves. Demographical and relevant data for the study were collected. All questions were standardised and took note of ethical considerations.

Each interview environment was selected or adapted to make it as calm as possible. The most common venue was either a local restaurant or the interviewee’s home. Before beginning the interview itself, a tea or coffee was offered to those who were interviewed outside their homes. In each case, some minor introductory conversation was conducted to win their trust and encourage communication and elucidation.

In order to extract any problematic behaviours of the professional nurses as narrated by the family caregivers, self-reported experiences were recorded based on 29 questionnaire items, investigating a timeframe of the past twelve months. It is clear that these reflect subtle differences in the formulation of the questions. Nevertheless, it significantly impacted the participants’ response behaviour. For example, family carers were aware of the work pressure and short-staffed situation that the nurses were facing, which prevented them from delivering adequate and holistic care. This was observed in the remaining 15 items, leading to various terms being noted, as depicted by the family caregivers. These identified items included defined good end of life care; providing residents with good primary care and spiritual support; competently recognising and treating symptoms; assuring continuity of care; respecting residents’ end of life wishes; offering environmental, emotional and psychosocial support; keeping the family well informed; promoting family understanding; and establishing a partnership with family caregivers by involving and guiding them in shared decision-making. These elements were identified to improve the quality of the end of life for both the patients and family caregivers, and ran in accordance with those identified by earlier studies (Gonella *et al.*, 2019).

A card technique was used during the interview to sort out negative and positive experiences. A method advocated in ‘Never at ease’ (Ateş *et al.*, 2018) helped each participant to jot down incidents and unpleasant experiences (if any). All persons involved were found to be relevant to the study. At the end of each interview, the notes made by the interviewer were cross-checked and read aloud to them. An audio tape made during the interview was then replayed in the presence of the interviewee to rule out any possible misunderstandings which might have arisen. However, the interviewer did design the help cards to make sorting out individual experiences efficient, and these proved to be well received. One side indicated ‘needs satisfied’ while the other side indicated ‘unmet needs’ that led to negative experiences. A third one was used to express some of the impacts of the unmet needs (King *et al.*, 2013). This card system was accepted and used by six of the caregivers. The six caregivers who preferred not to use this card system simply noted and separated ‘good’ and ‘bad’ experiences. Throughout all of the interviews, the participants allowed the jotting down of key topics using one format or another, which were read out after each interview to ensure authenticity and clarity.

These face-to-face audio-recorded interviews were then transcribed verbatim. All the interviews conducted with the selected participants were in their country’s language, German, and then the translation into English followed.

7.3 Socio-demographics of the Interview Group

Overall, the interviewees are predominantly women, with only 1 of the 12 being male. This figure points to the dominance of female caregivers, which exists widely among both professional and informal caregivers, especially to people in need of care when elderly. A summary of the socio-demographic characteristics of the interviewees is presented below in Table 7.1.

The youngest age of the participants interviewed was 43 years for informal caregivers and the oldest being 98 years for those in need of care. Within the care settings where the older persons spent their last days, the elderly person (parent/uncle/husband) in need of care was always first cared for by the adult caregiver (child/wife/ex-wife) or care shared between several people. Some lived locally, some 30-40 km away, and all had managed the household chores before institutionalisation in the nursing home.

Four were pensioners, seven were of professional status in addition to their nursing tasks as at the time of interview, and one was self-employed. The youngest (a grandson) was still in training school as at the time of interview and was not counted since his father was the sole caregiver. The duration of the care relationship between the caregivers and those requiring care ranged from six months to about 11 years.

Table 7.1: Summary of the Socio-demographic Characteristics of Family Caregivers

Inter-viewee	Descriptor Code	Relationship (caregiver to patient)	Age	Marital Status	Occupation	Number of children	Patient's religion
FC1	Mr. C	Son to mother	53	Married	Self-employed	2	Anglican
FC2	Mrs. H	Daughter to mother	63	Separated	Retired administrator	1	Unknown
FC3	Mrs. J	Daughter-in-law to father-in-law and mother-in-law	55	Married	Assistant Nurse	3	Anglican
FC4	Mrs. N	Niece to uncle	43	Divorced	Assistant Nurse	1	Anglican
FC5	Mrs. M	Daughter to father and ex-wife to ex-husband	57	Divorced	Full-time employee	2	Unknown
FC6	Mrs. C	Wife to husband	81	Married (widow)	Pensioner	3	Unknown
FC7	Mrs. P	Daughter to mother and father	56	Divorced	Full-time specialist nurse	2	Unknown
FC8	Mrs. Marlene	Wife to husband	82	Married (widow)	Pensioner	0	Catholic
FC9	Mrs. Melanie	Granddaughter to grandmother	46	Unknown	Professional nurse	0	Christian
FC10	Ms. U	Daughter to father	73	Single	Pensioner	0	Anglican
FC11	Mrs. G	Daughter-in-law to mother-in-law	54	Married	Professional nurse	0	Unknown
FC12	Mrs. Hannelore	Wife to husband who died at their own home	72	Married (widow)	Pensioner	0	Unknown

Source: Author's own presentation

It should be noted that all the participants were very cooperative and willing to narrate their experiences. As part of that agreement, all names have been changed for confidentiality, and a numerical code assigned to each (FC1, FC2 etc.). All interviewees questioned were told that whenever they were not comfortable with any question, they should omit it or indicate no answer. By special agreement at the time of interview, FC1's interview also included his son ('Mr. J'), who could not be assigned as a sole caregiver in his own right, but was included because he wanted to share his own experiences and was thus granted time within the interview.

7.3.1 Summary of Positive and Negative Experiences of Nursing Care Homes

A summary of the positive and negative experiences categories is presented in Table 7.2. The most negative experience expressed was that of psychological exhaustion or tiredness. This was described by the twelve caregivers using the following descriptors: emotional loneliness, experiences of powerlessness, fear and uncertainty of life situation, shock, anger, strain, anxiety, social isolation, regret, intolerance, grief, loss, discomfort, uneasiness, depression, guilt, denial, physiological sleep disturbance, a lack of sleep, experiences of fatigue, indigestion, loss of appetite, heartburn, general state of poor health, burden, time burden, financial burden, social burden, decreased social activity and being told lies.

Most studies on this topic reflect concepts which include ‘burden related to limited social activity’ and ‘physical burden’ as to why there is a transition to nursing homes. The concept of ‘burden’ related to personality growth was analysed comprehensively in one study (Krug *et al.*, 2016).

The motives that the family caregivers cited to initially take on nursing tasks are not unusual. Empathetic reasons such as love, care and affection were cited, which suggest a close, positive parent-child or family relationship. The most common answer given was that there was no acceptable nor practical alternative. By this, the family caregivers meant that they did not want their elderly loved ones to be treated by outpatient care services or to live in an inpatient care facility. At the same time, all interviewees perceived personal restrictions in various areas of life due to the home care initially of the physically dependent person. These included, for example, their reduction in living standards, the significant reduction of private contacts, the forced cessation of employment and the neglect of other interests and activities. This example of the deterioration of health in everyday life shows that there is a fundamental contradiction in domestic care initially. If one takes the self-determination of people in need of care seriously, then informal home care goes to the latency of their caring relatives. Putting oneself at the service of another leads to strong conflicts of need. They expect relief when a loved one is in the nursing home, where 24 hour qualified care is supposedly guaranteed. The family members who have grown old, on the other hand, are burdened in the knowledge that their physical and mental abilities are increasingly declining. They experience this as a loss of their independence. They also find it stressful to be the only person receiving help. They fear that their adult caregiver will be burdened by the high need for support. Most of the older people preferred their end of life to be in a nursing home, where they all believed they would be well cared for by professional nurses.

Table 7.2: Categories of Positive and Negative Experiences

Category	Positive Experience (out of 12)	Negative Experience (out of 12)
Psychological exhaustion (tiredness)	1	12
Emotional loneliness	1	4
Shown respect or recognition	0	6
Information giving (via prompt)	0	4
Good care of the loved one	0	4
Not enough nurses present	0	12
Network present for coping	0	0
Spiritual support provided	0	0

Source: author

Within the negative experiences subcategory, the most frequently discussed concepts were ‘role change’, ‘difficulty in doing work’, ‘household management’ as well as ‘caring for an older one at end of life’, and these were commonly stated by these caregivers while their loved ones were at home. The second most frequent complaint was ‘increased neglect of loved ones’, ‘shortage of nurses’ and ‘not enough time for their loved ones’, which increased their responsibilities towards their loved ones and resulted, in some cases, in family support conflicts and communication problems with the healthcare personnel. Two of the interviewees reported ‘missing clothes’ and ‘leaving the older loved person in their defecation for hours’ which they reported as unacceptable.

Nearly all the twelve interviewees expressed mixed feelings and mentioned some areas that caused them pain and regret. Some two thirds (8 out of 12) reported that they were not duly informed of what to expect. Hence, the participants were unaware of their loved one’s likely palliative needs. Since nurses on each shift were so limited in numbers, all interviewees at some point in their interviews expressed sympathy for the nurses on duty, whom they thought, given the necessary staffing level, tools and knowledge, would have done better. The remaining four expressed satisfaction in certain areas, but had the most negative experiences with how their loved ones were cared for by the nurses.

The most typical complaints were the lack of staff during all shifts, improper or late information about the change in health of their loved one, unknown illness trajectory and unknown changes in medication. These were heavily criticised by six of the participants.

For example, in the FC1 interview, Mr. C stated that: *"I came to visit my mother like I used to and saw her in a bad state, with signs of a fall, not reported."* When one of the nurses was asked by him about what happened to his mother, he narrated that the nurses could give no direct or clear answers to the questions being asked by him. Unfortunately, this was during the coronavirus pandemic and there was no chance of getting a new setting to accept his mother in that state, in a coma. He continued, *"I could not recognise my mom again, and of course, this broke my heart and made me feel guilty as to why I consented to put her in the nursing home."* He continued that he had family and work to consider, and there was no way he could have looked after his mother back at home.

He said the worst thing was that his mother was alone in that state, unkempt, room smelling and without any real privacy. He had wept as his mom died. He had asked for a doctor but none was around. There was no palliative team in attendance and no suction machine to remove the secretions from her mouth. His world had broken down, and his interview story continued intensely and ended sadly. His mother finally passed away that same day.

For him, *"the one good thing was that my mom did not die alone and was finally freed."* That was his last statement in the interview. He broke down and wept, and time was given for him to let his emotions out. He needed to talk - in the end, he said that he felt much better for speaking out.

Each participant appreciated speaking out during the interviews. In the end, for many it was a relief. However, a round table sitting is planned to be conducted in the future within each healthcare setting to work out a solution to prevent such incidents recurring with other patients in the future.

7.4 Cross-Case Issues

The individual motives for the initiation of each palliative/end of life care scenario for the family caregivers of their relative in a nursing care home (i.e., into long-term care services) were outlined, along with their experiences of the nursing care observed from their direct perspectives. Through this ongoing study, a considerable variety of experiences have emerged. To this effect, the family caregivers were encouraged to express their experiences from their own perspectives. This would thereby enable the assessment and documentation of these family caregivers' experiences within the nursing healthcare curriculum of the German healthcare systems, so as to find loopholes and address issues. Many authors report the family caregivers' involvement at end of life as playing a crucial role in the good death and dying of an older person. However, the nurses must attend to the current needs of family caregivers so as to encourage future family caregivers, by demonstrating that a more positive end of life nursing experience can be achieved within older people's nursing homes in Germany (and potentially elsewhere).

The questions nurses working in every care home setting should ask themselves, both now and in future, are 'how do family caregivers experience end of life nursing care?'; 'are we knowledgeable enough to recognise their needs?'; 'how about giving time to listen, to spend time with them and do the necessary nursing care for both the dying and the family?' and 'how can we identify family caregivers' experiences early enough and fill the gaps?'.

Moreover, what are the nursing aspects that led to these negative experiences, as reported by the family caregivers in the interviews? How can these be avoided and resolved in the future? Authors such as Gonella *et al.* (2021) believe that good communication with family caregivers contributes to good palliative/end of life care in the nursing home, but how this actually works is as yet unknown. The family caregiver's involvement at end of life in the nursing home is well recognised and discussed, but how each family caregiver experiences this in the nursing home is less discussed within the healthcare system. Therefore, the use of qualitative tools in the form of interviews and questionnaires, as per the present study, encourages family caregivers to unfold experiences that most times would have gone unnoticed. It becomes necessary to understand how family caregivers have interpreted various aspects of nursing care from their own perspectives. In this way, reports and recommendations can be made, with the hope that the various stakeholders in the nursing homes might get to read them and become more sensitised towards the family caregivers' experiences.

The fact is that family caregivers of older persons at end of life feel better and have reported good experiences when their loved ones are well cared for within a nursing home. Many authors have reported that positive family caregivers' experiences of end of life can be an important way towards achieving increased understanding between nurses and the family caregivers. From the interviews reported here, it can be seen that several family caregivers were able to forget their needs as long as their older persons were well cared for. The methodical approach used during these interviews, along with the conversation guide used, enhanced the flow of the conversation. In this way loopholes were exposed, conditions of palliative/end of life nursing care as perceived by family caregivers within German nursing homes could be reviewed and more attention paid to them, as this seems to be a common problem and recurring pattern. In a qualitative study by Ryan and Scullion (2000), family caregivers showed a willingness to assist in the care of their loved ones in the nursing home, but unfortunately they felt undervalued as a resource within that setting. Guo *et al.* (2021) promote the greater involvement of family caregivers in end of life care, although centred within a culturally sensitive environment. End of life care currently remains centred on the patients, while family caregivers, as stakeholders in holistic care, are neglected.

Therefore, the palliative/end of life care of an older dying person in a nursing home demands that all nurses in that home be involved in the many diverse learning processes so as to improve their knowledge of end of life care, particularly regarding the needs of both the older people in their care and, concurrently, their family caregivers' needs at that time. When nurses in nursing homes engage in such new learning processes and techniques, it has been reported that family caregivers who previously had been prone to neglect and had received terrible experiences are instead quickly recognised, loopholes addressed and gaps closed (Kristjanson, 2004).

The unmet nursing needs of older dying persons are proven to affect the quality of the lives of their family caregivers. Hence, unmet needs that amount to negative experiences on the part of family caregivers and the effects on these caregivers' quality of life are at the centre of research interest.

The interviewees' accounts illustrate their belief that they equally have needs. This supports the views of Becquè *et al.* (2021), who believe that professionals in healthcare should not only recognise and support family caregivers in their tasks as caregivers, they should also provide them with psychological and emotional support separate from the patients. "Nurses could play an important role in supporting family caregivers, but little is known about if and how they do so" (Becquè *et al.*, 2021).

The illness experience profoundly affects family caregivers both psychologically and physically, and recognition of this is necessary at the end of life of older people in nursing homes. Family caregivers, as advocates, judge the kind of care given to their loved ones. Publications have reported that some family caregivers feel guilty and have regrets if the nursing of their loved one at end of life in a nursing home goes contrary to their expectations (Kristjanson, 2004), and this was collaborated by several of the family caregivers' interviews in this present study.

During the summing up part of the interview, near the end, the interviewees were each asked what they hoped might be achieved from dissemination of the outcomes of this study. Nearly all those interviewed wanted their unpleasant experiences addressed or made known to the nursing care setting. Unsurprisingly, they all requested total anonymity. Uniformly, they all wanted the same thing, the ability to experience nursing at end of life positively, specifically with regard to better care for the dying older person and more involvement in the decision-making processes, both now and in future. In this respect, one of the interviewees had this to say: "*I am one person, speaking for many, because I know that I am not the only one complaining. There are many out there that are yet to be heard.*" He then added: "*for I know that if some of these ills are not corrected, our older persons will not* *receive better nursing care, and other family carers will continue to suffer in silence and are denied to have a better experience, and in the end letting go and bereavement are prolonged.*" This seemed to précis the family caregivers in this study who felt helpless, did not know or understand their needs and lacked confidence, because they were prone to neglect by nursing staff and had suffered in silence.

7.5 Motives for Family Caregivers Taking Care of the Elderly

The first part of the interview directly questioned the caregiver's demography, their relationship to the person in need of care and their motives for undertaking that care. Later there were questions regarding their personal experiences of the nursing care of their loved ones at end of life in a nursing home. In addition, the interviewees indirectly provided further information about their motives at numerous other points during the interviews. These passages were also included in the evaluation, so that the motives can be seen to vary between family experiences.

Unlike parenthood, most families are unable to decide beforehand who will care for an elderly family member. Most usually, somehow a family member slips into the responsibility as the caregiver. Questions about the future care of aging parents are discussed less openly and in less detail, if at all. The onset of the need for care by one's own family member(s), whether suddenly due to an illness or gradually arising over many years, is always to be evaluated as a crisis and stressful event. At the same time, it becomes a challenging situation for the innovative ability of a relationship with elders (Görgen *et al*., 2010). Indeed, some theorists consider family caregiving behaviours as normal and to be seen as very positive (McMahon and Luthar, 2007; Telzer and Fuligni, 2009).

As discussed in the earlier chapters, family caregivers worldwide have been reported as facing burdens as a result of poor nursing quality at end of life. In most cases, the dependency and initial care generate strong binding relationships, which can result in emotional, psychological and even financial burdens. When the family caregivers perceive this as too strong a burden, they opt for admission into a nursing home for their loved one to ease their burden, which in practical life can lead to private and social isolation and neglect of family roles. All the family caregivers interviewed in this study described stress associated with nursing homes. Many described an ugly state of things associated with everyday care, even if they did not specify the feeling as a negative experience. These can be assigned, on the one hand, to individual level feelings (e.g., expectations/opposing feelings) and, on the other hand, to the structural level (e.g. opposing roles and norms). Most often, the caring adults of older people in need of physical care cited the reversal of the parent-child role (7/12) and the pains felt between independence and dependence (6/12), meaning that the family caregivers sometimes found it difficult to accept their own health limitations or changing role and to accept that the nurses were, in fact, caring correctly for their loved ones.

However, taking on the care of a family member by an adult in the family can be justified for a wide variety of reasons. Some of the reasons could be altruistic or self-serving motives or normative expectations (Andrighetto *et al.*, 2015), but whichever particular reason can affect the design and the success or failure of the continued caring. After all, this decision often influences one's own life indefinitely, even when transition to a nursing home takes place.

The types of expressions by the family caregivers interviewed have been noted by Boszormenyi-Nagy and Spark (1973) and Boszormenyi-Nagy (1986) as a kind of family therapy approach in which dynamic psychology, existential phenomena and systems theory interact. An important aspect of this is the identification of loyalty conflicts that may commit the individual to his/her family and yet inhibit autonomy.

Four principal motivations were generated from the interview material obtained from the family caregivers, and these have been summarised in Table 7.3. The left column lists the motive subcategories inductively derived from the data material that had been mentioned, the middle column indicates the number of interviewees who mentioned such motives, while the right column notes under which conditions a text passage is to be subsumed under this motive subcategory.

Primarily, it is notable that empathetic reasons (such as love, care or affection, which indicate a close, positive parent-child, husband-wife, grandchild-grandmother relationship) were given by all twelve family caregivers. This is in clear accordance with the results of the six-country road study 'EUROFAMCARE' (Lamura *et al.*, 2009), which was also based upon reciprocation. Gratitude for past actions also played a subordinate role (10/12) to the above.

The interviews showed generally there is an emotional bond to do what is best for their loved one, but an in-depth analysis showed that they would all have chosen to retain their loved ones at home if convenient and possible. FC7 and FC2 were quick to stress that, after all, their mothers raised them and cared for them. FC5 cared for her ex-husband because of the love of her children.

Most often, the family caregivers expressed that they had no other alternative but to continue care at home. Here it should be expressed that the parents, husbands, mothers and grandmothers in need of care, when they entered the nursing homes, were cared for by complete strangers leading to dissatisfaction, as "*most family carers are never satisfied because it is not the same way it is done by them*" (FC12).

Table 7.3: Motives of the Family Caregivers to Take on Care Tasks

Motive	Number Citing Motive	Descriptive Reasoning from Interview
No other alternative	12/12	They first cared for their loved one at home, but were initially not willing to relinquish care to professional nurses, nor send their loved one to a nursing home. They had to, because with their own continued care at home, the feelings of 24 hours care, pressures of work, family and others gave them little choice.
Biographical	12/12	The family caregivers justified the care of the elderly person with their personal resources and the transfer to long-term care in the nursing home. Thus, only their entry into a nursing home offers the opportunity for their continued care and to provide the caregivers some time for themselves. The attitude of the family caregivers plays a decisive role in this.
Gratitude for past actions	11/12	Out of gratitude for past parental actions, adult children take over the care of their elderly parents
Feelings of responsibility or duty	10/12	The family caregivers felt that they had a responsibility or duty to take care of elderly parents. If they didn't, they would have the proverbial 'bad conscience' or feel guilty.

Source: Author's own presentation.

7.6 Motives for Institutionalisation of the Older Person and Reported Experience Received

Families can only prepare for the care of an elderly person to a limited extent. Most studies have confirmed that most family caregivers slip into the role of carer unprepared, and suddenly get trapped. The evidence of good palliative/end of life care in old age in a nursing home is always scanty, and how family caregivers experience this at the nursing home is open to more research studies in this field.

Questions about the future palliative/end of life care of elderly loved ones by relatives and family caregivers are not openly talked about or discussed in detail. Instead, the onset of the need for care of one's own parents, husband or wife, whether suddenly caused by an illness or creeping up over many years, is always to be evaluated as a crisis and stressful event for the patients and the family as a whole. Caregivers may often be in their 50s and above and have some underlying health issues already that are compounded by the illness experience of the dying older person. At the same time, some authors have reported caring for an older person as an opportunity that promotes the innovative gap, especially the state of relationships (Kristjanson, 2004; Görgen *et al.*, 2010). Taking over the care of a family member can be based on different motives and is not always very easy at home or even in the nursing home. Family caregivers have been reported as experiencing profound psychological, physical, spiritual, financial and even social isolation, although some family caregivers have been reported as having experienced end of life nursing positively within self-esteem-serving motives (Andrighetto *et al.*, 2015). Kristjanson (2004) stresses the importance of good information, counselling and practical assistance for family caregivers as they get involved in the care of their loved one at end of life, writing that "don't forget that family caregivers are hidden patients that need nursing care too".

Family caregivers everywhere are known for their popular role in the care of older people, both when at home and/or in a long-term nursing home. Many do not like to relinquish care to professional carers. However, studies have also reported cases of family caregivers' extensive carer burden, their reduced health-related quality of life (HRQoL) and their extensive time spent on informal care (Haikio *et al.*, 2020). Others have reported environmental problems leading to poor care, societal changes, the pressure and stress of the prolonged care of a loved one, burn-out, tiredness, insomnia, lack of appetite, anxiety and financial burdens; several of these were either directly cited or similar to reasons given by the participants of this study (Aujoulat *et al.*, 2002; Gomes *et al.*, 2012; Verbakel, 2014; Ateş *et al.*, 2018).

The reasons given by the interviewees for institutionalisation of a loved one were seen to vary slightly by their age. Younger caregivers included that they 'perceived a burden' and there was an 'unsuitable care environment', whilst the older family caregivers stressed their 'ill-health' (especially pains), 'loss of appetite', 'not enough rest', 'limited social activities' and 'poor support from family and friends', although throughout the interviews many other reasons were made manifest.

Most often, the family caregivers stated that they had no acceptable alternative other than to continue caring for them at home whiilst they could. This might have been intended to express that they could indeed provide their loved one in need of care with care from strangers through professional services or by eventual transfer to a nursing home, although this assessment was based less on their direct personal experiences. Rather, a second, parallel motive appears in several relevant interviews, where the caregivers name their own sense of responsibility and duty, or the family expectations that were placed upon them as further tasks: "*I have certain duties and I have to list them*" This was stated by three family caregivers. Financial and economic considerations come strongly into play, some of which have their origins in the past. In one case, a divorce forces the caregiving son to meet the material demands of his then wife and pay her half the value of a joint property. In order to be able to pay off the financial claims, he asks his mother to sell her own house and in return offers living space within his property. In the cases of two other families, for reasons of cost savings, the mother in need of care is not allowed to be cared for in a facility, as this would be too expensive.

It is essential for nurses and other professional healthcare workers in a nursing home to understand the experiences of family caregivers in order to provide appropriate care for them at the end of life of their loved ones (Yoo *et al.*, 2008). Experiences of family caregivers include psychological issues, physical problems, burdens, needs and interpersonal relationships (*op. cit.*). However, the data collected in this present study has identified some of the elicited family caregivers' experiences (see Table 7.4 below). The notion of family caregivers experiencing loss of control, being disempowered, feeling guilt, sadness and relief simultaneously, possessing a sense of failure and having to make forced or negative choices are discussed by Kellett (2000), and similar experiences were reported during the interviews described here. However, most family caregivers interviewed said, albeit not necessarily in direct words, that the change in role was mostly experienced negatively, and this supports the work of O'Shea *et al.* (2014).

In Table 7.4 below, the left column lists the subcategories inductively derived from the data material, the second column, 'definition', clarifies the conditions under which a text passage is to be subsumed under a subcategory, the third column provides a short description, whilst the final column indicates how often the individual subcategories arose within the twelve family caregivers' interviews.

It is notable that empathetic reasons such as love, care or affection, which suggest a close, positive parent-child or husband/wife relationship, are explicitly stated by all the family caregivers. This is in accordance with the six-country study in EUROFAMCARE (Lamura *et al.*, 2009), where the reciprocally-based exchange motive of gratitude for past parental action played a strong subordinate role. Only the family caregiving son FC1 indicates "*...but my mother raised us with our father, who died two years before*".

Most frequently, the family caregivers expressed their experience of the life-threatening disease of the elderly person, the increasingly psychological and physical demands, the thorned feelings between wanting to meet the expectations of the nurses and the needs of their loved ones, which all amounted to them becoming stressed. Here it should be reminded that the person in need of care, even while in the nursing home, is still cared for by a family member. In all twelve interviews, it was revealed that all of the elderly loved persons were first cared for at home. This was often with the support of health professionals who visited twice or three times a day, depending in most cases upon the Care Level assessment received.

Table 7.4: Motives for Handing Over the Care

Category of Experience	Definition	Description	Frequency
Psychological or emotional experience	Hoping upon hope for recovery of the loved one. Hope for pain-free date. Exhaustion, fatigue, insomnia. Constipation or sometimes diarrhoea. Loss of appetite. Feeling of social isolation. Uncertainty. Anger. Guilt. Depression. Discomfort. Pain. Crying.	The family caregiver saw themselves as being responsible for the older person and feel guilt when care is not meeting needs. They expected more attention, more time, more reassurance.	12/12
Lack of proper information from the nurses experienced by family caregivers	Information not prompt. Drugs changed and no information provided. Changes in condition but no information given.	Family caregivers expect prompt and accurate information on change of treatment, prognosis, length and duration, and information upon what to expect.	12/12
Support through receiving information, or where to get information	No nurse to talk to most times. No listening ears. No time to chat to nurses and let their emotions out.	Family caregivers expected to receive support from nurses in nursing homes, but they were absent, too busy or overworked.	11/12
Spiritual experience	Often no visiting pastor. One mother was missing Sunday mass.	Expected regular visits from a pastor or priest.	8/12
Burden experience	Time pressures. Financial burden. Decrease in personal social activity.	Expected information would be available on where to get financial help.	2/12
Social isolation experience	Loneliness. Reduced social activity, not meeting people. Sadness and depression.	Feeling lonely and missing interactions with other people/friends, leading to feeling sad and depressed.	4/12
Counselling experience	Feeling of confusion. Feeling of guilt for making the wrong decision.	Family caregivers expect to receive advice from the nurses on end of life decisions, amongst others.	4/12

Source: Author.

As an example, Mr. J (the son of FC1) narrated that since his father had a lot to do with their family business, he had to help his grandmother in most of her initial care. This was particularly when the visiting nurses were not around, according to him, and that when the needs of his grandmother became too stressful his father would take over. However, Mr. J explained, he reached a stage when this became all too complicated and complex for him, nor could his father cope. Due to the deterioration in the grandmother's health, there became a need for continued 24 hour care in a geriatric home setting. They hoped for knowledgeable nurses who were there 24 hours a day to constantly provide help for his grandmother. Other examples also arose during the interviews. For example, a second parallel complaint appears: here, family caregivers FC2, FC3 and FC6 maintained their own responsibility and sense of duty in the form of their continued care once their loved one was in the nursing home, their control of medication and their high expectations of care from the professional nurses. However, when this level of nursing care fell below their expectations, in their eyes, they felt guilty for not continuing their own care work of the elderly relative within their own home (see also Kristjanson, 2004).

Finally, with three family caregivers, financial and economic considerations also came into play, some of which reached back far into the past. For one, it included their resignation from work so as to care for their loved one. FC2 expressed how she had to plead with the family to sell the family house, so as to make up money for the institutionalisation of her mother. She still feels bad each time she reflects upon this, she said. Time was invested into checking nursing homes, comparing costs and making sure the environment would be acceptable. In the end, a decision on a suitable nursing home care was made, FC2 narrated. Unfortunately, despite the high cost of the nursing home, they were still required to provide a kind of pocket money for other expenses like manicures, pedicures and the hair-dresser. Indeed, all twelve interviewees expressed that a similar situation regarding occasional extra expenses ('pocket money') was encountered.

Last but not least, the biographical circumstances of the caregivers played a central role. Only the withdrawal from working life enabled two of the daughters (FC2 and FC10 temporarily) plus FC6 (now on a pension) to continue caring for their loved ones at home. Accordingly, they were able to invest their newly-found free time in the care of their loved one. Two of them gave little explanation as to why the care fell solely on them. However, FC2 stated that *"...my brother lives in* [place name supplied]*, and my other brother is seriously ill, so I have guardianship. I look after him practically as a volunteer caregiver. And the other sister, yes, she goes to work in three shifts...* [so cannot help]. *And so only I stay, providing care. In the beginning I came after work and so on, but then I went to zero work in '96. Since I was at home, I then had the appropriate time for my mother, until when it became impossible because of her stroke, dementia and pain. A decision was made for nursing home care and subsequently palliation. My worry was whether the nurses in the nursing home were able to take care of her at this stage, and if the experience was worth all the sacrifices."*

It can be assumed that due to family and professional situations, it is difficult for caregiving children to formulate arguments against the assumption of care. This is why the experiences they have with palliative/end of life nursing of their elderly loved ones matter so much to them, as they are torn between keeping their loved one at home and institutionalisation. The need for independence may also make it more difficult for some, for those who are career-minded to limit the amount of care and to pursue their own life goals, particularly when they are younger and still at an actively working age.

7.7 Experiences of Stress

Since the beginning of the 1990s, numerous research papers have shed light on stress experiences in the context of family care for the elderly. This is seen within all nursing care settings, as family caregivers continue caring irrespective of the setting. The interview material from the twelve family caregivers provides indications of subjectively perceived burdens (experienced as stress) as a result of some mentioned needs of their older loved ones not being properly provided for. This stress is formulated from two aspects, being both on the part of the caregivers and on the part of the elderly relatives in need of care while at home, and is one of the reasons for transitioning through to nursing home care. The load factors and experiences of stress (both direct and indirect) obtained from the data will now be presented.

The subjective perceived experience (psychological or emotional stress due to unmet needs) of the older person, as perceived by the family caregivers, can be assigned to two different levels, as direct and indirect stress effects as a result of their palliative/end of life nursing experiences of the nursing home. The former are subjectively experienced cases that are directly related to the unmet needs of the person in need of care. This applies to both care-related aspects as well as to certain behavioural acts of the professional nurses and the institution. The second level is related to the routines of everyday care in the nursing home and describes the personal effect of experience (limitations) and constraints that result from unmet needs and careless attitudes from the nurses towards the family caregivers and their loved ones that resulted in negative experiences.

7.7.1 Direct Stress Effects of Experiences

The family caregivers reported only rather sporadically with regard to the stress, guilt and regret relating to the situations observed from a lack of proper care of their loved ones when in nursing care. They indicated that the physical care of their loved ones, particularly regarding their intimate care, when not properly done, did create negative feelings to them. They often had to carry out intimate care of their loved ones when present at the nursing home, when they felt that their older person smelt of urine and/or faeces. These are very stressful situations when they can see their loved one in this state. Four of the interviewees stated that the intimate sight of their older loved person was not okay, as they became involved in the physical washing of them, the changing of dressings or incontinence pads, and similar actions. Such intimate care would, on occasion, exceed their areas of competence. For example, FC1 expressed his anger and frustration, "*which would be a very painful thing for me. I had to wash my mother in her intimate area when not properly cared for by the nurses maybe, or change her pampers. These things are not tolerable. I think I have limits, because I am not a nurse. That was also the reason why I chose my profession and was not a nurse, and the more reason why we agreed for her to be in nursing care. And there she would have 24 hours care".*

Similarly, FC10 stated that "*...so this bathing and drying and creaming and treating wounds, that's not a problem*", she said, but more importantly was her question "*what is the point of putting him in a nursing home if I still go on to do all these... sometimes his medications are left by his side*". FC3 commented that *"The major problem is when the nurses neglect to do this properly, when I have to come visiting and see my mother-in-law wet with urine and stool, these are not nice experiences"* and *"I had to plan time for some activities. I leave whatever I am doing just to make sure her drugs were administered and physical care done, is that a good experience?"* . Similar sentiments were also expressed by five other respondents (FC1, FC2, FC4, FC8 and FC10).

Table 7.5: Direct Experiences Leading to Stress, Frustration, Guilt and Burdens

Subcategory of Experience	Definition or Description	Frequency
Fear of death	The family caregivers are afraid of the death (of their parents, husbands, grand-parents) if no-one supports them nor says kind words to them.	12/12
Limit of competencies	The family caregivers express that certain care situations exceed their competence, which is the reason why they rely on professional nurses. When this is not met, they are unhappy.	12/12
Lack of attention	The family caregivers wish that the professional caregivers gave them more attention	6/12
Life weariness	The weariness of life or the longing for death by their loved ones is perceived by the family caregivers as a burden.	6/12
Financial aspects	Going to and from the nursing home, silently indicates the financial burden of the accommodation situation.	5/12

Source: Author.

Most heavily burdened is the confrontation with the approaching end of life of the loved one, which ultimately confronts the adult with their own aspirations (Koch-Straube, 2003). They need an understanding nurse, who is knowledgeable and who has the time to clarify things, tell them it is a normal process and help take away some of the guilt from them. In this study, six of the twelve caregivers found it difficult to deal with the weariness of life and the longing for death of their elderly loved one in need of care. However, the fact that their loved one 'gave up' often causes a feeling of frustration in the family caregivers, and the worst part is when no-one is present to comfort, speak or listen to their worries. No nurse to explain to them that this last stage is a normal process. They are also disappointed that the older person wanting to go means "*they do not appreciate their area of commitment and their personal renunciation: information is very important at every stage*" (FC6).

FC2 quoted her mother's opinion in this matter during her interview: *"And there were days when waking up in the morning and going to visit, when I visited her* [her mother said]*: 'I don't want to go home… I can't do it any more'. To hear the loved one begging to die, 'I want to die'. To see that palliative care is not incorporated in the nursing home programme brings frustration, anger and loss of hope. Most die without being properly placed on palliative care, again to hear from a loved one, things like 'I want to go', you feel like saying I'm ripping my butt open here so that you can get well, and we all come out of here, out of this beautiful old people's home and you are saying this. Of course, I know it is a wish some of them said. You can't say you want to die now, that's a completely different number."*

"*Yes, you're right… mother said to me, and then it goes around again*" FC2 continued. This is just one typical narration from some of the family caregivers who experienced nursing care differently. It must be noted here that some of the caregivers requested, indeed begged, that this aspect would not be not recorded as part of their transcript, and this wish has been obeyed. "*The nurse is too busy, or nowhere to be found when needed*". "*Who gives information*?" and "*it was as if we have to beg to be told the situation of things*" were also part of this problem, whereby family caregivers could not understand, nor gain information from professional nurses in the nursing home, as to how this sentiment could be a natural part of end of life and the dying process.

7.7.2 Indirect Stress Effects of Experiences

Stress can be felt indirectly, especially as a result of unmet palliative/end of life nursing needs. In two cases, this indirect stress was avoided, by FC4 and FC7, where both stated that had they not been in the nursing profession, their relatives would have suffered in some way. Both knew what was good for their loved ones and they went to achieve it, and they both reported that their nursing care home settings were glad they took the lead.

However, these two caregivers were the exception, as few family caregivers have nursing experience. Thus, the level of effect that indirect stress causes will vary person-to-person and situation-to-situation. These indirect stress effect factors often arise from poor nursing care or attention, where the family caregiver's needs are not met, or the nagging disappointment which a family caregiver feels during every visit to the nursing home, resulting in feelings of stress, annoyance and disappointment (see Table 7.6). On the one hand, each day is very strongly pre-structured in its course, from getting up thinking of the loved one in the nursing home at the end of their life that morning, through to going to bed in the evening (stressed by FC2 and FC10), along with severe feelings of guilt. The thought of being away, leaving others to do the caring, like changes in entangled catheters, cleaning and other unpleasant duties (as stressed by FC2, FC6 and FC8), "*never minding the institutionalisation, the feelings throw me out of balance*" (FC8). Against this background, those affected describe their situation as 'guilt feelings' in their thoughts, in speculations, in doubts (as stated by all caregivers apart from FC4 and FC7). Even when their loved one is in the nursing home, they stand by twenty-four hours a day in readiness for any call and feel shackled by it.

Being bound in time goes hand-in-hand with the fact that there is hardly any free time for a family caregiver's own interests. Spontaneous decisions are lost and impossible, such as going on holiday; the fear that accompanied the caregiver and the doubting question of 'what if' deprives them of any free social moment. Instead, the needs of the cared-for loved one is at the centre of everyday life for that family caregiver, despite that loved one being in a nursing home. Many family caregivers have reported forgetting their own needs in the process of the end of life of their loved one, and the fact that no perfect care for their loved one exists. Hence, "*the ongoing scenarios are partly experienced as an external determinant of one's experience. So sometimes I have an uncanny anger at me that I allowed her to go to a nursing home, this constricts me so much because I still need to be there every day and still do most of the carer's work I used to do while she was at home*" (FC2), albeit this sentiment was shared by FC10 and several others at various times during the interviews. FC1 said in anger that "*They have failed many times to tell me a change in my mother's condition ... or that a new plaster with higher dose was given*", to him this information was very necessary, and the lack of passing over this information caused FC1 considerable indirect stress. "*Still, they either forgot, or never considered it necessary telling me, that makes me angry and doubtful*". In another nursing home situation which caused considerable indirect stress to both parties, the lack of sympathetic care shown by nurses towards an elderly patient and his caregiver (FC8), "*by not allowing him to eat food he loved which was prepared for him by me broke my heart*".

For the majority of these family caregivers, personal restrictions arose and were identified in one or more areas of life (such as in work, leisure activities, partnerships, finances and social contacts), irrespective of the fact that their loved one was safely in a nursing home and cared by professional nurses. Thus, some important activities had to move into the background or be completely stopped, as specifically reported by FC4, FC7 and suggested indirectly by many others. For example, holiday plans were completely postponed, visits to the cinema cancelled, work in the garden was less frequent. FC6 said that if she had confidence in the nurses, she would easily travel for a break. But fear accompanies them. *"I do not want anyone telling me my mother-in-law gave up her last breadth without me being there"* (FC3), and this was repeated by several others, including FC8.

But it is not only the leisure activities that they are missing, but also the intensity of current partnerships, the development of new relationships or the frequency of contact with friends, these are all subject to major changes. The longer the care situation lasts, the more pronounced this process becomes full-time. They, the family caregiver, is always there, even when the older person is in the nursing home. There were those who, in their interview, reported poor or mis-information, who felt unable to trust the care setting. *"I couldn't enter into a relationship at all, that would never be in it. What man puts up with the fact that I'm constantly standing on the matter and constantly running around?"* FC2 narrated, speaking about when her mother was still being cared for at home. However, "*Now she is in the nursing home, things are not changing as I expected. I regret her being there. You visit, sometimes it takes hours to see a nurse to talk to, to ask questions. I feel I did wrong by taking her there, it is like I signed a death penalty for her*" (FC2), although similar sentiments were vividly expressed in similar words by FC1 and FC10.

The causes of this indirect stress were elucidated by FC2, as she continued her worries about this situation. "*My external activities are virtually zero, ... so even those days when I plan to travel and think of buying tickets... But I was happy for me, because I always like to travel sometimes.* [Now] *I have no rest, because I do not want anything happen to my loved one when I am away. Because she was still so bad, I don't have that yet, I have no rest. I wouldn't have been able to stand that. I wouldn't have been able to sit down watching a movie or go to see some good cabaret artist, that wasn't possible*" (FC2). "*Always looking at the time, on my phone expecting call from the nursing care home, thinking I have to be there to make sure drugs were administered, and that she was not left alone in her faeces and urine, is that a good feeling? No, good experience, no.*" (FC3). She went on to say that, initially things were good for all of them, they felt good by the presence of the nurses, their prompt attention and communication, but this faded with time and "*I am left to wonder why?*" (FC3), although similar sentiments were also expressed by FC1, FC2 and FC10.

The backing of friends and family is essential to caregivers. However, sometimes family members or friends react with intolerance to such a phase of upheaval. As a result, some family caregivers perceive a lack of support of their general social environment and thus feel socially isolated. This lack of support adds to the stress felt by caregivers at a very difficult time. "*The institution where my mother is staying is neglecting their duty*" (FC2). This sentiment was shared by several others during the interviews, particularly FC5, FC8 and FC10. While respondent FC9 complained regarding neglect of her loved one, she also complained of neglect from her family. Other caregivers responded that their siblings had withdrawn from visiting their mother in the nursing home, their need to reorganise their everyday life and lack of family support for their elderly parents in the nursing home regarding certain care tasks. Overall, they felt "*dumped*" by the family (both FC1 and FC5), while one caregiver (FC6) stated that "*even my children have betrayed me*". They feel dumped by the nurses and the institution. Unfortunately, some of the relatives, even sisters, only appeared when they are told or obtained information that their loved one was breathing their last. However, FC6 had no contact back from two of her children. She continued: "*I told them not to inform my sister-in-law without me knowing, because she never played a good role while my husband was at home. I am wondering who informed her, as she suddenly appeared, but no-one told me. So was that a good experience?*". She then elucidated about this lack of support and resulting stress caused. *"So you know, my sister-in-law had been like that. She was already murmuring while my husband was still alive... in the first hospital. There came from her this remark, 'why was he sent to the hospital'. She never even believed he was demented, so he must be cared for at home, my sister-in-law advocated. Why do you want my brother in the nursing home? It was just his illness, although she was not there every day to see and appreciate how her brother's behaviour had changed with the sickness. All efforts to explain to her became negative. For her, there was no reason to not have him cared for at home. But* [she still] *left all the tasks, everything for me to do*." (FC6).

And so, according to the caring daughter FC2, despite the lack of commitment of the siblings on the mother's side of the family, her son and partner were always "*so completely helpful together*". For the sake of their peace of mind, she avoided showing exhaustion while her mother was being cared for at home. Here, she expresses her wish that she would have loved it while her mother was able to remain at home, so long as she made all the arrangements and care. But the stress was there indirectly. *"Now I had to face these problems alone. I needed to talk with a nurse. I needed someone to listen to me, hear me, take control back into my hands and talk. I would have loved emotional support, but they are too busy, they don't have time. I don't blame them, but what do I do?*".

Even with acquaintances and friends, the topic of family care of the elderly, particularly in the nursing home, is one that is not well received and elicits incomprehension. The required emotional support from the social environment is then just limited to "smalltalk" and "platitudes" (FC1). He continued: *"I am lacking this support. I feel I am not even recognised by the nurses. They don't see what I go through. I do not blame them, they have no time, they work too much, so few nurses for so many older people"*. All twelve caregivers expressed the same sentiments at some point during their interview. This can be summed up as the following generalised statement: "*Imagine my* [mother/father/husband] *at their end of life. Most times, there is no-one in their room, they are just left there alone to die*" (synopsis of all twelve caregivers' opinions at interview). One can only imagine the direct and indirect stress this would cause anyone.

The indirect stress factors are now summarised in Table 7.6 below.

Table 7.6: Indirect Stress Factors as a Result of Certain Behaviours Towards Caregivers

Subcategory of Experience	Definition or Description
Personal restrictions in the areas of work, leisure activities, partnership, financing, social contacts	The family caregivers must partially or completely limit their free time and/or their social contacts and/or their profession and/or their finances due to their obligations towards the older relative in need of care.
External determination in everyday design	The caring relatives are burdened by the fact that despite the utility of the nursing home, they are forced to still be considered a caregiver in everyday life, they are no longer free in their everyday decisions and constantly feel time-bound and anxious about their loved one. There is the belief that the older person is not well cared for.
Lack of support from the social environment	The adult caregivers regret that their social environment (friends, siblings) does not provide them with instrumental support or the emotional understanding needed.
Care or support of other persons	The adult caregivers also look after other persons in addition to the loved one currently in need of care. This amounts to added pressure on them.

Source: Author.

Overall, these results coincide with the many other published studies in recent years, as discussed earlier, on the subject of family caregivers' experiences of palliative/end of life care in nursing homes. However, most published studies have reported on the unsatisfactory feelings of family caregivers when the needs of the dying older persons were not met. Both directly and indirectly, this plays a major role in the positive or negative experiences of family caregivers. If it is good, everyone expects a good end of life for the loved one, a good death. In this way bereavement is lightened. The family caregivers and other family members accept end of life more easily and tend to live in peace with themselves if all goes well. However, if not, they tend to experience bereavement differently and negatively, living with a feeling of guilt and regret.

7.7.3 Indirect Stress Effects on the Older Person in Need of Care

To date, publications analysing the subjectively experienced burdens have largely focused upon the care of the elderly person in palliative/end of life care. Although caregiving relatives are at the centre of a number of scientific debates, not much emphasis is made on family caregivers of older people at end of life in a nursing home (particularly in this survey area of Bremen, Niedersachsen). Both the older person and their caregiver’s feelings are interwoven and what affects one affects the other. Studies that deal with the perspectives of family caregivers’ experiences of palliative/end of life care in nursing homes for the elderly are largely absent, both in German-speaking and other countries worldwide.

One possible reason is the focus on dementia and other life-threatening diseases seen in old age that require palliation and good end of life care, together with holistic care that will embrace and acknowledge the role of family caregivers at the end of life and promote good nursing experiences. According to current forecasts, the number of people with advanced dementia alone will increase by 440,000 in 2021 in Germany if a medical breakthrough is not made (Deutsche Alzheimer Gesellschaft, 2023), and the same trend applies to the many other life threatening diseases of old age: COPD, heart disease, CNS disease, cancer and others. In the future, adequate care of this group of people and their family caregivers will represent a major challenge for the welfare state, as many of these cases require good palliative/end of life care. However, this is not currently taken care of at end of life in nursing homes and, as such, family caregivers suffer neglect and experience end of life nursing negatively.

In the future, the adequate care of this group of people and their family caregivers will represent a major challenge for the welfare state in Germany and worldwide. Hence, the search for solutions and strategies has led to numerous investigations and publications on end of life care relationships, palliation with dementia and other life-threatening diseases, and their family caregivers’ experiences, especially regarding nursing homes. However, this thematic focus is accompanied by numerous methodological problems as seen today, because of the typical symptoms of the diseases seen in old age at end of life and societal beliefs about ageing and dying. Symptoms of advanced dementia (such as forgetfulness, disorientation, loss of concentration, speech disorders and loss of ability) are seen as part of the ageing process, and the questionability of the experience of those affected and their family caregivers to accurately assess these symptoms is only possible to a limited extent. Unfortunately, because older people are not always able to express when and where they have pain early enough in the illness trajectories, no-one considers them for palliation sufficiently early, and their family caregivers’ experiences of end of life needs and care go unnoticed. As a result, a one-sided narrowed representation of family caregivers' life-worlds emerge from the point of view of family caregiving relatives.

With the approach pursued here of the family caregivers' experiences of end of life and the nursing care relationship analysis of older people and their family caregivers, the physically handicapped relatives with life-threatening diseases (including cancer and dementia) and their adult family caregivers are offered the opportunity to describe their personal points of view/experiences in their own words. The subjective experiences generated from the family caregivers of the older person in need of palliative/end of life nursing care is the subject of the following section.

In dealing with the data material, it becomes clear that these older persons are cared for first at home, but that this care at home becomes a burden as time progresses. First and foremost, through changes that are related to the state of health of the older person that deteriorates daily with no cure in sight. Only then do the family caregivers describe that they perceive certain behaviours of the older person or changes in their everyday care as depressing or stressful.

The parents who have grown old are most burdened by their diminishing physical and mental strength and capacity, as well as the loss of individual abilities that in the past made it possible, for example, to write, read, sing, knit, bake, shop or travel. They experience it as particularly drastic when physical functions such as independent locomotion (e.g., feeding oneself, going to the toilet), which are important for the maintenance of dignity, decrease. "*I had to say goodbye, as I can no longer do this*", as narrated by the daughter (FC2) and similarly echoed by a niece (FC4). These changes in body image also leave traces in the emotional state of people in need of care, and their family (especially their family caregivers) suffer a great deal.

One person in the family usually tends to assume the attorney of care and is responsible for the older person when he/she is no longer able, as a result of old age degenerative diseases, to care for themselves, although occasionally all family members assume equal responsibility. She/he undertakes all the necessary chores, often including the legal and lawful actions that may be required when care at home becomes difficult, as most family caregivers in this study narrated. Most of the family caregivers interviewed here are either children, grandchildren, a daughter-in law or wives, who also have a profession (either self-employed or employed), or are of retirement age. They all stated that they had to hand their relatives over to nursing homes not because they wanted to, but because of circumstances beyond their control.

"And so I'm here right now, and I'm very sad about the fact that you are helpless and in bed as well. These are tormenting thoughts... I don't know if you keep saying 'Well, there it is, there are worse things', but I myself feel that's pretty bad. If you've always been so crazy, so the children know their parents were always there for everyone... and now seeing them helpless, not knowing what goes on in their mind makes one sad. And if you get poor nursing attention, you regret it for the rest of your life" (FC6). Some of these thoughts are very painful to the caregivers, especially the sons and daughters, but they are helpless to change the situation.

The increase in health problems can also be accompanied by drastic changes in the areas of seeing older loved ones who previously cared and catered for their children vegetate and lose social contact. On the part of the family caregiver, structural barriers, steps, stove heating or spatial distances make it impossible for the older person to remain in their accommodation. The interviewed family caregivers stated how difficult it was to watch their loved older person say goodbye to their familiar environment consciously or unconsciously, as even for those who were not able to talk, their family caregivers knew them and were able to imagine what was going on in their mind. These thoughts give rise to guilt which can affect the quality of their social contact and possibly their experience of nursing care. "*Now there are not many* [acquaintances] *who are still calling*" (FC10) *"and this number reduces with time"* (FC5).

Those family caregivers often experience very consciously that older loved ones feel particularly dependent on their relatives, because of the support they need (12 out of 12). Not being able to offer anything in return, but to be the only person receiving help due to their high need for support, they experience this, even when unspoken *"as extremely stressful. 'It is terrible if you always have to bother others', that's what my mom kept on saying to me when she was still talking"* (FC2). "[because of this] *she wanted to be in a nursing home, but I am sad*" (FC7). All twelve caregivers' interviews stated that this results in a restraint in articulating one's own desires, feelings of guilt and the worry of how others would perceive it. "*Many out there may think I did that because I perceive my loved one as a 'burden'*" (FC1) and this worried him, imagining the way his mother would have felt before her condition deteriorated. In the end, he continued that "*this feeling accompanied me and made me sad whenever things don't go well in the nursing home"*; these same thoughts were shared by many of the participants at various times during their interviews.

"*My mom said to me* '*take me to the nursing home, sell my house so that you can pay for my last days'"* (FC2) and this was echoed by FC7. With many elderly loved ones in need of care, such negative thoughts and feelings continue to come into their heads, and this was cited by all twelve interviewees. Their older loved ones seemed to resign, seeing no further meaning to their lives, characterised by their significant health restrictions. Due to the continuous dwindling of their own power, they lack a perspective on life. In individual cases, the desire to die is expressed very clearly: *"I wish that I would soon close my eyes"* her grandmother had said to her (FC9) and similar sentiments were presented by FC11 regarding her mother-in-law. Most of all, these feelings remain constant in the minds of many family caregivers. They recall incidents when the end of life nursing of their loved ones fell short of their expectations. They blame themselves and feel guilty of abandoning them.

The problem of the age gap between their loved one and the nurses caring for them was again highlighted by several of the family caregivers. In the case of nursing activities, physical proximity is unavoidable. This can lead to discomfort in a male older person when a young girl about twenty years old, in nursing training, is sent to clean them. "*If you are a man you will have feelings of shame and embarrassment"* (FC8). Most caregivers had (perhaps wrongly) initially thought that the staff at a nursing home would be more mature men and women as the professional carers. However, as articulated by few of the family caregivers, these thoughts are not easily forgotten. When asked 'what was it like for them when their loved ones became in need of care?', one family caregiver said this about her mother "*feeling terrible. Imagine what one feels, unexpressed feelings, to hand over a loved one to a total stranger. At the same time they also feel helpless… to have a stranger washing and caring for your older person*" (FC2). *"In addition, older people in need of care are not able to address issues themselves as they are constrained as a result of health restrictions. This is* [made] *worse from the lack of interaction with the people around them and they are left in their own world"* (FC8).

Nearly all the family caregivers found the daily routine of care at home monotonous and demanding. In addition, they all (12/12) said that they felt bad and saddened to see the reversal in roles while their loved ones were still at home. Furthermore, feelings of loneliness determined their everyday life. *"Asked 'Well, how do you feel?' she said 'Lonely sometimes, very lonely'"* (FC12). Similar responses were given by other caregivers quoting their loved ones: "*She said 'My daughter can't always sit here, she has her own household'. And that's sometimes hard, hearing the feelings of older people*" (FC6).

When each of the family caregivers was asked at interview whether if today they were in the same situation to decide for or against taking over the care, allowing their older ones into a nursing home at end of life, what would they do? Was the decision to care for their loved one at end of life in a nursing home a good decision? Would they decide for or against it in the future? Their answers were cross-checked from both the interview transcripts and written questionnaires. The results were mixed. Some answered 'yes', with reasons of conflicts with work and other private issues often cited, while some said that, with hindsight, today they would have done it differently. Even from those who did not provide a direct answer, one could make it out from their unspoken words that they had some regrets.

The hesitation during interview from both FC2 and FC10 stem from them subjectively experiencing nursing staff shortages, arriving at the nursing home and seeing their loved one left alone for hours, with no nurse around. This sight "*awakens resentment, guilt, regret*" in her (FC2). This was for her, and many others interviewed, a bad experience. *"I had no other choice other than to put ... into a nursing home"* (FC10) was similarly stressed by all 12 respondents during interview.

What is striking is the negative response pattern of the caring daughters FC2, FC5 and FC10 on the nursing care of their loved ones regarding several similar issues. Here it is worth remembering the family situation, why the loved one was sent to the nursing home and what the experience in the nursing home had meant for them. It was the accumulation of the feeling of being left alone in their initial feeling of loss by the nurses, of no proper information, staff shortages, of the 'huge negligence' (as described by most of the family caregivers), that gave the interviews credence and which in turn characterised their general negative experiences.

Most of them described their experience whilst caring at home as giving them great financial independency. To a certain extent, unforeseen situations constrained them from not continuing care at home for their loved ones that they grew up together with which, according to most of the family caregivers, did not make them feel good when their loved ones were not properly taken care of in the nursing home. Despite everything, at the same time, there were strong motives in many not to re-enter into the current care relationship and not to send their loved ones to a nursing home *"I would not do it again"* (FC10). *"With today's knowledge I would have sold the house ... got another smaller place and hired a private carer to take care at home"* (FC8).

Overall, after the analysis of cross-case topics such as the motives for taking care of the older person initially at home, motives for institutionalisation, the experiences of family caregivers viewing their loved one's end of life in a nursing home and the retrospective balancing, a first filter is laid over the interviews. Significant similarities between the family caregivers' experiences of end of life nursing care have by now become visible. In the further examination of the interview material, it will become clear whether the palliative/end of life care experienced in nursing homes, particularly regarding communication, information dissemination, psychological support, spirituality needs being met, respect given, inclusion and careless attitudes towards medication and care on the one hand and the significant experiences of palliative/end of life nursing care on the other is either positive or negative to these family caregivers.

7.8 Identification of the Most Significant Experiences for Family Caregivers

This important section explores the question of which experiences of palliative/end of life nursing care can be identified in the everyday relationship design between nursing in the settings and the family caregivers. As a reminder, the interview study assumes that nursing settings, quality of nursing, level of education of the nurses, number of staff on duty and other factors are some of the situations that can generate different experiences, the practical implications of which can also lead to neglect of the older person and their family caregivers' needs.

With reference to the multidimensionality of the term, the phenomenon of palliative/end of life care in a nursing home should be holistic, family and patient-centred (WHO, 2020, 2023a). During the interviews, topics such as lack of information, poor communication, lack of psychological, emotional and spiritual support were mentioned. Additionally, the lack of proper physical care of their loved ones, where the needs of the elderly patients were not properly met, were drawn from the interviews. This caused the family caregivers feelings of psychological burdens, social isolation, guilt, blame, sleeplessness and others, as mentioned previously. Most of the family caregivers would be happier had they felt that the palliative/end of life needs of their dying loved one had been met properly. In the interviews, all the family caregivers spoke with interest regarding what they had experienced and expressed hope that in the future better nursing care in nursing homes will accommodate both the needs of the dying older persons and their family caregivers. Overall, older people in care should be treated with dignity that is in accordance with their wishes.

7.8.1 At the Individual Family Caregiver's Level

From the interviews conducted, it was ascertained that all of the family caregivers of older people in need of care learnt certain new realities whilst caring at home, in order to deal with the decline in the physical abilities of their loved one. The older people who are in need of this care, who are at the end of their life, in the present study, cannot properly share this drastic change in their lives with their social world or life partner, because they are already incapacitated as a result of their deterioration in health. As narrated by nearly all the family caregivers in the study, the elderly person lived normally at home first, then became in need of care but still living more or less in close proximity to their adult caregiver initially. This is a familiar situation that they know from the early family phase.

On the other hand, it is also a novel experience, because one's spatial proximity in the late phase of life is among many other factors which are very important and necessary. While the son/daughter caregivers reported how their parents had been responsible for them as children in many ways in the first phase of the family, when they became elderly the responsibilities were now reversed. Both sides have to familiarise themselves with this change of perspective. Family caregivers feel obliged to continue the care of their older loved one. Even when they are safely in a nursing home, they still continue their care and that is why a good experience of nursing care at end of life of their loved one is rewarding. For both now and in the future, end of life care within the nursing home should take account of the family caregivers' experiences.

7.8.2 Relationship Between Palliative/End of Life Needs of the Family Caregiver and that of the Elderly Person

Family caregiver FC6 expressed very mixed feelings during her interview. On the one hand, she described a reserved feeling, having had both bad and good experiences (similar to FC10). On the other hand, she expressed, in several passages of conversation, that she has definite concrete wishes that she would like to see implemented within the nursing home. Her stated demands include redesigning the bathrooms, redesigning the bedrooms, an increased presence of nurses, constant availability of learned up-to-date and accurate information, and far better daily communication and updates on the patient's condition between nurses and family. However, with regard to the day-to-day running of the institution itself, FC6 kept mute. However, she went on further to report that she did try to distance herself from some of the attitudes of both the nurses and the institution. These included the nurses arranging for hair and nails to be cut without providing any prior notification nor cost information, buying certain items for the patient but providing bills for payment which were unquantifiable, delaying sending bills, whereby the bills were allowed to accumulate or neglecting to adhere to the prior signed agreement to send all bills directly to the insurance company. Many times, FC6 expressed her anger and frustration when she stated that if it were not for her son and daughter in-law who helped her out, she would have been swamped with such issues: *"how would I have dealt with all the paperwork, paying of bills and follow ups?"*.

Timely implementation of the caregiver's wishes did not always occur. "*...if I planned or wanted to have them dress him in a particular shirt, or dress him appropriately and put him into a wheelchair, most times this was ignored. Often he was neglected or he was wearing the wrong clothes, or clothes that do not even belong to him. I had to do it all myself, and then sometimes I would wait for hours* [for nurses to arrive]. *Many times I have complained of missing* [personal] *items, items that never were replaced* [back into his room], *but there has been no proper explanation. Overall, it is difficult to accept this type of behaviour and attitude from the nurses, irrespective of circumstances"* (FC8).

Examples of mixed experiences could be drawn from all the caregivers' interviews (12/12). They applied right from the beginning of care being required, through to towards the last days of the older person's life. Verbal reports from the family caregivers about their loved ones were similar in many respects, with comments recorded such as "*...so she does not want to be a burden to other people*", "*she registered her needs clearly before she became very dependent. She wished to be in a nursing home*" and "*she feels she is a burden to others*". According to the family caregivers, all, except one, mentioned some aspect of their future hopes and requirements prior to requiring full-time nursing care, with the expectation of good end of life care. Only FC6 mentioned that her husband was unable to realise what he wanted, because of the rapid advanced dementia stage of his illness.

7.8.3 Family Caregivers' Perspectives and their Nursing Home Experience

Family caregivers talked about how they first cared for their older dying loved one at home, and the transition to an old people's home and its challenges. Based upon this period of learning, their gained experience of palliative/end of life nursing care, narrated from their own perspectives, was given during the interviews. They felt the need to further advocate for older dying people and their family caregivers, even (perhaps especially) in old people's nursing homes (Shield, 2010).

Family caregiver and daughter FC2 clearly articulated some of her experiences with her mother in need of care when she was at home. She referred to her mother and how she had expressed feelings of being a burden sometimes. This was something her mother never wished for, to be a burden to anyone. Her mother, she said, also suffered from dementia and high blood pressure. FC2 narrated how she would ask her mother to be considerate at times when she felt her mother was being extremely difficult. This included her failing to follow advice or taking her advice seriously. Regularly a dispute would break out between the two about the fact that the mother in need of care from the daughter's point of view goes into the garden without wearing appropriate clothing. The daughter's objections were based on the fact that she needed to protect her mother from danger, and to bear the additional burdens in the case of her degenerating ill-health. She complained that she herself had some medical challenges. For these reasons she was unable to cope when her mother became bedridden and the load of caregiving became too much for her. The next point was the nursing home. She felt bad, but she had to do it for the sake of both her and her mother's dignity. For her, she had a strong belief that her mother was going to get the adequate care necessary.

For another caregiver, FC4, the contradictory signals given by another family member moved between two poles, whereby "*I am always there for you*" and "*You must be considerate on your uncle*" led in an emergency situation due to the fact that her uncle did not have any contact with other family members. FC4 had avoided giving out any information about his hospitalisation probably out of fear and from the reminder that she, the niece, had asked for this consideration. She narrated this with her head held low. Obviously, flashing back on this past incident of the hospitalisation of her uncle made her sad.

FC10 said over and over, during the interview, *"I regretted sending my father to this particular nursing home"*, but she asked *"in redress, how would I have managed my own health?*"

Family caregiver FC11 described a similar situation. Her mother-in-law initially avoided contacting her for help, out of concern to not disturb her nor make her into a caregiver. But she quickly realised that she needed her help. She narrated what her initial experience was and compared it to what it was later in the nursing home, where she considered that the nurses were not meeting the needs of her mother-in-law. She said that when she thinks of all that transpired between her and her mother-in-law in the past, she still believes that she would do the same. But her concern was that even with her mother-in-law's poor condition, she experienced negligence of care by the nurses towards her mother-in-law.

The most common negative experience as reported by all (12/12), was regarding the last days of their loved ones.

The caring daughter FC2 refers to the actions of the nurses caring for her mother. She reported being worried about problems which arose, such as the delay in her receiving information about the change of medication, not knowing about a doctor's visit and the unreported change in her mother's condition. The nurses may have had the initial knowledge that her mother was used to doing it all by herself her while she was back at home, so now, she said, "*I guess she may have done this in the nursing home when she arrived*". She went further to express "*so perhaps that was why the nurses seemed to neglect her at the time she needed most nursing care*". The mother in her then condition may have failed to call, one can suspect. However, the reaction of the daughter to the nursing care is related to the contradictory signals of her mother. The daughter reacts less to the objective situation, but rather its subjective perception influences her behaviour.

A similar lack of nursing care was reported by FC1. He stated "*I can bet the nurses do not take care of her properly at night... not enough sign that her lying position was regularly changed, pampers changed etc., otherwise, why would she be lying on the floor and no-one noticed till the next day? Yes and almost bleeds to death.*"

Throughout the interviews, a number of good and bad experiences were picked out and jotted on post-its. Clearly, all in all, one could see that the good care of the older persons influenced how the family caregivers were able to express the positive end of life nursing experiences of their loved ones. However, both the met and unmet palliative/end of life nursing needs of the family caregivers were very clear. In the interviews, the family caregivers focused more on meeting the needs of their older loved one, as they considered their efforts as being a normal way of paying back to the older person. In most of the interactions during the interviews, the family caregivers expressed how their loved ones had helped them while they could. Hence, caring for an older person was just normal. That was why all of them reported why they cared for them first at home.

7.9 Experiences of Family Caregivers at the Structural Level

In addition to identifying family caregivers' experiences at their own individual level, the interviews would also be expected to reveal their experiences at a structural or institutional level, as social relationships. The concept of palliative/end of life care in nursing homes should be the same everywhere. Institutions have a responsibility to see that family caregivers' needs are not compromised for any reason. For example, when adequate accurate information is not readily passed to caregivers, nor regular updated information on the condition of the older person is not given to them. The general management should assist family caregivers to take care of some issues themselves, and react to any complaints.

Thus, from the interviews, when FC6 made a complaint concerning a change of medication. She had not been informed by the nurses about an increase in dosage of the strong analgesic morphine (via a plaster) being given to her husband. Similarly, the lack of suction machines, in good working condition, caused distress and subsequent complaints from FC1 and FC6. FC6 cried bitterly at interview that even the general doctor who had taken care of her and her husband did not initially mention this lack of facility, and this caused her a lot of distress and raised a feeling of lack of confidence in the overall palliative/end of life care being provided at the structural level to her husband.

All twelve family caregivers interviewed described elements of both good and bad experiences at the structural level within the nursing homes they had selected. Overall, the family caregivers had a collective need for greater information to prepare for the last days of their loved one. "*It would have been nice, if I was told of the morphine plaster, then I would have been present to witness him die… he died without me saying goodbye*" (FC6). FC8 reported on how the country-wide Covid-19 pandemic and the structural changes in regulations affected the last days of her husband's life, while FC1 said he was just lucky that he came at the right time, as no-one from the nursing home had informed him of the changes in condition of his mother.

7.9.1 Common Experiences

This section looks into the problems that were most frequently mentioned during the interviews by the family caregivers.

Firstly, between those professional nurses caring for the older person and the family caregivers' experience of this nursing. It was reported that there was a tendency for nurses to neglect their nursing tasks, sometimes due to a lack of professional knowledge at the structural level. Because of societal beliefs and varied definitions of old age, death and dying, older people with illnesses and frailty (apart from cancer cases) requiring palliative/end of life care are structurally handled differently at different points in their illness trajectory.

Secondly, the family caregivers of aging parents, in particular, need improved emotional support and practical help at the structural level. Many of these family caregivers are at the most productive and product-conscious years of their working life (40s to 60s) (Naegele & Reichert, 1998), thus their decreased capacity to continue working effectively, with consequent decreased spending capacity at this time, affects the whole structure of the economy. In addition, the willingness to switch to the role of a caregiver and to thus curtail career prospects, should raise concerns about the structural effects of this potential switch (Schneider, 1997) causing a noticeable decline in the structural national economy over the longer term.

This structural aspect was particularly noted during the interviews in three of the twelve family caregivers. It is especially true in the case described by FC2. Her mother in need of care had in the past expressed "*my daughter has a leading position in the [institution named]. She cannot let her work suffer, just sit there and say 'I have to look after my mother'. That is simply not possible*" (FC2). The competition between professional role and family caregiver role was perceived by many at interview as a problem in the nursing home setting, and was particularly stressed by FC1 and FC7. However, this was also stressed as being a problem structurally in all the nursing homes involved, between the caregiving of a family member when conflicts with work arose and the expectations from the nursing home's professional nurses and administrative personnel.

7.9.1.1 *Common experiences shared between continued nursing in the old people's home and family caregivers' personal needs*

When adult family caregivers initially decide to care for their elderly parents or loved ones at home, usually at the loved one's own home, the main nursing burden typically lies primarily with the women in the family (Schulz-Nieswandt, 2006). This was also reflected in the family caregivers presented here. With the exception of one son (FC1), it is exclusively a caring female family member who was involved in providing care.

Typically, the spouse or partner is not always willing, indeed usually unwilling, to share this responsibility and care of their partner with anyone else (Mauskapf & Hirsch, 2015). This was reported to lead structurally to permanent conflicts and points of friction when in the nursing home, especially if the partner was not being cared for exactly to their wishes. This point was stressed particularly by family caregivers FC6, FC8 and FC10.

Family caregivers are subsequently exposed to conflicting requirements at this time in their lives. On the one hand they want to fulfil the new tasks and continuing caring in the structural context of the care setting and, on the other hand, the private needs, for example, of their spouse or partner, their employment work and wider family conflicts all result in added stress. Doing justice to their loved ones in most cases resulted in higher expectations from the nurses, structurally across all the nursing homes mentioned during the interviews, who were already stressed due to their increased workloads and shortage of staff.

The dilemma was most evident in the interviews of six family caregivers, FC1, FC2, FC6, FC8, FC9 and FC10. FC6 had high expectations of the nurses, while at the same time she lacked the time to carry out all the activities she was used to doing when her husband was at home. FC9 talked about this in several interview passages, when she expressed being unhappy at the turn of events. FC8 complained of her husband's things going missing each time she went there, and she was constantly being the one to replace lost things bought for her husband. These events and many more comprised her bad and negative experiences of the structural nursing system and the nursing of her husband.

"But as I said, my husband needs this and that" FC8 stated. *"Such cases make him feel he is being neglected by me"*. Similarly, FC6 stated that "*He is 83, so 2 years older than me, and of course his expectations are higher, though he is not able to express it, but I feel it"*. This and many other reasons gave both FC6 and FC8 negative experiences of their chosen nursing homes and of nursing homes at the structural level.

FC6 continued, *"He has a sister, and I have my son, daughter-in-law and my granddaughter. Since last year, my son and daughter-in-law made a concession that we were to go on holiday together for at least one week last year, but I could not go with them for the sake of my husband."* For FC6, she expressed how she had experienced good nursing initially, as she described positively how the nurses treated her and her husband during the first three months at the nursing home. Later, she went ahead to express during the interview about what she described as a deterioration in the nursing care quality. This made the later part of her husband’s stay in the nursing home to comprise of a series of bad experiences of nursing. She said “*I did not trust they would be able to take care of him when I was not around, so I had better not go anywhere.*”

“*And what burdens me, about nursing care in this particular setting, is that is that I cannot do justice to him, my husband and my private life - I could not manage his continued deterioration, as both are relevant to me*” (FC8).

This sentiment was echoed also by FC12 as being something that bothered her. From her position, she would like more understanding and consideration from the nurses for the concerns and needs of her husband, so that ideally they would both “*pull in the same direction*”.

The daughter FC2 said that she appeared to be helpless as she was torn between either her duty to her mother or functional fulfilment of her own life. Similarly, according to her written statement, family caregiver FC6 faced emotional health problems. She said these problems were in connection with the *“friction with my husband being in the nursing home”*. She had been able to detect the changes developing in her husband and this affected how she became involved in his care. “*...and the partner, who likes to say ‘my wife this’ or ‘my wife that’, she already knows, if she is not there at three, that she comes at four, but well now when he wakes up depending on if no-one is there, then he is afraid again and becomes extremely disorientated. So I prefer to go to the nursing home again so that he has a certain peace for the last few hours. But I want to say that he being in the nursing home actually changes* [my] *life totally*” (FC6).

7.9.1.2 *Common experiences expressed between the family caregivers’ role and nurses’ role*

When adult caregivers try to take more and more responsibility for their elderly loved ones once they are in a nursing home, this requires a fundamental change in how they used to perceive their previous role of caregiver in their own home. “*Sometimes I think I am taking away the nurses’ role. She is my mother, but this certainty results from the fact that I am now the person who is responsible for her need of help*” narrated FC2, regarding the time her mother was nursed at home. *“The formerly strong parent, who radiated security and stability, suddenly becomes now dependent on support due to the loss of body abilities. This makes one crazy and want the nursing of the loved elderly one to be continued at home”* (stated emphatically).

However, research suggests that family caregivers are expected to leave the care of their older person in the hands of the professional nurses in the nursing home and under the bureaucracy of the institution (Ryan & Scullion, 2000). However, this research, from the twelve interviews, suggests either that the family caregivers overestimated their own roles, did not trust the nurses, or had higher expectations of the institution and the nursing of their loved one at end of life. Family caregivers perceive these professional nurses as having a good education and being capable of providing technical, social and emotional care. Family caregivers have great trust in these nurses, but unfortunately, professional nurses do not consider entrusting family caregivers with some of the roles at end of life. Many are blaming this problem onto their need for accountability, as family caregivers' actions may not be documented or accounted for (Ryan & Scullion, 2000).

"Of course, in the past [while at home] *there were no regulations for her. Sometimes she said to do it that way, because she just lived her life as she expected and for as long as she was able. Today, having seen her vegetate there, needing help, makes me sad. I think just the strained social contacts, which were limited to one or a few people due to the coronavirus outbreak, made it all the more difficult. I had to see her not as often as before. And before I could visit her during the coronavirus time, it was by appointment, so both of us suffered emotionally"* (FC8).

Family caregiver FC1 related about the time his mother had been in a nursing home, stating that *"we had been limited in our private lives. I've said that before, but God, I imagined people in the past who didn't want to have friends and didn't go to the theatre or to some kind of senior club. I thought it was their thing, and that certain incidences in our lives were unconsciously enforced on me. Now when she was in the nursing home, I did not see much difference in my social freedom* [compared to his experience when his mother was home]. *I think so, the nursing service had to come, and the doctor had to make visits here and the emergency call had to be made when there was need. And that became different once she was in the nursing home".*

Nearly all complained of not being involved in decision-making, the decrease in information given by the nursing home to them, not being told when a doctor came for a visit or when new drugs were prescribed. "*I have asked myself if I am not over reacting, or expecting too much from the nurses. I would tell myself no, my mother deserves good nursing care. I deserve to be told whatever is done on my mother. I deserve to be informed whenever there are any changes, but they were not doing that again. But* [generally] *they were good, or rather treated everything about us with respect. Now, when my mother was at the last phase of her life, when she needed much better care, sorry but what was seeing was no longer nursing, it was what... I can't explain*" (FC1). His son (Mr J) mentioned that *"I think it was the change... a completely different role to play. These experiences, expectations of the nurses by us, changes of role, all make me sad. But do we have to live with it? That is why we are glad to speak out, so that someone will hear us*".

But the change of parental care, of being a child to care for the parents, can cause frustrations on both sides. "*It can bring me to tears, and I felt depressed seeing my mum at that stage 'The care in the nursing home isn't meeting up' she told me*" (FC2). FC1 felt like "*loved ones were no longer sufficiently understood and not taken seriously in their personal concerns and needs"*, and that *"my mom is then treated like such a small child, and that sometimes hurt me*".

7.9.1.3 *Competing standards*

Nursing relationships with the family caregivers should be characterised by positive feelings such as empathy and warmth, as well as normative obligations towards these family members (Roberts *et al.*, 1991). In addition, when dealing with family caregivers' relationships with professional carers and the older person in care, the competition between the norms of those professional nurses in charge of end of life care and the family caregivers should be applied wisely, as they involve practical life and must be taken critically into account (Pillemer & Lüscher, 2003).

7.10 The Balance Between Self-Reliance and Dependence

In the late phase of parent-child or older people's relationships, the older generation develops into a fundamental field of tension and balance, from living independently for as long as possible and the increasing need for help due to illness or need for care. Explicit references to this can be found in the interview quotations cited below, along with the reasons for progression towards a nursing home (See Table 7.7).

Family caregivers feeling that necessary adjustments to their usual lifestyle can be accompanied without the feeling of losing sovereignty over one's own life. "*We always had a big apartment. So my thoughts here were, this was so difficult for me at first to give up. Sometimes the home no longer offers a protected space, and the needs for a nursing home arise*" (FC6).

"It's just a strange feeling, to see a loved one cared for by total strangers. ...when the family come to visit, then you already know that you have to call first for an appointment [this was during the Covid-19 pandemic]. *Sometimes you get there and stand outside with all the other people, you ring the bell and wait outside until the door is opened by someone who lets you in. Most times it is the cleaners or other visitors. But during the pandemic you could be turned back if no appointment was booked and also unless you could show proof of a negative coronavirus test*" (FC6). She then reported on an incident *"Imagine, after calling the nursing home and being granted an appointment for a visit, only for a nurse to turn her*

back, as she denied that I made an appointment before coming. That! For a person like me! I learnt during the time I was assisting my husband run our company, when I assisted him on bookkeeping. This rebuke affected me negatively. I kept good records of events, including telephone calls I made. On that day I showed her where I wrote the name of the person I spoke with and the time of appointment… I was angry because she didn't believe me… and it still annoys me" (FC6).

Even the younger generation who are caregivers are faced with the dilemma of continually helping their older loved one once they have left home and moved into a nursing home on the one hand, while on the other hand they have the wish and desire that the nurses should fully meet their needs of both themselves as (former) caregivers and their elderly loved one.

Most of the caregivers interviewed pointed out that the way older people are treated within a nursing home affects the quality of the life of the family caregivers. To elucidate and understand this concern, it becomes necessary to investigate the interview transcripts and document their everyday experiences. It becomes more difficult for the adult caregivers as they presume the needs of their loved ones are not being adequately met. The caregivers expect professional nurses to fully meet the needs of their elderly loved one. The more they gain the impression that their parents in need of care are well cared for by the nurses in the nursing home, the happier they are and are bound to report positive experiences.

"*How did I cope with my mother being in the new situation? She was now also severely limited by blindness. Yes. She did not imagine things would be this way …but that has to be, because it will not get better again. She would try to endure and yes, that's how she dealt with it, suppressing her anger. A bad experience, to suppress anger so many times, not to want to admit this was happening to my mother*" (FC2).

In addition, different family caregivers have different ideas about how to proceed in the event of a care situation for an elderly loved one(Family Carer Act, 2015). However, care of the elderly is mostly assumed by the female relatives. Parents expect the personal commitment of their children, in many cases (Lettke, 2002). In contrast, the adult children, when being the caregiver at home, tended to hire a professional service provider as required, but when they were unable to continue the older person was sent to a nursing home. However, as reflected in all (12/12) of the interviews, these decisions are regretted eventually. Moreover, when the nursing care of their elderly person falls short of what they had expected, they express this as a bad experience which affects them and causes regret. "*Everything that happens here in terms of care, in the nursing home, is not very pleasing. What you see here and so on, it is not nice. Under normal conditions, they would prefer care differently. Also the nursing service is not always in compliance, there are not enough nurses"* (FC11). *"…so I think like she expected an all-round care from me in any case. And* *that was always her wish. I could even imagine that she expected me to quit my profession and stay here or come to the nursing home regularly and that would have been her real wish and I very much suspect that"* (FC11).

Deep dissatisfaction and serious conflicts can develop when the intense needs of the older person are neglected due to negligence or pressure of work, and where there were only a few nurses on duty with correspondingly infrequent interactions. Overall, caring adults for the loved ones in need of care described experiences that corresponded to the ambivalent feelings within the nursing homes described, even if the term itself was not be used in the interviews. These are, as initially suspected, not the only families who partly regret the decision, in retrospect, to have organised the care. From the interview data, it can be deduced that family caregivers' experiences of nursing home care for their older relations generated ambivalent experiences that can be assigned either to the individual level (e.g., mixed, opposing feelings) on the one hand and to the nursing level (e.g. opposite roles and norms) on the other. These two dimensions are shown in Table 7.7 below.

Table 7.7: Palliative/End of Life Nursing Experiences

Gap between family caregivers' expectations and nursing homes caring for their loved ones
Family caregivers' identification of the information and communication gap
Family caregivers' positive perception of good end of life care, with loved ones dying in dignity
Lack of good palliative/end of life care that is patient and family caregiver oriented within nursing homes
Complaints from family caregivers regarding the lack of nursing staff on every shift
Family caregivers' experiences of psychological and emotional loopholes
Spirituality of those in need of care neglected
Lack of empathy or sympathy from the professionals towards family caregivers
More fully-working specialised equipment needed in nursing homes
Lack of professional nurses in nursing homes having adequate training to manage specialised equipment in end of life situations
Conflicts between family caregivers' care roles and the work of professional nurses in nursing homes

Source: author.

Within the nursing home, the family caregivers as the children, have observed how the slow reversal of their parents' initial roles and the twin-pillar shift between independence and dependence are often perceived in everyday care. For example, it is sometimes difficult for adult family caregivers (children or spouse) to accept that the health restrictions of their loved ones have caused the changeover in roles. However, there were also some family caregivers (FC2, FC3, FC6, FC8 and FC10) in which there is only a small degree of ambivalence.

In the case of FC3, it can be assumed that the cause of this is to be found in the severe state of nursing care required for her mother-in-law, who had had health problems since birth. Her emotions changed at the end of her mother-in-law's life. Old conflicts between her and her mother-in-law no longer existed. A phase of instability arose, of inconsistency, which resulted in ambivalence. Her father-in-law also needed care and eventually needed to be in a nursing home. All these factors may have affected her general experience of the nursing home. The all-dominating end of life care and imminent death of her mother-in-law seemed to create a conflicting phase that left little room for contradictions in actions and feelings.

Ateş *et al*. (2018) describe family caregivers as fulfilling multiple roles for a person in palliative/end of life care. They form part of both a formal and informal network, and unfortunately their own needs at their loved one's end of life are not properly met or often totally forgotten by professionals in every care setting (Gonella *et al*., 2019). In this study, rather, it is about the question of how family caregivers' experiences of end of life care in the nursing home were considered by them, negatively or positively. The 'hows' and some 'whys' on family caregivers' experiences have thus been identified and reported in this study. The following section will explore this question further, identifying complaints that affected them negatively and some further unmet needs that affected their experiences.

7.11 Interactions Between Family Caregivers and Care Home Nurses

The quality of interactions between family caregivers on their experiences of professional caregiving in the nursing home was determined by the narrative history of experiences made through the interview process. This means that the foundation of family caregivers' experiences of care in the nursing home and required relationships should be properly laid out well from the start of care to the end of life.

> "The premorbid relationship history is triggered when needs for care of the older person is not met - no matter how serious or unserious this is taking, this event has its consequences for health, functional competence, communication – hence, need for care that respects family carers' needs is now added as a new and significant variable in the relationship of the participants, but all interactions between family caregivers and their experience of nursing flow... also the previous interactions" (Görgen *et al*., 2010).

Against the background of this assumption, family caregivers' interactions are presented using type-forming content analysis. The focus is on the family caregivers' experiences with the nursing staff at end of life in the nursing home. In particular, the previously identified problems between met and unmet needs of family caregivers were formed from the basis of their nursing experiences.

In the following section, five principal features and their characteristics are presented (see Table 7.8). The focus is on the family caregivers' experiences, in particular how the previously identified met and unmet needs affected their experiences. The met and unmet needs of the family caregivers that led to various experiences should be fully understood. In order to better understand the dynamics of family caregivers' experiences in relationship to end of life nursing in the nursing home, four further characteristics complement the typology:

- the estimation of nursing care quality;
- the estimation of the current relationship quality;
- the assessment of the relationship of nurses' behaviour to family caregivers' experiences; and
- the estimation of its effect on them.

In Table 7.8 below, all five principal features are presented together with their characteristics. The results in this tabular overview show how they are distributed among the individual family caregivers. This is followed by an illustration of the familial interaction patterns found. The last part of the discussion of the results (section 7.12) shows which connection with the secondary variable of the nurses' roles caused problematic behaviours that had an effect on the family caregivers' experiences.

It is characteristic of the interaction sub-pattern of 'Protective Authority' that the generations also maintain a trusting relationship and that there is a close, emotional bond between adult caregivers and their older, physically limited relatives. However, in these families, decisions are mostly made by the caring children or family caregiver, with the family caregiver insisting on continuing the decision-making for the loved one while in the nursing home. In doing so, they may lead the maxim of acting in the sense of a substitute for the parents (or relatives) in need of care. This succeeds because their loved ones trust them. For current incidents of poor nursing experiences, or for future dangerous situations, there are no signs in the interaction pattern of Protective Authority.

The interaction pattern of one-sided dominance is characterised by a tense and overworked nurse-family caregiver relationship. With the increasing need for help and support on the part of the loved one, the family caregivers said their relationship at the initial time with the nurses was good or improving, at first glance. But this apparent new relationship quality has its price. Subsequently, the family caregivers reported that the nurses proceeded to dominate the relationship very strongly, without having the trust of the family caregivers. There were signs of regret and verbal exchanges with the nurses were mentioned. At the same time, these family caregivers showed situationally critical behaviours when things went contrary to expectations.

The expression of different experiences of nurses' general behaviours *per se* does not allow any conclusions to be drawn about the quality of the nursing care and family caregivers' experiences. Rather, it is about the question of how to find out how family caregivers experience nursing at end of life in a nursing home. Four familial interaction patterns in dealing with experiences of poor communication or lack of information could be assessed from the data material in a second analysis step. The Interaction Münster Equal Role Distribution is predominantly characterised by a balanced, friendly and trusting relationship between adult caregivers and professional nurses. The family caregivers perceive themselves as knowing the older person better and demand the nurses cooperate with them in their continued care. Decisions are expected to be on an equal footing. In the event of a disagreement, compromises are expected by the family caregivers to be negotiated. This can be attributed to the fact that the caring adults have the right to participate and have self-determination despite the care setting. At the same time, the family caregivers expect their physically dependent loved one to be adequately cared for by the nurses.

Also for the interaction 'Münster verbal', verbal confrontations and anger were typical characteristics This includes the criterion that the family caregivers did not accept information restrictions and the resulting loss of autonomy as a result of their loved one being in a nursing home. When the family caregivers attempted to make decisions on their own, the nurses and the administration within the care setting reacted with indignation and resistance. This was because they felt their line of care of the older person was being violated by family caregivers wanting to continue their usual way of care (self-determination).

7.11.1 Assessment of Relationship Quality (Nurses and Family Caregivers) and Experience Development

As part of the interview study, the family caregivers were asked to say how they assessed their experience, how they interacted with the nurses (or rather, how they interpreted the nursing care) and how they came to terms with each other (in terms of their nursing experience). These assessments refer on the one hand to the initial experience (before the end of life phase of the care) and, on the other hand, to the end of life situation (since the beginning of the end of life care to their last days of care).

This comparison concludes with the question of why most family caregivers described their initial experiences positively on entering the nursing home and yet experienced nursing care negatively as it progressed towards the end of life care. The experiences, as perceived by the family caregivers and the characteristics inductively obtained from the data material, are presented in Table 7.8.

Table 7.8: Assessment of the Five Principal Features of Relationship Quality Experienced Since Onset of Care in the Nursing Home

Principal Feature	Characteristics
Connected familiar	The interviewees expressed that in the beginning they had maintained a very good and mutually trusting relationship with the nurses, but this seemed to decline with time. Most of them reported that the nurses contacted them regularly and supported them, but this faded with time. One of the interviewees described their assessment of the past relationship with the nurses before the onset of end of life care as 'cordial'. One interviewee reported that they maintained a very good and trusting relationship.
Tense, full of conflict	Interviewees described the relationship as tense and conflictual - they felt neglected.
Improved	Interviewees said that their relationship with the nurses improved initially.
Deteriorated	Interviewees said that their relationship with the nurses has deteriorated.
Unchanged	Interviewees said that their relationship with the nurses had not changed.

Source: author.

7.11.1.1 Influencing decisions and dealing with the dichotomy between independence and dependence

In addition to characteristics of relationship quality, the decision-making process and dealing with negative experiences also flow into the type formation. It is about the question of how decisions between the family caregivers and the nurses came about and how the various experiences between dependency or independence are negotiated. The characteristics obtained from the interview data can be taken from Table 7.9.

Table 7.9: Characteristics of Experience Processes and Dealing with the Experience of End of Life Situation

Characteristic	Definition of Characteristic
Willing to compromise at the beginning of care	In the context of the care relationship, one perceives oneself as a 'team'. Decisions are discussed with the nurses. Compromises are made in the event of disagreements.
Influence on decisions	Assertion of caring by the family caregiver, disembarkation of the parent in need of care. In the context of the care relationship, the decision-making sovereignty lies with the family caregiver, while at the same time a reduction in the role of the parent in need of care takes place. And the children protect their parents.
Dealing with experiences of no trust between family caregivers and nurses: *allow trust to be granted*	The older persons in need of care have accepted their dependencies. They fit into their new situation and let the family caregivers' decisions be granted on the basis of trust. Thus, the family caregivers intend to protect their loved older persons.
Dealing with experiences of information provision between nurses and family caregivers: *allow participation*	The family caregivers focus on their participation in connection with the dependence of the elderly person in need of care. They feel left out, sad and disappointed when not properly informed about the nursing care of their older person in need.
Feeling of suffering from the responsibility	The family caregivers suffer from the responsibility they have in connection with the dependence and the care needs of their family loved ones in need of care. They feel sad when their loved ones are not properly cared for.
Feeling of exclusion	Felt by family caregivers when excluded from the care process of their loved ones in need of care. Feeling of sadness.

Source: author.

The overview in Table 7.10, below, shows how the five characteristics and their respective characteristics are distributed among the individual interviews. The interaction patterns fastened together are not ideal hypothetical types in the sense described by Keppe and Weber (1995). Rather, they are real types that can be derived from the empirical data material.

Before the five familial interaction patterns in dealing with negative experiences are presented individually, it must be pointed out that, in the context of the type-forming qualitative content analysis, a strongly condensed presentation of total results is presented. In the interests of transparency and reliability for the reader, this is done on the basis of numerous original quotes. However, this approach does not rule out the possibility that the empirical data material collected does not used mixed forms - for example, the relationship characteristics between the family caregivers and the nurses are not always told stringently in an interview report and may sometimes be evaluated differently. The goal, however, is to bring out the dominant factors.

Table 7.10: Category Bases for the Development of Family Interaction Patterns

Family's assessment of past relationship quality
Assessment of current relationship quality
Assessment of relationship development
Influence on decisions
Dealing with experiences of ambivalence between independence and dependency
Summarised interaction patterns

Source: author.

7.11.2 Equal Recognition of Family Caregivers' Contribution at End of Life Nursing in a Nursing Home

In order to categorise the experiences of the family caregivers, interaction patterns become relevant. However, there must be a narration of experiences with peculiar and particular characteristics. Fortunately, they can be found in the interviews of nearly all the family caregivers, having heard the intergenerational relationship between the adult family caregivers, which are described as balanced, friendly and trusting always up to the time of dependency. In all their narrations through the interviews, each family caregiver cared for and supported their older person while at home. Thus, they expected that their older loved ones would be treated the same way by the nurses whilst in the nursing home.

It therefore becomes very annoying when good communications between the family caregivers and the nursing home nurses are lacking. The descriptions of some of these experiences have already been cited and discussed previously. However, very importantly, the exact motives of the nurses for acting the way they did that led to these negative experiences are unclear. Unfortunately, the older persons in care at the nursing home rarely have the ability to lucidly describe their exact experiences, so their experiences can only be as observed and postulated through the observations of their family caregivers.

Nevertheless, according to their own statements at interview, all (12/12) family caregivers felt well connected to their loved ones in care. As an example, the adult daughter-in-law FC3 describes the relationship between herself and her mother-in-law in the past, before her dependency, as being "*my best friend*".

The spatial differences in expectations and the associated possibilities available should allow compromises to be achieved. All family caregivers perceived themselves as having equal rights to the care of their loved ones. Pending decisions were expected to be made on an equal footing with the nursing staff and would usually require mutual agreement. In the event of any disagreement, compromises were expected by the family caregivers to be negotiated. However, in reality all such compromises were stated by the family caregivers as being lacking on the part of the nursing staff.

When asked at interview ‘How much influence do the nurses have and how much influence do the family caregivers have in end of life nursing?’, responses included “*Both of us have the some* [influence]. *If something doesn’t suit him*”, FC10 said, “*He used to swallow everything down, but if something doesn’t suit him today in the care, he says, ‘Listen, I say, so and so, I don’t want that again’ so he has some influence as well*”.

When asked at interview ‘To what extent has the care of your older person in the nursing home affected your role since the nursing home took care of them?’, FC3 responded *“Yes, I can tolerate a lot. When I reflect on what my mom-in-law did for me in the past we have become friends. Because we have grown together that is why any less care of her gives me a bad feeling* [bad experience]*”.*

When asked at interview ‘How much influence did the nursing at end of life affect you in decisions and how much influence does their not caring for your loved ones have on you? Who makes the decisions?’, FC1 stated *“I already have my wishes for my mother, so it’s not so that I could somehow decide something about her without the nurses knowing. But then, if the nurses are not doing it properly, I know clearly what her wishes are at that time and everything she wants”.*

Similarly, when asked ‘And did they always fulfil them or were there some times you felt a negative experience?’, FC2 related “*...it depends. Yes. When she was not properly cared for, not mobilised, left uncared for in her urine. When I was not properly informed, communicated about changes.* [They didn’t do] *all the things that she had wanted to be done. But there were some things that were very necessary. Sometimes I didn’t have time* [to do them] *and since she was just lying there, not communicating, she should have got all the help she needed, even when I was not there.”*

7.11.2.1 Competing norms: nursing at end of life and family caregivers’ experiences

However, family caregivers’ experiences of end of life nursing should be characterised by positive feelings, such as respect and warmth, as well as normative obligations to family members. However, when examining nursing at end of life, account should be taken of the norms and the way in which they are practically applied in end of life matters.

FC6 described her relationship with the nurses as "*cordial initially, but not personal.*" In nursing care of loved older ones, the highest guiding principle should be, according to FC2, *"to meet the wishes and needs of the elderly and their family carers."* It meant a lot to this daughter that her mother in need of care was well cared for, especially now at her end of life, and that her demands were taken into account. FC2 had "*wished to work with the professional carers as a team. That, however, was not always easy*" she said, "*because the nurses always had a lot to do, many older people to care for and not enough staff on duty.*" At interview, all 12 caregivers mentioned this point.

All family caregivers had been affected in some way by the coronavirus pandemic restrictions. FC2 continued that "*overall we accepted that, because of the health restrictions, what was done to the dying person*". But she stated that *"the caring child, on the other hand, has the right to participate in the care of their dying older person and should be allowed or enabled self-determination, despite the existing relationship of dependency on the nurses."*

7.11.3 Protective Tendencies from the Family Caregivers

The interview data provided examples of protective tendencies from the family caregivers towards their older cared-for persons. This was more evident in some caregivers than others, with a number of common characteristics observed, but principally those of a trusting relationship and a close emotional bond.

Despite the close, trusting bond at times shared with the professional nurses, the majority of the family caregivers still aimed to make the key decisions for their loved ones, thereby displaying protective tendencies.

FC2 experienced her relationship with the nurses as, said in her own words "*not sufficient*". She said that her mother in her time had been very loving, friendly and humorous, and she had hoped for a friendly style of care from the nurses. However this, she reported, was not so. FC3 describes her relationship with the professional nurses as being friendly initially. Regarding her relationship with her mother-in-law, while she was mobile, she described her as a "*most faithful soul*". Meanwhile, FC2 narrated her feelings of the relationship towards the professional caregiving nurses as initially good. However, she had a stronger, more emotional bond with her loved one in care.

FC1 stated that he still had to do most of the things for his mother - clean her, even wash her sometimes when he visited. "*That's not a very good experience*" he said, considering her care was now trusted to the nursing home staff. He thus continued to demonstrate protective tendencies towards his mother within the nursing home.

However, most of the family caregivers stated that, at the same time, they loved to do that kind of caring. This demonstrates a clear conflict of experience between the family caregivers and the nurses.

"*However, this kind of behaviour may be understood as a one-sided exercise of power. Rather, the caring children act according to the moment, acting as substitutes for mothers. However, trust and empathy form the basis for this relationship in the end*" (FC7).

As spoken by FC7: "*You know, if you are used to taking good care of your older one, one expects the same or similar care from others, especially the professional carers. This perfect, meticulous care of the older person may not be the same though.* [If not], *then you have to be angry and show dissatisfaction in many ways. Then you feel disappointed in many ways, especially when things don't work out fine with the elderly in the nursing homes, particularly at the last days of their life. Well! Oh! That was not good. And until then it was always good. In short, I am not in happy regarding those last days.*"

FC11 considered that *"The asymmetric relationship is accepted by the parent in need of care. They fit into the dependency situation and let the daughters do it all. They trust their adult children and know they will take decisions in their favour, protecting them. No wonder when their loved ones are in the nursing homes at their end of life, they expect nothing less. The nurses are expected to continue the good care, even when they [the patient] are no longer able and can't anymore. Family caregivers must learn to deal with the responsibility assigned to them, or which they accepted to do, for their elderly ones. In individual cases, this can be perceived as a burden or not. But it becomes bad when older ones are neglected, or when they fail to get the family care that is appropriate."*

"So it's hard for you? Yes, it's hard that my old mother's health deteriorated and was for a long long time dependent on helps. At the end she was no longer cared for wholly by me at home. She was in a nursing home and cared for by strangers. Although she had me as her close person, I felt that her being in the nursing home, is like me not protecting her and sending her out to strangers" (FC2).

7.11.4 One-sided Dominance of Decision-making from the Professional Nurses

A third pattern of interaction and explanation can be described as one-sided dominance. This was especially true of family caregivers FC3 and FC6, but also seen with FC1 and FC2. The following characteristics are the basis for this belief.

In the past, both parent-child relationships were characterised by once in a while tensions overwhelmed by more friendly and loving periods. From the point of view of the interviewees, disagreements are sorted out immediately. This improved with the increasing need for help and support by the now aging parent. When the parent had to go into the nursing home, they were initially happy, but this happiness tended to fade the minute they perceived that the older person was becoming neglected, and also when they as family caregivers were not being adequately involved in the care of their older person. From the interviews, one could understand the claim of one-sided dominance of the nurses in decision-making and this was interpreted quite negatively.

As spoken by FC3, *"I never expected that I could actually deal well with the feeling that my mother-in-law, in this last year, was in a nursing home. Yes, within me the reality of a nursing home. But I feel I made these feelings vanish the minute I signed for my mother-in-law to be in the nursing home, only for the fears to quickly reappear again."*

FC2 gives two reasons for her feelings: *"On the one hand, according to me, the adult daughter, the old mother getting so dependent, who at least mentally gave up her independency. On the other hand, the caring daughter closely resembling her mother in need of care. She suffers too and needs care, support and understanding from the professional nurses."* Like a common thread, FC2 often addresses the parallels between the recent care situation and the past existence of her own childhood. This infantisation allows the daughter [FC2] to relate to her older loved one in a new way. She feels fully responsible for her when things go wrong. She is sad and feels guilty and regretful.

One of them (FC1) said: *"I needed more help against the control of the nurses at end of life in the nursing home. So, in the beginning I would probably have not worried too much, but ended up hitting my head* [against a brick wall] *in the last days of my mother's life. I have actually pushed them into this and thus it works, because I know parents take care of their children and, in their old age, the roles are reversed. So I felt that now she can't, I should do everything to make sure she gets all the necessary care she needed. While I didn't have to continue care like when she was at home, I realised I continued with my worries on how* [badly] *she was being nursed".* While she was in the nursing home, *"I initially had good* *experiences, but towards the end, I felt so bad at the kind of nursing I had experiences in the nursing home"* (FC1).

This means that the relationship between the older person and the family caregiver (daughter, son, daughter-in law, grandson or spouse) is not to be evaluated solely as a biographical opportunity. Because the relationship quality also has its price, as in the judgement of the professional nurses and other carers of the older person in the nursing home. Since the onset of care was required, the family caregiver had dominated the decision-making regarding care very strongly, simply because the older person no longer can. The result is not always considered to be positive by the nurses within the nursing homes, because decisions are now shared (at best) with the redistributed power structure. In this, the family caregiver, such as FC6 and a few others, at the same time felt the need to continuously be a part of the care of their older person, although the one-sided dominance of the nurses at times prevented this.

"I never wanted to assert myself on her. I love her and treated her with respect. She then accepted that in the last days. She never objected, but I still didn't impose anything on her because she already was failing in health. I think she was already aware that she was dependent on me in her last days. So, and of course, she was already aware of her inability to care for herself, so all the more reason why professional nurses, who took over, should have done better for her" (FC2).

In contrast to the interaction of simple family caregivers depicting their protective roles for their older loved one, the foundation of care through professionals though not pronounced is based on trust. But a lack of practical alternatives drove the family caregivers to institutionalise their loved ones. Many of them stated how they regretted having their loved ones in a nursing home, particularly financially. In addition, the amount of paperwork was not reduced just because the loved person was in a nursing home. So although it is not beneficial economically, a bit of extra private time was enjoyed. Unfortunately, the lack of proper and sensitive care observed for the older person and the loss of family caregiver autonomy to the nurses, actively negatively shaped their everyday cares and experiences.

FC6 at interview, stated: *"My husband lost his company and house, because of our younger son's carelessness and greed. This caused financial ruin. My husband had to declare bankruptcy, because in the end he had nothing again, we possessed nothing in the end. Maybe..."*, she said, *"maybe we made a mistake and gave our youngest son too much to manage... maybe we shouldn't have done that. In the end, my first son will have nothing from the inheritance. We would have left them their part at the end, but what is gone is gone. Afterwards, we had no more money for care. I am so sad"* In addition, FC6 often drew striking comparisons between everyday childrearing "*But now the nurses have control.*

I am happy when he smells good, looks good. This is really similar to a baby. Only that my baby is 83."

7.11.5 The Fight for Recognition: the Fourth, Final Pattern of Interaction is Called Recognition

This section is largely derived from the empirical interview material of FC3, FC6 and FC12. The relationship between the family caregivers and those needing care is often determined by past relationships, including numerous conflicts both in the past and in the present. In recent years, FC6 has repeatedly supported her husband all round. She said "*it has not always been easy with him, but we managed to resolve issues in the past"*. Because of his health problems, she managed the household at that time and helped with the education of the children. To this day, her youngest son cannot find any words of appreciation for this sacrifice. And he feels she failed the family by allowing his father to spend his last days in a nursing home. But FC6 added, *"I did everything. I was ready to continue nursing him at home with the help of my oldest son and daughter-in law. But his dementia was getting worse every day. We felt he was better in the nursing home."* At first *"I managed everything, the washing machine, the cooking, and just everything here, the kitchen, the finance… When I wasn't there, he felt helpless"*. Once in the nursing home, "*I didn't want my husband's hair not being properly combed, or not being kept trim. I didn't want him wearing scruffy clothes or smelling. I didn't want that. You did whatever you wanted, you nurses. You took control when I wasn't there. You could mess around. But when I was there, I wouldn't let you treat my husband just anyhow"* (FC6).

At that time, for 12/12, the family caregivers' greatest need was for good care of their older persons. Their experiences of the nursing care of their older persons at end of life was a central field of tension. Nothing enables them to experience end of life nursing of their older persons more positively than to see that the rules are followed in the nursing home, and that they too are equally recognised as hidden patients also in need of care. Reflecting upon the end of life activities of the professional nurses and how she had helped them, FC2 stated "*...but as I said, I helped where I could... but I hated it when my mother didn't get adequate attention and care, never minding the state of her health and how many days I was absent"*. Fulfilling this wish is also very difficult for the son (FC1), who reacted to the presumably "*negligent nature"* of the care of his mother.

"*I still liked to get involved in the care of my husband, so if I had spare time… I would perhaps say to the nurses in the setting to let me do all the care*" (FC8). FC6 stated "*...initially I was happy, later not. Then they didn't give me proper information. Sometimes, I went to look for someone to ask or talk to about things, sometimes it took an hour to see a nurse to talk to. This is not the kind of experience they all promised at the beginning".*

"Well, certain specifications and laws have to be followed, although she was a completely dependent person. And yes, against these requirements, sometimes, the law protects them, and then you just have to say, then I have to say clearly, well, that is not possible now. For example, this living will she made, when she refused to talk to me" (FC2).

Also in the case of family carer FC6, the conflicts from the point of view of the youngest son and only daughter were mainly due to the fact that they felt their trust was misused, so they were happy that she had the oldest son and his wife to help care for their father. Initially her husband did not accept his health restrictions and the resulting loss of autonomy. "*So, as long as I did what he wants or what he advocates, then it was fine. When he was sent to the nursing home, he deteriorated so fast and and...",* but she couldn't find a word to complete her sentence.

"But just as I said to the nurses that I want something different for my mother, better attention, better care, then it would be difficult" (FC2).

Some of the family caregivers reported on how their older persons would have rejected any support measures from any carer who was a 'foreigner' or 'stranger'. Such a situation arose with the dedicated nursing service initially used by FC6, when her husband became aggressive at home, very disorientated, with extreme childlike behaviour. Nevertheless, the wife, son and daughter-in law did not act against the will of the father. With massive help from their general practitioner and legal processes, he was transferred to a nursing home, after some days spent in a psychiatric home.

Regarding the lack of nursing staff and subsequent insufficient care, FC2 reported how, on occasions, she has resorted to crying "*that is, if every hope then becomes too narrow, then I sought refuge in tears*". FC2, who felt neglected, simply evaluates this behaviour as follows: "*I am quite sure that if the nurses were to have enough capacity, they would do better."*

Most of the negative experiences of the family caregivers analysed in this qualitative study are similar to those described in existing publications relating to end of life care (Verhaeghe *et al*., 2005; Hunt, 2020). These negative experiences correspond to the results of the quantitative studies analysed in Hunt's (2020) study. For example, 'burden of time' was mentioned in several studies (Yoo *et al*., 2008).

"I am also quite sure that the nurses were not neglecting me or my husband because they wanted to annoy me or something, but because they either think differently of old people and their family carers, or they lack the necessary education. And because most of them

think dying and old age is normal. And that family carers don't need much [help from them] *so they don't do things any more"* (FC6).

In Hunt's (2020) study involving family caregivers, both positive and negative experiences are analysed. Interestingly, the positive experiences suggested from the qualitative studies reviewed in this analysis are similar to those described by Hunt. For example, "*perceiving oneself as a person who is essential for the patient*" indicated positive recognition of one's existence and satisfaction. This is similar to the concept of 'self-respect as a caregiver' mentioned in the study by Hunt. The positive concept of *"personal growth after reflecting on life"* is also similar to the 'search for the meaning of life through caring' discussed by Hunt. Positive interpersonal experiences, such as "*recovering relationships with other family members after sharing patient care*", "*feeling respected by the healthcare provider*", and "*support from a social network*" were similar to the concept of a 'positive experience from using a caregiver's resources through care' (coping and social support) discussed by Hunt. Many of the qualitative studies reflected similar experiences. When the nurses shared care duties among family caregivers and enough social support was provided, and the older persons were well cared for, then the family caregivers tended to have stated these as being positive experiences. This included "*recovering relationships*", suggesting that efficient interventions to facilitate social support improve care; good communication and prompt information were also necessary and well received.

Many negative experiences analysed and elucidated in this study were related to the lack of social support, lack of information from the nurses and poor communication from them. Other negative experiences were in regard to communication problems with healthcare providers and the family caregivers' needs relating to information about the patient's overall condition, often from administrative workers. Hence, and as mentioned in many studies discussed earlier, the guidance that helps nurses understand the family caregivers' role needs to integrate them into a nursing care curriculum which is likely to lead to holistic end of life nursing. Many family caregivers felt that these nurses should be responsible for achieving positive outcomes, especially at the end of life of older persons and for their family caregivers. Nurses should respect and support the patients' family caregivers as being knowledgeable and able caregivers, listen to them open-mindedly and meet their concerns. Nurses should never forget that this is an essential duty, which eventually positively influences the end of life patient and the patient's family caregiver. Finally, developing standardised tools for measuring the experiences of end of life patients and their family caregivers in future studies has been suggested by a number of authors. To achieve this, it is necessary to identify which characteristics are related to positive versus negative experiences to strengthen positive aspects and minimise negative aspects involved in the process of patient care.

Overall, FC2 and FC6 stand for a tenacious struggle for positive change. However, they differ in the quality of their previous and current family relationships and care processes for their older persons. With FC1, due to the tense, conflict-ridden personal issues, neither the old, physically restricted mother nor the adult caring son, find a level of concession except through institutionalisation. For them, this may have been the best solution for the discrepancies due to the change in the older person's condition. In contrast, FC6, a pensioner, is a wife with her own health issues, being almost as old as her patient husband with health challenges. Also, all the other interviewees, even the younger daughters, faced challenges; they had conflicts with work or pressure from immediate families.

To conclude, after all the presentations above of the family caregivers' interaction patterns, the next and final part of this discussion of results chapter will investigate and discuss the relationships between the experiences of family caregivers at the end of life of their loved ones in nursing home care and the second variable of 'problematic behaviours' on them. The situational descriptions of acts of negligence and possible future dangerous situations at the end of life of their older persons are at the helm of these discussions.

7.12 Situational Descriptions of Experiences and Future Hazardous Situations

The family caregivers in this study have reported upon some of the unexpected challenges they faced due to their loved ones being in a nursing home. However, some behaviours from the nurses and institutions they reported on failed beyond their expectations. In some cases, they needed to adapt to some situations; for example, when their loved ones were not well cared for, information about a change in medication, not knowing about planned doctor's visits, and changes in health conditions not reported to them by nurses. Some reported on experiencing financial difficulties, the role changes within the family, and upon the different problems and changes in the overall health condition of family members (Hwang *et al.*, 2003). For example, family caregivers faced emotional and/or psychological problems such as sadness, anxiety, fear and depression, and physical exhaustion such as tiredness and fatigue (Lee, 2005; Yoo *et al.*, 2008).

Evaluation of the qualitative interview material indicates that severe, physical and emotional deprivation of care measures did occur in some of these nursing home settings. However, the statements suggest that such behaviours of the nurses, as perceived by these twelve family caregivers, are only sometimes interpreted as being problematic or of being a potential danger. Instead, the attitude and behaviour of the nurses led to family caregivers complaining of negative experiences in the nursing homes regarding current nursing practices. These complaints were almost unavoidable, with some nurses' failures incomprehensible and inexcusable.

As reported by many authors, professional nurses working in care homes may fail to deliver quality nursing care to older people and their family caregivers due to the pressure of workloads caused by staff shortages, and this is an increasing problem overall in healthcare in Germany (and elsewhere in Europe). In addition, it is noticeable that almost exclusively, all the family-caregiving children and spouses verbalised such situations during the interviews. The person in need of care could not have spoken themselves or have reacted to these questions about experiencing stress or destructive behaviour by the nurses, hence their family caregivers advocated, mediated and spoke for them. However, answers to identical questions such as "*but that is bad*" compared to "*was not bad, it had to be that way*", "*nevertheless, that was rare*" compared to "*would be common*", plus "*I'm not well*" and "*I'm doing really well*", and similar phrases provided, all demonstrate the inconsistencies that may lead to confusion regarding categorising bad experiences.

It is conceivable that the usually one-sided information gathering situation prevents family caregivers from expressing themselves freely. Despite the promised anonymity, the fear of possible reprisals or sanctions could prevail. In addition, it should be borne in mind that the evaluation of family caregivers' experiences does not take place along the lines of social legal norms, but that private standards and modes of understanding prevail, which are influenced both by the social milieus and by the specific family history.

As part of the complex questions on each family caregiver's nursing experience of palliative/end of life care, the following question was asked at interview: 'What are the family caregivers experiences of palliative/end of life care, whose elderly loved ones are at end of life in a nursing home? It is known that sometimes they might not be treated well by the nurses. Can you imagine what kind of experience family caregivers go through at the end of life of their older loved ones? Something like this or looks like this, and how can it happen?'

In the following section, the experiential actions described during the interviews are presented. These parallel quite closely to those described the final report of the cooperation project on palliative/end of life nursing of old people (Görgen *et al*., 2010).

Family caregiver FC6 perceived certain situations as psychologically stressful. She tells of verbal arguments and altercations between herself and the nurses. The reason for these was the continuous neglect in the care of her husband, causing her psychological and mental stress. *"...we questioned the nurse. Then I said, 'watch out, if I am not informed on everything about my husband* [named him] *I will take my husband away, or report you to the appropriate quarters. I am breaking down. How can you not administer drugs to my husband or dress him properly?' So, of course, that was pretty hard. However, for me, it* *was also essential to have an outlet there".* In this case of a deteriorating state of health, FC6 considered using external support, by employing someone who could help when she could not visit.

From the author's point of view, the conflictual situation in care between the nurses and the son FC1 suggests an increasing need for nursing homes to officially and formally document all complaints from family caregivers, as this will help assess the family caregivers' experiences. In this way, the tools developed for measuring family caregivers' experiences of nursing care at end of life can only be satisfied if both the nursing needs of the dying elderly ones and their family caregivers' needs are met. However, what kind of acts of neglect come to light becomes highly relevant.

But the context can become highly relevant. For example, when asked about general care in nursing homes, FC6 commented: *"Well, I can already imagine that even biological children can harbour aggression against such old people, and I can also imagine that sometimes one gets old feelings coming back. For example, when children have experienced something with their parents in their childhood, it somehow comes up again in another form. Moreover, for example, when a nurse is not doing it right, so you are constantly reminded of your past. You see yourself working beyond the borders and not a small amount of gratitude from the nurses, but maybe just everything you did while he was at home… Then at some point you see red. So I think I would always confront the nurses, but then you scream or then say 'now you have to do everything right', I can, I could, imagine, if you all had to do things constantly poorly and shabbily, I would say farewell*" to you and this place.

Similarly, FC1 stated at interview that *"I've also yelled at a nurse before. I've said 'Enough is enough'. I would tell them that my mother is now here and things should be done the way I want them to be: It's the same as you used to do to others. My mother is here, I expect something better, things should be done the way I do it. I would say to them 'you have no idea about my mom, how she valued this and that'. I would say that sometimes."*

In the case of family caregiver FC2, the relationship between herself and her elderly mother had been "*perfect and improved considerably*" as her care continued. Accordingly, she expected better and continued care in the nursing home. However, at such a time there were shifts in the power dimension. FC2 stated that "*some nurses dominate care relationships very strongly. They want to assert themselves with their views and react verbally aggressively when asked 'why' questions*", especially in situations where her mother "*was not changed, not washed, and areas of information*".

Likewise, it is unacceptable for caring daughter FC2 to imagine her mother in pain, for example during washing and dressing her mother. According to FC2, this could not be avoided and happened unintentionally. *"...but yes, I often felt hurt by some nurses' behaviour towards my mother, but that also has a lot to do with the fact that sometimes in the past you don't even know where to touch her. She screams with the pain, but I still have to wash her. But with care. Yes, not on purpose so as to make her feel pain, but because I needed to wash her. But of course it is clear that you get into a certain routine in your actions over the course of time, and then sometimes it has to go a little faster, and then maybe she is not touched quite so gently, she is just washed. I guess the nurses do same, but I don't believe they were considerate when she showed signs of pain, because they haven't as much time. They just do the washing, then move on to the next and so on."*

FC2 then went back to clarify: *"But I say, then I sometimes felt that I was hurting her, not consciously and not intentionally. But because of the fact that she of course had many fragile areas or places where her bones hurt."* Asked about how the nurses washed her mother, FC2 clarified *"Sometimes she felt a bit roughly handled, but not on purpose. But when I spoke to the nurses about this some of them were verbally aggressive to me."* She reported that she had to *"keep calm and keep my mouth shut. I tried to keep calm because of my mother in need of care - I showed understanding* [towards them]. *Other carers, older people, most of them told me* [when we spoke together at the nursing home] *that they had also shown gratitude to the nurses when they were able. It is not possible to think the nurses will hurt our loved ones. Other carers believed that we were there to make sure everything goes well. But the nurses can't hurt her at all. I love my mother far too much for that, to allow anyone, any nurse, not to care for her as expected."*

When asked to explain a little further, FC2 said *"Oh God, these were sometimes little things. For example, I would tell them* [the nurses] *off when I came in at 10am and she was not yet washed. And this happened regularly. With me not taking care of her as I used to do before, for me this was not nice. Before here, she was always washed and cleaned early* [in the morning], *when the visiting nurses were coming to her home. I was very much impressed then. But here in the nursing home, they were not adequately taken care of. 'Don't be so angry' one nurse always told her. Nothing will make me feel happy if she is not well cared for. Her quality of care was my concern."*

When asked about information received from the nurses, family caregiver FC7 answered *"this sometimes worked and sometimes not"*. Every now and then there were situations where she did not feel that her mother was adequately cared for. Unfortunately, these were not explained by her in more detail.

This is what FC6 said of her husband's nursing care: *"Due to his chronic pain, my husband was treated with morphine. As a result, it was difficult for him to maintain a regulated day and night rhythm. Coupled with the dementia, he was constantly expressing the desire to go* *to the toilet."* FC6 elucidated upon this problem when it had arisen earlier, whilst they were still living together at their home. Since she initially had slept in the same bedroom back at home, this could lead to tense situations. She described that every now and then, in a very specific tone towards the husband, she had asked him - with reference to her own need for sleep - to stay in bed. Once she had even screamed at him out of frustration.

Regarding poor nursing attitudes or behaviour, FC3 commented that *"Of course, I do not always get what I want for my mother-in-law. We are dependent on their care. That is clear."* When asked if the nurses had ever shown poor care or aggressive behaviour towards her older persons in care (her mother-in-law and later her father-in-law) she replied, *"I will not lie, I had positive experiences initially. For God's sake, in the recent situation of dependency, I could not afford to bear any such behaviour. But sometimes it happened."*

FC2 stated that there had been an exchange of words in disagreement with the nurses. Remaining specific in her statement, she said that she never did anything in the past without her mother's consent, except with regard to the nursing home care that she arranged without the direct involvement of her mother (when her mother's condition deteriorated, she made the decision with the family doctor to transfer her to a nearby nursing home). She found her mother's end of life stage sad and quite negative, when she said, *"she who had provided for me, motivated me, and now seeing how she was cared for in the nursing home and seeing the carelessness by the nurses as insulting, their negligence. It was at times quite mean."*

The caring daughter FC2 was particularly annoyed when her mother in need of care was not given her pain medication at the right time. *"She guessed the* [level of] *pain without administering the drugs."* She reacted irritably to this episode. FC2 had reported this to the nurses' office, where she had previously also reported the poor state of things regarding her mother. She had expected remorse, but instead explanations were given that were unimaginable - they tried to cover for their inadequacies. That, she said, was out of concern against her own reactions. "*So, if I was not present, what would have happened? What if I had been taken ill?*"

The caregiver wife FC6 found that her husband was not dressed adequately when she arrived to take him out into the garden, despite her previous request for this outing to be prepared for. A reaction that she finds frustrating. The anger of FC6 about the behaviour of the nurses stemmed from previous misdemeanours from the nurses. Overall, she expected more consideration to be given to her husband. FC6 sees herself as a person who was responsible for him when something didn't go well. At such times, though, she did not relent and did everything necessary to confront the issues with the nurses.

When asked about any problems regarding lack of information provision or poor communication, all twelve caregivers stated that such situations arose. There were a lot of sad and quiet moments regarding this area of concern in the interviews. FC1 was particularly vocal in this regard, saying that his mother's case had bothered him. "*But it was quite sad.*" The son answered openly that he sometimes got angry and "*freaked out*" against the background of neglect.

However, there were no opportunities in this study for the loved ones in care themselves to describe their own personal impressions and experiences. As such, it is always the caregivers who relate their experiences of the end of life nursing of their loved ones in need of care during all interviews.

Other incidents of physically inappropriate behaviour existed in this care setting, as described by FC2. "*Directly hurt never, but she once left her hair unkempt in anger. I asked why? The nurse was immediately sorry for her behaviour.*" In the further course of this conversation, the interviewer had to reassure the unrestricted confidentiality of the material. However, the absence of any ability to conduct cross-inquiries of the nurses prevents the further description or discussion of any clear facts in this case. It is possible that the caring nurses directly inflicted pain on the family caregivers, causing negative experiences, when their older persons in need of care were not properly cared for. Whether these actions can be identified as clearly intentional is difficult to assess, as the explanations are purely one sided in this respect.

Overall, all twelve interviewees stated at some point in their interviews that, on at least one occasion during their loved one's care, one or more of the nursing home nurses, and sometimes administrative staff within the institution, appeared to intentionally neglect their duty of care across a wide variety of situations and commit negligent behaviours against the elderly people in their care. This can only be considered to be critically poor and negligent behaviour. In the end, the burning question of whether the daily repetitive, shameful, neglectful actions in their everyday care were intentional cannot be definitively answered. Essentially this is because, from the descriptions given by the interviewees, it cannot be clearly deduced whether this apparent neglect was the result of the overall shortage of nurses in Germany today or whether it was due to the routine actions inherent within some or all of the health settings that caused the neglect leading to the various experiences witnessed and reported. If the cause was indeed either that of the nursing homes' internal rules and routines, or whether it was due to the chronic lack of staff, then either or both could then be identified as the cause and consequently one could consider this as an avoidable behaviour.

7.13 Summary of the Chapter

The concept of the ‘family caregiver’s experience’ is applicable to the relationship between the family caregivers and professional carers. The innovative approach of this study has proven to be extremely fruitful. Analysis of the twelve family caregivers was able to robustly characterise the experiences and expectations of these caring relatives. With the help of qualitative content analysis, family caregivers’ expectations were elucidated, in particular regarding the tensions felt between their expectations and the nursing home nurses’ behaviours that led to various family caregivers’ negative experiences and ill-feelings being generated. In addition, these negative experiences led to conflict-ridden situations being identified. Based on the twelve identified family interaction patterns, inequality in decision-making, a shameful lack of authority and/or negligence, one-sided nurse dominance as well as nurse negligence, delays in giving information to family caregivers, poor management and/or recording of medical care and medication information given, and a lack of nurse competency all dominated their experiences. Some of these many complaints led to family caregivers losing trust or feeling aggrieved towards both the nurses involved in their loved one’s care and the institutions in which they were being cared for.

CHAPTER 8: CONCLUSION

Through the use of a single-method study, it has been possible to analyse the experiences of caregiving relatives of elderly people in old people's nursing homes in detail. It was possible to make statements about family relationship dynamics from this method. It is not clear that the present work reached its limits, and these limitations will be discussed in more detail below.

8.1 Detailed Summary and Critical Discussion of the Results

Compared to published international research results, the described experiences narrated by the twelve family caregivers are peculiar to Germany rather than globally. From the observed number of cases, all of their elderly dependent relatives were first cared for at home and were later transferred to nursing homes for 24-hour care by professional nurses when their family caregivers could no longer continue with their care. Unfortunately, how family caregivers of these vulnerable persons experience care at end of life in nursing homes in Germany is not currently well documented. Similarly, neither is it clearly defined. The experiences of the majority of family caregivers go unnoticed and, as such, no follow-up to these effects are ever made. Hence, these family caregivers suffer in silence, so the topic of this study is appropriate and opportune.

The results obtained from this study reflect closely the published results from a similar study on the experiences of family caregivers of older people using support services in six European countries: Germany, Greece, Italy, Poland, Sweden and the UK (Lamura *et al.*, 2009). The authors did not study or discuss family caregivers' experiences in nursing homes *per se*. as they studied a variety of support services, but all caregivers experience nursing differently. Nevertheless, concerns regarding the poor quality of support for family caregivers of older people at end of life in nursing homes appear to be common across all countries. European efforts to improve carer support and provision of a good nursing experience in care settings need to focus on improving the care system in general (particularly nursing homes) and improve the ability of professional nurses to provide timely, high-quality care. This needs to be delivered by staff who treat the older person and family caregivers with dignity and respect and thereby enhance cooperation between health professionals and caregivers, thus providing a better end of life nursing experience for family caregivers in all countries. This should also extend across the more informal networks (particularly seen in south-eastern Europe), social services (particularly in Sweden and the UK) and voluntary organisations (in Germany and the UK) (Lamura *et al.*, 2009).

Regarding potential negligence, one of the family caregivers, FC2, said *"I guess they cause pain when putting on clothes or brushing hair of older people in need of care."* However, whether this was an intentional action cannot be clearly deduced from the data material, nor if there is a future risk of neglectful acts or neglect is also a difficult question to answer.

8.2 Limitations of this Study, Applicability to Other Situations and Proposals for Further Studies

There are limitations to most studies on this topic. Many published single studies consider families caring for relatives with illnesses or diseases including dementia and cancer, and those with physically degenerating diseases dependent on others for care and who are at end of life in a nursing home.

This study identified family caregivers whose older persons died within one year of this study. However, difficulties were experienced during the recruitment of participants and in gaining access to this target group. The original number of participants planned for the study was twelve, but initially only six suitable participants were identified who consented. The timing of this study was unfortunate, as it coincided with the Covid-19 pandemic and consequent lockdowns and restrictions. As a result, it was agreed to extend the study post-pandemic to include further suitable participants, thus reinstating the original target group size of twelve participants. This was achieved and the results amalgamated to achieve a small but representative sample of this care sector. However, it is accepted that the total number of family caregivers who have negative experiences of end of life care in nursing homes is currently unknown and this is likely to continue into the future. Thus, only tendencies are seen and depicted here. The use of larger numbers of caregivers in future studies might assist in providing improved assuredness of the problems identified in this study, as well as potentially identifying other negative experiences as yet uncovered and unidentified due to new or changed circumstances.

A limitation of this study is that, in order to focus upon the specific research questions and family caregivers' experiences, the results are only from this viewpoint. This therefore only provides a one-sided argument and viewpoint, and a future study might encompass the viewpoints of nurses working in nursing homes on the negative experiences reported here from this study. As such, routes to more positive experiences for both parties might be identified.

Regarding this study's socio-demographics, future studies might consider incorporating and investigating the effects of certain other demographics, such as financial hardships, ethnic minorities along with their cultural beliefs and traditions, the assessment (and related problems of being of a younger age) of younger family caregivers' experiences (as not all caregivers or care receivers are necessarily elderly), and the additional problems faced by non-family caregivers (such as friends) to loved ones, where not being directly 'family' might cause exclusion in some circumstances. All aspects are worthy of further study, but were beyond the focussed remit of this study.

Whilst the results from this study may be applicable to nursing and care home settings throughout Germany and not just the region of Niedersachsen and Bremen, they will also have some (albeit, in some cases, limited) bearing and applicability to other countries worldwide. Application of this study's findings to non-end of life care in nursing homes might also be of relevance, due to the somewhat similar interaction of family caregivers and nurses in more chronic longer-term nursing situations, such as within hospices.

This work identified two predictors of significant problem behaviours: the first was from the nursing home nurses and the second was the disturbing negative experiences of the family caregivers. Subjective stress on the part of the practising nurses caring for older people, and negligent behaviour on the part of these nurses towards older persons who were physically dependent were recorded through interviews with the family caregivers. With the application of qualitative methods, many family caregivers with negative experiences were identified, along with a common relationship to the quality of their lives from these negative experiences. Thus, the perceived deterioration of the relationship between nurses and the family caregivers from the phase of end of life care predicates significant problems and behaviours in nursing home care. Other implications include risk factors such as depressive symptoms, feelings of regret, sleeplessness, poor coping in bereavement and addictions to alcohol or even drugs by caring relatives, disability in private lives and the lack of support in the social environment. However, as seen in this present study, these results are not easily transferable or generalisable, partly due to the low number of participants involved and single geographical location studied. As mentioned above, the number of participants who initially consented to the study was affected by the Covid-19 pandemic. Additionally, at the time of initial data collection, there were not many older people diagnosed at end of life in the nursing homes involved in this study, leading to the reduced number of available participants (i.e., family caregivers of relatives in need of care of severe or very severe care classes - Pflegestuffe III-V). Further post-Covid-19 participants therefore had to be added to bring the study sample back up to the desired number of twelve. The representativeness of the final sample is, therefore, not a guarantee of accuracy for this investigation, but more an indication. As seen in this study, this low number of participants in the present study (twelve) ideally needs to increase to higher numbers in future research studies dealing with family caregivers' experiences to better understand the extent and risk factors in nursing home care.

The survey instrument used to ask family caregivers how they experienced end of life care in their nursing home is considered appropriate. However, family caregivers would generally rely on the support and resources of nurses to provide high quality holistic care in the nursing home when their old loved ones are in their care. In the data analysis section, it became apparent how family caregivers answered all the questions, revealing their various experiences. Hence, upcoming questionnaire studies in the context of nursing home care experiences of family caregivers could benefit from this study and adopt a similar instrument.

The background of the family caregivers plays an important role in the care and medical treatment of their loved older ones, with them acting as caregivers or decision-makers rather than just passive observers. In order to also provide appropriate care for family caregivers and improve their nursing experiences, it becomes necessary for professional nurses to understand these family caregivers' experiences (Yoo *et al.*, 2008). In the current study, some of the behaviours exhibited by nursing home nurses towards the family caregivers led to negative experiences. However, some of these negative nursing behaviours towards the family caregivers were considered to be as a result of low staffing levels and consequent stress factors. Older persons and their family caregivers need care in the context of end of life nursing in the nursing home. In most instances, trust was lost by family caregivers as time progressed. It is therefore recommended that future surveys should adopt a uniform approach and more studies must be applied in this field to throw further light on family caregivers' experiences. This study also indicated some potential ethical issues and the question of inequality and discrimination; hence further studies are recommended to detect family caregivers who are prone to be neglected and encourage nurses' enhanced training in palliative nursing.

Depending on whether the family caregivers' experiences in relation to end of life nursing were positive or negative when evaluated by the interviewees, incidents involving family caregivers and the danger of the continued negligence of documenting family caregivers' experiences and dangerous situations are a relevant factor regarding how family caregivers judge their experiences of end of life care in a nursing home. Certain negative experiences, both at the beginning and later on in the end of life care in the nursing home were allegedly not well documented. Verbal disputes, expressions of anger or disappointment, emotional and psychological pains, spiritual neglect, lack of support, inappropriate dissemination of information, incomplete or lack of communication and changes in medication were some of the accusations of the interviewees against the nurses. Hence, an increasing need for care is most probably accompanied by an increased risk of negligence, leading to more negative experiences for family caregivers. However, it can also be deduced from the data that nearly all the adult caregivers stated that the nurses had never intentionally, nor across all situations, carried out acts of neglect against them or their loved ones. Nevertheless, with the help of the qualitative interviews, the many grey areas of family caregivers' experiences regarding potential neglect by the nurses in the nursing home have become more visible.

It would thus be worthwhile to transfer this approach, which is not very widespread in practical research, to help nurses in nursing homes understand how family caregivers experience the nursing of their loved ones in a nursing home. For example, family caregivers' experiences have received a distinct lack of attention in the health sector regarding nursing and home care. Complaints of family caregivers against nurses in everyday care of the older person at end of life are often overlooked or totally ignored. It would be desirable for further studies to continue from this point, as there are increasing expectations from family caregivers with regard to the end of life nursing care of a loved older person. It is important to shed further light on the experiences of family caregivers in this situation and to understand how they feel. Indeed, so doing helps to sustain them in this role. Information gained from the present study may give health professionals a greater understanding of family caregivers' experiences and what helps to promote a more positive experience during this important phase of their care roles.

Lastly, it is suggested that the development of standardised tools for measuring the experiences of end of life patients and family caregivers should be investigated in future studies. It is necessary to identify which of the families' characteristics are related to positive versus negative experiences, in order to strengthen positive aspects and minimise negative aspects involved in the experiences of family caregivers who are providing care to older persons at their end of life within old people's nursing homes.

8.3 Practical Relevance of the Results

The practical relevance of studying older persons and their caregivers is rising in awareness. Older persons are celebrated internationally every year on 1st October (United Nations, 2023). For example, in Australia, the Family Carers Awareness Day is highly relevant and celebrated as the International Day of Families, which is usually on May 15 every year. Estimates of the number of long-term care-dependent elderly in 2030 range from 3.17 to 3.37 million, and by 2050 around 4.4 million people are expected to need long-term care (Bundesgesetzblatt teil 1, 2011). Unfortunately, instead of being celebrated, many older people aged 65 and above, including their family caregivers, suffer physical or psychological neglect. The risk increases when the need for help from professional nurses, support and care increases due to deterioration in the older person's health.

Caring can come at a personal cost to many family carers' well-being. Several authors have reported upon the adverse effects of end of life nursing on family caregivers of older people in nursing homes, including their physical, emotional and social well-being (Szmukler, 2004; Kenny *et al.*, 2012). Approximately one in five family caregivers of people with severe mental health and other old age related health problems report that caring had a moderate to significant adverse effect on their general well-being (Pinfold and Corry, 2003).

Not only is the family caregiver's health adversely affected, but the whole family's physical and emotional well-being is also affected (Kenny *et al.*, 2012). In some cases, the burden of care placed on primary caregivers, in particular, can have significant undesirable effects on their ability to manage their own lives, manifesting as psychological distress, grief, anger, depression and anxiety (Bailey and Grenyer, 2013; Bruvik *et al.*, 2013). However, the family caregiver's guilt and anger worsen when the end of life care in the nursing home falls short of expectations. Nurses and family caregivers rarely agree about specific needs or problems likely during end of life care in a healthcare setting, admission or discharge (Rose *et al.*, 2000). Because nurses are often unaware of the strengths and weaknesses of the relationship between the patient and the family caregiver, they tend to limit them from inputting care at end of life. Unfortunately, the nurses consider family caregivers as having inadequate knowledge and skills. Hence, family caregivers may not be allowed to be fully involved in end of life nursing care. These nurses believe family caregivers are unfamiliar with the type of care provided or the amount needed. Family caregivers may not know when they need community resources, how to access them or how to best utilise available resources (Given *et al.*, 1994). As a result, family caregivers often neglect their own healthcare needs in order to assist their older family members. In most cases, family caregivers have faced deterioration in their own health and well-being (Stommel *et al.*, 1993).

This study has embraced important questions and areas of practical conflict. It has asked how the outcome of this study may help improve family caregivers' experiences of end of life nursing. It has questioned and evaluated the undoubted value of experiencing end of life nursing positively. It has also investigated how family caregivers might be protected from their loved ones experiencing potential acts of nursing care negligence at their end of life.

Where there is suspicion that a family caregiver for an elderly person in need of care is experiencing end of life nursing negatively, attention could be drawn to this through clear reporting. The implication is that there is currently no standardised reporting procedure nationwide concerning what nurses should document regarding the experiences of end of life nursing and family caregivers' experiences. Of course, at present, who defines a family caregiver's experiences and what kind of experiences are termed negative remain open to debate. Similarly, there are currently no formally defined responsibilities for family caregivers during end of life situations within nursing care institutions. Nor have nursing home settings any formally defined measures towards preventing future occurrences of poor care or potential neglect. In Germany, the Care Authority, the Geriatric Social Service and nursing care centres themselves are all endowed with a wide variety of rights and laws and all should endeavour to intervene by conducting random interviews with family caregivers to ascertain and better understand how they currently experience end of life nursing care.

The extent to which care for older persons at end of life affects the family caregiver's well-being must be discussed and evaluated further in future research. Which functions the Public Health Service and nursing care institutions should play in the future in encouraging family caregivers to speak out about their experiences need to be emphasised. The task of protecting older people and their family caregivers from experiencing negative nursing in nursing care homes, integrated around the German Federal State's health service law, needs further attention. They need to formally define what makes a family member a family caregiver, who these family caregivers are and what do they do, and what harm they might face. This study has answered these questions and emphasized the need for nurses to proactively approach family caregivers as hidden patients who need support in their own right, albeit in a limited study format. However, this study has indicated ways to assess the experiences of these hidden patients and identify evidence-based interventions to prevent or reduce negative experiences that are harmful to their quality of health, and concur with other studies in this more general area (Reinhard *et al.*, 2008).

German law recognises family caregivers and has already drawn up provisional laws to protect them. For example, The Care Leave Act of 2015 ('Pflegezeitgesetz') is Germany's most significant legislation to support family caregivers. The Act builds on the foundations of previous laws, while adding legal entitlement to financial provisions (Bundesgesetzblatt, 2011). It is also relevant and necessary to anchor laws protecting family caregivers in nursing homes into the nursing school curriculum. Currently, all persons nursing older people in nursing homes receive exclusively professional courses, cash benefits and good working conditions. However, as these benefits filter through the system, in time, more family caregivers are bound to experience such institutionalised care more positively, because the nurses will have improved job satisfaction and enough time to attend to their patients and family caregivers without being under undue work pressure (including pressure due to shortages of staff). These legal assignments "serve to ensure the quality of nursing care and the regular assistance and practical nursing support of in-family caregivers" (*ibid.*, cf. §37, para. 3, SGB XI). Their aim is to optimally support family caregivers, not only in the home care setting and thus stabilise it in the long-term, but also, frequent interactions with family caregivers should make it possible to prevent family caregivers having grievances and/or negative experiences with institutional nursing care or, if necessary, initiate interventions to remove such negative experiences.

So far, in Germany, the primary care assignments for older persons have mainly been carried out by family caregivers, often initially involving some employees of outpatient care services. In some cases, the scope of a family caregiver's assignments can vary greatly. Likewise, the care situation of the elderly within a nursing home varies, because a precise design determination still needs to be made to meet the nursing standard. In practice, family caregivers' needs are recognised to range from simple to more complex needs-based maintenance of their loved one, with expert discussion and involvement of care and support from the nurses, “with considerable potential for avoiding negative experiences” (Büscher *et al.*, 2010:103).

A proposed remedy could be the standardisation of nursing counselling interventions. However, to date, no consensus between cost-effective methods and service providers has arisen based on the recommendations according to §37 para. 5 SGB XI for quality assurance of the consultation visits (Büscher *et al.*, 2010). Standardisation is still pending, with no reliable nationwide statement made about it. As a result, there is no legal or set procedure to assess how often, as a result of the counselling assignment, the end of life nursing experience in the nursing home is noted as being negative.

However, there is some legislative action in this respect. A legislator has reacted to the issue of family caregivers and currently the Federal Government has drafted a second law strengthening family caregivers in all healthcare settings in Germany.

> “In order to promote the further development of counselling in accordance with Paragraph 37(3) to (8), to observe the effects of the new statutory regulations and to systematically evaluate and have scientifically processed those provided for in Paragraph 37(3) of the consultation assignments, a reporting obligation is now also introduced for consultation in the nursing home in accordance with Paragraph 37(3).In this context, providing information about what is happening is important. This refers in particular to determine whether and with what effects findings and prevention of negative experience from the family carers are actually implemented in practice by the nurses” (Deutscher Bundestag, 2015: 96).

Over a decade ago, an interdisciplinary team of experts from the Berlin Counselling and Complaints Centre for Care in Need and the Specialist Office for Caring Relatives developed a vital building block for improving counselling interviews. As a result, the guidelines developed for the use of counselling no longer focus solely on defined care aspects but also consider family relationships and their emotional dimension. Questions can be explicitly asked during counselling about the relationship between the quality of care provided by the family caregiver compared to that encountered from the practising nurses. For example, whether negative experiences have intensified since the beginning of care or if regrettable feelings have increased. If such questions are answered in the affirmative, relief possibilities such as discussion groups, self-help offers or improving nursing courses can be identified immediately during the consultation.

However, extensive use of these advisory guidelines has yet to take place. The reasons for this are manyfold, although financial aspects appear to play a pivotal role. For example, about 40-60 minutes are needed for a qualified consultation, and appropriate remuneration for the nursing expert would be necessary for this. However, the consulting assignments, according to §37 Abs. 3 SGB XI, are flat-rate remunerated at only 22 euros for Care Levels 1 and 2, and only 32 euros for Care Level 3. An increase in remuneration of one euro per session for each level is planned, although this amount does not cover any materials or personnel costs incurred. It might be suggested here that perhaps this level of remuneration should be reassessed and, potentially, increased to more accurately reflect the potential importance of such sessions.

In 2015, one of the demands of the German Bundestag was that municipalities should be more closely involved in advising people needing care and their family caregivers. These could act as "recognized counselling centres with proven nursing competence" (Deutscher Bundestag, 2015: 10). This is associated with the hope of ensuring meaningful consultations for people in need of care and caring relatives according to § 37 Abs. 3 SGB XI, being run independently by the municipalities. In this way, deficiencies or deficits in old people's nursing homes could be identified earlier, and family caregivers of such older people could be protected from experiencing negative end of life nursing care.

Finally, in the future, reported cases of negligence by nurses against family caregivers of the elderly and people in need of care could play a key role in reforming courses in Nursing Schools in Germany and elsewhere.

8.4 Final Conclusions: What This Thesis Adds

This study has proven that having a better understanding of family caregivers' experiences at the end of life of their loved ones in nursing homes is one way of improving the working relationship between such family caregivers and the associated nurses. Such better understanding would also improve the current negative nursing care image which has been embattled out of negligence, an image which has dominated the minds of most people in Germany.

Qualitative thematic evidence reveals that family caregivers who feel fully understood by nursing home nurses tend to experience nursing care more positively. This important fact gives hope, new meaning and help in bereavement, and can only be a good thing.

Most research on caring has concentrated on assessing the burden of caring for people with medical illnesses. As a result, the mental health aspect of family caregivers' experiences has received only limited attention, especially for those caring for older adults (Wynaden, 2007; McCann *et al.,* 2011). As such, this experience remains predominantly out of the public gaze and, therefore, undervalued (Wynaden *et al*., 2006). In light of the increasing expectation on families to take responsibility for their older members with mental illnesses or advanced dementia, it is vital to shed light on the experiences of family caregivers in this situation and understand what helps sustain them in this role.

The information gained from the present study may provide healthcare professionals with a greater understanding of the effects of caring on primary family caregivers and what helps to sustain them in this vital role at this critical time. This present study aimed to understand the experiences of family caregivers of older persons with severe and persistent diseases diagnosed as being end of life in a nursing home and to explore what, if any, negative experiences family caregivers experienced and what helped to sustain them in their caring role. A qualitative approach was used because the emphasis was on understanding these caregivers' subjective personal experiences, which are valuable in helping to shed light on how they develop the resilience to sustain their caring role, especially in under-researched areas and settings. Finally, a round table sitting is planned to be conducted in the future within each healthcare setting to work out a solution to prevent such incidents recurring with other patients in the future.

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APPENDICES

APPENDIX 1: LETTER INVITING CAREGIVERS TO ATTEND AN INTERVIEW: FAMILY CONSENT & INFORMATION LETTER

Personal address redacted

Town redacted, 15.06.2021

FAMILY CONSENT FORM

Dear Sir/Madam,

I am a doctoral student at Bremen University and I am undertaking a research study that focuses on family caregivers' experience of nursing care of the older loved ones at end of life in the nursing home. Within this research, family carers who have being caring for a dying older person (age of older person from 60 and above) from 2 months and above or an older person with chronic cases, and have met the criteria, are interviewed after signing consent form. The person must be 18 years old or above. This will help know more about how much family carers are integrated in the nursing care plan of their older person, palliative care of an older person, and the family carer's experience of nursing care in the nursing long time care. Care is still developing in Germany and more research is needed in this field to achieve international standards and, in so doing, make palliative care of an older person both for patient and family carer-centred. In this way, responses gotten from individual interviews will ascertain some nursing care activities that led to a good or negative experience for carers. In this way, it will help this research develop a working model that will help the healthcare system (in Bremen, Niedersachsen and elsewhere in Germany) to be conscious of family carers as also patients in their own forms that equally need care. The focus of this study: the stakeholders in palliative care of the elderly at end-of-life, the palliative nurses with the palliative teams to improve on shortcomings. The aim of end-of-life care of an older person is to achieve a dignified end and make decisions for family carers and all concerned bearable.

The time needed for this interview is approximately 1 hour or more depending on each participant for their individual needs. This will not be teacher-like, ideally conducted in a nursing home, but in this case the family carer's preferences are considered. You can choose what day and a time convenient for you. You have the right to discontinue with the interview at any stage. All information given at the interview is strictly confidential. Please would you decide whether you will be willing to participate in this study, kindly do let me know by signing and returning this letter along with the questionnaires, on or before the planned interview day.

The interview will be audio-recorded and depending on your wish there won't be any need for an external observer. During the study, audio-cassette, writing materials, papers and of course a quiet environment will be useful on the interview day.

You will have the right to withdraw at any time should you wish to do so.

Kindly fill in the answers to the questionnaires and sign this consent letter, as below. I look forward to hearing from you.

Yours sincerely,
Meierdierks Clara Chinyere.

We/I the family carer of (full name/s), hereby consent to be observed for the purpose of the research project detailed above.

APPENDIX 2: INFORMATION SHEET

To the survey “family caregivers experience”. Information sheet for family caregivers.

Study on family caregiver: the author looks for a conversation participant who is caring for a family member at end of life in a nursing home. The study investigates how family caregivers of older people experience nursing at end of life in the nursing home, focusing on Bremen and Niedersachsen. The nurses should recognise the problem early enough and in good time. In so doing, it helps improve the family caregiver’s experience. More information under [redacted].com

How did this Study Come About?

The question aims to inform insurance companies, nursing homes and those who provide care for older people through palliative/end of life care in nursing homes. There are published reports from various encounters with family caregivers, especially those caring for older people in nursing homes, about how they experience nursing care at this critical stage of life. These experiences have influenced them in so many ways. Nevertheless, nursing experiences of family caregivers of older people are not very well documented and, as such, this study targets family caregivers’ own perspectives of nursing care in a nursing home. Investigation into the selected family caregivers’ experiences will provide a better understanding of these experience and lead to better policies and nursing practices that will dignify both them and their older people.

Why the study?

The number of older people in our society is growing in number on a daily basis. This has led to an increase in the amount of family caregivers and professionals, both at home and in care settings. Most of these older people are taken care of first by the family and eventually within the nursing home.

Nursing homes are very popular in the Western world and are seen as a last stop for many older people, as many are admitted in their last stages of life with acute or chronic cases. However, the need for long-term care of these older people poses particular challenges for everyone involved, especially the family caregivers, whose caregiving has been reported by some authors as sometimes leading to problems and burdens. This can also be problematic for family caregivers when dealing with others, for example, with professional nurses.

It would be helpful in nursing today to learn how family caregivers experience nursing care at the end of life of their loved ones in a nursing home and how this may affect future nursing care. This is especially important where situations may not go the way family caregivers would like them to go.

This study aims to find out how the nursing care situation of older persons at end of life in a nursing home affects the everyday lives of family caregivers and how their experience of unmet needs and possible conflict situations are addressed. It also aims to make a contribution to improving awareness in the stakeholders/nursing homes and those involved in providing professional care within nursing homes, by documenting family caregivers' experiences and assessing them. Through these actions, family caregivers might be helped to effect a more positive experience from their loved ones' time of palliative/end of life care in nursing homes.

Who do we want to reach?

This study is interested in the perspective of everyone who sees himself/herself directly involved in the care situation of an older person in palliative or end of life care in a nursing home Therefore, this study aims to conduct an interview with the caring relatives themselves.

How will this happen?

The interview is planned to last about an hour, in an informal setting, so it shouldn't take too long. However, it might last longer depending on the needs of the person being interviewed, who might possibly report a larger number of experiences. Of course, your answers will be treated with the strictest confidentiality, will be anonymised, and your data confidentially held in a secure location.

Thank you for your cooperation!

Particularly in a society where more and more elderly people live, the questions and issues related to care at the end of life and the place of death affect us all. By participating in this study, I can go a long way to incorporating the experiences of family caregivers and those in need of care directly into the further development of ways of assisting future family caregivers.

I would like to thank you all in advance for this opportunity!

I will be happy to answer any questions you may have.

APPENDIX 3: AGREEMENT TO PARTICIPATE IN THE STUDY

I am a family caregiver myself and willing to take part in an interview.

I agree that my information may be used for the purpose of this study.

Name --

Contact telephone number:

APPENDIX 4: TOOLS FOR CONDUCTING PROBLEM-CENTRED INTERVIEWS

Short Questionnaire
Guide
Sound recording
Postscript

The guidelines were written down on paper, although most of the individual questions were flexible in the interview. The guideline structure was topic-centred and follows the principle of 'from general to specific'. It began with a deliberately open chat, followed by specific questions. Topics were jotted on paper as a guideline and checked frequently to make sure that concerns of the study contained in the guide had already been addressed.

The interview situation was based on individual needs. The interviewed person was not given the impression of anyone being in a hurry. In most cases they were allowed enough time, more than the originally planned time. If areas had already been discussed in detail by the respondent, they no longer need to be inquired about. If aspects arose that were not previously considered in the guideline, it was possible to expand the range of topics and increase the amount of time (Przyborski & Wohlrab-Sahr, 2014).

Mainly open-ended questions were asked, along with a few closed questions. However, questions were kept short and clear. Emotional moments were respected, but sometimes the respondent went on to bring out detailed narratives that reveal difficult and sensitive experiences. Kind words and extra time was considered and provided when necessary.

APPENDIX 5: INTERVIEW QUESTIONS FOR THE RESEARCH STUDY
(THE STUDY GUIDE AND QUESTIONNAIRE)

Initial General Questions:

1. Full name
2. Address
3. Sex & Age
4. Marital Status
5. Number of Children
6. Profession
7. Relationship to the Person in Need of Care
8. How long have you being taking care of your loved one?
9. How old is the person in need of care, diagnosis and what was her complaint?
10. Whom did you first approach for her complaint?
11. Who is the General Practitioner?
12. What was done to reduce pain?
13. What was the line of treatment before now?
14. Where has the person in need of care been before now?
15. How were you informed about their condition and change of treatment?
16. Were you satisfied with the way things were communicated to you?
    (a) from the nurses/palliative team? (b) from the doctors?
17. How do you rate communication and readiness from the nurses and doctors?
18. In what areas were you not very satisfied?
19. What role did the nursing home play to affect your experience?
20. Any advance testament?

Questionnaire

ORIGINAL QUESTIONNAIRE, IN GERMAN, AS USED

GERMAN ÜBERSETZUNG

1 Ihr Geschlecht?

A Female
B Male

2 In welchem Jahr und in welchem Monat sind sie geboren?
Jahr 19--------------Monat-----------

3 Welchen Familienstand haben Sie?
A Verheiratet
B Ledig
C Verwitwet
D Geschieden oder getrennt lebend
E Mit einer/m Partner in zusammenlebend

4 Haben sie Kinder?
A Nein
B Ja, ich habe-----Kinder (bitte Anzahl angeben)

5 In welchem Bundesland leben sie jetzt?---------------(bitte Bundesland angeben)

6 Wo leben sie jetzt? Bitte kreuzen Sie nur die Möglichkeiten, die am besten auf Sie zutrifft
A In Großstadt/ unmittelbar in der Nähe einer Großstadt
B In einer Kleinstadt/ in einer mittelgroßen Stadt
C in einem Dorf auf dem Land

7 Haben Sie die Deutsche Stadt Angehörigkeit?
A Ja
B Nein --Welche Staatangehörigkeit haben Sie?-------------(bitte angeben)

8 Sind sie in Deutschland geboren?
A Ja
B Nein, sondern in---------------------- bitte Ihr Geburtsland angeben)

9 Wie viele Personen leben in derzeit in Ihrem Haushalt?
A Ich lebe alleine
B In meinem Haushalt leben außer mir ----------Personen (bitte Anzahl angeben)

10 Mit wem Leben sie in der Zeit in Ihrem Haushalt zusammen? bitte kreuzen sie in der folgenden Tabelle an, mit wem Sie in Ihrem Haushalt zusammenleben und tragen sie jeweils das Geburtsjahr der entsprechenden Person ein .

In welchem Jahr ist das HH-Mitglied geboren

(Ehe) Partner	
Kind1	
Kind 2	
Kind 3	
Kind 4	
Kind 5	
Vater	
Mutter	
Enkelkind	
Bruder	
Schwester	
Schwiegermutter	
Andere Person, nämlich-----	
Andere Person, nämlich-----	
Tante	
Onkel	

11 Welchen höchsten allgemein bildenden Schulabschluss haben Sie?
A Hauptschule/Volksschule/Polytec. Oberschule mit Abschluss 8. Oder 9. KL
B Realschule/Polytechnische Oberschule mit Abschluss 10. Klasse
C Abitur/ Erweiterte Oberschule mit Abschluss 12 Klasse/ Fachabitur
D Einen anderen Schulabschluss, nämlich------------------------(bitte angeben)
E keinen Schulabschluss

12 Welche berufliche Ausbildung haben sie? (bitte kreuzen Sie alle zutreffende an).
A Ich habe eine abgeschlossene Berufsausbildung nämlich----------------------(bitte angeben)
B Ich habe eine Fachhochschulabschluss, nämlich------------------------------(bitte ankreuzen)
C Ich habe einen Universitätsabschluss, nämlich---------------------------------(bitte angeben)

13 Welche der folgenden Aussagen trifft derzeit auf Sie zu? (bitte kreuzen Sie alle zutreffende an

A Ich bin ganztägig berufstätig
B Ich bin halbtags, Teilzeit-oder geringfügig beschäftigt
C Ich bin in Rente / Pensionierte / Vorruhestand
D Ich bin arbeitslos
E Ich bin Hausfrau/ Hausmann
F Auf mich trifft was anders zu. Ich bin …………………………(bitte angeben)

14 Was ist zurzeit Ihre beruflich Position? Bitte kreuzen Sie alles zutreffende an

A Selbständiger/ Selbstständiger
B Angestellte/ Angestellter
C Beamtin/ Beamter
D Arbeiterin/ Arbeiter
E Sonstiges, nämlich-- bitte angeben)

15 In welchem familiären Verhältnis stehen Sie zu dieser Person? Ich bin die/der…….

A Ehepartner/ in, Partner/ in
B Tochter/ Sohn
C Schwester/ Bruder
D Schwiegertochter/ Schwiegersohn
E Enkel/ in
F Neffe/ Nichte
G Sonstiges, nämlich--(bitte angeben)

16 Geschlecht Ihre / Älter pflegebedürftigen Angehörigen?

A Weiblich
B Männlich

17 In welchem Jahr und Monat ist Ihr/e Angehörige/r geboren?

Jahr 19---------- Monat

18 Welchen Familienstand hat ihr/e Angehörige/ r?

A verheiratet
B ledig
C verwitwet
D geschieden/ getrennt
E mit einer /m Partner / in zusammenlebend

19 Aus welchem Land stammt Ihr/e Angehörige/r?

A aus Deutschland
B aus einem anderen Land, nämlich --------------------------- (bitte angeben)

20 Wo wohnen Sie und Ihr/e Angehörige/r

A in einem gemeinsamen Haushalt
B in verschiedenen Haushalten, aber im selben Gebäude
C in verschieden Gebäude, aber zu Fuß erreichbar
D Mit PKW Innerhalb von ------------Minuten erreichbar?, Bus /Bahn

21 Wie lange haben Sie ihr/e Angehörige zu Hause gepflegt?
A
B
C

22 Seit wann ist Ihr/e Angehörige Pflegebedürftig?
A
B

23 Warum war sie in Krankenhaus angewiesen?
A
B
C

24 Wer hat die Entscheidung getroffen?
A
B

25 Waren sie mit einbezogen?
A Ja
B Nein
Wenn Nein, wie haben sie es erfährt dass Ihr/e Angehörige/r in KH kommt?

Bitte angeben

26 Wie zufrieden oder unzufrieden ist nach Ihrem Eindruck Ihr/e Angehörige/ r alles allem mit die Kommunikation und Verlegung Ihr/e Angehörige/r in Krankenhaus?
Bitte angeben----.

27 In welchem Pflegestufe ist/ Ihr/e Angehörige derzeit?
A Pflegestufe 1
B Pflegestufe 2
C Pflegestufe 3
D Pflegestufe 5

28 Welche Form von Leistungen erhält ihr/e angehörige/r aus der Pflegeversicherung?
A Pflegegeld
B Pflegeeinsätze
C Teils Pflegeeinsätze im Haushalt, teils Pflegegeld („ Kombinationsleistung“)

29 Seit wann ist Ihr/e Angehörige/r auf palliative Station?

30 Was war der Grund / was wären der Grunde für die Transition?

31 Wer hat die Entscheidung getroffen?
A Der Arzt/Ärzte
B die Ärzte in ihr Beisein

32 Wie zufrieden sind sie mit der Entscheidung?

33 Hat Ihr/e Angehörige Testament vorher geschrieben

A Ja
B Nein
C Wenn Ja! Wie haben sie die Entscheidung getroffen das ihr/e Angehörige zum Palliative Unit kommt?

34 Sind sie zufrieden/ unzufrieden mit alles?

A Pflegerisch Verhaltes, Kommunikation und sonstiges?
Wenn unzufrieden was wären der Grunde?
A Pflegerisch Mängel?
B respektlos verhalten gegenüber ihre Angehörigen?
C Kommunikation Problem?
D bei Abrechnung?
E Etwas anderes, nämlich--------

35 Bitte lesen Sie nun die folgenden Aussagen. Wie oft kommen solche Gedanken und Gefühle bei Ihnen vor?

Ich habe das Gefühl das ich durch die Pflege mehr Unterstützung habe	1 2 3 4
Die Situation meiner Pflegebedürftige belastet mich sehr	
Ich fühle mich sehr emotional erschöpft	
Ich fühle mich durch die Pflege sehr frustriet	
Ich glaube mein/e Angehörige ist nicht von der Pflege gut behandelt	
Ich bekomme weniger Information von der Pflege.	
Ich weiss nicht mehr weiter	
Ich fühle mich durch der Situation hilflos	
Ich bekomme wenig Unterstützung von meiner Familie	
Mein Job Leidet darunter	
Ich habe Ängste	
Ich wird von der Pflege nicht erkannt	
Ich muss mit Behörden und Institutionen kämpfen für die dinge die meine angehörige benötigen	
Ich habe keine Möglichkeit an Geld Unterstützung zu bekommen	
Wie ist deine Beziehung zu der Pflege?	

36 In welchen folgen Bereich erhalten Sie Hilfe von Ihrer Angehörige/r

37 Wenn sie an die Pflege denke, wie würden die die Pflege in Hospital palliative ihre angehörige/r bewerten

A sehr gut
B gut
C Mittel
D Schlecht
E Sehr schlecht

38 Wie sind sie mit bestimmten Situation umgegangen?ie zufrieden / unzufrieden sind

39 Wie zufrieden / oder unzufrieden sind sie

40 Hatten einmal Grund sich über eine/ pflege zu Beschwerden?

A ja, einmal
B ja, mehrmals,
c Nein, noch nie

41 Wenn Ja was war der Grund für Ihre Beschwerde?

42 Haben Sie mit jemand darüber geredet?,
a Ja
b Nein

43 Würden sie Ihr/e Angehörigen weiter da lasen

44 Was verstehen Sie unter Palliative?. Würden Sie genug aufgeklärt?

45 Sind Sie in allgemein mit allen zufrieden?.
A Von der Pflege und die Behandlung Veränderung Plan
B Lebens erhaltende Maßnahme wie PEG, Tracheotomie,

46 Warum haben sie entschieden Ihr/e Angehörige/r zu Pflegen?(bitte kreuzen zutreffende an).
A Weil ich mich dazu verpflichtet fühle .
B Weil sie vorher viel für mich getan hat.
C Weil ich sie/ihn liebe.
D weil das für mich selbstverständlich ist.
E da, ich nicht möchte das sie in einem Heim gehe.
F weil mir die Pflege meiner Angehörige ein gutes Gefühl gibt .
G Heimplatz zu teuer ist.
H weil sie/er das gleiche für mich tun würde.
I weil sie/er das so Will.
J Weil Ich ihr/Ihm das versprochen habe .
K Andere Gründe, nämlich---(bitte angeben)
(welche ist die wichtigste gründen, ihrer /m Angehörige/r vorher zu Hause zu Pflegen?)

47 hier geht es um Ihre Einschätzung von sich selbst und Ihrem Privatleben(bitte kurze Antwort mit „ Ja“ oder „ Nein“ .

A Fühlen sie sich manchmal hilflos?
B Wenn sie den Wahl hatten, wollen sie ihr/r angehörige/r mit nach Hause nehmen?.
C Fühlen sie sich missverstanden von der Pflegefachkräfte?.
D Was bedrückt Ihnen am meisten?.
E Gibt noch was anders was Ihn/ Ihnen bedrückt?.

48 Was kann in der Pflege verändert werden?
A Kommunikation
B Pflege Ihr/e Angehörige/r
C zuhören und
D sonstiges, nämlich----------------------

49 Macht Ihnen/Ihn was aus was mit ihrem/ihnen Angehörige passiert ist?

50 Welche Empfehlung/en geben sie der Institution über der Pflege sehr kranke Menschen weiter?

ENGLISH TRANSLATION

1 Your gender?
- A Female
- B Male

2 In which year and month were you born?

Year 19-------------Month----------

3 What is your marital status?
- A Married
- B Single
- C Widowed
- D Divorced or separated
- E Living with a partner

4 Do you have children?
- A No
- B Yes, I have-----children (please specify number)

5 In which federal state do you live now?--------------(please specify federal state)

6 Where do you live now? Please tick only the options that best apply to you

- A In a large city/ in the immediate vicinity of a large city
- B In a small town/ in a medium-sized city
- C In a village in the countryside

7 Do you have the German city affiliation?
- A Yes
- B No --Which nationality do you have? ------------(please specify)

8 Were you born in Germany?
- A Yes
- B No, but in--------------------- please specify your country of birth)

9 How many people live in your household at present?
- A I live alone
- B In my household live besides me ----------Persons (please specify number)

10 With whom do you live in your household at the moment? please mark in the following table with whom you live in your household and fill in the year of birth of the respective person .

In which year was the HH member born?

Marriage Partner	
Child 1	
Child 2	
Child 3	
Child 4	
Child 5	
Father	
Mother	
Grandchild	
Brother	
Sister	
Mother-in-law	
Other person, namely -----	
Other person, namely -----	
Aunt	
Uncle	

11 What is your highest general education degree?
A Hauptschule/elementary school/Polytec. Oberschule with graduation 8th or 9th KL
B Realschule/Polytechnische Oberschule with 10th grade degree
C High school diploma/ extended high school with completion of 12th grade/ specialized high school diploma
D another school-leaving qualification, namely-----------------------(please specify)
E no school-leaving qualification

12 What vocational training do you have? (please tick all that apply).
A I have completed vocational training, namely----------------------(please specify)
B I have a technical college degree, namely-----------------(please tick all that apply)
C I have a university degree, namely--------------------------------(please indicate)

13 Which of the following statements currently apply to you? (please tick all that apply)
A I am employed full-time
B I am employed on a part-time, part-time or marginal basis
C I am retired/retired/early retired
D I am unemployed
E I am a housewife/househusband
F Something else applies to me. I am ....(please specify)

14 What is your current professional position? Please tick all that apply to you
A Self-employed/independent
B Salaried employee
C Civil servant
D Worker
E Other, namely--- please specify)

15 What is your family relationship to this person? I am the.......
A Spouse, partner
B daughter/ son
C sister/ brother
D Daughter-in-law/ son-in-law
E Grandson/granddaughter
F Nephew/ niece
G Other, namely---(please specify)

16 Gender of your / elder relative in need of care?
A Female
B Male

17 In which year and month was your relative born?
Year 19---------- Month

18 What is the marital status of your relative?
A married
B single
C widowed
D divorced/ separated
E living with a partner

19 From which country is your relative?
A from Germany
B from another country, namely --------------------------- (please specify)

20 Where do you and your dependant live?
A in a common household
B in different households, but in the same building
C in different buildings, but within walking distance
D Within ------------ minutes by car?, bus /train

21 How long did you care for your relative(s) at home?
A
B
C

22 How long has your relative been in need of care?
A
B

23 Why was she hospitalized?
A
B
C

24 Who made the decision?
A
B

25 Were they involved?
A Yes
B No
If No, how did you find out that your relative was going to be hospitalized?

Please specify

26 How satisfied or dissatisfied do you think your relative is with the communication and transfer of your relative to the hospital?
Please specify----.

27 In which care level is/is your relative currently?
A Care level 1
B Care level 2
C Care level 3
D Care level 5

28 What type of benefits does your relative receive from long-term care insurance?
A Care allowance
B Care assignments
C Partly care work in the home, partly care allowance ("combination benefit")

29 How long has your relative been in a palliative care unit?

30 What was the reason / what would be the reason for the transition?

31 Who made the decision?
A The doctor/doctors
B the doctors in their presence

32 How satisfied are they with the decision?

33 Did your relative(s) write a will beforehand
A Yes
B No
C If yes! How did you make the decision to have your loved one come to the Palliative Unit?

34 Are you satisfied/ dissatisfied with everything?

A Nursing behaviour, communication and other?

If dissatisfied what would be the reason?
A Nursing deficiencies?
B disrespectful behaviour towards your relatives?
C Communication problem?
D in billing?
E Something else, namely--------

35 Now please read the following statements. How often do such thoughts and feelings occur to you?

	1 2 3 4
I have the feeling that I have more support through care	
The situation of my care recipient burdens me very much	
I feel very emotionally exhausted	
I feel very frustrated by the care	
I think my relative is not treated well by the caregiver	
I get less information from the care	
I do not know what to do	
I feel helpless by the situation	
My job suffers	
I have fears	
I am not recognised by the care	
I have to fight with authorities and institutions for the things my loved one needs	
I have no possibility to get financial support	
What is your relationship with care?	

36 In which following area do you get help from your relative?

37 When you think about the care, how would you rate the care in hospital palliative your relative?

A very good
B good
C average
D Poor
E Very bad

38 How did they deal with certain situation? i.e., satisfied / dissatisfied

39 How satisfied / or dissatisfied are you?

40 Once had reason to complain about a/ care?

A yes, once
B yes, several times,
C no, never

41 If yes what was the reason for your complaint?

42 Have you talked to anyone about this?
a Yes
b No

43 Would you continue to let your relative(s) stay?

44 What do you understand by palliative care? Have you been given enough information?

45 Are you generally satisfied with all
A Of the care and treatment change plan
B Life sustaining measure such as PEG, tracheotomy,

46 Why did you decide to care for your relative(s)?(please tick as appropriate).
A Because I feel obliged to do so.
B Because she/he has done a lot for me before.
C Because I love her/him.
D because it is natural for me.
E because I do not want her to go to a home.
F because caring for my loved one makes me feel good.
G because a place in a home is too expensive.
H because she/he would do the same for me.
I because she/he wants it that way.
J Because I promised her/him that .
K Other reasons, namely---(please specify).
(which is the most important reason for caring for your relative at home beforehand?)

47 this is about your evaluation of yourself and your private life(please short answer with "yes" or "no".

A Do you sometimes feel helpless?
B If they had the choice, do they want to take their loved one home with them?
C Do you feel misunderstood by the nursing staff?
D What bothers you the most?
E Is there anything else that bothers you?

48 What can be changed in the care?

A Communication
B caring for your loved one
C listening and
D other, namely----------------------

49 Do you care about what happened to your relative?

50 What recommendation/s do you give to the institution about the care of very ill people?

Thank you very much for taking the time to complete the questionnaire, I really appreciate your support in gathering the information that is important for this study. If there are any other things you would like to tell me, please use this page,

Please send your completed questionnaire to the above address or you send me a WhatsApp message to know when to pick it up from you or you can post it to me in the enclosed stamped addressed envelope.

APPENDIX 6: SOCIAL HISTORY DATASHEET

Social data sheet for the family caregiver.

Interview Code:

About the respondent(s):

Gender female/male

How old are you?

Your Nationality

Mother tongue

Marital status

Do you belong to a church/faith community? Yes/No.

If so, which one?

What (highest) school-leaving certificate do you have?

Have you learned a profession? Yes/no

If so, which profession(s)?

When was the last time you were working? (year/month if possible)

What kind of activity was/is it?

Scope of professional activity (if applicable: hours/week):

What is your marital status? (Are you married, single, divorced or widowed?)

How many people are living in your house?

Do you have children? Yes/No?

If yes, how many children?

How old are they?

CARING PERSON AND PERSON IN NEED OF CARE

Type of (kinship) relationship (FP is from PB):

Are you the main caregiver? yes /no/unclear

Start of care by interviewee (month/year):

Were you living with the person in need of care before transfer?

THE PERSON IN NEED OF CARE.

Gender? female / male

Age?

In need of care since when? (M/ J).

Deceased since? (M /J)

Last profession of your elderly in care?

Diagnosis since when?

Current level of care?

- No care
- Care Level I
- Care Level II
- Care Level III
- Care Level IV
- Care Level V with hardship
- I don't know.

Type of services selected SGB X1.

Cash benefit, benefit in kind?

Combined benefit?

APPENDIX 7: INTERVIEW GUIDE

Interview Guide for the family caregivers. All printed questions are so-called ‘guiding questions’, which were either to be asked directly in each interview or at least should be worked through in terms of content.

Q1: What does a normal daily routine look like for them at the moment?

When does your day start and when does it end?
What about your usual routine?
Are there any differences between the time your loved one was at home and in the old people’s home?
Do you know at the beginning of a day what to expect?
Are there any terms that are very important to you?

Q2: How did it come about that you care for your loved one? (mother/father/husband/wife/uncle/aunt/grandmother etc.)

To what extent were you able to prepare yourself for taking over the care?
What prompted them to do this? To take care of it?

Q3: How is your (x)at the moment?

How is he/she doing physically?
What is his/her mental state?
What is his/her mood like? How does he/she feel? How does he/she cope with his/her situation?
What can he/she do on his/her own? Where does he/she need help?

Q4: What help and care do you receive €(x)?

How does other than you participate in the care?

Is there support from an outpatient service or other helpers outside of when you were at home, in the private and family area? What does this support look like?

How many hours per day are you available for the care of his/her (x)?

How is the cooperation between her/her(x) and you in the care?

Are there any behaviours of his/her(s) that cause you problems?

If necessary: what are they?

To what extent has it already happened that you assert yourself in the care for your (x)?

Have you ever been afraid that your (x) would not be well cared for in the old people’s home?

How often have you had confrontation with care? If yes, why?

Have the professional caregivers in the old people's home always met the wishes and needs of your relatives, or are there situations in which this is not as you would have liked it to be (in relation to the care of your relatives)?

If so, can you describe such an incident to me?

Q5: What has changed in your life since your (x) came to the old people's home?

What has changed in your life, family or partnership?

How have your other relationships developed, e.g. with friends, neighbours and acquaintances?

How has your living situation changed?

How has the care affected your leisure activities?

What changes have occurred in terms of their professional and financial situation? How would you describe your current economic situation?

Q6. How are you doing today?

How would you describe your general state of health?

When you think about your current life situation?

What is difficult for you?

What's bothering you?

If burdens in connection with care in the old people’s home should not be discussed, what do you find very difficult in caring for your relatives in the old people's home? What burdens you there?

Q7: Who supports you in your situation?

(if applicable) what kind of support do you get from (y-1)?

Who else supports you? [+if necessary again?: what kind of support do you still get? (y-2)?.

[if only practical and/or informational support is mentioned] to what extent are you supported by contacts and conversations with other people?

[if the question of support is initially summarily denied ("by no one", "I do everything on my own"):

Support can mean many things. This includes practical help as well as tips and information, but also contacts and conversations. What kind of support do you get in this broader sense?

What are your experiences with the long-term care insurance funds? Care in an old people's home? Have you used counselling services or courses offered for family caregivers so far? (if not : why not so far?) What support do you miss? Who would you like to see more support from?

Overall, how satisfied or dissatisfied are you with the support you are currently receiving?

All in all, what about your social contacts? How with those of your/your(x)?

Q8: How would you describe the relationship with his/her [x]? How do you treat each other? How do they get along with each other?

How much do you feel connected to him/her through the care?
How much influence do you have, and how much influence does your [x] have in your dealings with each other?
To what extent in which areas does your[x] (still) hit. Even apologies?
What decisions do you make for your [x]? How else do decisions come about? What do you get back from your x?

Q9: What was the relationship with your[x] like before you took over the care?

What problems may have occurred?

Q10: What has changed in the relationship with your [x] since you took care of him/her?

Why don't you compare it with the time before the care?
To what extent has your role as a relative etc changed compared to your [x]? To what extent has your role towards you changed?

Q11: Whenever people have close contact with each other on a regular basis, there are also situations in which one is angry with the other.

What about you and your [x], what do such situations look like for you?

Q12: Even for people who are cared for at home by their loved ones, it can happen that they are sometimes not treated well. Can you imagine what something like this looks like and how it can happen?

INTRODUCTION TO QUESTION BLOCK 13-21

I would now like to ask you a few questions about your experience, which can occur everywhere and of course also in nursing home care between people. We ask these questions to everyone with whom we have such a conversation. If what I am describing to you has never occurred to you, please tell me, and then we will move on to the next question.

Q13: Have you ever experienced that your [person in need of care] has been roughly touched by the nurse, physically injured, inflicted pain on her relative?

On the other hand: can you describe such an incident to me?

Q14: To what extent has it ever happened that your [x] has become loud or abusive towards you, shouted at or insulted you, or something similar?

If so: can you describe such an incident to me?

Q15: And what about the other way around? Has it ever happened that you have roughly touched your [x] or have physically injured him/her in any other way or inflicted pain on him/her?

If necessary, can you describe such an incident to me?

Q16: To what extent has it ever happened that you have become loud towards your [x], abused or insulted him/her, or something similar?

If necessary: Can you describe such an event to me?

Q17: What about other people? Think of family members, neighbours, acquaintances or, for example, employees of an outpatient service: To what extent have you ever experienced that someone has touched your [x] roughly or physically injured her/him in any other way or has inflicted pain on her/him? I mean the time since your [x] care is in need.

If necessary, can you describe such an incident to me?

Q18: To what extent have you already experienced someone else being loud towards your [x], insulting or abusing him/her or something similar?

If necessary, can you describe such an incident to me?

Q19: To what extent has it happened that someone has stolen something from your [x] or has otherwise taken possession of his/her possessions since he/she became in need of care? Something like this can also happen, for example, by deliberately drafting a contract or a document to the detriment of a person.

If necessary: can you describe such an incident to me?

Q20: From your point of view, are there things that would be important in relation to your experience in caring that we have not talked about so far?

Q21: If you were in the same situation today to decide for or against taking care of your [x], what would you do?

APPENDIX 8: SUMMARY RATINGS SCALE

1: How do you assess your current state of health?

1	2	3	4	5
Very good				Very bad

2: If you think about your life in general, how would you evaluate your current situation?

1	2	3	4	5
Very good				Very bad

3: How would you rate your personal well-being in the last 2 weeks?

1	2	3	4	5
Very good				Very bad

4: Overall, how do you assess the help for people in need of care and their families?

1	2	3	4	5
Very good				Very bad

5: How much support, help and encouragement do you receive in total?

1	2	3	4	5
Very little help				So much help

6: How stressful was the conversation for you?

1	2	3	4	5
Not at all				very stressful

APPENDIX 9: INTERVIEW PROTOCOL (POSTSCRIPT)

Interviewer:

Date of the interview:

Start: End:

Social data sheet available? Yes / No

If applicable: why not an SD sheet?

Tape recording available? Yes No

If applicable: why no recording?

Place of conversation (also: type of room)?

Were there any external disruptions to the course of the conversation? Yes No

Was the person in need of care still in a nursing home as at the time of the Interview or deceased? Yes/ no, and if deceased, when?

If necessary, give a little explanations about the person in need of care/nursing.

Single or group interview, if group interview how long? Start: end

If necessary: explanations for information (from the interviewee) after the end of the tape recording?

What central content/leitmotif themes are presented?

“Aha“ experiences” of the interviewer during the course of the conversation, thematic abnormalities / interpretation ideas? Otherwise: abnormalities / special features / impressions / problems?

Assessment of essential conversation characteristics
(mark the appropriate value in each case)

-3 -2 -1 0 1 2 3
Very reserved very open

Perceived quality of contact with the interviewee

-3 -2 -1 0 1 2 3
Very bad very good

The concreteness of the information from the interviewee

-3 -2 -1 0 1 2 3
Very vague very concrete

The reliability of the information collected

-3 -2 -1 0 1 2 3
not reliable at all very reliable

Perceived stress of the interviewee throughout the conversation

-3 -2 -1 0 1 2 3
Not at all stressed Very stressed

Initial contact between researcher and family caregiver was initiated by:

The researcher
Some community members from the church
Other person directly from colleagues
Other, namely......were helpful.