

**The meaning of formal palliative care family meetings and their
consequences for people receiving specialist palliative care in two Slovene
hospitals: a phenomenological hermeneutic study**

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

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Abstract

Background: There is an increased need for palliative care in Slovenia. In a society with persistent problems in healthcare communication, palliative care family meetings – where patients’ voices can be heard – are rarely organised occasions. The evidence on patients’ experiences of these meetings is extremely scarce in the Slovene literature.

Aim: The aim of this study is to illuminate the meaning of the palliative care family meeting for patients receiving specialist palliative care.

Methods: A hermeneutic phenomenological approach was used to elicit the meaning of the palliative care family meeting for patients. Semi-structured interviews were conducted with palliative care patients who participated at the family meetings in two Slovene hospitals. Purposeful sampling was used to recruit six participants. Data were analysed with the use of the crafting of stories as suggested by Crowther et al. (2017) and thematic structural analysis as recommended by Lindseth and Norberg (2004). In the interpretation of the data, Crowther’s and Thomson’s (2020) outline of interpretation was used.

Results: In the interpretation of participants’ stories four themes emerged. The first theme, ‘unhomelike being-in-the-world’, reveals the constant changes of the palliative care patients’ bodies, moods and social roles due to the developing disease. The second theme, ‘being-toward-death’, uncovers the dying of the patients’ well known way of life and the need for constant adaptations. The third theme, ‘being-with others’, reveals a constitutive role that the others are playing in palliative care patients’ lives. The fourth theme, ‘the meaning of palliative care family meeting’, uncovers the family meeting as a tool to address the existential needs of palliative care patients.

Conclusion: This hermeneutic phenomenological study contributes to a deeper understanding of the meaning of the palliative care family meeting for patients receiving specialist palliative care in Slovenia. It provides insights that can inform improvements in the practice of the palliative care family meeting.

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Chapter 1. Introduction and background

1.1 Introduction

Patients are rarely included in the decision-making regarding their care within the Slovene healthcare system. Palliative care family meetings are one of the rare occasions for their voice to be heard by healthcare professionals and relatives. Our knowledge of the experiences that Slovene palliative care patients have with family meetings is scarce, indeed almost non-existent, and neither do we know what is the meaning that these meetings have for them.

As a nurse practicing on surgical wards and later as a nursing coordinator in palliative care service, I had the opportunity to observe and experience various modes of communication between patients, their relatives, and healthcare professionals. I have witnessed how participants were reassured and empowered at the family meeting, but also how palliative care patients strived for recognition and understanding and how they were sometimes left defeated in the process. My clinical experiences contributed to my desire to better understand palliative care patients' experiences of the family meetings.

My aim is to illuminate the meaning of the family meetings for palliative care patients through a hermeneutic phenomenological study of their experiences. I hope that the findings of this study could stimulate further research, inform changes at the healthcare policy and education level, and inspire improvements in the clinical practice of palliative care.

This chapter presents the concept of palliative care, communication as one of its foundations, and the family meeting as a form of communication in palliative care. Human experiences are influenced by their contexts; therefore, this chapter outlines the context of the Slovene healthcare system, the communication culture within it and the organisation of palliative care. The chapter outlines the gap in Slovene research and the literature regarding the palliative care family meeting.

1.2 Background and context

1.2.1 Palliative care

In its Global Atlas of Palliative Care, the Worldwide Hospice Palliative Care Alliance states that there is an immense burden of severe illness and health-related suffering in the world and consequently an increased need for palliative care (Knaul et al., 2020). During the second part of the twentieth century, palliative care was developed as an attempt to humanise care for patients at the end of life. In this sense, von Gunten and Romer provide a simple and succinct definition of palliative care as “interdisciplinary care that focuses on the relief of suffering and improving quality of life” (von Gunten & Romer, 2000, p. 115), which explains its most essential goal. The World Health Organization expands this definition to explain for whom palliative care is intended and how it should be provided:

“Palliative care is an approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual” (World Health Organization, 2021).

Patients do not suffer in isolation but in the networks of their families and witnessed by healthcare professionals (Ragan et al., 2008, Stevens, 2018). In such circumstances, communication is particularly important.

1.2.2 Communication in palliative care

Communication in palliative care takes place between different participants, namely: between patient and healthcare professionals; between patient and their family members; between healthcare professionals and the patient’s family; between different healthcare professionals; and between different healthcare services. It is one of the essential prerequisites for quality palliative care (Ragan et al., 2008; Radbruch & Payne, 2009).

“Communication is a cornerstone of palliative care...” (Dahlin & Wittenbers, 2015, p. 81). It enables a good assessment of problems and needs which is essential for the treatment of symptoms and relieving of suffering (Dahlin & Wittenberg, 2015). Effective communication provides a way for people to relate and build relationships which give them a sense of security and provide supportive networks, especially valuable at the time of illness, dying or bereavement (Duke & Bailey, 2008).

Communication is often defined as a linear process where the sender transmits a message to a receiver. Since this one-way model of communication insufficiently depicts the complexity of healthcare communication, a different and more influential definition of communication in healthcare was developed that explains “effective communication as a two-way process in which patients are informed about the nature of their illness and treatment and are encouraged to express their anxieties and emotions” (Duke & Bailey, 2008, p. 123). However, traditional roles of sender and receiver of information make little sense, since both communicators are sending and receiving messages at the same time, and are influenced by what is going on during the communication event (Wittenberg-Lyles et al., 2013). In the phenomenological view, communication is based upon “sharing a common existence with others but with each as a unique individual within the mix of human life... in a shared world that may be constituted differently in experience” (McCabe & Timmins, 2013, p. 3). Communication could be thus defined as “the mutual creation of meaning by both communicators” (Wittenberg-Lyles et al., 2013, p. 1).

Despite the importance of good communication for the well-being and satisfaction of patients and their family members, there are well-documented problems in communication in the context of palliative care between healthcare professionals and patients or their families, as well as inside the families, between patients and their loved ones. Both patients and family members often perceive communication about palliative care issues as poor. They are not satisfied with the quality and type of information and have difficulties understanding the language used. They also perceive staff as being busy and unavailable (Robinson et al., 2014). Due to a lack of skills and time on the part of healthcare

professionals, communication often times lacks clarity and is not supportive (Caswell et al., 2015). Clinicians themselves are well aware of the barriers for good communication with patients in an end-of-life care context such as a lack of skills and experience, which can contribute to a lack of confidence in the discussion of end-of-life topics, not knowing the patient well enough and concern about the emotional impact of discussion on the patient, plus organisational challenges such as lack of appropriate space and time for discussion (Scholz et al., 2020).

It is important for patients at the end of their life to be engaged in humane and egalitarian communication which enables their autonomy and inclusion in decision-making (Murray et al., 2015). Generally, they appreciate honesty and openness in communication (Murray et al., 2015) but they prioritise the balance between honesty and hope (Thorne et al., 2014). Although patients are aware of the emotional benefits of communicating their experiences, their concern that voicing them would create emotional distress for themselves and others often prevents them from doing so (Murray et al., 2015).

The literature describes severe communication difficulties between patients and their family caregivers who struggle to speak openly about end-of-life themes (Nagelschmidt et al., 2020) or avoid communicating their distress (McCauley et al., 2021). Zhang and Siminoff (2003) describe this situation as a 'phenomenon of silence'. They discovered that avoidance of family communication in the context of palliative care is a widespread phenomenon. This is because both parties want to avoid psychological distress, want to protect each other, and believe that positive thinking and consequently positive talking could bring positive clinical outcomes (Zhang & Siminoff, 2003). Unfortunately, a lack of mutual disclosure could result in a lack of mutual support and raise conflict between patients and their family caregivers (McCauley et al., 2021).

Family caregivers play an important role in instrumental, emotional, and informational support for their sick relatives (Hudson & Payne, 2011; Lessard et al., 2014). Due to different responsibilities and considerable physical and emotional stress, they need continuous assistance, care and support from

the palliative care team and are perceived as second-order patients (Hudson & Payne, 2011; Sherman, 2019). In their experience, mutual understanding with healthcare professionals can contribute to enhanced end-of-life care for their relative. Unfortunately, sometimes the communication they experience is not effective. When communication lacks clarity, they are unsure of what they have been told and unaware of the actual situation, which could lead to the development of unrealistic expectations regarding health care (Caswell et al., 2015).

1.2.3 Family meetings in palliative care

A family meeting is supposed to be one of the answers to the problems that arise in communication between the patient, family members, and healthcare professionals in palliative care. It is perceived as a valuable clinical tool for communicating information, specifying goals of care, facilitating decision-making, considering patient preferences, processing emotions in a safe environment, and acknowledging the role of the family caregivers (Glajchen, 2016). There is no universal definition of a family meeting. In short, it can be defined as a formal meeting where healthcare professionals, the patient, and their family can exchange information, discuss problems and fears, and make joint decisions concerning treatment and care. A family meeting is also called a family conference or a case conference.

In one of the first descriptions of a family meeting in palliative care, family physicians emphasise the importance of open communication and of getting to know the patient and the family well, which results in building a confidential relationship between physicians and family members (Liebman et al., 1975). They presented a case history of a cancer patient at the end of her life who was discharged from the hospital to the care of her family and her family physician. The physician arranged for a series of family meetings to support the family in order to take the best care for the patient. For Liebman et al. (1975) a family meeting has the following positive contributions in the care of dying patient: the feeling of inclusion for family members; the recognition of the family members' efforts to understand the patient's situation and their contribution to the patient's care; the information of family members

about patient's needs; the provision of direct, accurate medical information to the family in order to avoid misunderstanding and confusion; better knowledge of the patient and their living situation due to information provided by the family; the increased patient's sense of security; and the development of a sense of trust between the patient, the family and healthcare professionals (Liebman et al., 1975).

Despite the fact that family meetings were commonly used in palliative care practice, for several decades there were no clear guidelines regarding the structure, content and as to who should attend. This void was filled by the publication of the first comprehensive guidelines written by Hudson et al. (2008). The draft version of the guidelines was based on a review of the literature and then further refined with the help of a panel of experts (Hudson et al., 2008). According to guidelines, the family meeting comprises three main parts, namely, preparing for a family meeting, conducting a family meeting, and documentation and follow-up (Hudson et al., 2008). The main topics of the family meeting are addressing problems and concerns, providing information, and facilitating the optimal care plan (Hudson et al., 2008). The family meeting is usually organised for the patient and their family because both are supposed to benefit from it (Hudson et al., 2008).

Occasionally, patients are not included in the family meeting. This can be due to their deteriorated health condition and consequent physical or mental inability to participate. In some cases, patients are deliberately excluded to give the family members an opportunity to express their feelings and concerns and ask questions without worrying about the patient's reaction (Meeker et al., 2015). But even when patients participate in family meetings, questions arise of whether the patient's voice is present and heard, and whether family meetings serve both patients and their family (Tobin et al., 2011), or is the family meeting more about solving the problems of family members and healthcare professionals.

Since it is difficult for patients to participate equally in a family meeting at the end of their life, a new model of a family meeting was tested to help the patient's voice be heard (Sanderson et al., 2017). The authors called it a 'patient-centred family meeting'. The main goal is not the frail patient's equal participation in the discussion, but their presence and centrality to conversation. The aim of the

patient-centred family meeting is to abandon the practice of a clinician-determined agenda and instead to facilitate a conversation about issues that are important to the patient and/or family (Sanderson et al., 2017).

1.2.4 Slovene demography, healthcare system, and mode of communication in health care

Slovenia is a country of slightly more than two million inhabitants, geographically located in southern Central Europe. The Slovene population, as in most of the developed world, is aging. Twenty percent of the population is aged 65 and over (Zaletel et al., 2021). The most common cause of death are diseases of the circulatory system, followed by cancer and other non-communicable diseases (Albreht et al., 2016).

Primary care is decentralised. It is provided by community health care centres, owned and organised on a municipal level, and by the contracted office-based physicians in private practice (Albreht et al., 2016). Secondary and tertiary public healthcare institutions, which include public hospitals and national institutes, are owned and regulated by the Ministry of Health. A small minority of specialised hospitals are private (Albreht et al., 2016).

The Slovene healthcare system is mainly funded through compulsory health insurance. The remainder is covered from voluntary health insurance and direct out-of-pocket payments (Albreht et al., 2016). The benefits package from compulsory health insurance covers primary, secondary and tertiary services, medicines, medical devices, sick leave of more than 30 days and transport costs to healthcare facilities (Albreht et al., 2016). Some of the healthcare services are fully covered, including but not exclusively: health services provided for children, pupils and students up to age 26; antenatal care and childbirth; diagnosis and treatment of infectious diseases; treatment and rehabilitation of malignant diseases; occupational diseases; advanced diabetes, muscular or muscular nerve diseases, mental diseases and certain other diseases; mandatory vaccination; emergency healthcare services and long-term nursing care (Albreht et al., 2016). Other healthcare services involve cost-sharing with co-payments. For that reason, the majority of compulsory insured individuals purchase voluntary health

insurance. Medical services from compulsory health insurance for which co-payment is required are, e.g., dental care, sterilization and abortion, treatment abroad, hearing aids and other aids and appliances, certain medicines etc. (Albreht et al., 2016). For visits to physicians who do not have a contract with the Health Insurance Institute of Slovenia, to specialist services without general practitioner's referral, to private dental services, to cosmetic plastic surgery and in some other cases, individuals pay fully out of pocket (Albreht et al., 2016). Patients who receive palliative care either in the Slovene healthcare system or in hospices operating outside the healthcare system do not have to pay for these services out of their own pocket.

Despite the demographic situation, long-term care which would benefit elderly and chronically ill people is dispersed through different routes across the healthcare, social care, and pension and disability sectors, with different procedures concerning the assessment of entitlements for supporting the care needs. Consequently, some people may benefit from such arrangements while others have difficulties to access what they need (Albreht et al., 2016). Geriatric medicine is poorly developed and palliative care is still in its developmental stage.

The dominant relationships among Slovene healthcare professionals are hierarchical, and paternalistic in relation to patients. A group of authors, who more than a decade and a half ago researched the relationships between physicians and nurses in the Slovene healthcare system found that, according to a significant part of the respondents, Slovene healthcare was permeated with status hierarchy, stereotypes, lack of mutual respect and closed communication (Ovijač et al., 2006). There were no elements of cohesion in the teams. Joint work, i.e. a more instrumental aspect, has been highlighted as a characteristic of these teams (Domanjko et al., 2006). The flow of information between health professionals was often described as poor. Nurses felt disrespected by physicians due to the underestimation and reduction of their role to the level of professional and personal assistants (Domanjko et al., 2006).

The situation has not changed since then. Physicians are still the main decision-makers nowadays. According to their own findings, they are almost always the exclusive initiators of decision-making process e.g. regarding limitation of life sustaining treatment in the Slovene intensive care units. On the other side, nurses are very rarely involved in this process. (Groselj et al., 2014).

The Patients' Rights Act (2020) gives patients the right to be informed, to participate in decision-making and to make advance decisions regarding their own future health care. Despite this, quite often healthcare professionals, especially physicians, do not include patients or their family members in the decision-making process concerning patients' health care (Terjav et al., 2019). Patients and their relatives are rarely perceived as team members (Domanjko et al., 2006). According to the evidence the participation of patients and their family members in end-of-life decision-making in the intensive care units is infrequent (Groselj et al., 2014). The same applies to elderly patients, who have a subordinate status in the relationship with authoritative general practitioners who often do not allow them to be involved in health care for fear of 'spoiling' the treatment plan with their views, wishes and expectations (Rotar-Pavlič et al., 2008).

The prevailing culture of relationships within the healthcare system is paternalism (Kavcic et al., 2015). This attitude has persisted for a long time. In the early 1980s the relationship between the patient and physician in the former Yugoslavia, of which Slovenia was a part, was described as "largely hierarchical" (Parmelee et al., 1982, pp. 1392; Kavcic et al., 2015); not much has changed since then. A survey published in 2019 on citizen satisfaction with the healthcare services in Slovenia, identifies problems in communication, and with relationships between healthcare professionals and citizens (Terjav et al., 2019).

Kavcic et al. (2015) describe that the atmosphere in certain healthcare settings sometimes resembles a total institution, where patients' questions are not welcome and decisions regarding their care are made without them. They often feel a patronising attitude from some healthcare professionals and a lack of acknowledgement of them as people (Kavcic et al., 2015).

Apart from the widespread culture of paternalism, there are other structural barriers which hinder open communication and patients' inclusion in decision-making, one of them being a shortage of healthcare professionals and consequent work overload, and a lack of time for communication and collaboration with patients (Kavcic et al., 2015). The other barrier is so-called defensive medicine, a practice where diagnostic and therapeutic measures serve primarily to protect the physician from the patient's accusations of treating them negligently, inappropriately, or harmfully. It manifests itself in excessive additional investigations and unnecessary treatment (Mesec, 2014). All of this, however, takes valuable time and effort that could be devoted to developing a relationship with patients and initiating inclusive communication.

The most common complaint from patients and their relatives about treatment within the Slovene healthcare system relates to communication issues and relationship problems (Nemec et al., 2016). Patients are bothered by unfriendly communication, a lack of compassion, a lack of information regarding their treatment and a lack of explanations regarding the use of prescribed medicines. (Nemec et al., 2016). The reason for dissatisfaction is also the feeling that physicians do not devote enough time to patients' medical treatment and that they do not consider patients' wishes (Nemec et al., 2016). Patients value kindness and a respectful attitude the most (Terjav et al., 2019).

Due to this medical dominance in the Slovene healthcare system, nurses' opinions are often not considered, and patients' voices are not sought. Due to a prevailing paternalistic culture and emphasised hierarchy in relationships, it is difficult to establish functional team work with open communication and inclusion of patients and their family members.

1.2.5 Palliative and hospice care in Slovenia

Rigid interprofessional hierarchy and resulting difficulties in effective teamwork and open communication, as well as a paternalistic attitude towards patients, are not the best basis for the development of palliative care approach with its emphasis on communication and mutual support. As

a consequence, palliative care in Slovenia is poorly developed and poorly regulated (Teršek, 2020), and is systemically still unorganised.

The hospice philosophy entered Slovene society in 1995 with the establishment of the Slovene Hospice Association, a non-governmental, non-profit and humanitarian organisation with the aim to contribute to the alleviation of suffering for people at the end of life and their relatives in their homes, education of volunteers, and removing the taboo of talking about death in society. In 2000, the Institute for Palliative Care Development began educating health and social care professionals.

Hospice care is provided by two hospice organisations; one is located at a stationary hospice with 12 beds and the other is organised as mobile hospice teams providing care in the homes of the patients. Hospices operate outside of the public healthcare system. At the primary level of public healthcare, general practitioners and the community nurses mainly provide basic palliative care. At the secondary and tertiary level, specialist palliative care is provided by small palliative care teams in some of the hospitals. Until recently, there was one mobile hospital palliative care team in Slovenia. In 2021, the financial incentives for mobile palliative care teams began, which initiated the organisation of mobile teams throughout the country.

In the field of palliative care education, Slovenia is slowly breaking new ground. A basic 60-hour course was developed and for the first time organised for a multi-professional audience by the Slovene Palliative Medicine Society in 2011. A specialist accreditation was awarded to physicians who complete this course and pass the exam. Later, shorter compulsory or optional palliative care modules or parts of modules were introduced in the undergraduate education of physicians and nurses. In 2016, the first palliative care masters study programme for nurses in Slovenia was launched. Two years later, the first 120-hour programme called Education to Acquire Special Skills in Palliative Care for Nurses and Midwives commenced. This course provides attendees with basic palliative care knowledge and skills. To acquire more comprehensive knowledge Slovene healthcare professionals must enrol in palliative care programmes abroad.

A national programme of palliative care together with the action plan for its implementation was endorsed by the government in 2010. Unfortunately, the financing of palliative care programmes was not defined and actualised until the year 2021, which has long hampered the development of palliative care in healthcare settings. This means that the organisation and provision of palliative care service was largely dependent on the enthusiasm of a few dedicated individuals and the support of the management of the individual institution. For this reason, organised and comprehensive palliative care is rarely provided in healthcare institutions.

From my experiences and conversations with patients and their family members, it seems that healthcare professionals are still unaware of the crucial importance of communication in palliative care. Since the majority of healthcare professionals who take care of patients at the end of their life still have no education in palliative care or they have only basic knowledge, the prevailing mode of communication follows a well-known pattern of exclusion from decision-making, concealment of information, and a paternalistic attitude. In rare situations, mainly where palliative care services are led by healthcare professionals educated abroad, communication among different professions and with patients and their relatives is more inclusive, and family meetings are a routine part of palliative care service.

1.2.6 Family meetings in Slovene research literature

Formal family meetings were introduced to the Slovene healthcare system during the last fifteen years, with the organisation of the first hospital palliative care services. Nowadays, there are still predominantly conducted in the palliative care context.

To this day, a family meeting was rarely thematised in research projects and the literature. Apart from occasional anecdotal reports of healthcare professionals' experiences (Mikloša, 2013; Jakhel, 2013; Koštomaj, 2014), some simple analysis of family meeting effects (Mikloša, 2014; Genorio & Zajc, 2014), and short instances of advice for the implementation of a palliative care family meeting in clinical practice (Slak, 2011; Lunder & Červ, 2014; Guček, 2016), there are only two studies exploring palliative

care family meeting. The first deals with its organisation (Kristanc, 2020) and the second with the role of a social worker at a family meeting (Zlodej, 2016). The findings regarding patients' experiences of the palliative care family meeting are that they expressed a positive opinion about the family meeting and that this was, in most cases, their first experience of such a form of conversation (Zlodej, 2016). There is a lack of robust studies of palliative care family meetings or in-depth studies of patients' experiences with such family meetings in Slovenia.

1.3 Summary of the problem

According to demographic data, it can be anticipated that an increase in the need for quality palliative care will exist in Slovenia. Communication is one of the foundations of palliative care and a family meeting is one way to improve it. In an environment where patients' voices are rarely heard, it is important to know what patients' experiences of the family meeting are and what is its meaning for them. The study of palliative care family meetings is neglected in Slovenia. In particular, there is a lack of understanding of the meaning of family meetings for palliative care patients. A better understanding of this meaning could be the basis for improving the quality of developing palliative care in Slovenia.

1.4 The aim of the research and research question

Given the lack of research regarding patients' experiences of palliative care family meetings in Slovenia, this study will aim to illuminate the meaning of family meetings for patients receiving specialist palliative care in two Slovene hospitals. With this study I would like to answer the following research question: *What is the meaning of formal palliative care family meetings and their consequences for people receiving specialist palliative care in two Slovene hospitals?*

1.5 Overview of the thesis

In Chapter 1, communication in palliative care, the Slovene healthcare system and communication culture, palliative care in Slovenia, and the lack of interest in researching family meetings, which set the context of the study, are outlined.

In Chapter 2, a review of the literature as a way to see things reported previously in a new light and to motivate thinking regarding the palliative care family meeting and research methodology is presented.

In Chapter 3, the philosophical underpinnings of this study are presented and the choice of hermeneutic phenomenological methodology is justified. Methods of the study design: sampling, recruitment, data collection, analysis, and interpretation are presented. Trustworthiness and ethical considerations are outlined.

In Chapter 4, the findings comprised of the three main themes which were identified in the analytical process of crafting the stories and the thematic structural analysis are presented.

In Chapter 5, the final interpretation of data in light of the hermeneutic phenomenological and philosophical literature is presented. Recommendations for practice, policy, education and further research are proposed.

1.6 Summary

There is an increased need for palliative care worldwide. Good communication is an essential prerequisite for quality palliative care. Despite its importance, palliative communication can be inadequate and inappropriate, contributing to the dissatisfaction of those involved and to conflicts between them. Family meetings involving patients, their relatives and healthcare professionals were designed to support end-of-life communication. Recently, new models of family meetings are being developed to allow fragile patients to have their voices heard.

The Slovene healthcare system culture is predominantly paternalistic, and patients are rarely invited to participate in decision-making regarding their health care. Their most common complaints concerning health care relate to poor relationships and communication. Palliative care in Slovenia is poorly developed. Therefore, patients are rarely given the opportunity to participate in a family meeting, which would allow them to present their views and participate in decision-making. Little is known about palliative care family meetings in general and patients' experiences of them in particular. Understanding the meaning of a palliative care family meeting for patients can open up new horizons

of knowledge and consequently contribute to the opportunity for improving the situation for palliative care patients in the future.

Chapter 2. Literature review

2.1 Introduction

Although my research interest is solely in patients' experiences of family meetings in a palliative care context, I decided to review the literature concerning patients', family members', and healthcare professionals' experiences to widen my horizons regarding this topic. As Smythe and Spence (2012) explained, the key purpose of hermeneutic literature review is to provoke thinking. With provoking thinking, the literature becomes "an essential dialogical partner...from which new insights emerge" (Smythe & Spence, 2012, p. 12). In pursuing this idea, I gave up a more conventional approach to literature review and decided to reveal hidden unspoken meanings still dwelling within and between the words of the selected papers (Crowther et al., 2014), for, according to Heidegger (1962), we can never reveal the whole truth. Whenever one aspect of a phenomenon is revealed, the other aspects remain in the shadow (Heidegger, 1962). I therefore decided to try to see things reported previously in the literature in a new light, and in that way, motivate my thinking regarding the phenomenon of family meeting in a palliative care context.

2.2 Review question

To review literature in a hermeneutic manner is to question and be open for the possibilities that might be revealed (Crowther et al., 2014). As Gadamer says, "the essence of the question is to open up possibilities and keep them open" (Gadamer, 2006, p. 298). Reviewing literature hermeneutically is to enter into a dialogue with the text, which becomes our "partner in our journey of thinking" (Smythe & Spence, 2012, p. 14). Hermeneutic literature review is thus a play of asking questions and listening to the answers from the text. My questions to the texts were: what is the meaning of a family meeting in the context of palliative care for patients, family members and healthcare professionals who had experiences of participation in such meetings? What might be unrevealed and unsaid about palliative care family meetings' experiences in scientific literature?

2.3 Inclusion and exclusion criteria

The conception of relevant literature in hermeneutic literature review is wide and could, in addition to articles, encompass “philosophical texts, fiction, poetry and anything else which engages the reader in a thought-full encounter” (Smythe & Spencer, 2012, p. 14). But since the review does “not have to start by identifying all potentially relevant texts” (Boell & Cecez-Kecmanovic, 2010, p. 133), I started with studies presenting adult palliative care patients’, family members’ and healthcare professionals’ experiences, perspectives, perceptions, views of or opinions about family meetings in end-of-life or palliative care context, written in the English language. My focus was participants’ descriptions of experiences of family meetings included in the studies as quotations. Although these quotations were previously already interpreted by the authors of the studies, my intention was to read them afresh through a new lens and to possibly find “hidden unspoken meanings within and between words” (Crowther et al., 2014, p. e2). Thus, I tried to open up the space for “what was always there but unseen because of our prescribed ways of viewing our world” (Young, 2011, p. 61).

Quantitative and qualitative studies without explicitly presented quotations were not included in this review, nor were studies where there was no identifying information of any quotation from different participants, which prevented the discrimination between patients, family members and healthcare professionals. Also excluded were studies presenting family meetings in paediatric or adolescent palliative care, psychiatric care, education, genetic or legal context.

2.4 Search and selection strategy

After some trials and a suggestion from a librarian, I kept my search strategy relatively simple for the purpose of retrieving as many relevant texts as possible. As presented in Table 1, I searched for family meetings or family conferences in a palliative care context.

Table 1: Search strategy

Database	Search strategy
PubMed (1. 8. 2016)	(CareSearch palliative care PubMed filter) AND (family meeting*(TW) OR family conference*(TW) OR professional-family relations(MT))
CINAHL (8. 8. 2016)	((palliative care* TX) OR (hospice care* TX) OR (end of life care* TX) OR (terminal care* TX) OR (palliative care SU) OR (hospice care SU) OR (terminal care SU)) AND ((family meeting* TX) OR (family conference* TX) OR (patient-family conferences SU) OR (professional-family relations SU))
Academic Search Complete (2. 8. 2016)	(palliative care(TX) OR hospice care(TX) OR end of life care(TX) OR terminal care(TX) OR palliative treatment(SU) OR hospice care(SU) OR terminal care(SU)) AND (»family meeting*«(TX) OR »family conference*«(TX) OR patient care conferences(SU))
EMBASE (2. 8. 2016)	(TW: palliative care* OR hospice care* OR end of life care* OR terminal care* OR SH: palliative therapy OR hospice care OR terminal care) AND (TW: family meeting* OR family conference*
Web of Science (2. 8. 2016)	#1 TS=(palliative care* OR hospice care* OR end of life care* OR terminal care*)

	Restrict: language English #2 TS=(family meeting* OR family conference* Restrict: language English #1 AND #2
PsycINFO (2. 8. 2016)	(palliative care(TX) OR hospice care(TX) OR end of life care(TX) OR terminal care(TX) OR palliative care(DE) OR hospice(DE) OR terminally ill patients(DE)) AND («family meeting*« OR »family conference*«)

After searching, retrieving and selecting texts from the databases, I expanded my searching to grey literature. For this reason, I searched the Open Access Theses and Dissertations website, EAPC congresses abstract books 2004 – 2015 and CareSearch Grey Literature database. I also electronically searched relevant journals, and references and citations of studies included in literature reviews as well as those which were firstly included and subsequently excluded. All sources of evidence are presented in Table 2.

Table 2: Sources of evidence

Databases	Search date	Number of hits	Number of studies included for literature review
PubMed	1. 8. 2016	3084	
EMBASE	2. 8. 2016	351	
Web of Science	2. 8. 2016	629	
PsycINFO	2. 8. 2016	74	
Academic Search Complete	2. 8. 2016	2126	
CINAHL	8. 8. 2016	4443	

All databases		10707	17
Grey literature			
Open Access Theses and Dissertations	25. 8. 2016	16	2
EAPC congresses	25. 8. 2016	47	
CareSearch grey literature database	25. 8. 2016	16	
All grey literature		79	2
Electronic search of journals			
BioMed Central	26. 8. 2016	181	
Palliative Medicine	26. 8. 2016	30	
American Journal of Hospice & Palliative Medicine	26. 8. 2016	81	1
Journal of Palliative Medicine	26. 8. 2016	17	1
Progress in Palliative Care	26. 8. 2016	2	1
All electronic search of journal		311	3
Personal contact			1
References of included studies			1
References of unincluded studies			1
All		11100	25

I refined my search as documented in Figure 1 below and selected 25 studies for literature review.

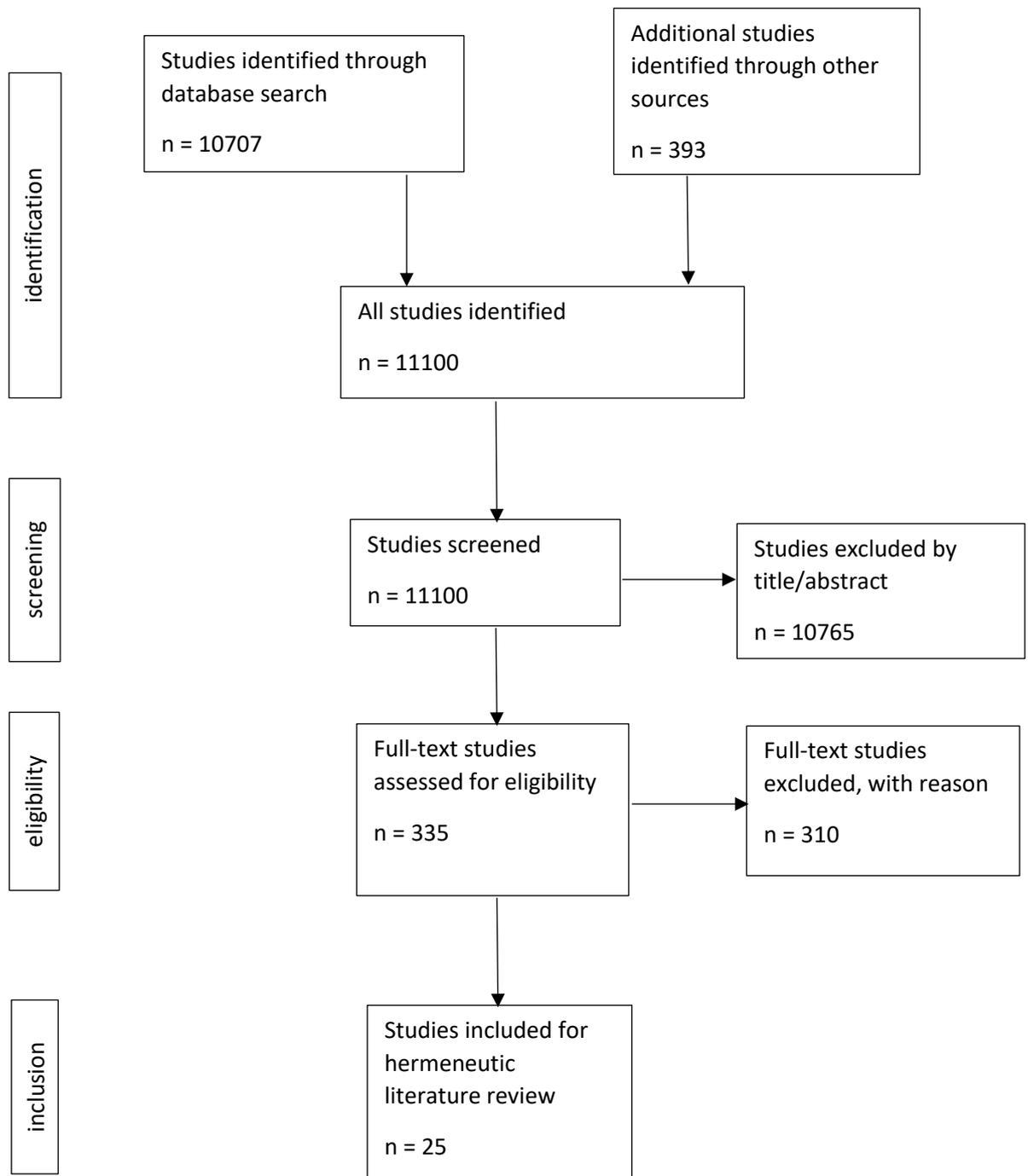


Figure 1: Flowchart of selection of studies

2.5 Reviewing the literature

As stated by Smythe and Spence, “the nature of hermeneutic review is that there are few rules to follow; rather a way to be attuned” (Smythe & Spence, 2012, p. 23). To become more familiar with the texts and more attuned, I decided to work with the texts in two manners. Firstly, I interpreted the quotations as proposed by Svedlund et al (2001), and Lindseth and Norberg (2004). I started with a naïve reading of the individual study to be able to grasp the general sense of the study. Then I continued by structural analysis, which involved several phases: a) read meaning units, which were comprised of quotations or a part of the quotations, b) condense meaning units to shorter forms, c) abstract these condensed forms to sub-themes, d) come to a theme, which presents the participant’s ontological position in the family meeting. An example of naïve understanding and structural analysis is shown in Table 3.

Table 3: Example of naïve understanding and the structural analysis

Author & title		Date of analysis	
Kogan et al (2015) Does disclosure of terminal prognosis mean losing hope? Insights from exploring patient perspectives on their experience of PC consultation		16-6-2017	
Naïve understanding			
Seriously ill patients were interviewed about their participation in a FM and perception of it. Patients were satisfied with a more holistic approach than usual when approached by health care professionals. They received explanations, which made them feel comfortable, and gave them hope. Although some of them were ready to discuss end-of-life issues, others were not prepared for this.			
Meaning units	Condensed meaning units	Sub-themes	Themes
<p><i>“They [IPC team] were a little more in depth. I always viewed the doctors at the hospital giving me surgical answers...and taking care...from the physical standpoint. The emotional standpoint came from the palliative care team where it shows me...[that] there were things involved in medical care that were much deeper than just, say, physical well-being.” (ID 204)</i></p> <p><i>“The conference was very good. It gave me an open mind on things that were said for me and my family. They took the time...and they gave me the time to go over things.” (ID 203)</i></p> <p><i>“Well basically, this department in the hospital...was concerned about not only the advance directive but, you know, also with the level of pain and being able to manage it.” (ID 204)</i></p>	<p>The answers received were more holistic than expected</p> <p>The patient realised that also deeper needs could be addressed</p> <p>The patient better understood the situation To have enough time is important</p> <p>For HCP was not important only the work which need to be done, but also the patient’s wellbeing</p>	<p>The feeling of being more than just a body</p> <p>The feeling of being more than just a body</p> <p>The feeling of being accepted</p> <p>The feeling of being accepted</p>	<p>Being whole</p> <p>Being whole</p> <p>Being accepted</p> <p>Being accepted</p>

Secondly, I read and re-read the studies asking the texts the review questions, as suggested by Crowther et al. (2014) and Smythe and Spence (2012). I entered into a dialogical partnership with the

text, listened to what was read, tried to hear questions posed by the text, and developed new questions. First, I read each text separately. I then read all of the text of a specific group of participants, i.e. patients, family members and healthcare professionals. At the end, I read across all the texts in search for the meanings of the family meeting in light of the philosophical literature.

2.6 Findings

I identified 25 studies eligible for literature review. Twenty-two of the studies were qualitative and three were mixed methods studies. Out of the twenty-five eligible studies, eight each were conducted in the United States and Australia, three in Canada, two in Hong Kong, and one each in France, Ireland, Sweden, and Japan. Studies took place in different settings: patients' homes, hospices, hospitals, local palliative care services, residential long-term services, and family medicine sites. Although there is no exact data on the number of participants in all of the studies included in this literature review, I can estimate that around 51 patients, 340 family members and 610 healthcare professionals participated in them. Twelve of these studies contain quotations describing family members' experiences; ten studies contain quotations of healthcare professionals' experiences, and seven of the studies contain quotations of patients' experiences of the palliative care family meeting (Table 4). Three research projects were presented more than once from different perspectives. Tan (2008) presented patients' and family members' experiences of a family meeting as an instrument for spiritual care in a doctoral thesis and later on in two papers (Tan et al., 2011a; Tan et al., 2011b). Ho presented family members' views of a dignified living and dying in a nursing home first in a doctoral thesis (Ho, 2013) and later in a paper (Ho et al., 2016). Lastly, healthcare professionals' views regarding family meetings were presented in two papers (Tuckett et al. 2014; Tuckett et al. 2015).

Table 4: Research studies identified through literature search

Author, year, title & location	Participants providing family meeting experiences	Study design & method	Findings
Marchand & Kushner (1997) Getting to the heart of the family conference: the residents' perspective, USA, family medicine training sites	Healthcare professionals (n=65)	Focus groups and a brief questionnaire, thematic analysis	Family conferences: 1) are valued as an important communication tool; 2) occur primarily in inpatient settings when a crisis exists; 3) fail to occur due to significant barriers; 4) are best taught experientially with involvement of role model.
Chunlestskul et al. (2008) Lived experiences of Canadian women with metastatic breast cancer in preparation for their death: a qualitative study. Part I-preparations and consequences, Canada, place of the study was not defined	Patients (n=5)	Interviews, comparative thematic analysis, and thick description	The women prepared for their death by: acknowledge their grief; preparing mentally; seeking information and support; preparing the family; and preparing for the end of life. They engaged in creating life projects that enhanced their connections with loved ones, and lived full and joyful lives.
Tan (2008) The family meeting as an instrument for the spiritual care of palliative patients and their families (doctoral thesis), Australia, patients' home, hospice, hospital	Patients (n=12) and family members (n=36)	In-depth interviews, phenomenological interpretation of coded data using Ricoeur's theory of interpretation	Outcomes for patients and family members were: experience of increased openness of communication; positive and constructive feelings and emotion; gaining new understandings; and strengthening or renewal of significant relationships.
Radwany et al. (2009) End-of-life decision making and emotional burden: placing	Family members (n=23)	In-depth, semi-structured interviews, grounded theory	From the perspective of the family, decision making at the end of life is described within a theoretical model of salient experiences that are relevant to families' emotional burdens. Three

family meetings in context, USA, hospital			temporal stages were evident: 1) the illness experience, 2) decision-making in the family meeting, and 3) the dying process
Hudson et al. (2009) Family meetings in palliative care: are they effective?, Australia, hospital	Healthcare professionals (n=4)	Focus group, thematic analysis	Participation in the family meeting was beneficial for family carers and the treating team. Family carers met the team, got information, clarified goals of care, asked questions, debriefed and vented feelings, and improved understanding. Treating team identified family concerns early, shared information with family all at once, clarified information. Particularly challenging was the coordination. Family meeting guidelines were experienced as useful but also restricting.
Nelson et al. (2010) In their own words: patients and families define high-quality palliative care in the intensive care unit, USA, hospital	Patients (n=15)	Focus groups, thematic analysis	High-quality ICU palliative care comprising: timely, clear, and compassionate communication by clinicians; clinical decision-making focus on patients' preferences, goals, and values; patient care maintaining comfort, dignity, and personhood; and family care with open access and proximity to patients, interdisciplinary support, and bereavement care.
Tan et al. (2011a) The experience of palliative patients and their families of a family meeting utilised as an instrument for spiritual and psychosocial care: a qualitative study, Australia, home, hospital, hospice	Patients (n=11) and family members (n=36)	In-depth interviews, hermeneutic phenomenology study	Data analysis revealed seven main themes: personal experience of the meeting; personal outcomes; observation of others' experience; observation of experience and outcomes for the family unit; meeting facilitation; how it could be different; and the general applicability of the family meeting. Throughout the themes were references to aspects of the web of relationships.

<p>Tan et al. (2011b) The family meeting addressing spiritual and psychosocial needs in a palliative care setting: usefulness and challenges to implementation, Australia, home, hospital, hospice</p>	<p>Patients (n=12) and family members (n=35)</p>	<p>In-depth interviews, hermeneutic phenomenological study</p>	<p>Participants indicated that participation in the studied type of the family meeting would be a valuable addition to regular palliative care services. Practical barriers to its application were identified and included the need for specific meeting facilitation skills, funding priorities, staff time, and possible language and cultural issues.</p>
<p>Kryworuchko et al. (2012) A qualitative study of family involvement in decisions about life support in the intensive care unit, Canada, hospital</p>	<p>Healthcare professionals (n=9)</p>	<p>Interview, qualitative descriptive study</p>	<p>Participants describe two options (life support and comfort care) and values associated with these options: maintaining quality of life; surviving critical illness; minimizing pain and suffering; not being attached to machines; needing adjustment time; and judicious healthcare resource use. Barriers to involvement included not being offered alternative options; no specific trigger to initiate decision making; dominant influence of professionals' value; and families lacking understandable information.</p>
<p>Shahid et al. (2013) Improving palliative care outcomes for Aboriginal Australians: service providers' perspectives, Australia, hospitals, home-based and local PC services, community health services</p>	<p>Healthcare professionals (n=15)</p>	<p>In-depth interviews, thematic analysis</p>	<p>Palliative care providers reported lack of understanding of Aboriginal culture and being uncertain of the needs and priorities of Aboriginal people during end-of-life care. According to participants, very few Aboriginal people had an understanding of palliative care. Managing issues such as anger, denial, the need for non-medical support due to socioeconomic disadvantage, and dealing with crises and conflicts over funeral arrangements were some of tensions between</p>

			Aboriginal patients and families and service providers.
Fukui et al. (2013) Effectiveness of using clinical guidelines for conducting palliative care family meetings in Japan, Japan, hospital	Family members (n=15)	Pre- and post-family meeting questionnaires, comparing the degree of agreement in pre- and post-meeting questionnaires, thematic analysis of topics discussed during the meeting	There was a significant improvement in family carers' psychological well-being in the post-meeting questionnaires compared to the pre-meeting questionnaires as follows: how upset/worried they were about the problem, $t(14)=3.1071$, $p<0.000011$; frequency in which problem occurs, $t(14)=3.2857$, $p<0.000013$; life interference with the problem, $t(14)=2.7857$, $p<0.00008$; and the confidence to deal with the problem, $t(13)=-2.3007$, $p<0.005480$.
Enguidanos et al. (2013) Family members' perceptions of palliative care consult services: a qualitative study, USA, hospital	Family members (n=23)	Semi-structured interviews, thematic analysis and descriptive statistics	Four themes were identified: perceived quality of the inpatient palliative care consultation, family readiness, impact on decision making process, and focus on comfort and quality of life. Most comments reflected positive aspects of the inpatient palliative care consultations, such as improved pain control and communication, and increased access to medical professionals and time to discuss patients' condition. Some themes reflected lack of adequate preparation for the inpatient palliative care consultations and readiness for discussing prognosis.
Ho (2013) Living and dying with dignity: an interpretive-systematic framework in Hong Kong (doctoral thesis), Hong Kong, hospital, home	Family members (n=18)	Meaning-oriented interviews, thematic analysis	The 31 themes are organised in 9 categories that reflect individual, familial and institutional dimensions of dignity at end-of-life. Individual dimension includes: 1) personal autonomy; 2) family connectedness; and 3) spiritual plastic.

			Familial dimension involves: 1) social agency; 2) family integrity; and 3) filial compassion. Institutional dimension entails: 1) regulatory empowerment; 2) family-centred care; and 3) collective compassion.
Carlsson (2014) A separate structured conversation with relatives of patients enrolled for advanced palliative home care: a care development project, Sweden, site not specified	Family members (n=55 who answered the questionnaire; n=8 who participated in interviews) and healthcare professionals (n=not specified)	Questionnaire with open-ended questions, semi-structured interviews, focus groups, systematic text condensation inspired from Giorgi and modified by Malterud, coded statements searched for similarities and differences	Family members have difficulties separating separate structured conversation (SSC) from the advanced palliative care home care team's (APHCT) care as a whole. They underline that the SSC was a part of an ongoing process. They emphasise the value of having a conversation of their own, without the patient in which the focus was on their situation. The main problem was conducting the SSC soon after the patient's enrolment with the APHCT.
Tuckett et al. (2014) What general practitioners said about the palliative care case conference in residential aged care: an Australian perspective. Part 1, Australia, residential care facility, home, clinic	Healthcare professionals (n=11)	Face-to-face semi-structured interviews, qualitative content analysis	The evaluation of the palliative care case conference in residential aged care is explained through three core themes: people, place, and performance. Understanding what GPs say about the people involved and the place in which they work, namely the residential aged care facility, can purposefully inform practice and policy.
Clifford (2014) The palliative care patient's role in the formal family meeting: a mixed methods study (master's dissertation), Ireland, hospice	Patients (n=7)	Mixed methods using the convergence model. Quantitative method: retrospective chart review, descriptive statistics, and Chi-squared tests. Qualitative	36% admissions during the 6-month study period involved a formal family meeting, with younger patients and patients who were subsequently discharged being more likely to have a meeting. The patient was present at 34% of meetings, with patients closer to death being less likely to attend. Themes generated from interviews included:

		method: semi-structured interviews, thematic analysis	patient's sense of control; concern for their family; anger at family's questions; anxiety about the meeting; perceived benefits and satisfaction with the meeting; and patients' views on the timing and frequency of meetings.
Meeker et al. (2015) Examining family meetings at the end of life: the model of practice in a hospice inpatient unit, USA, hospice	Healthcare professionals (n=8)	Phase 1: semi-structured interviews, grounded theory, Phase 2: ethnographic observations, calculation of frequencies, constant comparative analysis	The core of the family meeting was characterized by cognitive and affective elements aimed at supporting the family and facilitating quality care by clarifying the past, easing the present, and protecting the future. The inductive model was found to be highly aligned with a sense of coherence, an important influence on coping, and adaptation to the stress of a life-limiting illness.
Tuckett et al. (2015) What general practitioners said about the palliative care case conference in residential aged care: an Australian perspective. Part 2, Australia, residential care facility, home, clinic	Healthcare professionals (n=11)	Face-to-face semi-structured interviews, qualitative content analysis	The evaluation by GPs of the conference in residential aged care is explained through three core themes: people, place, and performance. Understanding what GPs say about the performance or 'doing' a conference can purposefully inform practice and policy.
Anderson et al. (2015) A multicentre study of key stakeholders' perspectives on communicating with surrogates about prognosis in intensive care units, USA, hospital	Family members (n=47)	In-depth semi-structured interviews, qualitative descriptive analysis	There was a broad support for existing expert recommendations, including truthful prognostic disclosure, emotional support, tailoring the disclosure strategy to each family's needs, and checking for understanding. Suggestions to add to existing recommendations were: 1) clinicians should help families to "see prognosis for themselves"; 2) using numeric estimates to convey prognosis to family could be helpful; 3) clinicians

			should conceptualise prognostic communication as an iterative process that begins with a preliminary mention of possibility of death and later on becomes more detailed; 4) although prognostic information should be initially disclosed by physicians, other members of the multidisciplinary team should be given explicit role responsibilities to reinforce physicians' prognostications and help families to emotionally process a poor prognosis.
Kogan et al. (2015) Does disclosure of terminal prognosis mean losing hope? Insights from exploring patient perspectives on their experience of palliative care consultations, USA, hospital	Patients (n=12)	Individual semi-structured interviews, grounded theory, descriptive statistics	Four themes were identified from the interview transcripts: 1) holistic care approach; 2) knowledge/information gained; 3) hope and enlightenment; and 4) patient readiness
Roze des Ordon et al. (2015) Strategies for effective goals discussions and decision-making: perspectives from a multi-centre survey of Canadian hospital-based healthcare providers, Canada, hospital	Healthcare professionals (n=468)	Open-ended questionnaire, descriptive statistics, thematic content analysis	Effective strategies and ideas for improving communication and decision-making about goals of care clustered under five themes: patient and family factors; communication between healthcare providers and patients; inter-professional collaboration; education; and resources. Subthemes highlighted core elements of shared decision-making.
Parker et al. (2016) Palliative care case conferences in long-term care: views of family members, Australia, long term care facilities	Family members (n=29)	Mixed methods study. Examination of documents of resident/family dyads participating in a conference, interviews with families,	Main concerns raised by family members prior to the conference were: physical and medical needs; pain; end-of-life care planning; and nutrition and hydration. A formalised palliative care case conference process ensured issues relating to end-

		descriptive statistics, thematic analysis	of-life care planning, pastoral care, pain and comfort, and physical and medical needs were well-documented by staff. Issues relating to care processes and the family role in care were less well-documented. Post intervention, all families recommended the conferences and over 90% of families felt their issues were addressed to their satisfaction. Families reported increased understanding of their relative's current and future care.
Garrouste-Orgeas et al. (2016) Impact of proactive nurse participation in ICU family conferences: a mixed-method study, France, hospital	Family members (n=88)	Mixed-method design with qualitative study embedded in a single-centre randomized study, semi-structure interviews, interpretive phenomenological analysis	The qualitative data indicated that families valued the principle of the conference itself. Perception of nurse participation clustered in four main themes: trust that ICU teamwork was effective; trust that care was centred on the patient; trust in effective dissemination of information; and trust that every effort was made to relieve anxiety in family members.
Ahluwalia et al. (2016) Nurses as intermediaries: how critical care nurses perceive their role in family meetings, USA, hospital	Healthcare professionals (n=30)	Focus groups, qualitative analysis by using the constant comparative method	Three major themes describing nurses' involvement in family meetings were identified: nurses can play multiple roles in supporting conduct in family meetings; nurses face critical barriers to fully recognise these roles; and nurses end up as intermediaries in family meetings.
Ho et al. (2016) Dignified palliative long-term care: an interpretive systemic framework of end-of-life integrated care pathway for	Family members (n=6)	Interpretive-systemic focus groups, framework analysis	Framework analysis revealed 10 themes, organised in 3 categories: 1) regulatory empowerment (interdisciplinary teamwork, resource allocation, culture building, collaborative policy making); 2) family-centred care (continuity of care, family care

terminally ill Chinese older adults, Hong Kong, site not specified			conference, partnership in care); and 3) collective compassion (devotion in care, empathic understanding, compassionate action).
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2.7 Participants' attunement

During the first part of the literature review, I was attentive to the attunement encountered in the descriptions of patients', family members' and healthcare professionals' experiences in the quotations, since mood discloses the way in which our being matters to us (Blattner, 2006). According to Heidegger, mood is not a psychological feature. "It comes neither from 'outside' nor from 'inside', but arises out of being-in-the-world, as a way of such being" (Heidegger, 1962, p. 176). It is an aspect of our familiarity with the world. When we 'feel down' or we 'feel high', this is not some inner tendency but a way of how we are dealing in our life (Blattner, 2006).

"Person's mood sets a tone for her environment" (Blattner, 2006, p. 77). It is like a shared atmosphere into which we tune and resonate accordingly (Polt, 1999). "Mood... tunes us in to...the way in which something matters to us" (Blattner, 2006, p. 78), in the way things, persons or events are important for us. It "sets the tone of life" (Blattner, 2006, p. 78) and "makes manifest 'how one is and how one is faring'" (Heidegger, 1962, p. 173). Thus, I was interested in what was the mood of people's experience of participation in a family meeting, or, in other words, what the atmosphere of their narration was.

2.8 Patients' experiences

Being satisfied

Different things helped patients to feel good and be satisfied regarding family meetings, some unspecified and others more specific.

Although sometimes patients were unable to specify what contributed to their satisfaction with participation in a family meeting, they agreed that their experience was positive (Clifford, 2014). They often described it as good and helpful, which they would recommend to others (Tan, 2008; Tan et al., 2011b). They were satisfied when, during the family meeting, something they would have considered negative did not happen. On one occasion, a patient was satisfied despite the fact that no specifics were discussed or maybe because of this (Tan, 2008).

One patient's description of immersion in the family meeting and of the feeling of the mastery of the situation gave the impression of deep satisfaction both with oneself and with the event (Clifford, 2014). For some patients, the fact that they were able to express themselves, had an opportunity to talk about their feelings or their situation and then felt better afterwards also contributed to their satisfaction (Tan, 2008). The holistic focus of communication at the family meeting enabled patients to realise that they are treated as whole human beings (Kogan et al., 2015). They were relieved to know that it is possible to receive treatment congruent with one's religious belief (Kogan et al., 2015) and comforted with the possibility of presenting their memories at the family meeting (Tan et al., 2011a). Patients were grateful for information received. They felt good and enlightened with healthcare professionals' presentation of their care options. Healthcare professionals' explanations made patients feel relaxed and comfortable despite the seriousness of their situation and initial scare. Discussions of discharge arrangements and pain management was something that brought patients hope. They were satisfied with new knowledge, which enabled them to make decisions when needed (Kogan et al., 2015). One patient was satisfied with the right timing of the family meeting due to their approaching death, and another with the sufficiency of time needed for explanation and reflection (Tan, 2008; Kogan et al., 2015). Appropriate facilitation of a family meeting was another reason for satisfaction among patients (Tan, 2008).

Patients were satisfied when a family meeting was beneficial for all the participants, for instance when their relatives were more collaborative and supportive for each other afterwards because they could understand each other better (Chunlestskul et al., 2008; Tan, 2008). One patient believed that information received at the family meeting would be useful for their family members who would be able to know what to expect in the future (Nelson et al., 2010). Even when patients did not attend the family meeting, they said they were happy with it because their family members received the required answers (Clifford, 2014).

Being (re)connected

Patients often times addressed relational issues and concern for their family members when describing family meeting experiences. In patients' opinion, it was important for the family to come together at a family meeting and discuss the situation (Tan, 2008, Tan et al., 2011a). It was relieving for them when family members who might have had difficulties with talking about a patient's disease could receive answers to their questions which helped them to better understand the patient and better support them (Clifford, 2014).

Patients paid special attention to their family members' feelings and reactions during and after the family meeting. They were pleased when their relatives felt comfortable and eager to participate in the family meeting (Tan, 2008). Some patients mentioned that they enjoyed the unity and harmony of those moments (Clifford, 2014). One patient expressed pure happiness because of a joint discussion among relatives and their collaboration during the encounter (Chunlestskul et al., 2008). Similarly, others also found the opening up of their relatives and the reconnections between them interesting and encouraging (Tan, 2008; Tan et al., 2011a). The new bonds developed among different family members during and after the family meeting might function as a safety net for one who would be afraid to die alone (Tan, 2008).

Sometimes participation at the family meeting brought a surprising awareness to the patients about how caring their families could be and what could worry them regarding the new situation (Tan, 2008; Chunlestskul et al., 2008; Tan et al., 2011a). Discussions and exchange of opinions during the family meeting, helped patients and family members to be better equipped for the shared decision-making (Kogan et al., 2015). In some patients' opinion, the presence at the family meeting of not only adult next-of-kin but also of teenagers and extended family could be beneficial for the family cohesion (Tan, 2008).

Being empowered

Patients' feeling of empowerment derived from different sources. The family meeting could be an initiation for joint preparation for the forthcoming death. As one patient described: "The facilitator

explained what will happen to me. They heard it all at the same time and understood..." (Chunlestskul et al., 2008, p. 11). Being informed was important. During the family meeting, patients could learn about services and health care options that they did not know about before. Knowing their own disease, its potential development and treatment options enables one to make informed decisions (Kogan et al., 2015).

Some patients had a strong feeling that a family meeting is not only about the family but also about them. They felt that they were important, and they wanted to be in control of their situation: not only that they wanted to be involved in decision-making, but also that they did not want their decisions to be overridden. The family meeting was a good opportunity to present and defend one's viewpoint. Even when not invited to the family meeting, patients were interested in what was said and decided. By instructing their relatives beforehand, they were able to influence decisions accepted at the meeting (Clifford, 2014).

Being dissatisfied

A patient complained for not receiving satisfactory answers to important questions they had prepared in advance (Clifford, 2014). Other things that can contribute to dissatisfaction were inappropriate timing and frequency of family meetings. Some patients thought that the family meeting could be more beneficial if it took place later in their disease trajectory than it did (Tan, 2008; Clifford, 2014). One patient suggested regular family meetings so it would not happen unexpectedly (Clifford, 2014). Sometimes patients did not see the family meeting as a valuable opportunity because they did not think it could bring any changes (Tan, 2008).

Being unprepared

Being unprepared can mean that one does not know what to expect from the forthcoming event (Tan, 2008). It could also mean that one is not prepared to participate openly in such an event due to different reasons. As Kogan et al. (2015) reveal, not all patients are ready to discuss end-of-life issues during the family meeting. They can feel unprepared and being pushed into an undesired situation.

For some of them, information on terminal prognosis and life expectancy is not something they would like to hear (Kogan et al., 2015). The lack of openness in the family meeting discussions could be an arduous experience (Tan, 2008). To avoid hearing distressing information, some patients decided not to participate at the family meeting or to be present just during a part of it (Clifford, 2014).

Being vulnerable

Patients felt hurt for different reasons. For patients in Clifford's (2014) study, autonomy and control over their own care were important. They felt ignored and without control when not involved in decision-making regarding a family meeting and they worried when not being invited to participate.

Although they wished to be autonomous, their family members' wellbeing was important for the patients. However, being part of a family did not just mean that one could find support when needed; it could also contribute to one's vulnerability. Sometimes patients observed their relatives being anxious in preparation for the family meeting but were not able to help them (Clifford, 2014). In other cases, they were concerned with the family members' difficulties to communicate openly during the event (Tan, 2008). It happened that the participants of a family meeting were not able to talk and found themselves in a long, uncomfortable silence (Tan, 2008). One patient was hurt because of his estranged son's tactless enquiry about his prognosis for which, in his opinion, he was not entitled (Clifford, 2014).

2.9 Family members' experiences

Being satisfied

In a similar vein as the patients, sometimes family members did not elaborate much about their positive experiences with family meetings. Their approving comments ranged from 'alright' to 'great'. They often labelled family meetings as helpful or beneficial, sometimes even more than expected. For that reason, they considered them worthwhile (Tan, 2008; Tan et al., 2011b).

Family members felt reassured and comforted when receiving information from a team of healthcare professionals, which gave them a more holistic picture of their relative's situation (Enguidanos et al., 2014; Garrouste-Orgeas et al., 2016). They felt good to be able to discuss difficult topics with someone outside their family. It was comforting for them to listen to their relatives openly talking and it was freeing to hear what they were prepared to say. The family meeting was perceived as an opportunity to talk with their loved ones about things people prefer to avoid (Tan, 2008).

A great deal of family members' satisfaction with the family meeting emerged out of its observable benefits for their relatives or for the family as a whole. They were satisfied when they could act in a way that their relative would want, for instance, having participated in a family meeting or being involved in a shared decision-making (Ho, 2013; Ho et al., 2016). It was important for them to come together and talk about everything needed together (Tan, 2008; Enguidanos et al., 2014). They felt good when a family meeting was not a frightening occasion for their sick relative (Enguidanos et al., 2014). They were pleased when their relative was able to talk openly about their wishes or express their emotions (Tan, 2008; Tan et al., 2011a; Enguidanos et al., 2014), even if what was said was somehow unusual (Tan et al., 2011a). Sometimes family members admired their relatives for their courageous conduct during a family meeting (Tan, 2008).

Being peaceful

Peace of mind and calmness after the family meeting were sometimes explicitly mentioned, and sometimes felt in family members' reflection about a family meeting. This was an opportunity for concerns to be answered (Parker et al., 2016). Good explanation brought relief even when healthcare professionals could not promise a patient's recovery. Afterwards, it was easier to realise and accept the situation (Tan, 2008; Enguidanos et al., 2014; Anderson et al., 2015; Parker et al., 2016; Garrouste-Orgeas et al., 2016).

Equally important for family members was the possibility to talk and express their concerns and feelings. This helped to ease their pain (Tan, 2008). A family meeting could bring up topics that needed

to be discussed but would otherwise be avoided (Tan, 2008). Family members sometimes felt neglected in their care for a sick relative. During a family meeting, they could discuss practical issues of their tasks and own problems, which brought them serenity despite the difficult situation (Carlsson, 2014; Parker et al., 2016; Garrouste-Orgeas et al., 2016).

A family meeting gave the family members a feeling of mutual acceptance, since everyone could express their views in an atmosphere of togetherness (Tan, 2008) and no-one had a feeling of being excluded (Enguidanos et al., 2014). Being together in a family meeting reduced distress for the family and the patient. A family meeting was an opportunity to share the burden and to receive support from other family members (Ho 2013; Carlsson, 2014).

Family members felt good to come together with the healthcare professionals and to discuss things they found important with them (Parker et al., 2016; Garrouste-Orgeas et al., 2016). Although they did not receive all the answers, they met people who were able to help them (Carlsson, 2014). Healthcare professionals' attention gave them a feeling of being cared for and protected (Garrauste-Orgeas et al., 2016).

Being enlightened

A family meeting helped family members to attentively listen to others, understand them better and to realise the situation (Tan, 2008). During the event, they acquired explanations of their relative's situation, information of care options, other people's opinions, others' wishes, even intimate details and things they would never expect to hear or asked for (Tan, 2008; Radwany et al., 2009; Enguidanos et al., 2014; Carlsson, 2014; Garrauste-Orgeas et al., 2016). They witnessed the hidden inner battles of their relatives. All this helped them to be more aware of other people and to recognise and appreciate each other (Tan, 2008). It enabled them to focus on what was the most important in the battle against time (Enguidanos et al., 2014).

Being dissatisfied

Family members sometimes thought that a family meeting was not useful and that they did not receive the required information (Tan, 2008). Some families were too embarrassed to ask for explanations for things they did not understand (Anderson et al., 2015). It was disappointing for them when certain things were unsaid, and frustrating when they perceived the event as a 'sorting out' of participants' personal issues. Some of them did not see that a family meeting could bring some changes in the future (Tan, 2008). It was not possible to remove all concerns; for instance, some worries on how to deal with financial problems still remained (Fukui et al., 2013).

Sometimes, family members thought that a family meeting happened too late in their relative's disease trajectory to be of help (Enguidanos et al., 2014). They did not expect that their relative's viewpoint could be changed towards the end of their life (Tan, 2008).

Being helpless

Family members did not ask or say certain things during the family meeting because they were afraid that they could offend their relatives or simply they did not feel comfortable to say everything or even speak in front of others (Tan, 2008; Carlsson, 2014). Sometimes, when they decided to speak openly, they had a feeling that this was not accepted well in their family circle (Tan, 2008).

To observe their sick relatives' distress and to know that they could not change this, made family members feel helpless (Tan, 2008). Sometimes they would like to protect their relatives from sadness and on other occasions from too open communication and emotional outbursts of other participants (Tan, 2008; Tan et al., 2011a; Enguidanos et al., 2014). They felt sorrow for their loved ones who were facing death and silently admired them for their courage (Tan, 2008).

Being unprepared

It happened that a family meeting came at the time when family members thought that the situation was under control and that their relative would get better and went home. Family members were unprepared and surprised. The rush of healthcare professionals and their neglect of family members'

need for adequate information was not helpful in such situations. On the contrary, the family felt that they were not given enough time to understand and adapt (Radwany et al., 2009).

When the family meeting took place at an inappropriate time, family members had problems realising the seriousness of the situation (Carlsson, 2014). Even when this was not the case, they needed time to contemplate the discussion of the family meeting. Sometimes they had difficulties realising whether it was appropriate to talk about death or not (Tan et al., 2011a).

2.10 Healthcare professionals' experiences

Being helpful

General practitioners working in nursing homes felt that family meetings positively contributed to their patients' well-being. They describe family meetings as positive, worthwhile, meaningful, nice, even fabulous (Tuckett et al., 2015). Hospice and palliative care hospital nurses thought that a family meeting was helpful and should be offered soon after the admission (Hudson et al., 2009). Similarly, in the opinion of physicians, family meetings were perceived as an essential part of palliative care in nursing homes (Tuckett et al., 2015).

Nurses saw themselves as potential advocates for patients and families due to establishing a good relationship with them during the considerable amount of time spent with them, and as healthcare professionals who are able to interpret medical jargon for the patients and families so they could understand what was said at a family meeting (Ahluwalia et al., 2016).

For some physicians, the most important thing that they could contribute to the family meeting was their medical knowledge (Marchand & Kushner, 1997). Others also acknowledged the importance of their psychosocial support and the time spent sitting and listening to the families (Tuckett et al., 2015). Mostly, they perceive themselves as the ones who are able to provide different information, e.g. medical, end-of-life, care options and to give prognostic explanations (Marchand & Kushner, 1997; Tuckett et al., 2015).

A social worker explained that health care professionals organised a family meeting to stimulate the physician to engage with the family and speak with them (Kryworuchko et al., 2012). In the majority of cases, the patient's healthcare team invited different professionals to help them to conduct a family meeting without the families' knowledge (Kryworuchko et al., 2012).

In the healthcare professionals' opinion, they could help families and patients to harmonise their opinion during a family meeting. Sometimes, their decision was to organise a family meeting just for family members to enable them a safe place for openness and honesty in their expressions. A family meeting was also perceived as an opportunity to support families by acknowledging their contribution (Meeker et al., 2015).

In the healthcare professionals' opinion, a family meeting helped families meet the multidisciplinary team and receive information. Families had the opportunity to ask questions, express opinions and vent feelings. They could gain certainty in a new situation and sort out things between themselves (Hudson et al., 2009; Tuckett et al., 2014). Since healthcare professionals were able to get to know the families better, they could provide the right information, which improved families' understanding and helped them to avoid misconceptions (Marchand & Kushner, 1997; Meeker et al., 2015). Healthcare professionals could prevent unnecessary suffering through the family meeting discussions (Meeker et al., 2015). A family meeting was time for reaching a consensus, shared decision-making and planning the future care and activities (Marchand & Kushner, 1997; Meeker et al., 2015; Tuckett et al., 2014). Healthcare professionals could provide new perspectives and contribute to a bigger picture, which helped families in their planning (Roze des Ordons et al., 2015).

Being supported

Healthcare professionals, predominantly physicians, listed different prerequisites, which helped them to be successful at a family meeting. Firstly, they admitted the importance of adequate training to acquire knowledge and skills (Tuckett et al., 2015). It was also important for them to have some backup when they started to practice family meetings (Marchand & Kushner, 1997). A family meeting needed

preparation. This included time planning, provision of an adequate place, and funding. A formalized framework enabled healthcare professionals not to miss something and to identify the major problems. Documentation helped physicians to find adequate information when needed (Tuckett et al., 2015).

Physicians also expressed their need for help from other healthcare professionals. In general, a team was a key dimension of a good family meeting (Tuckett et al., 2014; Tuckett et al., 2015). A competent and experienced person who was good at dealing with a team, coordination, delegating, and organising was perceived as good help. Nurses were valued for their knowledge of the patients and family situations as well as for their organisational skills and note-taking (Tuckett et al., 2015). Similarly, social workers were also perceived as helpful in organizing and facilitating family meetings (Marchand & Kushner, 1997; Tuckett et al., 2015; Roze des Ordonns et al., 2015).

Physicians working in the nursing homes admitted that they did not know patients and families as well as nurses. They relied heavily on what nurses told them. A team approach was valued as a way to receive different perspectives of patients' and families' needs (Tuckett et al., 2014).

Being efficient

A family meeting was perceived as an opportunity to gather family members and talk to all of them at once instead of over many occurrences (Marchand & Kushner, 1997; Tuckett et al., 2015). To be as efficient as possible, physicians suggested careful planning of family meetings. It was useful if participants brought a list of questions with them. As mentioned before, it was perceived as useful to also have a general framework that covered all of the important topics to be addressed. The right timing was important because things could change, and when this happened, the family meeting needed to be repeated once again to address the same things (Tuckett et al., 2015). A family meeting should be planned, and it should be made clear how long it would take (Hudson et al., 2009). If the family meeting lasted too long, healthcare professionals suggested to conclude it and decide to hold another one (Tuckett et al., 2015).

In the physicians' opinion, nurses could save their time by organising a family meeting. Physicians also saved their time by participating only at the beginning of a family meeting, to ask questions, acquire answers and answer family's questions, with nurses taking the initiative later on. Sometimes, technology could be a reasonable solution; use of a telephone for a family meeting had a time-saving quality, as well as teleconferencing and filling out forms on a computer instead of writing them down. Documentation needed to be done appropriately, best done during the family meeting. Good documentation enabled the healthcare professionals to quickly find the required information, such as who was present, or what the outcomes were (Tuckett et al., 2015).

Being unsupported

Nurses felt unsupported in their ambition to actively participate in a family meeting. They knew the patients and their families well and they knew how to talk with them and explain information given to them by the physicians. Instead, they were asked to take notes or occasionally express their opinion at the family meeting. They were also offered the role of organisers of family meetings, but they refused this role, saying that they lacked time (Ahluwalia et al., 2016).

Physicians had constant difficulties in organising their time appropriately, but despite that, they were not able to claim for more time. Because of this, sometimes they decided not to participate at family meetings. On other occasions, they did not attend because they concluded the whole thing was not worth their time due to poor remuneration for the family meetings (Tuckett et al., 2015).

General practitioners who worked in nursing homes explained that they receive poor remuneration for difficult and time-consuming work; conducting family meetings was not financially attractive. In their opinion, they could earn more by sitting in their outpatient practice examining patients (Tuckett et al., 2014). They complained that the biggest problem was the lack of time available (Tuckett et al., 2015). Lack of time and an appropriate place were also mentioned as barriers to having a family meeting in an outpatient setting. Managers did not support the provision of family meetings because they were not financially interesting enough (Marchand & Kushner, 1997).

Being distressed

Nurses felt restricted and frustrated at family meetings. They held information about the patients and knew patients' complaints but were not included in a family meeting discussion. They felt that they were not allowed to contradict what physicians said. They were stuck in a disapproving observation of physicians' mixed messages sent to the patients and their families, which often caused confusion in care plans and additional work. When nurses were asked to discuss a prognosis with patients, they knew that this was beyond their competences and avoided doing it (Ahluwalia et al., 2016).

In the time-constrained framework of a family meeting, it was difficult to let people talk, as they needed (Hudson et al., 2009). Sometime, healthcare professionals experienced distress as a result of family members' expectations. Relatives came to the family meeting with their own views, sometimes with unreasonable expectations. They came with feelings of guilt or in an overly sensitive emotional state. It was difficult to conduct a family meeting when there was an obvious conflict between siblings (Tuckett et al., 2014; Tuckett et al., 2015). Families were sometimes hostile. This prevented problem-solving (Tuckett et al., 2015). When family members behaved aggressively, it was very difficult to manage the whole situation (Shahid et al., 2013; Tuckett et al., 2014).

For some physicians, it was not easy to work in a nursing home, not least because family members experienced difficulties realising that their relative was approaching the end of their life. The realisation that a nursing home is an environment where the majority of patients die and that they were unable to change this outcome was also difficult for the physicians (Tuckett et al., 2014).

Being unprepared

In an earlier article about family meetings, physicians mentioned that they lacked role models for facilitating a family meeting (Marchand & Kushner, 1997). More recently, general practitioners reported that their younger colleagues did not like to work in the technologically unsupported and uncontrolled environment of nursing homes. Consequently, older physicians conducted family meetings with older residents of nursing homes and their relatives (Tuckett et al., 2014). In general,

the majority of physicians felt better partaking in medical therapeutics than in psychosocial dynamics (Marchand & Kushner, 1997). Therefore, during a family meeting it could be difficult for them to adapt from medical management to feelings and emotions. That they admitted to feeling somehow inadequate in managing palliative care family meetings was not a surprise (Tuckett et al., 2015).

2.11 The meaning of a palliative care family meeting

What is the meaning of family meetings for different participants, patients, family members and healthcare professionals? What is their being?

As human beings, we are immersed in the world to the point that we cannot distinguish ourselves from it (Blattner, 2006). As such, we are always in the world with others. We understand each other through our common humanity (Galvin, 2021).

Human beings live in complex networks of contexts. The 'sight' that guides us in our dealings in the world is guided by the totality of assignments that contextualise our task. It is guided by the in-order-to relations. These relations define what kind of equipment we need and what we need to do to finish our task. The structure of the involvement of the in-orders-to leads to the for-the-sake-of, which pertains to the being of human beings (Blattner, 2006). For instance, when we talk about family meetings, we can say that, in-order-to get to know healthcare professionals who take care of their relative, and in-order-to contribute to their relative's health care, as well as in-order-to make their relative satisfied, family members participate in a family meeting for-the-sake-of being a loving relative. Similarly, healthcare professionals did whatever was necessary; for example, they organised and led family meetings to be good healthcare professionals, namely experts in helping their patients.

Others' lives matter to us (Blattner, 2006). "Thus as being-with, Dasein 'is' essentially for-the-sake-of others" (Heidegger, 1962, p. 160). Heidegger called this mattering or care for others solicitude (Blattner, 2006). In Heidegger's view, solicitude has two possibilities: leaping in and leaping ahead (Heidegger, 1962). Leaping in for the other is taking away care from the other, taking care of things for

them (Smythe, 2011). “Leaping ahead goes ahead of the other, not to take away their care, but to give it back to them” (Smythe, 2011, p. 48).

Healthcare professionals were leaping in in their wish to help patients and family members in a way that they thought was the best. Nurses felt that they know patients and their relatives and wanted to contribute at family meetings by advocating for them. Similarly, physicians knew best as to what medications patients needed, which information was useful and what the prognosis was. Family meetings were sometimes organised without certain participants’ - families’ or physicians’ - knowledge, all in the best intention to help.

Although family members as well as patients sometimes came to the family meetings with their own ideas and expectations, they were also able to help their relative “to see themselves in their care” (Smythe, 2011, p. 48). This leaping ahead kind of care for the other was done through being observant, empathising with relatives and supporting them in their endeavour. Sometimes they participated at the family meeting only to support their family member, despite the fact that participation was difficult for them.

Patients and family members perceived a family meeting as a being-with: as an opportunity to come together, discuss the situation, exchange thoughts, gather information, make shared decisions, and make plans together. They prioritised these social aspects of the family meeting over practical ones such as discharge arrangements or pain management. However, healthcare professionals did not experience a family meeting as a gathering. They perceived it more as a tool for solving practical and organisational problems with which they can do their work as efficiently as possible.

The technological approach to beings “reveals beings as resources available for our use” (Polt, 1999, p. 171). “Technology is the way of revealing” (Heidegger, 1977, p. 12), a way of seeing the world, thinking about it, and acting in it. This “is a revelation of beings... as exploitable and manipulable objects” (Polt, 1999, p. 142) which does not pertain only to the objects but also to the human beings which become human resources. Physicians were supposed to do as much work as possible in a short

time for a small payment. Nurses who knew their hierarchical position were available to take notes at the family meeting. Technology conceals the essence of being a healthcare professional. It turns it into present-at-hand beings (Thomson, 2011).

2.12 Summary

“Engaging hermeneutically with literature is distinctive” (Smythe & Spence, 2012, p. 23). It brings neither final definitions or predictions, nor does it help in developing theories (Crowther et al., 2014). It does not build up research evidence from extracted knowledge, or search for gaps in knowledge. It is about the possibility to see things in a new light, to “open new territory and reclaim taken-for-granted and forgotten meanings” (Smythe & Spence, 2012, p. 23). It is to see the already known anew, and to invite others to this journey (Smythe & Spence, 2012).

In the review I included the literature obtained by the summer of 2016, when I completed the search. My purpose in conducting the literature review was to motivate my thinking regarding the phenomenon of the family meeting in a new way. Firstly, I wanted to see the phenomenon afresh. Secondly, I tried to come to the new insights in a hermeneutic way. The literature collected until the summer of 2016 was sufficient for this, and guided my approach to the empirical work which was conducted between 2016 – 2022. Therefore, after this period, I did not update the literature review, as this reflects the knowledge that guided the subsequent stages of the research. However, I followed the publication of new articles on this topic and presented some of the later published ones in the introductory and in the discussion chapter, to contextualise this work in contemporary literature.

Although the purpose of this literature review was not to look for gaps in scientific evidence or to quantify it, it is obvious that the literature on patients’ experiences of family meetings in a palliative care context is scarce. The literature review revealed what was not disclosed previously in scientific literature and consequently stayed hidden and unreported. It broadened my understanding of the meaning of family meetings for different participants. In addition, it has provoked my previous

understanding concerning family meetings and inspired me to widen my horizons of understanding with further research of the phenomenon of the family meeting as experienced by the patients.

Chapter 3. Methods and Methodology

3.1 Introduction

This chapter presents the research aim and question which serves as a guiding idea for the choice of research methodology and methods. First, the philosophical underpinnings are outlined: the relativist ontological position and the interpretivist epistemological position. Second, the choice of hermeneutic phenomenological methodology for answering the research question is justified. Third, the study design is outlined, and the methods of this research are presented. The sampling strategy, recruitment of the participants and data collection using semi-structure interviews are presented. Fourth, the process of data analysis and interpretation is presented with the outline of my pre-understanding of the phenomenon in question as a starting point of the interpretation circle following by the data transcription process, naïve reading, crafting stories, thematic structural analysis, and interpretation leap. At the end, the trustworthiness and ethical considerations are outlined.

3.2 Research aim and question

The aim of this study is to illuminate the meaning of a family meeting for people who experienced it while receiving specialist palliative care in Slovenia. I want to look beyond the everyday understanding of the family meeting and to elicit its meaning for palliative care patients.

The research question that I want to answer in this study is: *“What is the meaning of formal palliative care family meetings and their consequences for people receiving specialist palliative care?”*

Researchers come to the study with a certain pre-understanding of the topic. Without this pre-understanding they would not be able to ask a research question (Crowther & Thomson, 2020). My research question arose from my clinical experiences as a nurse and study of the literature. In a practical sense, I was able to observe and experience the communication practices in the Slovene healthcare system and participate in the palliative care family meetings. In theoretical terms, I was expanding my knowledge of the palliative care family meeting by reading the literature.

I brought certain beliefs and philosophical assumptions to my research which influenced my decisions on what kind of problems to study, what research question to ask (Creswell, 2013), and what methodology I chose to answer the research question. It is difficult to say exactly how the philosophical assumptions relate to the overall process of research but we can perceive them as the guiding philosophy behind the research (Creswell, 2013). These philosophical assumptions pertain to ontology or beliefs about the nature of reality and to epistemology or beliefs about the nature of knowledge (Creswell, 2013; Braun & Clarke, 2013).

3.3 Choice of research methodology

3.3.1 Philosophical underpinnings of this research

Ontological position

Ontology is a philosophical assumption about reality. It determines whether or not we think reality exists independent of human practices and understanding or, on the other hand, it cannot be separated from human practices and understanding and therefore reflects human perspectives (Braun & Clarke, 2013). There are two main, essentially opposite, ontological positions, namely; realism, where there is one objective reality which exists independent of human ways of understanding, and relativism, where there are different realities which depend on human interpretation and ways of knowledge (Braun & Clarke, 2013).

In this study, I am interested in different perspectives of palliative care patients who had various experiences of palliative care family meetings within the Slovene healthcare system. In this sense, I formulated my research question. This is in line with the relativistic philosophical assumption that there is not a single human independent reality but multiple constructed ones that depend on human interpretation, ascribed meaning, context, and time (Braun & Clarke, 2013). I am not searching for a fixed and unchangeable truth about the palliative care family meeting. To pursue the aim of my research, an ontological approach is needed to ensure that various views of different participants are considered as relevant. My research project is best underpinned by relativist ontology.

Epistemological position

Epistemology is concerned with the nature of knowledge, addressing questions of what it is possible to know and how meaningful knowledge can be created (Braun & Clarke, 2013). Similarly, as in the case of the ontological position, the epistemological position can also be realist or relativist. The distinction between the two is that realists think that truth is discovered through the process of research and that it is absolute. For them, the knowledge exists independent of human practices and can be uncovered. On the other side, relativists argue that truth is created through the process of research and cannot be absolute. In their view, knowledge is co-constructed, always perspectival, and singular (Braun & Clarke, 2013).

I am not interested in the explanation of participants' actions but in the understanding of their experiences, and I tried to take this into account when formulating the research question. To obtain the narratives of the patients' experiences, I need to come close to the participants and their immediate world. In that way, I will be able to gather their individual views concerning the phenomenon being studied (Creswell, 2013). The interpretivist epistemological perspective supports my intention, since it requires the researcher to grasp the subjective meanings of social actions (Bryman, 2012). The knowledge obtained in this way is subjective, contextual, and co-constructed.

3.3.2 Methodological consideration

Choice of qualitative methodological approach

The choice of research methodology is guided by the research question and philosophical underpinnings of the research. My research question requires a qualitative approach. Qualitative research methodology grows out of the negation of positivism and objectivism of the natural science model characteristic for quantitative methodological approach, and embraces relativism, and interpretive and constructionist philosophical position (Bryman, 2012). In contrast to the quantitative methodological approach that uses numerical data, tends to be theory or hypothesis-testing, deductive in nature and tries to identify relationships between variables and to provide explanations

or predictions, qualitative methodology deals with textual data, tends to be theory generating, inductive and seeks to reach understanding through the interpretation of different meanings. Qualitative research does not provide a single answer. It is contextual and the knowledge it produces cannot be generalised although it can contribute to a general understanding of the phenomenon in question (Bryman, 2012; Braun & Clarke, 2013). Due to the fact that the aim of my research is to elicit the meaning of the palliative care family meeting out of the participants' stories, the qualitative research methodology is the right choice for that purpose.

Choice of phenomenological approach

In order to answer the research question and guide the research towards the intended aim, it is necessary to choose an appropriate qualitative approach. There are different qualitative approaches to address questions of meaning and understanding. All of them are useful to explore social phenomena but their research goals differ. Grounded theory postulates meaning as negotiated and understood through social interactions and processes (Starks & Trinidad, 2007). People are viewed to act based on the perceived meaning of experiences of social interactions (Urcia, 2021). The goal of grounded theory is to explore how people make sense of social phenomena and to develop an explanatory theory of social processes grounded within data (Starks & Trinidad, 2007). The research question of my study asks about the meaning of the experienced phenomenon. The intent is to acquire deeper understanding of the phenomenon and not to generate an explanatory theory of social processes which would be a result of using a grounded theory approach.

Discourse analysis is concerned with language and how people use it to accomplish personal, social and political goals (Starks & Trinidad, 2007). It is underpinned by the idea that meaning and reality are created through the shared use of language (Braun & Clarke, 2013). The goal of discourse analysis is to understand how language is used in social interactions to define social roles and to shape identities, relationships and activities (Starks & Trinidad, 2007). The aim of my research is the understanding of the meaning of the phenomenon for the people who experienced it and not of the language and its

use to accomplish certain goals. For that reason, discourse analysis is not the appropriate approach to elicit the answer to my research question.

Phenomenology as a research methodology is interested in peoples' lived experiences in order to describe the universal essence of a phenomenon (Creswell, 2013) or to deeper understand the meaning of experiences by exposing taken-for-granted assumptions regarding these meanings (Starks & Trinidad, 2007). The truth of the phenomenon of research is subjective and emergent (Creswell, 2013). The goal of phenomenological research is to describe or interpret the meaning of the lived experience (Creswell, 2013). In light of the above description, the phenomenological research approach seems to be the most appropriate methodology to obtain an answer to my research question, as the focus of this approach is on understanding the meaning of the phenomenon in question.

Choice of hermeneutic phenomenology

Phenomenology as a research methodology is still evolving. There are several methodological approaches or schools of phenomenology. One of the important features of phenomenology, as a research methodology, is that it is closely related to philosophy (Urcia, 2021). When contemplating my research, I firstly needed to make the decision about which one of the two approaches, namely descriptive or interpretive phenomenology, which have different philosophical backgrounds, would be most congruent with my beliefs and will be most appropriate to answer the research question.

Descriptive phenomenology is based on the teaching of Edmund Husserl, often referred as the father of phenomenology (Lavery, 2003). His approach grew out of the critique of the use of natural science methods in the study of human issues, especially in the field of psychology (Lavery, 2003). Despite the critique of the prevailing positivist view of science, Husserl himself did not completely break away from it with his recognition that reality exists independently of the human mind and can be "critically examined based on lived experience and pure consciousness" (Urcia, 2021, p. 4). The main focus of this approach is the study of phenomena as they arise in consciousness in the process of intentionally

focusing the mind on the objects of study (Laverty, 2003). In order to understand the essence of living experience as clearly as possible and to achieve objectivity, Husserl introduced a reflective process known as bracketing. Bracketing means suspending prejudices, assumptions or biases regarding the phenomenon studied (Urcia, 2021). As explained by Dibley et al. (2020), the ability to see the essential features of a phenomenon without preconceptions is a topic of discussion in phenomenology and one that often guides the choice of phenomenological research approach. The fact that I do not believe that I can suspend my preconceptions and biases about the palliative care family meeting contributed significantly to the rejection of the choice of descriptive phenomenology as the methodology for my research. Another reason for rejecting descriptive phenomenology is its focus on cognitive processes while studying the essence of a phenomenon as it occurs in consciousness (Urcia, 2021). My interest is in the understanding of a practically experienced and unarticulated meaning of the phenomenon, since we know something before we know it in our consciousness (Rapport, 2005).

Interpretive phenomenology, or hermeneutic phenomenology, is influenced by Martin Heidegger's thinking. In contrast to Husserl, Heidegger argued that bracketing preconceptions is impossible (Heidegger, 1962). On the contrary, as explained by Gadamer (2006), who expanded Heidegger's work, prejudice is a condition of knowledge because our understanding is based on our previous experiences. According to Heidegger (1962), we cannot separate our consciousness from the world and observe it objectively. The two are interconnected and understanding is the way we are, not a way we know the world (Laverty, 2003). Our involvement in the world is "a priori to conscious knowing" (Walsh, 1996, p. 232). These are the main reasons why I opted for hermeneutic phenomenological methodology in my research.

Before I present Heidegger's philosophy and hermeneutic phenomenology as the research methodology I used in my research, I would like to say a few words about interpretative phenomenological analysis (IPA). This is remarkably similar in name to interpretive phenomenology, which is another name for hermeneutic phenomenology. In terms of content, however, at first glance

it resembles descriptive phenomenology, as it similarly has "cognition as a central analytic concern" (Smith & Osborn, 2008, p. 54). But in fact, IPA shares its "concern with mental processes" (Smith & Osborn, 2008, p. 54) with different psychological approaches in its commitment to explore sense-making (Smith & Osborn, 2008). Phenomenological scholars criticise it for "lack of scholarly familiarity with relevant (primary) phenomenological literature" (van Manen, 2018, p. 1966) and deficient and superficial connection to phenomenological philosophy and hermeneutics (Giorgi, 2011). IPA's concern with psychological sense-making (Adams & van Manen, 2017) and its weak connection with Heidegger's philosophy were the main reasons why it did not seem a suitable methodology for my research.

Heidegger's phenomenological perspective

Heidegger's philosophy is holistic. He rejects the Cartesian division on self-sufficient subjects and all the rest as self-sufficient objects as well as division into the inner and outer realms of human beings (Heidegger, 1962). In his opinion, such divisions are inappropriate because they go against the basic constitution of the Dasein, which always already dwells amidst the world, in its situation (Heidegger, 1962).

"Because the usual separation between a subject with its imminent sphere and an object with its transcendent sphere – because, in general, the distinction between an inner and an outer is constructive and continually gives occasion for further constructions, we shall in the future no longer speak of a subject, of a subjective sphere, but shall understand the being to whom intentional comportments belong as Dasein, and indeed in such a way that it is precisely with the aid of intentional comportment, properly understood, that we attempt to characterize suitably the being of the Dasein, one of the Dasein's basic constitutions. The statement that the comportments of the Dasein are intentional means that the mode of being of our own self, the Dasein, is essentially such that this being, so far as it is, is always already dwelling with the extant. The idea of a subject which has intentional experiences merely inside its own sphere and is not yet outside it but encapsulated within itself is an absurdity which

misconstrues the basic ontological structure of the being that we ourselves are” (Heidegger, 1988, p. 64).

In his philosophy, Heidegger introduces the term Dasein, which denotes “this being which each of us is himself and which includes inquiring as one of the possibilities of its Being” (Heidegger, 1962, p. 27). The term which in colloquial German means “everyday human existence” is used to refer to human being (Dreyfus, 1991, p. 13), but also to the human way of being (Dreyfus, 1991, Haugeland, 2013). We, as human beings, are thrown into the world and we find ourselves in the particular world that is already arranged in a particular definite fashion (Wrathall & Murphey, 2013). We are immersed in the world, we cope within it and our fundamental experience of the world is that of familiarity (Blattner, 2006). Being-in-the-world does not mean a spatial situatedness of one entity in another entity. It means that Dasein dwells amidst the world as that which is familiar to it (Heidegger, 1962) and knows how to deal with things and human beings it encounters in this world. Dasein and the world are not separate entities, but an intertwined whole, and being-in-the-world is one of the names of human beings (Blattner, 2006).

Being-with-others is an aspect of being-in-the-world (Dreyfus, 1991). “The world of Dasein is a with-world” (Heidegger, 1962, p. 155). That means that we are always involved in a shared world. In most cases, we do not strictly separate ourselves from others. Even when we are alone, others are with us (Blattner, 2006), for example, when we think about them. The way others matter to Dasein, Heidegger (1962) calls solicitude. There are two different ways we treat others. We can dominate them and make them depend on us, which Heidegger (1962) calls leap in. But we can allow them to be authentic and empowered. This mode of solicitude refers to the existence of the other and not to their problems. Heidegger (1962) calls this leap ahead.

Other people are not the only entities that we encounter in the world. In our coping activities, we encounter things which Heidegger (1962) calls equipment. These things have a special significance for us, namely, we manipulate them and put them to use (Blattner, 2006; Harman, 2007). “Equipment is

essentially something in-order-to” (Heidegger, 1962, p. 97), it serves some purpose. When using equipment, we are immersed in our work without noticing the equipment we are using. We focus on equipment when it is broken, or it malfunctions (Blattner, 2006). Its function or purpose becomes obvious when it is unusable for its purpose (Heidegger, 1962).

Hermeneutic phenomenology as research methodology

Hermeneutic phenomenology as a qualitative research methodology goes beyond describing a phenomenon in seeking to reveal its meaning in the context of everyday life (Bynum & Varpio, 2018). It is an interpretive research methodology focused on lived experience which includes the researcher's experience into the data collection and analysis process (Bynum & Varpio, 2018). “Hermeneutic phenomenology seeks to illuminate the meaning of the phenomenon and understand the contextual forces that shapes it” (Bynum & Varpio, 2018, p. 252). Its goal is to better understand human experiences in the context of their lives. Hermeneutic phenomenology allows us to have a deeper understanding of the human experience hidden beneath the surface of our awareness and to understand how the world we live in influences this experience (Bynum & Varpio, 2018). Hermeneutic phenomenology gives voice to human experience as it is (Van der Zalm & Bergum, 2000). It illuminates human experiences and provides plausible insights helping us to better understand the world we live in (Bynum & Varpio, 2018). Hermeneutic phenomenology requires that researchers acknowledge and present their past experiences and preunderstandings as a part of the interpretive process and that openly reflect on “their subjectivity during data collection and analysis “(Bynum & Varpio, 2018, p. 252). There is no prescribed way of hermeneutic phenomenological analysis; rather, “the researcher relies on ‘cultivated thoughtfulness’” (Bynum & Varpio, 2018, p. 253) in analysing data and presenting insights. The analysis takes place in a dynamic circle of thinking, reflecting, and writing. The researcher is focused on the phenomenon and on the research question to be answered during the process of analysis. The researcher reflects and writes in an iterative circle of movement between the parts and the whole, considering how the data contribute to the evolving understanding of the phenomenon

and “how each enhances the meaning of the other” (Bynum & Varpio, 2018, p. 253). The interpretation of the phenomenon illuminates the hidden meanings that may otherwise remain unnoticed.

3.4 Study Design

This study uses a hermeneutic phenomenological approach to illuminate the meaning of the palliative care family meeting for palliative care patients. In this study the research design included:

- purposive sampling
- recruitment of participants
- data collection through semi-structure in-depth interviews
- data analysis and interpretation:
 - transcription of the interviews
 - naïve reading of transcripts
 - crafting stories
 - thematic structural analysis
 - interpretation

Prior to the start of data collection, all necessary governance and access approvals and ethical approvals were obtained, and my pre-understanding of the phenomenon was described.

3.5 Population/Setting

The study population of this phenomenological hermeneutic study comprised adult patients receiving specialist palliative care who have participated in a formal family meeting. Therefore, palliative care patients from two Slovene hospitals, with the practice of conducting formal family meetings by the palliative care team, were invited to participate in this study.

Inclusion criteria:

- Adult (18+) patients receiving specialist palliative care
- Patients who participated in at least one formal family meeting

- Patients who have mental capacity to consent to participate in the research
- Patients who have mental and physical capacity to participate in research interview
- Slovene-speakers

Exclusion criteria:

- Patients receiving specialist palliative care who are not able to give informed consent to participation
- Patients receiving specialist palliative care who are not capable to participate in a half to one-hour in-depth interview due to aggravation of their health

3.6 Sampling

In a phenomenological hermeneutic study, the researcher tries to obtain a dense description of the phenomenon. Such description can be provided by those who have already had experience of this phenomenon. Sampling is therefore purposeful (Patton, 2002; Groenewald, 2004). Individuals are selected for the study because they are able to purposefully inform an understanding of the experiences of participation in a palliative care family meeting (Creswell, 2007).

According to Creswell (2007), the number of participants in a phenomenological study can vary considerably, from one up to 325. Some authors recommend the inclusion of three to ten participants in the phenomenological study (Creswell, 2007). According to Norlyk and Harder (2010), the number of participants in different phenomenological studies ranged from one to 76. Since in phenomenological hermeneutic study theoretical saturation is not sought (Whitehead, 2004), the decision about the sample size reflected the advanced stages of disease of the participants, their willingness to participate in the study, time needed for the interpretation of the text, and preferred time of the completion of the study. In view of all the above, six palliative care patients participated in the study out of nine invited. Table 5 presents basic data about patients identified for the participation in the study, interview date, place and duration, and reasons why certain interviews did not take place.

Because participants were guaranteed anonymity and confidentiality, their names were replaced by pseudonyms. I chose the pseudonyms myself. First of all, I did not want to burden the exhausted participants, who were originally only asked to present their experiences of attending the family meeting, with additional requests. In addition, I did not want them to focus on anything other than the research question during the short time they were able to dedicate to the interview. I chose culturally appropriate personal names because personal names are, according to Edwards (2020), current governing conventions in ascribing pseudonyms in qualitative research. Names also better reflect the 'real life' situation as opposed to categories of individuals and/or numbers, e.g., Participant 4.

3.7 Recruitment of participants

Participants were purposively selected. I was looking for palliative care patients who previously participated in a family meeting to obtain their stories about the event.

3.7.1 The process of recruitment

First, the palliative care team on the research site identified a patient who had recently participated in a family meeting and would be able to participate in an interview. Second, a healthcare professional, who was not involved in the patient's care, approached the patient, gave them basic information about the research and asked them if they would be willing to participate in an interview. If the patient agreed to participate, I was informed to contact them after a couple of days to arrange for the interview under the participant's conditions.

I received contacts of nine patients who were willing to participate in the interview. Two of them were too sick to be able to participate. The third patient was unable to remember the family meeting she previously participated in. Six interviews with six older female palliative care patients took place between the autumn of 2016 and the summer of 2018. Three of the participants were in the late stages of their disease and obviously exhausted during the interview. Three interviews took place in a hospital, two in the participant's homes and one in a nursing home.

During the course of the research, I had to change my research site. Shortly after the start of recruitment at the first research site, the palliative care physician left the hospital, and as the hospital did not have a suitable replacement, the work in the department of palliative care was performed by physicians of other specialities. This meant that patients no longer received specialist palliative care, which was a prerequisite for participation in the study. However, it also had practical implications for conducting the study, as these physicians were not interested in recruiting patients. Because of this, I had to look for a new research site with a specialist palliative care team. On the new research site, recruitment began after obtaining the governance and access approval from the new hospital and ethics approval for research amendments from both the Republic of Slovenia National Medical Ethics Committee and Lancaster University.

Table 5: Basic data about patients identified for the participation in the interviews, interview date, place and duration, and reasons why certain interviews did not take place

<i>Patient pseudonyms</i>	<i>Male/female</i>	<i>Date of the interview/visit</i>	<i>Place of the interview/visit</i>	<i>Duration of the interview</i>	<i>Reasons for not interviewing</i>
Izet	M	6. 8. 2016	Hospital 1	/	I visited him at the hospital but he was not able to talk due to sudden deterioration of health
Sanja	F	16. 9. 2016	Hospital 1 – The interview took place at a table in a quiet room on the hospital ward	00:15:54	
Dragana	F	16. 9. 2016	Hospital 1 – The interview took place in the participant's hospital room. She was able to sit on the edge of her bed, leaning against the bedside table in front of an open window	00:13:10	
Angela	F	28. 3. 2017	Hospital 2 – The interview took place in	00:27:44	

			a quiet room of the hospital ward that had access to an oxygen line. The participant sat in a wheelchair. Her sister was present		
Darja	F	/	/	/	I never met her. Her daughter explained on the phone that her mother was too weak for the interview
Pavla	F	23. 6. 2017	Home – The interview took place at a kitchen table in her family's house	00:23:51	
Dora	F	13. 7. 2017	Nursing home – The interview started in a quiet corner of a common living area of the nursing home but after some disturbances we moved to the dining room and continued our conversation there	00:37:37	
Vida	F	1. 9. 2017	Nursing home	/	I visited her in the nursing home. She was not able to remember a family meeting
Helena	F	13. 6. 2018	Home – The interview took place at the kitchen table in her flat	00:19:26	

3.8 Data collection

I collected data by semi-structured conversational interviews (Kvale, 1996). At the beginning of the interview, I provided the thematic framework of the conversation, namely, the participant's family meeting experience, and encouraged the participants to talk about it. By asking additional questions, I helped them to present their experience in more detail and offer explanations. Participants spoke

Slovenian. They used their everyday language, different dialects, and slang. In three cases, the data were obtained at the hospital, in two cases at the participant's home, and once in the nursing home. Due to the poor health of the participants, the interviews were short. They lasted from about 13 minutes to 37 minutes.

3.9 Introduction of the participants

Sanja was a woman in her sixties. She had been divorced for a couple of decades. She mentioned that she had two children, but she talked only about her daughter and her family. After the divorce, she led an independent life, working and helping her daughter taking care of her child. She lived in a city in a flat located on the fifth floor. Less than a year before our interview took place, she got suddenly sick which came as a surprise for her because she was never seriously ill before. After she got sick, she was less able to take care of herself and to live alone. Her primary carer was her daughter.

Dragana was a woman in her late fifties. She lived in a bigger town. She was a labour migrant from a nearby country. She was estranged from her family members who were all located in her native country. She lived alone. Her social circle consisted mainly of her work colleagues. She could not expect any practical help from her relatives since they all had serious health problems and lived far away from her. She was still employed, on sick leave. She was not financially well off. She was already quite sick at the time of the interview, breathing hard.

Angela was a woman in her seventies. She lived in a small town in a house together with one of her sons and his family. The other son lived in another town. Her illness started approximately eight years ago. Towards the end, she had difficulty taking care for herself. Nevertheless, she tried to organise her life in such a way as to be as independent of her family as possible. For that reason, she hired a woman to help her for five days a week. She had problems with breathing and therefore needed oxygen support. She was depressed and afraid of the idea that she would need to move to a nursing home.

Pavla was in her eighties. She used to be a farmer who also raised six children. She lived in a farmhouse in a village together with one of her sons and his family. Throughout her life she worked in and with

nature, which may have been the reason for her 'matter-of-fact' attitude towards her own illness and dying. These themes seemed a natural part of her life. She had cancer. The biggest problem was ascites for which she needed help from a palliative care doctor. An important thing for her was to continue to function in a similar way to before the onset of the disease and to be useful for her family. Despite the illness, she still worked in the garden and cooked for her grandchildren.

Dora was a retired educated woman in her seventies who used to work in the public service. She was active all her life. She always enjoyed culture. She used to live on her own in a house in a bigger town. A week before the interview, she was unexpectedly forced to move to the nursing home due to the deterioration of her health and consequent inability to take care of herself. Despite the fact that she perceived this move as shocking, she mentioned that she was satisfied with the decision to be cared for by others. She was a widow. Her carers were her deceased husband's nephew and his wife.

Helena was in her seventies. She lived alone in a flat on the fifth floor of an apartment building in a small town. Her illness advanced to the point that chemotherapy was no longer feasible. She mentioned having difficulties climbing stairs due to a lack of energy. She became easily tired and was also more forgetful than she used to be. That made it difficult for her to participate in a conversation with health care professionals. She had a son who accompanied her whenever she visited the doctor and discussed her treatment on her behalf. She perceived that as a great and indispensable support.

3.10 Data analysis and interpretation

At this point, I would like to present the process of data analysis and interpretation.

Hermeneutic phenomenology is "an interpretive process that seeks to bring understanding and disclosure of phenomena" (Laverty, 2003, p. 24). The interpretation is achieved through a hermeneutic circle, a moving from the parts of experience/text to the whole and back to achieve understanding (Laverty, 2003; Debesay et al., 2007). In Heidegger's view, it is important how we enter the hermeneutic circle (Heidegger, 1962). This is because the interpretation is always influenced by the individual's cultural background and history, by their pre-understanding of the phenomenon (Laverty,

2003). For that reason, van Manen (2016) suggests using personal experience of the phenomenon as a starting point.

That is the reason why I am at this point disclosing my pre-understanding of the phenomenon of the family meeting, which, according to Koch (1995), I cannot eliminate since it is a structure of my being-in-the-world.

3.10.1 Presenting my pre-understanding as entering the hermeneutic circle of interpretation

I was professionally socialised in a paternalistic healthcare environment. As such, I used to do things for and to the patients, and less often with them. A paper that I co-authored describes the process of a family meeting (Lunder & Červ, 2014). In my opinion, a family meeting was a useful 'tool' for managing patients' and their relatives' problems, an effective way of communication, something good which could be offered to them by the healthcare professionals, who know what is best for them.

As a nurse and especially as a nursing coordinator in palliative care, I had many opportunities to observe the communication between patients and healthcare professionals and also between families and patients or healthcare professionals. I myself have also experienced communication with patients, families, and healthcare professionals. Although a lot of the time these encounters were rewarding, sometimes I found myself thinking that things could be done better or differently.

I remember one occasion when I was asked to have a conversation with a patient in our hospital regarding his imminent discharge. A physician and a nurse who contacted me seemed embarrassed when telling me that they did not talk with the patient openly about his prognosis and what he might expect at home. They hoped that I could talk with him about everything needed to prepare him for the discharge. I felt uncomfortable in this role but decided that I nevertheless could go to the patient and ask him about his perception of the situation and about what he would need in the case of the discharge. We had a really nice conversation. The patient openly talked about his disease and his prospects. He knew how sick he was, and he looked forward to going home to die. Together, we agreed that it would be good to also include his wife in that communication regarding discharge the next day,

when she was supposed to visit him. When I returned the next day, his wife was sitting on the chair beside his bed. After a short introductory conversation, the patient asked me to explain to him the nature of his disease and its future development. At first, this request seemed somehow unusual, since we had discussed exactly that same topic the day before, but then when I started to talk, I had an intuition that his request was not meant for him but for his wife. As soon as I had begun saying, "So, as we talked yesterday...", the wife jumped from her chair, grabbed my hand and pulled me out of the room. She was agitated when said to me, "Do not talk about these kinds of things in front of him. This is too much for him." She seemed very scared, too scared to hear what was going on with her husband. I tried to reassure her with a promise that I would not talk about his illness and then I went to the room to say goodbye to the patient. When I was leaving, he lay numb and resigned among the pillows. He did not seem disappointed; he seemed trapped in his own life's situation. This image made me sad. On the way out, I thought that maybe that situation could have been different if family meetings were an everyday practice on this ward – commonplace, open discussions about diagnosis and prognosis, questions and answers, plans for the future with healthcare professionals whom patients and families know and trust, consolation, and reassurance. My second thought rose from doubt because sometimes I met patients who rejected participation in a family meeting: who knows if this is really what the patients would like? Although this patient would obviously have benefited from an open conversation with healthcare professionals and his family, we cannot say that everybody would like family meetings. This is one example of how I began to think about possible research of patients' experiences with family meetings from their point of view. I was interested in their perceptions of family meetings, especially when they are approaching the end of life. I began to think about how it must be to be a patient at the end of life involved in a conversation with family and healthcare professionals about their own situation and future. How do they feel on such occasions, what such occasions mean to them and what such occasions can bring to them? I thought that hearing patients' voices might be a valuable contribution to this poorly researched topic in Slovenia.

3.10.2 The process of data analysis

There is no prescribed method in hermeneutic phenomenology regarding data analysis. Although certain authors provide useful methodological instructions (van Manen, 2014; Lindseth & Norberg, 2004), in Gadamer's (2004) view, hermeneutic phenomenology is more an approach, an emerging process of understanding things in a different way (Debesay et al., 2007), than a strict methodological guide to new knowledge. If we insist on describing the method in hermeneutic phenomenology, then perhaps Crowther (2014) best explains it as a 'messy', nonlinear process, following steps that overlap and change their order as required by the occasion. Thinking, questioning, and remaining open to possibilities is of central importance in this methodological approach (Crowther, 2014).

Since there is no prescribed way of data analysis in hermeneutic phenomenology, I decided to use a combination of different approaches of working with data to be able to answer the research question concerning the meaning of a family meeting for palliative care patients. The starting point of data analysis was the transcription of the interviews. This was followed by naïve reading of interview transcripts and crafting patients' stories. Crafted stories were then thematically analysed. Through re-reading transcribed interviews, crafted stories and the literature and re-listening to the interviews, the interpretation leap was made and a more comprehensive understanding of the phenomenon emerged.

3.10.2.1 Transcription of the interviews

The first step of the analysis started during the process of the verbatim transcription of the interview. "The transcription process induces a particular and detailed kind of listening to the original interview data" (Mann, 2016, pp. 2005). This enabled me to hear things I might not have paid attention to during the interview and to think about the possible meanings that lay beyond the speech, in the way the participants speak. The first transcription of each of the interviews was made in the Slovene language. I decided for a denaturalised approach to transcription (Oliver et al., 2005) to make transcripts more

understandable, since the participants used different dialects and slang that were also grammatically incorrect (Figure 2). Transcripts were later translated into English.

B: In s pomočjo takega pogovora, ko se lahko vsak predstavi, je potem lažje.

1: Ja, s pomočjo takega pogovora. Čustva imam pa tako zelo., človek ne joka, da bi se smilil sam sebi, ampak je treba to dati ven iz sebe. Psihično, psihološko sem bila samostojna, vedno sem si znala pomagati. Kar se tega tiče sem zelo trda, pa še glede drugih stvari. Petindvajset let sem bila poročena in sem marsikaj prestala, tako da sem otrdela. Veste kako je ko se človek življenjsko utrdi?

B: Ja, ja, ja.

1: Do 60. leta ni bilo z mano nič narobe, nič nisem bila bolna.

B: Do 60. leta niste bila bolna?

1: Ne, nisem bila bolna, nisem jemala zdravil, ničesar. Ne do 60., do 62. decembra. Februarja pa sem začutila bolezen. Lahko si mislite kakšen šok je bil to zame. Nikoli nisem bila v bolnišnici, razen 8 dni. Tri dni za sina, ki sem ga rodila v bolnišnici in 5 dni za hčerko. To je vse, kar sem bila v svojem življenju v bolnišnici.

B: Če prav razumem, vas je življenje prisililo v to, da ste morala biti dokaj samostojna.

1: Ja, ja.

Figure 2: Example of a part of a transcribed interview in the Slovene language

3.10.2.2 Naïve reading

I listened to the interview recording several times during the transcription process and then read the transcript several times over to grasp the general meaning of the whole. This was the first attempt to “switch from natural attitude to phenomenological attitude” (Lindseth & Norberg, 2004, pp.149). Although Lindseth and Norberg (2004) suggest the use of phenomenological language to formulate the naïve understanding, I decided to use ordinary language (Figure 3). Nevertheless, my naïve understanding of the text in some way guided the next step of analysis where I crafted the stories.

DATA ANALYSIS FORM-2-INTERVIEW 1-E-1

<i>Interview</i>	<i>Date of analysis</i>
1	
<i>Naïve understanding</i>	
A 62 years old female patient who led independent life and was never sick become dependent upon her daughter’s help due to serious illness. It was very difficult for her to adopt to a new situation. The family meeting brought new insights into her relationship with her daughter and helped them to come to an agreement concerning future life in the shadow of a terminal disease. They were able to understand each other better and they were able to start with practical arrangements as well as with relationship rearrangements and identity shifts.	

Figure 3: Example of naïve understanding of the audio-recorded interview and its transcript

3.10.2.3 Crafting stories

Crafting stories from the transcribed interviews was the next step of the interpretive analysis. This was another way of working with data to help understanding to evolve (Crowther et al., 2017). As suggested by Crowther et al. (2017), I polished grammar and reordered sentences. I removed repetitions and irrelevant details that did not add to the story. I kept sentences that seemed to hold the meaning and were necessary for the flow of the story (Figure 4). Through this approach, I deepened my attunement with the text and started to perceive glimpses of emerging new understanding (Crowther et al., 2017).

INTERVIEW 1-3 (CRAFTED STORY 1.2)

By the time I was 62, I wasn't sick, I wasn't taking medication, nothing. Then came the disease. That was a huge shock to me. I've never been to the hospital except for the birth of my son and daughter, all together for 8 days. It was a shock to me that I was suddenly sick and needed to be treated, but I had to deal with it.

I can tell that my daughter and I were at odds when we came to a family meeting because we couldn't cope with my illness. There was disagreement between us. We both cried a lot. We cried because we could not come to terms with the fact that I would probably no longer be independent. She is my baby and I as her mom feel her fear, I feel she has experienced shock. It was a new situation for both of us.

Figure 4: Example of a part of a crafted story

3.10.2.4 Thematic structural analysis

I divided the text into meaning units, shorter parts of the text like paragraphs or sentences, which conveyed a meaning (Lindseth & Norberg, 2004). After re-listening, re-reading and reflection upon the naïve understanding and the story crafted previously, I was able to write their essential meanings in a condensed way. After considering the condensed meaning units, the next step was the abstract formulation of sub-themes (Lindseth & Norberg, 2004). I tried to capture the mood of the narrative when thinking about the main themes, since the mood reveals how we are in-the-world (Heidegger, 1962; Blattner, 2006) (Figure 5). Somewhere at this stage of the analysis, the first outline of the structure of understanding of what was 'hidden' in the text, which had previously only been hinted at, began to become clearer.

<i>Meaning units</i>	<i>Condensed meaning units</i>	<i>Sub-themes</i>	<i>Themes</i>
By the time I was 62, I wasn't sick, I wasn't taking medication, nothing. Then came the disease. That was a huge shock to me. I've never been to the hospital except for the birth of my son and daughter, all together for 8 days. It was a shock to me that I was suddenly sick and needed to be treated, but I had to deal with it.	A quick change from health to illness was shocking	The feeling of being changed	Being different
I can tell that my daughter and I were at odds when we came to a family meeting because we couldn't cope with my illness. There was disagreement between us. We both cried a lot. We	It is difficult to face up with disease and dependency	The feeling of being dependent upon others	Being vulnerable

Figure 5: Example of thematic structural analysis

3.10.2.5. Interpretation

“When we have to do with anything, the mere seeing of the Things which are closest to us bears in itself the structure of interpretation...” (Heidegger, 1962, p. 190). The first thing that the mind does is interpreting and we continue with it while coping within ordinary contexts. I was continuously engaged interpretively throughout my research project, without paying special attention to it. At this stage of the analysis, I began to make a conscious effort to be able to perceive the hidden meaning of the phenomenon. I went back to re-listening to the recordings of the interviews because they were hiding nuances that were not noticeable in the written stories and themes. I also returned to re-reading seminal and secondary texts of Heidegger’s works and other related authors (Crowther & Thomson, 2020) and re-listening to lectures related to the explanations of Heidegger’s philosophy. I was writing simple drafts, but I put the most effort into trying to stay within the data and capture their complexity (Smythe & Spence, 2020). I tried to internalise the research data and philosophical teachings, contemplating the whole and the parts of interviews or a theme across the interviews and in every one of them, and stayed in this iterative process until meaning, unspoken in my data, began to emerge.

3.11 Trustworthiness

Since the research method is not prescribed in hermeneutic phenomenology, it is necessary for the researcher to think through and harmonise each step of the research, from the formulation of the research question to the interpretation of the findings, with the philosophical underpinnings of the study. Congruence of the study design with the relativist interpretivist philosophical assumptions in general and hermeneutic phenomenology in particular was the basis for the methodological rigour of my research.

As an inexperienced qualitative researcher, in order to ensure the rigour of my research, I first decided on the criteria that Lincoln and Guba derived in 1981 from the criteria for rigour in quantitative research (Guba & Lincoln, 2000). For judging the trustworthiness of findings in qualitative research

they suggest four criteria: credibility, transferability, dependability, and confirmability (Guba and Lincoln, 2000).

Credibility

We can talk about the credibility of the research when it is carried out in accordance with the canon of good research practice and when the research participants can confirm that the researcher correctly understood their stories (Bryman, 2012). Koch (2006) suggests that for this purpose researchers describe and interpret their experience as researchers and inquire with the research participants how they see the findings, and whether the findings correctly reflect their reality (Guba & Lincoln, 2000). In order to make my research credible, I presented my research experience. For practical and ethical reasons, I could not share the interview transcripts or the results of the research with the participants due to the rapid deterioration of their health. On the other hand, according to some authors, returning interviews or analysed data to the participants for verification and assessment can be methodologically unsuited in a hermeneutic phenomenological study (McConnell-Henry et al., 2011; Alsaigh & Coyne, 2021). de Witt and Ploeg (2006) talk about philosophical inconsistency when credibility, as a criterion of rigour with its underlying assumption of the search for a single truth as the goal of research, is used in an interpretive phenomenological study, where the research goal is a better understanding of the multiple interpretations of meanings of lived experience and there is no absolute truth (de Witt & Ploeg, 2006; Young, 2011).

Transferability

Transferability refers to the reader's ability to judge, after examining the research, whether the findings could be transferred to a new context (Dibley et al., 2020). Such a decision is possible if the original context is adequately described (Koch, 2006). Guba and Lincoln (2000, p. 377) suggest enough "thick description", i.e. rich account of the context to make such judgement possible. My purpose was to present the broader context in which the participants in my research lived, as well as the narrower context of their existence as seriously ill persons. I described the Slovene healthcare system and the

relationships within it, as well as the palliative care system and the lack of interest for researching the topic of the patients' family meeting experiences. I also presented the research participants in sociodemographic terms, as well as their experience of the disease and relationships with significant others.

Dependability

Dependability refers to the extent to which a study can be replicated (Dibley et al., 2020). It is therefore suggested that "records are kept of all phases of the research process" (Bryman, 2012, p. 392), since a clear description of the research process allows the reader to follow the decision path used by the researcher (Koch, 2006). In the Methods and methodology chapter, I presented the research goal and question, as well as the philosophical underpinnings of the research. In addition, I described in detail the inclusion and exclusion criteria, sampling and recruitment process, and data collection process. I also explicated my decisions, and their justification, during the research process. Auditability as an expression of rigour in hermeneutic phenomenological study is seen by de Witt and Ploeg (2006) as methodological inconsistency since this generic qualitative criterion of quality competes with another more concealed expression of rigour specific for interpretive phenomenology, namely, the depth of insight which is elicited by reading the study findings.

Confirmability

Researchers must be able to demonstrate that the findings are derived from the data and not simply from their own presuppositions (Dibley et al., 2020). For that reason, robust description of the analysis process, presentation of biases and prejudices, and verbatim extracts from the research data are suggested (Dibley et al., 2020). According to de Witt and Ploeg (2006), confirmability as an expression of neutrality or freedom from bias is another criterion which is philosophically inconsistent with hermeneutic phenomenology since such studies are not value-free. In fact, researchers' preconceptions are incorporated in the study findings (de Witt & Ploeg, 2006). To achieve confirmability criterion, I presented my preunderstanding of the phenomenon in question and then

the process of data analysis, namely, transcription of the interviews, naïve reading, story crafting, and thematic analysis. Finally, I described the process of interpretation. I used verbatim extracts to present participant voices and to enable readers to judge my analysis and interpretation process.

Due to the inability to fully comply with all the generic criteria of rigor in qualitative research and due to the philosophical and methodological inconsistencies of these criteria with a hermeneutic phenomenological approach, I also followed specific recommendations for ensuring rigour in hermeneutic phenomenological research (de Witt & Ploeg, 2006). The components of the expressions of rigor proposed for interpretive phenomenology are: balanced integration, openness, concreteness, resonance, and actualisation (de Witt & Ploeg, 2006; Dibley et al., 2020).

Balanced integration

Balanced integration refers to those considerations which concern philosophical matters and their integration in interpretive phenomenology. Three characteristics are important here: firstly, “articulation of the general philosophical theme and its fit with the researcher and the research topic” (de Witt & Ploeg, 2006, p. 224); secondly, “intertwining of philosophical concepts with the study methods and findings” (de Witt & Ploeg, 2006, p. 224); thirdly, “balance between the voices of study participants and the philosophical explanations” (de Witt & Ploeg, 2006, p. 224). I presented the philosophical underpinnings of my research and justify their choice, as well as the incorporation of philosophical concepts in my study. In the Findings and Discussion chapter, I presented participants’ voices in the light of hermeneutic phenomenology.

Openness

This expression of rigour relates to the systematic explicit process of considering the many decisions made throughout the study process (de Witt & Ploeg, 2006). The presentation of these decisions and their justification allows the study to be opened up for scrutiny of the readers (de Witt & Ploeg, 2006). I tried to clearly describe the research process and made it open for critical examination. I presented the most important decisions made during the research process and the reasons for those decisions.

Concreteness

“Concreteness reflects the relationship between findings and the real world” (Dibley et al., 2020, p. 154). When reading the findings, the readers are situated “in the context of the phenomenon” (de Witt & Ploeg, 2006, p. 225), and able to associate the phenomenon with “experiences in their lifeworld” (de Witt & Ploeg, 2006, p. 225). I tried to present research findings in a way that enables readers to link the findings with their life experiences, that they can better understand people at the end of life out of their own experiences of uncertainty and fragility.

Resonance

This expression “refers to the impact the findings have on readers” (Dibley et al., 2020, p. 154) and how meaningful they find them. It encompasses the experiential insight that the reader achieves when reading the findings (de Witt & Ploeg, 2006). The findings resonate with the reader’s lived experiences. For me, the interpretation process was a reminder of our common humanity (Galvin, 2021). I hope that readers will understand my interpretive insights as something meaningful, something that resonates with who they are and how they understand the world and themselves.

Actualisation

Actualisation refers to the impact that the findings will have in the future (Dibley et al., 2020). Because phenomenological interpretation is never-ending, the findings will continue to be interpreted by future readers, which will lead to new insights and consequences (de Witt & Ploeg, 2006; Dibley, 2020).

3.12 Ethical issues

3.12.1 Attitude towards seriously ill patients

Patients invited to participate in this study were in an advanced stage of disease with a considerable symptom burden and low level of energy. There is a debate among palliative care researchers about whether or not it is appropriate to label palliative care patients as vulnerable and whether studying such patients is justifiable (Duke & Bennett, 2010). On the other side, there is the opinion that

researchers are not supposed to act paternalistically and make decisions on behalf of patients but that they should rather be as inclusive as possible (Duke & Bennett, 2010). The patients were approached as fragile human beings capable of making decisions on their own. I paid attention to the problems and needs of the participants who decided to take part in the research, and I tried to provide an appropriate environment that allowed them to tell their story during the interview meeting. As established by Duke and Bennett (2010), the opportunity to participate in the study or to tell the story brings hope and meaning to participants who, when seriously ill, often want to participate in research.

3.12.2 The practicalities of participants' recruitment and data collection

Patients who would be able to participate in the study were selected by their palliative care physician who then informed the research nurse who then contacted the patients directly and asked them if they would be interested in participating in research. The research nurse was asked not to emphasise the importance of the study for palliative care knowledge and practice since it could lead to feelings of coercion in patients. Patients were told that their decision would not affect their health care. If they showed interest to participate, they were given written materials. They had the opportunity to read the materials and ask additional questions. After a few days, patients were contacted by me to communicate their decision regarding their participation in the study. They were given the opportunity to choose the time and the place of the interview most suitable for them. The consent form was completed at the interview meeting where the participant had the opportunity to talk with me and ask questions before the start of the interview. The participants were informed that they could withdraw from the study whenever they chose to do so and that their withdrawal would not affect their health care.

3.12.3 Anonymity and confidentiality

Patients were informed that their participation in the study was voluntary and that anonymity and confidentiality would be secured for any information they would provide during the interviews. That meant that any information which may make the participant recognisable would be changed and

pseudonyms would be used in the research report. The interviews were transcribed and coded by me to secure anonymity of the participants and confidentiality. Anonymised data in the English language were available to the research supervisors.

3.12.4 Handling in the case of harm to the participant

While there was no expectation of physical harm to participants during the interview meeting, the very effort of talking to the researcher may exacerbate their physical condition (Whiting & Vickers, 2010). I was attentive to signs of tiredness or breathlessness in participants and gave them the opportunity to rest or cut the interview short if needed. Participants can experience psychological distress and anxiety (Whiting & Vickers, 2010) due to the sensitive topic of the interview. They were given enough time to become calm and the opportunity to continue or to conclude the interview. In the event of feeling distressed as a result of taking part in the study, they were given the contact number of a qualified professional for assistance. Participants who wanted to make a complaint or raise a concern about any aspect of the research and did not want to speak to me had the opportunity to contact their palliative care physician, the patients' ombudsman in their region, the research director at the Division of Health Research at Lancaster University or the Associate Dean for Research at Lancaster University Faculty of Health and Medicine, when they would prefer to speak to somebody outside the Palliative Care Doctorate Programme at Lancaster University.

3.12.5 Informed decision and power balance

The main question of the interview was provided in the participant information sheet. That enabled the potential participant to make an informed decision regarding participation in the study and to think about a narrative in advance. Data were gathered by an in-depth face-to-face audio-recorded interview performed in a conversational manner at the participant's pace to balance the power relations between the participant and myself as the researcher as much as possible (Kvale, 1996). For the same reason, the participants themselves chose the time and place of the interview meeting.

3.12.6 Gaining ethical approval

For this research, I firstly received a governance and access approval from the first research site, the ethics approval from the Republic of Slovenia National Medical Ethics Committee, and the ethics approval from the Faculty of Health and Medicine Research Ethics Committee at the Lancaster University and started interviewing there. Later, when I needed to move to another hospital to be able to continue my research project due to organisational difficulties at my first research site, I received a similar approval from the second research site, an additional approval for the research amendment to my previous research project from the Republic of Slovenia National Medical Ethics Committee, and an additional ethics approval for the amendment to my research project from the Faculty of Health and Medicine research Ethics Committee at the Lancaster University. These approvals were obtained prior to the start of data collection.

3.13 Summary

This chapter presented the research question, the aim of the study and the philosophical underpinnings of hermeneutic phenomenological research approach, as well as a hermeneutic phenomenological research methodology selected to answer the research question. The study design and the explication of sampling strategy, recruitment of participants and data collection were outlined. My preunderstanding of the phenomenon in question was presented, as it is considered a starting point of the hermeneutic circle of interpretation. The process of data analysis and interpretation was described. Further on, my attempt to follow the criteria for research rigour was explained. At the end, ethical considerations in researching palliative care patients and ethical approvals needed to execute my research were presented.

Chapter 4. Findings

4.1 Introduction

This chapter presents the findings that were identified in the process of crafting stories and in the thematic structural analysis of the data. Three main themes were identified. The first theme was ‘the palliative care meeting as a tool’ which was experienced in two opposing ways: as useful, and as unhelpful. The second theme was ‘the importance of other people’ whose care was perceived in two ways: as supportive and helpful, and as unsupportive. The third theme was ‘the sick human beings in changing circumstances’.

4.2 The palliative care family meeting as a tool

One way of perceiving a family meeting by the participants was seeing it as an instrument for achieving certain goals. In this regard, the family meeting could be more or less useful. During my interviews with palliative care patients, it was often perceived and described as useful.

The family meeting as useful

The broad aim of the family meeting was ensuring patients’ safety as their health worsened in the future. Namely, because their health deteriorated irrevocably, they were not able to live independently as they used to do. During the family meeting, the participants tried to find a viable solution for the future, oftentimes starting with a general discussion about the future way of living for the patient. Dragana, Angela and Dora mentioned this general aim of the family meeting.

We had a general discussion about my future. (Dragana)

Our conversation was about how my life will be in the future. What and where will be the best for me considering my illness. (Angela)

We talked about my view of life in the future after I fell. (Dora)

The family meeting was an opportunity to discuss the necessity and possibility to move to the nursing home. It was a reminder that some kind of solution is needed to enable a person as safe and as

comfortable a life as possible after leaving the hospital. Even though Dragana did not want to think about leaving the hospital as she did not have a social support network and the option to move to the nursing home was too demanding for her in her last weeks of life, she participated in the debate about that possibility. Sanja thankfully accepted the help of her daughter and the social worker in searching for the nursing home because she was not able to help herself and because she knew she was too sick to live on her own. Angela briefly explained that it has been suggested to her to start thinking about moving to the nursing home in the future. Dora was grateful for such a suggestion, which helped her in the decision she needed to make before discharge from the hospital.

We discussed a nursing home. We talked about how to help me personally. For instance, to take care of me until we will know what is wrong with me and then further. Nursing homes are cheaper in Bosnia but I would need to arrange all the other things...and this will take time. (Dragana)

The social worker and my daughter are trying to find me a nursing home. I need to go there because I have nowhere to go. I live on the fifth floor; my heart is weak and I cannot live alone so they try to find a nursing home for me. We agreed that the nursing home would be the best solution for me. (Sanja)

We talked about it being best for me to go to the nursing home. (Angela)

I never thought that I would need to go to the nursing home, but I am grateful that they suggested this decision to me. (Dora)

Dora perceived the family meeting as a rare occasion to express her views and feelings in a safe environment, and to share them with all the important persons at once.

I liked it that I had the opportunity to share my views about life... and my feelings....

Everyone heard what I said... They all heard the same thing first hand. (Dora)

For Dora, the family meeting was a time for expressing her preferences and making decisions about health care in the future, which would hopefully be respected.

They asked me whether I would prefer to make difficult decisions about health care myself or would I leave decisions to the doctors.... I will try to arrange a meeting with my family doctor and ask her to write down my wishes. (Dora)

For Pavla, the family meeting was the opportunity to discuss a troublesome symptom and possible treatment. Such discussion helped her to better understand her situation and the treatment, and to be able to organize her life.

We didn't talk much because I had no pain. We only discussed the fluid [ascites]... I wanted this drainage because it's not pleasant to have water in your belly. But the doctor said that it is better to make a puncture from time to time.... I accepted that. It was good that he told me that.... Now I will visit him every two weeks if the water will bother me. (Interviewer: The discussion helped you to better understand the situation and to decide when is the best time to visit your doctor again?) Yes, yes, exactly.... Now everything is flowing as it should. Whenever I need him, I call him. I don't have another doctor. (Pavla)

Helena found it useful to get new knowledge about the medicines, about how they affect her and about their side effects. She was able to collaborate with the doctor regarding the appropriate dosage of her "powerful medicines" by presenting him with the side effects.

We talked about how I feel, about my treatment, and my drugs, how I take my pain medications...then he adjusted my therapy the last time.... The clarification regarding my medicines was useful... He explained to me how the medicines affect me. He asked me whether I understand the effects of the medicines. I didn't read about the side effects because I then would rather not take them. And then he explained to me how medicines affect me. I think it was the most useful that he told me that. (Helena)

For Sanja, the family meeting brought alleviation in tense relationships with her daughter due to problems emerging with the onset of her illness. At first, they both had problems adapting to a new situation. After the family meeting, they were able to better understand each other and accept their situation.

I was on bad terms with my daughter because we couldn't accept my illness. We cried a lot during the family meeting but towards the end we got closer, we understood each other. (Sanja)

The family meeting as unhelpful

Although the participants were never openly critical about the usefulness of the family meeting, there was sometimes a feeling of an air of slight disappointment in their way of talking about it or just a lack of otherwise oftentimes expressed enthusiasm about it.

Dragana had an advanced disease. She participated in the family meeting with the two of her sisters. Although healthcare professionals wanted to help her by discussing her transfer to the nursing home, this was annoying for her, since she knew she had no strength to obtain all the necessary documents. All she wanted was to stay in the hospital where she felt supported and safe. The topic of the family meeting was somehow irrelevant for her, but she did not want to oppose healthcare professionals or her relatives and decided to participate in the discussion.

We talked about how they [healthcare professionals] would help me and take care of me until it became clear how it was with me. Then we'll move on, because, you know, I'm still employed. I'm still working.... Everything is cheaper in Bosnia, but you should arrange various things. We also talked about this with a social worker. That would take some time.... It is necessary to arrange different documents and arrange where I will be and how I will be, various things. I don't know yet.... I would like to take care of myself, but.... Let them heal me here [in the hospital] first because they take really good care of me. (Dragana)

Although Angela participated in the discussion about going to the nursing home after the discharge from the hospital, she personally contemplated another solution. Namely, since she was afraid to go to the nursing home due to weakened immunity, she preoccupied herself with a question of how she could hire a person who could help her and take care of her in her home. The focus of the family meeting discussion on her transfer to the nursing home left her dissatisfied. The family meeting did not bring the solutions that she would prefer at that moment of her life.

It's been five years since my health deteriorated so much that I realised I was going to have to go to a nursing home. I was always afraid of the moment when I would really have to go there.... Maybe I can do it at home. I now found out about three women. Each commit to help for three months.... The woman they help is very satisfied with them, even though they take turns. So, I decided to try to contact them to see what it would be like if I really had three months of help provided 24 hours a day. I only recently found out about these women.... I didn't even know before that they could come to the help. I used to think the only solution was a nursing home. (Angela)

During the interview, Helena mentioned that she would like to know how long she would live. Despite this wish, she never asked the doctor at the family meeting about the prognosis of her disease because she did not want to upset her son with this question, who did not want to accept her dying. Unfortunately, healthcare professionals never asked her whether she would like to know the prognosis nor started a conversation about it. The family meeting was a lost opportunity for answering this hidden question.

I just want to know how much longer I will live.... No, no [we didn't discuss this at the family meeting]. I didn't ask. I didn't even dare ask.... I would have asked the doctor, but I didn't want to because of my son who was with me.... He is reluctant to hear [such things]. (Helena)

This last example illustrates how important is the wellbeing and support of loved ones for the patients. Human relations were a significant topic in patients' narrative concerning the family meetings.

4.3 The importance of other people

Family meetings are inherently interpersonal events. Healthcare professionals, patients and family members come together to discuss the situation, try to find acceptable solutions for problems and make plans. At the family meetings, patients meet with two important groups of individuals they depend on for help and support, namely, their relatives and healthcare professionals. According to patients' narratives, the care received from both those groups of participants has two sides. On the one side, it can be supportive and helpful, on the other side it can contribute to dissatisfaction and alienation.

Care as supportive and helpful

Participants talked about different kinds of practical help that they received from their relatives with activities they were not able to do themselves. This help was received during the family meeting or as its consequence. Since this kind of help was in accordance with the patients' preferences, it was welcomed. It supported their sense of independence, gave them the feeling of strength, and drew them closer together with their relatives.

Sanja appreciatively told that her daughter together with healthcare professionals struggled to find a vacancy in a nursing home for her. She was grateful that her daughter was willing to help her despite her problem with accepting the fact that her mother would go to the nursing home. Sanja knew that this was the best solution for her because it would enable her to receive adequate help when needed. It would also enable her to remain independent of her daughter's interference and to avoid being a burden for her. In her view, things were going in the right direction.

The social worker, the psychologist and my daughter are looking for a vacant place in a nursing home for me. They need to find this place because I have nowhere to go.... This is very difficult; you know.... My daughter had difficulties to accept that I would go

to the nursing home. I also had a hard time coming to terms with it, but it was easier for me because I knew I couldn't take care of myself. I can't live with my daughter... [I can stay more independent by going to the nursing home] because I can do everything and take care of myself, I'm still poised... [It is best to go] to the nursing home, yes. So you are not a burden to anyone. (Sanja)

For Helena, her son supported her by talking at the family meeting with healthcare professionals about her medication and diet. This helped her because she was never an eloquent person. Apart from this, she had difficulties remembering things due to the stress and strong medications and she tired quickly. She relied on her son's willingness to take care of these practical things. She felt stronger and supported when he accompanied her.

I'm saying I'm not a good speaker, so that is probably the reason that we didn't have long conversations.... [The son was talking] more about medications.... more about how I take medications and about food, regarding diet. He's with me more for this kind of things... I think he is [supportive]. It seems to me that he remembers things better than I do. Especially now, in this situation. I am under stress, now I am more distracted about medications... They gave me very strong medications. It's all morphine. And because of that, I'm glad he's there to remember better and ask different things better.... I feel like I'm stronger, to know that I have someone, that I have some support. It seems so to me. Support. (Helena)

For Sanja, her daughter's help with simple everyday things brought a new equilibrium in their relationship. That was reassuring for her. It brought her satisfaction and peace.

She visits me for two hours almost every day. She does my laundry, fixes my fingernails and toenails...we are closer. I tell her what I would like to eat if she can bring it to me. She always asks me if I need anything, if I want anything else. That's a lot, you know. (Sanja)

The practical help and support the participants received from their relatives alleviated the difficulties they were facing. But it was also valuable because it gave them a sense that they were not alone and that they were understood in some way.

The healthcare professionals' kindness also brought a lot of satisfaction to palliative care patients lives. It contributed to a sense of support along with the professional expertise of healthcare professionals, team spirit, and the opportunity and time for conversation.

For Pavla, who had some trouble verbalising what was going on at the family meeting, the doctor's kindness was unambiguously the most important impression about that event and the most supportive.

The doctor is very kind. I don't know anything else. (Interviewer: Was that a good feeling?) Yes, of course, of course. If a person is kindly received, it is completely different than if you... It was good, good.... (Interviewer: What did you like about this meeting?) I don't know. That he [the doctor] is a kind man. (Interviewer: Is that the best?) Yes, kindness.... The doctor is always kind, always greets us. (Pavla)

For Dora, the kindness and expertise of the doctor were the things giving her a good feeling and trust about the family meeting.

I felt very relaxed [at the family meeting] because the doctor is a wonderful man.... I think he is a great expert in his field, but he is also extremely kind, one would just talk to him. (Dora)

At the end of the interview, Sanja expressed her admiration for the ability of healthcare professionals to support her during her illness and to do that with a team spirit.

It is admirable that they can help us in this way. A nurse as well as a doctor, a psychologist and a social worker... Conversations and their ability to stand by a person

in such an illness. Do you understand me?... They are... like soul mates, as they say. It looks like soul mates coming together. (Sanja)

In Angela's view, the opportunity for a conversation at the family meeting was more important than the medications.

It seems good to me [to have a conversation]. Let me tell you that one conversation can mean more than five medications to a patient.... Conversation means a lot to me. (Angela)

For Helena, the family meeting was like a family gathering. The fact that the doctor devoted more time to her than usually filled her with a sense of value.

It seems to me that it was simple, family like.... I think it was just fine. It's possible for the doctor to take time for you, which I found nice.... You usually see them in a hurry. So, it seemed very good to me that he took time for me. (Helena)

Participants felt supported as worthy human beings. The friendly attitude of the healthcare professionals that they encountered during the family meeting was supportive and comforting. This relationship acted as a kind of anchor in the uncertain times of advanced disease.

Unsupportive care

Sanja explained how her daughter wanted to help and take care of her by also trying to control her life. Because she found this unacceptable, they found themselves in a conflict situation, which they began to resolve with the help of healthcare professionals at a family meeting. Her daughter's efforts did not help her. She wanted to maintain her independence whenever possible and accept illness and changes at her own pace.

We both cried a lot [at the family meeting] towards the end, we somehow got closer. We realised that she wanted to make decisions about me, and I am not the person to let a child make decisions about me. I didn't let her. She wanted to explain to me about

my illness, saying that she had read it on the internet, but I said that it was not necessary, that I want to deal with my illness on an ongoing basis. What the doctor tells me, what they show us on the screen during chemotherapy... to accept it gradually, not to have someone to force it into my head and then I think about it all the time. This was hard for my daughter to accept.... (Sanja)

When she fell ill and it became clear that she would need her daughter's help, Sanja was unhappy to find that she had become an object of care. She did not want that, so she resolutely defended her ability to make independent decisions.

Angela said that the main topic of the family meeting was a conversation about the possibility of her going to a nursing home after discharge from the hospital. Although her children were aware of her fear of going to a nursing home, and her son supported the idea that she would try to stay at home first, Angela was aware that her relatives would support her going to a nursing home in every way, including financially. This move would relieve the family of their duty, but she, on the other hand, would be doomed to isolation or to the danger of infection. Neither the efforts of healthcare professionals to help with recommendations, nor the efforts of relatives to make staying in the nursing home affordable by helping her financially, went in the right direction. Although she wanted to stay in her home as long as possible, no one offered to help her with this. Her only option was to try to arrange help at home on her own.

We talked about it being best for me to go to a nursing home.... I live alone. But I have a lady I can call if I need her.... I can't expect much from children.... But it worries me because I have no immunity. Every bacterium is dangerous to me.... So, although living in a nursing home would be more comfortable for me, I fear it.... We agreed that the first solution for me would be to go home from the hospital.... Maybe I can do it at home.... When I'll get the answer from the nursing home, I will decide whether to go there or stay at home.... [My son] agrees with this plan but he would be most pleased

if I decided to go to a nursing home right away without first trying to live at home. I understand that because then they don't have to worry about me. They would be relieved because they would know I was taken care of.... They would rather pay another 100 or 200 euros just to know that I have been taken care of. And that's exactly what I'm afraid of.... I wouldn't want to go.... I would rather pay 100 or 200 euros more to a woman to help me at home than to go to a nursing home. (Angela)

Despite a discussion during the family meeting about accommodation options after discharge from the hospital, Angela was left alone with her desire to try to continue to live at home. Relatives had a different opinion. The family meeting did not bring unification of positions that would support Angela's wishes and needs.

Although Dragana's sisters visited her, probably to support her, this visit brought her the realisation that she had virtually no one to stand by her side. Because of work, she had moved to another country and the ties between her and her family slowly weakened. When she got sick, she didn't want to burden them with bad news about her health problems. Since every one of her relatives was sick, she realised they couldn't help her. Instead of solving problems, the family meeting brought her even more uncertainty. The only safe place for her was the hospital. Her awareness of her own solitude was articulated in the mention of a colleague who "is also alone".

My sisters were at the [family] meeting.... They didn't have much time to talk to me. We didn't talk much in advance on the phone either. At first, I didn't tell them for a while how very sick I was.... They [healthcare professionals] explained a little to them about my situation. My problem is what and how after the treatment.... My family is all sick and they can't help me much. Although they would like to help, medical help is something completely different than what they can offer. So, I would like to stay here in the hospital.... We talked about how they would help me and take care of me until it is clear how it is with me.... Not specifically, more generally.... About how it would be

then. Nothing definitive.... I don't know what's waiting for me (sobbing). I don't know... I would like to stay in the care of nurses here.... Earlier, a colleague called me... She is alone too. (Dragana)

Dragana was alone in her end-of-life situation. She could not talk with her relatives about her disease or about her needs. She could not imagine their support. The family meeting brought the realisation of those facts.

Helena recounted her desire to be able to openly share her end-of-life situation with her son. On the other hand, she never wanted to start this conversation openly with him because she knew that he did not want to talk about her dying and death. She waited in vain for the doctor to open this topic during the family meeting. However, she did not want to embarrass her son in the presence of others by opening up the topic that was so unpleasant to him. In order not to embarrass her son in front of healthcare professionals, she introduced the discussion of funeral arrangements, when he visited her at home.

After all, we're also talking about where my end will be and where I'm supposed to be buried. Although he [son] does not want to talk about it, I think that it is also necessary to talk about it. [Son] is reluctant to hear that. We talk about this at home. (Helena)

In this way, Helena was able to present her awareness of her deteriorating condition to her son. Although he did not want to hear about death and funerals, she tried to prepare him for future events. In addition to joint visits to the doctor and help with housework, she also needed her son's understanding of the situation she was in.

4.4 The sick human beings in the changing circumstances

Although the family meeting was the only leading theme in my conversations with the participants, not one of them focused their story exclusively on it. When talking about family meeting experiences, participants often described themselves as people with various difficulties and changing ways of life

brought about by their illness. Family meetings were encounters where these problems were discussed and sometimes solved.

Sanja was able to lead an independent life for the majority of her life. She was always able to take care of herself and also to help her daughter with raising her child. The illness came unexpectedly and quickly. All of a sudden, she became dependant on healthcare professionals and her daughter. She found herself in a completely new role, which was shocking for her since she was never seriously sick before. Her way of life and her relationship with her daughter were turned upside down almost overnight.

There was nothing wrong with me until I was 60 or 62, I wasn't sick at all.... However, in February, I felt sick. You can imagine what a shock this was for me. I've never been to a hospital. (Sanja)

Due to her advanced illness, Sanja was no longer able to live alone in her apartment. She suddenly felt she had nowhere to go. She was aware that the only solution was to go to a nursing home, and in all probability, to another town.

...they are looking for a vacancy for me in a nursing home.... I need to find this place because I have nowhere to go.... [They are looking for one that would be] suitable, even if it is outside [the name of the town]. (Sanja)

Before she fell ill, Sanja actively and regularly helped her daughter to take care of her grandson. Due to her inability to take care of herself, she had to give up previous activities as a grandmother and allowed her daughter to take care of her. This was a heavy sacrifice for a previously independent person.

My daughter had to accept responsibility for me, which I found hard to accept. ... that I depend on her [cries]. I am like her child now. She likes that. She says, "You used to take care of me, now I take care of you." And in my opinion, she's happy to be able to

do that.... And I'm proud to have allowed myself that. You have to allow that. I used to refuse that.... You know, I have to let my daughter help me because I can't do it on my own. (Sanja)

After she got sick, life has changed radically for Sanja. In addition to her health and physical capacity, she also lost her home and her social role. The last period of her life was marked by major life changes, losses, and a constant adaptation to them.

Dora was always active and sociable. She had a responsible job. She loved culture and art, especially theatre. At first, she attributed her physical decline and psychological changes to ageing and tried to accept own limitations. But with the progression of illness her life changed completely. After a loss of consciousness due to hypoglycaemia and the subsequent fall, she was no longer able to live independently in her house. She had to move somewhere where she would be safe and cared for. This abrupt change 'turned everything upside down' for her. It was difficult for her to accept the decision to leave her home and move to the nursing home instead.

As the years go by, life functions decline. You can't do it so fast, you don't think the way you used to anymore, you have other views on life. Now let's just say I can't drive a car anymore... I didn't think that because of my condition I would have to go to a nursing home.... If someone had told me two months ago that I was going to fall and that this fall would turn everything upside down, that I would land in a nursing home.... Such a change in life is very difficult to accept... You have to consider whether you are able to accept this, as the way of life is completely different, especially if you have been very active in all areas all your life. (Dora)

Even before the fall, Dora was not able to drive her car anymore and she needed the help of her relatives in daily chores. After moving to a nursing home, she was no longer able to manage her own affairs. She therefore authorised her relatives to represent her.

They [relatives] help me. Because I trust them, I have authorised them for everything from a bank card onwards. (Dora)

Due to severe health complications, Dora suddenly moved from a well-known living environment to an unfamiliar environment of a nursing home. Formerly an independent and self-sufficient person, she became one of the residents of a nursing home in need of help from others.

Angela was affected by her physical illness on different levels. Due to breathing problems, she needed the help of other people as well as the help of oxygen delivery devices. She was no longer able to live alone in her house, so an assistant moved in with her for most of the week. After a few years, the realisation that the disease had taken away her familiar way of life forever severely affected her and plunged her into depression. Her mental health was seriously shaken.

I have had nerve problems since I got sick. I have depression [sobs].... This disease has hit me really hard. I got sick eight years ago, but for the last few years... have been depressed. This was not the case before. I was not taking any medication. Then you begin to realise that you will no longer be able to do all that you could have done before. It is a realisation that affects you. (Angela)

Angela spoke about the inevitable changes that disease brings to people's lives. Ever since she became ill, she has been observing her physical and mental changes. From her own experience, she learned how illness changes a person. At the same time, it was clear to her that those close to her could not really understand these changes.

Now I know that a sick person feels that way. If I were healthy, I wouldn't even notice.... Everything would pass by me. It would seem normal to me. If I were healthy and my mom was sick, I probably wouldn't have listened to her so carefully. (Angela)

Her own illness experience enabled her to better understand the plight of others. She felt she was a different person on many levels than before the onset of the disease.

Not so long ago, Dragana was still working. She was still employed at the time of our interview although she was lying in a hospital bed due to her advanced illness. While talking, she caught her breath. She looked tired. She told me that radiotherapy is exhausting. That was the reason why she slept most of the time.

I sleep all day after radiation. Yesterday the doctor came to see me, and I slept... Earlier, a colleague called me, she said, yesterday I left you a message [but she missed the message because she was sleeping]. (Dragana)

Dragana was exhausted from the disease as well as the treatment. In addition, her life became increasingly unpredictable as the disease progressed. She did not know where she would go after being discharged from the hospital.

In Bosnia [her native country], who will take care of me ... I don't know what awaits me ... I have everything here [in Slovenia]. In Bosnia there are hospitals, but I don't know who could drive me around... If I stay in my apartment, my sister could come for a week or so, but it's difficult to coordinate all this... They [relatives] find it hard to come. They are all sick... If someone is so sick, it's hard to take care of others... I would like to stay in the hospital to get better, to be able to take care of myself. (Dragana)

Dragana could not return to her homeland because there was no one there who could help her and take care of her. At the same time, she was aware that her needs for help after the discharge would exceed her capabilities. Because of such problems, her wish was to stay in the hospital where she felt safe. The disease surprised her. It progressed rapidly. She was too weak to be able to adapt to the changes. Her world shrank to a hospital room.

4.5 Summary

Three main themes emerged in the analysis process. The first theme, 'the palliative care family meeting as a tool', presented the family meeting as an instrument or tool that palliative patients use to achieve

their goals. The positive experiences of the participants are described under the sub-title 'the family meeting as useful'. Under the second sub-title, 'the family meeting as unhelpful', the patients' disappointments during the family meeting and following it are described. They reveal that the original purpose of the family meetings, to help people, is not always achieved. If we look at a family meeting as a tool, we can perceive it as broken or, according to Heidegger (1962), unready-to-hand.

The second theme, 'the importance of other people', presents the significance of other people, family members and healthcare professionals, in palliative care patients' lives. Heidegger (1962) teaches us that Dasein is being-with. The first sub-title 'care as supportive and helpful' presents care that supports and helps a person to overcome difficulties and develop good relationships. The second sub-title 'unsupportive care' presents frustration of the participants due to a lack of understanding of their situation and inability to receive help.

The third theme, 'the sick human beings in the changing circumstances', reveals the constant uncertainty of the palliative care patients' lives. Their familiar way of being-in-the-world is changing. Their world is becoming unhomelike.

Chapter 5. Discussion

5.1 Introduction

The aim of this thesis is to illuminate the meaning of the palliative care family meeting and consequent experiences for people receiving specialist palliative care in Slovenia. The goal is to use the hermeneutic phenomenological approach to gain understanding of the palliative care family meeting as experienced by patients. The three main themes emerging during the analysis were: 'the sick human beings in changing circumstances', 'the importance of other people' and 'the palliative care family meeting perceived as a tool'. This chapter looks at the previous findings in more depth. The intention is to elicit deeper meaning of the family meeting for palliative care patients in light of the philosophy of Martin Heidegger and the hermeneutic phenomenological literature.

5.2 Reflections on the entry into the interpretation

The important part of participants' narrative concerning the palliative care family meeting was a description of their predicaments caused by illness. Apart from this, they talked about people significant for them, both relatives and healthcare professionals. In my analytical focusing on the meaning of the family meeting, this part of the narrative seemed somehow redundant at first, as it did not speak directly about the family meeting or its meaning. In the hermeneutic cycle of working with the transcripts, reading philosophical texts, and listening to the recordings, that impression changed. It became apparent that, when talking about their health problems, people important to them, as well as the family meeting itself, the participants were actually presenting their contextualised account of the family meeting experience and meaning. Both the event and the contexts were intertwined in their stories and necessary to understand the meaning that the family meeting had in their lives.

The palliative care family meeting as an event, which was initially designed for helping patients and their family members in coping with problems during their referral to palliative care, and patients' life situation or their life context, should be seen as interconnected. The palliative care family meeting, as a tool for helping people, gets its meaning in the life circumstances and needs of the patients who

participated in it. The event gets its meaning in “something with which one has to concern oneself in one’s everyday circumspection” (Heidegger, 1962, p. 112).

5.3 Unhomelike being-in-the-world

Human beings dwell in the world which is familiar for them. They are immersed in the world in their everyday dealings. Such a world is to a certain degree safe and comfortable and taken for granted. It is like a home where we know what to do and how to do it without any excessive effort. We are not just intertwined with this world in our absorbed coping, but our human identity is inextricably connected with it (Blattner, 2006).

In his phenomenological theory of health, Svenaeus (2000) describes health as a homelike being-in-the-world. We know our body and how ‘to use’ it, what to eat, how to move, how to engage with others to be able to stay in equilibrium, to restore our energy, to be healthy. According to Gadamer (2004), health is a balancing process:

“Health is not a condition that one introspectively feels in oneself. Rather, it is a condition of being involved, of being in the world, of being together with one’s fellow human beings, of active and rewarding engagement in one’s everyday tasks ... health is a state of equilibrium ... It is a rhythm of life, a permanent process in which equilibrium reestablishes itself” (Gadamer, 2004, pp. 113-114).

The onset of a serious illness “can catapult people into the orbit of an unfamiliar universe” (Knox, 2020, p. 707). In the unhomelike attunement of illness, the balance and unobtrusiveness of health is lost. One starts to strive to continue everyday life and normal activities. The taken for granted homelike attunement and familiarity with our own body changes. It turns into a sense of insecurity and a daily struggle to maintain some basic balance in life.

The research participants were palliative care patients towards the end of their lives. The disease has left its mark on them. Ever since they became ill, their condition worsened. They could no longer rely on their bodies, which were altered and depleted by the disease. Some of them had serious breathing problems that limited their movement and required the use of oxygen. Others were not able to use

stairs anymore due to their heart problems, or to live independently in the privacy of their home, because of the complications of their disease. Living with a sick and altered body, which became a burden for them, was exhausting. They put a lot of effort into maintaining the ever-changing balance of their lives.

All of them entered a realm of constant uncertainty. They could not say for sure when the pain would return, when fluid would build up in the abdomen again, or how effective the medication prescribed by the doctor would be to relieve symptoms. That situation gradually eroded their mood as well. Some of them said they cannot and do not want to control their emotions and therefore cry more often than in the past, also during the interview. A participant who was overcome by depression was aware that the health she once had was like an unobtrusive homelike attunement, a rhythmic equilibrium that did not call for her attention (Svenaesus, 2000). With the onset of the disease, she stepped on unfamiliar and shaky ground. Such a situation required a lot of effort from her to maintain a minimal balance.

New, unfamiliar bodily experiences and mood changes brought about by the disease led participants to lifestyle changes. The known ways of their life were collapsing and needed to be substituted with new ones.

5.4 Being-toward-death

In his existential analysis of death Heidegger (1962) emphasises that death, understood existentially, is not the event at the end of life. Instead, he calls the end of living organisms perishing. Perishing is understood as the cessation of biological functions in organisms and the onset of organic decay (Haugeland, 2000). But because it is a socio-cultural phenomenon, the end of life of Dasein as human being is called demise (Haugeland, 2000). Dreyfus (2016) explains that there are various interpretations of Heidegger's notion of death. To help illustrate the notion of being-toward-death concerning research participants, I decided to use the interpretation developed by Haugeland (2013).

As explained by Haugeland, "demise is a social event upon which you cease to be countable in the census, your spouse becomes a widow or widower, your property ceases to be yours and passes to

your heirs ... and so on" (Haugeland, 2000, p. 66). On the other hand, death of Dasein is the end of a distinctively human way of being. It is a way to be and a matter of being-towards-death (Heidegger, 1962, Dreyfus, 2016). "The death of Dasein is thus the collapse of that way of life and being-towards-death is the way we relate to that possibility of collapse" (Lear, 2008, p. 162).

With the onset of the disease or its worsening, the familiar way of life for the participants was over. They spoke about the collapse of their individual worlds. Blattner (2006) explains that existential death is not a stopping of a process but more a kind of a limit-situation of the ability to be, which cannot be exercised in such a death. The majority of the participants needed to leave their homes because it was impossible for them to stay there and be safe or even survive at the same time. They were hospitalised or they needed to move to care facilities. They admitted that moving to a nursing home was an extremely difficult act for them. This, in some cases, meant moving from a familiar environment to a new town and among unknown people. This meant leaving their neighbours and acquaintances behind. This led to a sudden complete change in their social circles.

The participants were not able to perform their everyday activities as they once used to. Their disease forced them to stop working. Although one of the participants was still employed, she was no longer able to work. The only connection to her previous active life were telephone conversations with colleagues. Other participants could no longer help their loved ones as they used to. What maintained their identity of useful family members, became too strenuous. Their roles of a mother, a grandmother, or an aunt changed. The people they once cared for, took on their roles. A participant, who had to admit that she will irrevocably need her daughter's help, expressed her feelings with the words: "I am like her child now". The participants had a feeling that they had lost their identity and had difficulties to understand who they are. The meaning-structure of their familiar being-in-the-world collapsed. Blattner explains that death is "when a self-understanding stops functioning as a guiding principle in one's life" (Blattner, 2006, p. 148).

5.5 Being-with others

Human beings exist as being-in-the-world which is the world also inhabited with other entities – things and other human beings. “Dasein in its essence is always being-in-the-world and being-with others... We experience our world and our possibilities with those in the same world” (Dinkins & Sorrell, 2006, p. 305). Being with others is something different than sharing world with things because these entities are quite distinct from equipment and things, they are “*like the very Dasein...*” (Heidegger, 1962, p. 154).

The others are not meant as all the other people from whom one differs, “they are rather those from whom, for the most part, one does not distinguish oneself – those among whom one is too” (Heidegger, 1962, p. 154). Human beings share the world and common humanity with other human beings close to them (Galvin, 2021). Dasein is immersed in the shared world with others and it understands itself through these encounters (McMullin, 2013). Others play a constitutive role in one’s being because “each self is dependent on the others to institute and maintain the shared world in terms of which it understands who it can be” (McMullin, 2013, p. 7) and who it is since “our very understanding of ourselves is always in terms of being-with” (Dinkins & Sorrell, 2006, p. 305).

It was important for the participants to be understood – to be able to share their world of a sick and dying person with other human beings since this helped them to understand themselves in a rapidly changing situation amid constant uncertainty of their life’s ending. They wanted to be recognized and accepted. They tried to present to their family members their awareness of their deteriorating condition and, in this way, invite them into their world of persons at the life end.

Heidegger (1962) explains that in its world, Dasein encounters things and other human beings. How we treat other human beings differs from how we treat things, since other human beings do not have the character of useful things. This specific way of concern, which we show for other human beings, Heidegger (1962) names solicitude:

“Being-with, like concern, is a Being towards entities encountered within-the-world. But those entities towards which Dasein as Being-with comports itself do not have the kind of Being which belongs to equipment ready-to-hand; they are themselves Dasein. These entities are not objects of concern, but rather of solicitude” Heidegger, 1962, p. 157).

Solicitude has two extreme poles named leaping in and leaping ahead (Heidegger, 1962). In leaping in for the other we take away from the other that what they should be dealing with themselves. In this way, we do not really help but dominate them (Heidegger, 1962). This kind of concern for others encompasses “all sorts of abuse and disregard” (McMullin, 2013, p. 143). The other kind of solicitude is leaping ahead of the other, giving care back to them and helping them to develop their potential (Heidegger, 1962).

An important aspect of the participants’ account regarding their relationship with others was related to disrespectful care. Instead of being cared for as they needed, they were cared for in the way their relatives and healthcare professionals thought was best for them. Participants got a sense that they did not matter. One participant described her distress over her daughter’s way of caring for her in a manner of leaping in. Being seen as an incompetent person, for whom other people need to make decisions, was irritating for the participant who insisted to be allowed to make her own decisions. This led to a conflict which was burdensome for the participant. Her familiar world of good relations with her relative was fading away.

In the majority of cases, participants accepted the help of their relatives or healthcare professionals as welcome and necessary, as they were often not able to do their daily chores on their own. When they were helped in a leaping ahead manner in accordance with their preferences, their sense of independence was supported, and they felt stronger. The welcome help of relatives was mainly related to practical help with simple daily chores, transportation, personal hygiene, and advocacy. It gave participants a sense of closeness with their family. With respect to the healthcare professionals, the participants appreciated their kindness and willingness for conversation. They admired their

professional expertise and ability to support them during the difficult period of their illness. The willingness of healthcare professionals to devote their time and attention to them, gave them a sense of worth and self-esteem. As written by Paddy (2010, p. 190): “The self takes meaning from the way one is respected by others. The possibilities for growth, change and adjustment lie in how one perceives oneself amongst others”.

5.6 The meaning of a palliative care family meeting

Our dealings in our immediate world in which we are immersed are guided by a practical intelligence which is shaped by our knowledge of that world. The things we encounter in the world are things of use, equipment, materials, tools, handy things. In Heidegger’s (1962) words, these are entities whose being is readiness-to-hand, also referred to as availability (Dreyfus, 1991). These things of use are understood in terms of the role they play in our dealings (Blattner, 2006). In this sense, the palliative care family meeting could be understood as a (useful) tool for coping with problems that palliative care patients are preoccupied with.

Heidegger argues that the event gets its meaning in “something with which one has to concern oneself in one’s everyday circumspection” (Heidegger, 1962, p. 112). The palliative care family meeting gets its meaning in the life circumstances and needs of the patients and families who participated in it.

Our practical intelligence is guided by the totality of assignments in the in-order-to-structure. A family meeting serves a certain function, for example, to inform a patient about proper use of medication; it is something in-order-to. The tools are described in “terms of the role they play in our lives” (Blattner, 2006, p. 55). When dealing with them, we focus on the goal we are preoccupied with. Participants took part in the family meeting in-order-to be able to express and share their views, feelings, and preferences and to make informed decisions. In their view the family meeting was in-order-to discuss troublesome symptoms and possible treatments as to get information about the medicines and their side effects. For some of them, the family meeting was useful in-order-to discuss their transfer to the nursing home and the needed activities to achieve this goal. A family meeting proved useful in

resolving disputes between relatives. Patients participated in the family meeting in-order-to acquire practical help and to be supported in their coping with health problems.

Blattner (2006) explains that the structure of in-orders-to define the equipment which we use in our everyday dealings in the world. The in-orders-to are not just an “abstract network of functional roles” (Blattner, 2006, p. 60). They are rather “bound together by their common involvement in a way of being Dasein for the sake of which I do what I do” (Blattner, 2006, p. 60). There is an ultimate goal in our dealings in the world which is connected to ourselves and our way of living.

“The primary ‘towards-which’ is ‘for-the-sake-of-which’. But the ‘for-the-sake-of’ always pertains to the Being of Dasein, for which, in its Being, that very Being is essentially an issue” (Heidegger, 1962, p. 116-117).

Heidegger wrote that the assignments of the in-order-to of the equipment are normally not observed, “but when an assignment has been disrupted – when something is unusable for some purpose – then the assignment becomes explicit” (Heidegger, 1962, p. 105). When the tool, which is taken for granted most of the time, breaks down, it reveals its importance for our existence. When a participant expressed dissatisfaction with an aspect of the family meeting, this opened up the opportunity for the meaning to emerge. The meaning of the family meeting for the palliative care patient, who needed to be understood and accepted, was to obtain a forum where her new identity as a dying person can be recognised and acknowledged.

Crowther and Thomson argue that “one participant’s lived experience description may provide the glimpse to the phenomenon not spoken by others” (Crowther & Thomson, 2020, p. 5). In contemplating other participants’ stories explaining their life struggles and the significance, they attribute to the family meeting in resolving them; a realisation emerged that the palliative care family meeting’s meaning stretches beyond helping with immediate practical problems, since the structure of involvements which lead to the for-the-sake-of pertains to the being of human beings (Blattner, 2006). The palliative care family meeting for palliative care patients has a meaning in virtue of their

existence. The ultimate for-the-sake-of of the palliative care family meeting pertains to the participants' identity as palliative care patients approaching their end of life, and to their struggles to live a dignified life in the midst of constant change and uncertainty.

There are three phenomenological themes that helped to understand the meaning of the palliative care family meeting for palliative care patients. Firstly, unhomelike being-in-the-world which illuminated the unfamiliar bodily experiences and mood changes of the participants due to progressive disease. Secondly, being-toward-death which uncovered the death of their familiar way of life due to constant changes of and adaptations to new circumstances inflicted by progressive disease. Thirdly, being-with others which reveals the others as important for palliative care patients since their identity, which is constantly influenced by the changes caused by the disease, requires "acknowledgement and validation in the 'gaze of the other'" (Nanton et al., 2016, p. 367). The meaning of the palliative care family meeting for palliative care patients is in its potential to be a place where this recognition and validation can occur.

5.7 Personal reflections

My first encounter with hermeneutic phenomenology was in the late 1990s, when I attended a lecture where Birgit Holritz Rasmussen presented the findings from her doctoral thesis entitled 'In pursuit of a meaningful living amidst dying: Nursing practice in a hospice' (Rasmussen, 1999). I was not interested in the methodology of the research at the time, but I was fascinated by the insights presented, which resonated in me long after. The next encounter with hermeneutic phenomenology was during the contemplation on how to answer a research question that I wanted to ask in the context of my own doctoral thesis.

Since I was trained in a quantitative research approach, the first challenge encountering hermeneutic phenomenology was the realisation of the necessity of understanding its philosophical foundations. Reading, and above all, understanding Heidegger's philosophy was a time-consuming and initially discouraging effort. His book 'Being and time' (Heidegger, 1962) is filled with neologisms and therefore

an extremely complex read for a beginner. Therefore, reading books written by authors who interpreted his philosophy in a more popular way, attending lectures on his philosophy, and attending workshops on hermeneutic phenomenological research were of great help to me during the whole time of working on the thesis.

In the beginning, I spent a considerable amount of time looking for a suitable method to analyse the data. The realisation that there is no prescribed way in hermeneutic phenomenology to arrive at a result (Smythe & Spence, 2020) was liberating. Crowther and Thomson (2020) say that conducting a hermeneutic phenomenological study is about acknowledging the uniqueness of each researcher in their approach to the execution of the study. For that reason, I decided to find a way that best suited my knowledge and abilities as the researcher at the time of the beginning of the research. I decided to combine different strategies used by other authors. I used thematic analysis as suggested by Lindseth and Norberg (2004), crafting of stories as suggested by Crowther et al. (2017), and suggestions for the interpretation as outlined by Crowther and Thomson (2020).

The recruitment of the participants was also time-consuming. Soon after the start of the recruitment at the first research site, the situation there changed. Because it no longer met the research criteria, I had to look for a new research site. Although I was in frequent telephone and email contact with the staff who recruited study participants, the recruitment process went slowly. I tried to maintain the best possible relationship with them, therefore I visited them in person at their hospital. At our meeting I was told that the delays in recruitment were due to the fact that their patients were very sick and fragile and many of them did not meet the inclusion criteria. Namely, at the start of our collaboration, staff were asked not to recruit those who would not be able to give informed consent or participate in the interview.

To secure participants' anonymity and confidentiality and also to get familiar with the data, I myself transcribed the interviews as a starting point of the analysis process. Then I continued with crafting stories and thematic analysis. Working with the data was challenging at the beginning, as nothing

significant emerged. It was only later that the first outlines of the main themes began to emerge. Although the story crafting and thematic analysis led me at first in the ontic direction, this was helpful because it deepened my familiarity with the data. With a better knowledge of data and philosophy, a transition to interpretation has become possible. Crowther and Thomson (2020) claim that the meaning surfaces through the process of reflexive engagement. I tried to achieve this by internalising Heidegger's philosophy and at the same time also the life stories of the participants, and then constantly using the iterative process of moving between the parts of the whole and questioning. I waited for the meaning to surface. Gadamer's advice that the essence of the question is to open up the possibilities and leave them open (Gadamer, 2006), helped me to try to stay open at the times of periodical disorientation regarding my way of data analysis and interpretation. At this stage of the research, I was also helped by the reflections of other authors who state that due to the unlimited possibility of interpretation, it is not uncommon if researchers experience feelings of discomfort and uncertainty (Crowther & Thomson, 2020). A good advice of hermeneutic phenomenologists was that "the way is to go forward not knowing the way in advance" (Smythe & Spence, 2020, p. 7).

According to Smythe and Spence (2020), there are many different ways for insight to emerge. In my case, insight came one morning before dawn. I quickly wrote it down and fell asleep again. The insight was not a fully formed thought. It read: "for the sake of being a patient as a dignified human being". I later reshaped and upgraded this short thought but kept its meaning in working toward the formulation of the meaning of palliative care family meeting for palliative care patients.

5.8 Strengths and limitations of the research

The strength of hermeneutic phenomenological research is that it allows participants to tell their story, that their experience acquires a voice, and that it is carefully considered and interpreted. The findings help to understand human existence, which is valuable in the healthcare and nursing context in general, and in palliative care in particular, since palliative care is a holistic approach for preventing and reducing suffering. This research provides a deeper insight into Slovene palliative care patients'

experiences of their changing bodies and ways of life due to the advancing disease, and in the meaning of the family meeting for them in such circumstances. To my knowledge this is the first research in Slovene healthcare addressing this theme using a hermeneutic phenomenological approach.

This research took place in Slovenia, which is a small geographical area, with its specific culture, healthcare system and development of palliative care. In addition, a small number of participants engaged in this study, all of whom were women. Because of this, generalisation is not possible. Nevertheless, the transferability of findings from this research to other environments might be feasible considering the fact that they illuminate an aspect of our common humanity (Galvin, 2021).

A limitation for conducting hermeneutic phenomenology research might be the necessary acquaintance with the philosophy, uncertainty during the process of interpretation and the need for the researcher to stay immersed in research for long periods of time and to be comfortable in this insecurity (Smythe & Spence, 2020).

5.9 Recommendations for practice, policy, education, and further research

“Hermeneutic phenomenology does not aim to create a robust theory, solve problems or to determine fixed conclusions, rather it aims to reveal, enhance and extend understanding of a human experience as it is lived” (Crowther & Thomson, 2020, p. 3). Hermeneutic phenomenological research is valuable for the palliative care practice because it offers insight into the usually hidden meanings of the phenomena of human lives. Knowing the life experiences of others allows us to understand them better. In order to provide quality palliative care, we need to understand patients and their families, as well as healthcare professionals. To be able to support others well, we need to know their worlds. My research offers insight into the hidden and unspoken needs of palliative patients. The findings invite us to reflect on our current practice and the ways to improve it. Heidegger (1977) expresses concern over the dominance of technology in human lives. He is not concerned with the instrumental value of technology, but with its essence, with the certain technological way people perceive the world and think about it. We perceive the world increasingly focused on achieving results efficiently and

quickly. In healthcare, technology is increasingly present, as well as the technological, calculative way of thinking. Hermeneutic phenomenology takes us back to human beings, their experiences and their world. It allows us the understanding we need to decide for a leap ahead mode of care for others, which pertains to “the existence of the other, not the ‘what’ with which he is concerned” (Heidegger, 1962, p.159). My research highlights the fact that focusing on quick practical solutions can miss the deeper concerns of patients. Hermeneutic phenomenological studies are therefore needed to inform palliative care practice if it wants to be holistic.

From the beginning, I wanted to use the findings of my study to influence clinical practice. My intent was to contribute to the humanisation of care for patients at the end of life by illuminating the human dimensions of illness which are often obscured by more technological perspectives (Todres et al., 2009) and thus support the basic purpose of palliative care, i.e. the relief of suffering. As argued by Todres et al. (2014), patients with the life-threatening conditions need a more existential concern to be addressed beside the symptoms of their illness. To address existential concerns of palliative care patients, specifically identity- and dignity-related suffering, some authors suggest a person-centred approach which requires "intimate knowledge of a person's needs, hopes, and preferences" (McClement & Thompson, 2018, p. 190) and consequently care organised around these needs rather than the illness (McClement & Thompson, 2018). One way to support the patient's identity and dignity is the introduction of a dignity-conserving care model (Chochinov, 2002; Chochinov et al., 2002; McClement & Thompson, 2018) which helps clinicians understand the main issues that affect the patient's sense of dignity (McClement & Thompson, 2018), namely, distress related to physical and psychological symptoms of illness, patient's perspective of the situation and their dignity-supporting practices, and how they believe that they are seen by others (McClement & Thompson, 2018). Another tool which can be recommended to support the sense of self, identity and dignity in palliative care patients is a simple Patient Dignity Question which asks: “What do I need to know about you as a person to give you the best care possible?” (Chochinov et al., 2015, p. 974). Beside these approaches it is possible to recommend the introduction of a ‘patient-centred family meeting’, which was recently

developed and studied by Australian researchers (Cahill et al., 2021), to Slovene palliative care practice. The 'patient-centred family meeting' model was designed to give palliative patients a voice with the help of a patient-set agenda "to assist patients in expressing their concerns" (Cahill et al., 2020, p. 1309) while being supported by the clinicians (Cahill et al., 2020). As reported by Cahill et al. (2021), what the patients had specifically included in their prepared agenda was "the need for discussion about prognosis" (Cahill et al., 2021, p. 311). According to patients' experiences, such a family meeting provides "a forum for them to speak openly about their end-of-life concerns, clarify what was happening to them and is of comfort for them" (Cahill et al., 2021, p. 309). These patients' experiences and expressed needs are congruent with the finding of my study where the meaning of the family meeting is perceived as a forum for presenting the patient's situation to their family members with the potential to stimulate their better understanding and to gain appropriate help from them. A new model of the family meeting might help certain palliative care patients to articulate and address end-of-life issues and their families to better understand their relative's situation (Cahill et al., 2021). The results of my study highlight the need for patient-centred care that preserves patients' dignity and supports their identity through open interaction during the family meeting.

Since healthcare practice is closely related to policy-making, education and research, I would like to briefly mention the latter areas as well. Concerning the healthcare policy area, statistical data alone are not enough to make informed decisions. It is necessary to add experiential data, insights from hermeneutic phenomenological studies, to inform the numerical data when making decisions that will influence human lives (Thomson & Crowther, 2019). Findings from qualitative research should be included in policy documents (Thomson & Crowther, 2019) which, consequently, should emphasise "professional compassion, dignity in care and greater patient choice" (Todres et al., 2009, p. 75) in an effort to humanise healthcare practice (Todres et al., 2009). The findings of my research should be considered when making recommendations and guidelines regarding palliative care practice. Patients' needs should inform the decisions on the allocation of resources and staff and the organisation of work in palliative care.

In healthcare educational practices that predominantly provide “technical and content knowledge” (Hörberg et al., 2019, p. 57), new learning strategies are needed to support healthcare professionals’ capacity to care: “one that meets patients as humans and not just recipients of treatments” (Hörberg et al., 2019, p. 57). Ekebergh and Lindberg (2020) suggest the development of a reflective attitude in students. To that end, the student must be supported and recognised as an “active, interested and knowledge-seeking person” (Ekebergh & Lindberg, 2020, p. 559), so that they can consequently recognise the patient as a person who is able to provide answers to questions about their “experiences with illness, treatment and life in general” (Ekebergh & Lindberg, 2020, p. 560). Furthermore, students should learn how to listen attentively to the patient and ask questions. They should develop an open attitude to be able to come close to the patient’s lifeworld to get “the meaning of living with illness and suffering from disease” (Hörberg et al., 2019, p. 60). In that sense, I suppose that my study can contribute to students’ understanding of what it is like for patients to be terminally ill and what their existential needs are in this regard.

In our effort to support patients’ well-being, it is important to not only explore technological, organisational, economic and political perspectives, but also to devote ourselves to exploring the existential aspect of well-being, i.e. the human and ethical dimensions of the patient’s situation (Dahlberg et al., 2009; Todres et al. al., 2009). My research points to the need to better understand palliative care patients, especially to better understand their existential concerns. Although my research reveals the meaning of the family meeting in a palliative care context, hermeneutic phenomenological research does not give finite answers. The voices of palliative care patients are rarely heard; therefore, additional research could add valuable insights into palliative care patients’ lifeworld. However, many voices were not heard in this study: male palliative care patients, younger palliative care patients, family members, and healthcare professionals, to mention just a few. Based on the findings from this research, an improved model of the family meeting could be contemplated, tested, and patients’ satisfaction with it explored.

5.10 Conclusions

This study began with an observation that, in Slovenia, we do not know much about how patients experience palliative care family meetings. The purpose of this study was to deepen the understanding regarding these experiences and to illuminate the meaning of the palliative care family meeting for patients receiving specialist palliative care.

In making sense of participants' lived experiences, this study reveals that palliative care patients live in a world of constant change and uncertainty. Their bodies and moods are changing due to the advancing disease. Their social roles are changing, and they feel they are no longer what they used to be. They constantly need to adapt to new living conditions. In this vortex of change and uncertainty, others have a constitutive role in affirming their identity. The meaning of the palliative care family meeting for them pertains to their existence and not just to the problems they are currently dealing with. A palliative care family meeting has the potential to be a gathering where other participants can recognise and validate the patient's new identity and thus it can be a tool for the alleviation of their existential suffering (Charmaz, 1983).

The insights of this research contribute to a deeper understanding of palliative patient's life situation and their hidden, unarticulated needs and hopes regarding the palliative care family meeting as a tool for making sense of their changing life for others and for receiving their recognition and support. This study points toward the requirement for palliative care practice for being observant to the existential needs of palliative care patients in addition to the alleviation of symptoms and the arrangement of practical matters.

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Appendices

Appendix 1: The Republic of Slovenia National Medical Ethics Committee ethical approval for research



REPUBLIKA SLOVENIJA
MINISTRSTVO ZA ZDRAVJE

Štefanova ulica 5, 1000 Ljubljana

T: 01 478 60 01
F: 01 478 60 58
E: gp.mz@gov.si
www.mz.gov.si

Branka Červ
Univerzitetni klinični center Ljubljana
Zaloška 2
1525 Ljubljana

Številka: 0120-071/2016-4
KME 39/05/16
Datum: 30. maj 2016

Zadeva: Ocena etične sprejemljivosti raziskave

Spoštovana gospa Červ,

Komisiji za medicinsko etiko (KME) ste 15. 4. 2016 poslali nove dokumente k vlogi za oceno etične sprejemljivosti raziskave z naslovom

"Pomen formalnih družinskih sestankov in njihovih posledic za ljudi, ki prejemajo specialistično paliativno oskrbo v eni od slovenskih bolnišnic: fenomenološka hermenevtična študija", ang. *"The meaning of family meeting and its consequences for patients"*. Raziskava v okviru doktorskega študija na Univerzi v Lancastru, Združeno kraljestvo Velike Britanije in Severne Irske. Raziskovalni mentorici na Univerzi v Lancastru sta dr. Catherine Walshe in dr. Nancy Preston, v Sloveniji bo potek raziskave nadziral doc. dr. Matjaž Fležar, dr. med. KME 37/02/16 (MZ 0120-071/2016-2).

KME je na seji 17. maja 2016 ugotovila, da ste upoštevali njene pripombe, vlogo ustrezno dopolnili in zadovoljivo odgovorili na njena vprašanja. Pridobili ste tudi strokovno pomoč izr. prof. dr. Janka Lozarja Mrevljeta z Oddelka za filozofijo Filozofske fakultete v Ljubljani. Prilagam seznam članov, ki so odločali o vlogi.

Lepo pozdravljam,

*Approved by the Republic of Slovenia
National Medical Ethics Committee*

Pripravil:
Tone Žakelj

**Anton
Žakelj**

Digitalno
podpisal Anton
Žakelj
Datum:
2016.07.13
13:15:12
+02'00'

dr. Božidar Voljč, dr. med.,
predsednik KME

P.S.: Pri morebitnih nadaljnjih dopisih v zvezi z raziskavo se obvezno sklicujte na številki tega dopisa.

Appendix 2: The Republic of Slovenia National Medical Ethics Committee ethical approval for amendment to previously approved research



REPUBLIKA SLOVENIJA
MINISTRSTVO ZA ZDRAVJE

Stefanova ulica 5, 1000 Ljubljana

T: 01 478 60 01
F: 01 478 60 58
E: gp.mz@gov.si
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Podprnik: Božidar Voljč
Izdelek: Republika Slovenija
Dokladna številka: 04.160.53.1.00.00.00.00.16.01.01
Datum: 16. februar 2017
Referenčna številka: 0120-071/2016-8

Branka Červ
Univerzitetni klinični center Ljubljana
Zaloška 2
1525 Ljubljana

Številka: 0120-071/2016-8
KME 36/01/17
Datum: 16. februar 2017

Zadeva: Ocena etične sprejemljivosti raziskave

Spoštovana gospa Červ,

Z datumom 7. 12. 2016 ste Komisiji za medicinsko etiko (KME) 28. 12. 2016 dostavili nove dokumente k vlogi za oceno etične sprejemljivosti raziskave z naslovom "Pomen družinskega sestanka in njegovih posledic za bolnike", ang. "The meaning of formal family meetings and their consequences for people receiving specialist palliative care in one of Slovene hospitals: a phenomenological hermeneutic study". Raziskava v okviru doktorskega študija na Univerzi v Lancasteru, Združeno kraljestvo Velike Britanije in Severne Irske. Raziskovalni mentorici na Univerzi v Lancasteru sta dr. Catherine Walshe in dr. Nancy Preston, v Sloveniji bo potek raziskave nadziral doc. dr. Matjaž Fležar, dr. med. KME 37/02/16, 39/05/16, 25/08/16.

KME je na seji 17. januarja 2017 brez pripomb vzela na znanje vaše obvestilo, da boste raziskavo opravili v . . . , kjer ste nadzoru raziskave pridružili še dve novi imeni: Matjaž Figelj, dr. med., vodja paliativne enote, in Klemen Šuligoj, zastopnik pacientovih pravic.

Ocenila je, da ni etičnih zadržkov za izvedbo raziskave, in vam s tem zanjo izdaja svoje soglasje.

Lepo pozdravljam,

*Approved by the Republic of Slovenia
National Medical Ethics Committee*

Priloge:
Tone Žakelj

dr. Božidar Voljč, dr. med.,
predsednik KME

P.S.: Pri morebitnih nadaljnjih dopisih v zvezi z raziskavo se obvezno sklicujte na številki tega dopisa.

Appendix 3: Lancaster University research ethics approval



Applicant: Branka Cerv
Supervisors: Bruce Hollingsworth, Catherine Walshe & Nancy Preston
Department: Health Research
FHMREC Reference: FHMREC15131

05 September 2016

Dear Branka

Re: The meaning of formal family meetings and their consequences for people receiving specialist palliative care: a phenomenological hermeneutic study

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 592838

Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

A handwritten signature in black ink that reads "Diane Hopkins".

Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC.

Appendix 4: Lancaster University research ethics approval for amendment to previously approved research



Applicant: Branka Cerv
Supervisors: Catherine Walshe and Nancy Preston
Department: Health Research
FHMREC Reference: FHMREC16

27 February 2017

Dear Branka

Re: The meaning of formal family meetings and their consequences for people receiving specialist palliative care in one of Slovene hospitals: a phenomenological hermeneutic study

Thank you for submitting your research ethics amendment application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 592838

Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

A handwritten signature in black ink that reads "Diane Hopkins".

Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC.

Appendix 5: Expression of interest



Expression of interest

to participate in a research interview about patients' experience of a family meeting

I may wish to participate in an interview with Ms Branka Červ about my experience of a family meeting and consequent experiences.

Please contact me on the details below after a couple of days to receive my decision:

Name: _____

Surname: _____

Address: _____

Phone-home: _____

Mobile phone: _____

Email: _____

I was informed that my decision will not affect my health care.

Signature: _____

Date: _____

Appendix 6: Letter of invitation



Date _____

Dear _____

I would like to invite you to participate in a research study 'The meaning of family meeting and its consequences for patients'.

The purpose of this study is to understand patients' experiences of participation in a family meeting. To illuminate this, you would be asked to talk with me about what it was like being in the family meeting and any consequent experiences regarding it. This would be a face to face interview which would last about half to one hour.

Please, read the *Participant Information Sheet* and *Consent Form* you have received from the research nurse. Have a think about this and make a decision about whether you would like any more information about the study or are potentially interested in to participating in the study. If you have any questions about the study, you are welcome to contact me.

I will contact you in a few days time to see if you have any questions or are interested.

I would like you to know that your decision will not affect your health care.

Yours sincerely,

Branka Červ, researcher

My telephone numbers: +386 (0)1 522 22 07 (in the morning)

+386 (0)1 427 26 67 (in the afternoon)

My Email address: b.cerv@lancaster.ac.uk

Appendix 7: Participant information sheet



Participant Information Sheet

Title of Study:

The meaning of family meeting and its consequences for patients

My name is Branka Červ and I am conducting this research as a student in the PhD programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to understand patients' experience of participation in a family meeting and consequent experiences.

Why have I been approached?

You have been approached because the study requires information from people who already have an experience of a participation in a formal family meeting. I understand that you will shortly participate in a family meeting or have recently done so.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part in this study. Your health care will not be adversely affected if you decide not to take part.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to talk with me about your experience of a family meeting and consequent experiences regarding it. The main questions will be: "Can you describe a family meeting you have participated in?", "Can you tell me what it was like participating in the family meeting?", "Can you tell me what it has been like since?". I expect that the interview will take half to one hour. With your permission, the interview will be audio-recorded. This will allow me to interact with you without losing important information. The interview could be conducted at the _____ in your home or in other place convenient for an interview discussion that suits you. Family member(s) or friend(s) could be present if you wish so.

Will my data be confidential?

The information you provide is confidential. The data collected for this study will be stored securely and only I, my research supervisors and my Slovene research advisor will have access to this data:

- Audio recordings will be downloaded as an encrypted file onto password protected computer. The file will be destroyed within ten years after the conclusion of the research.
- Hard copies of the typed version of your interview will be kept securely in a locked cabinet at University Medical Centre Ljubljana for ten years. At the end of this period, they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, are at significant risk of harm, I will have to break confidentiality and speak to my research supervisors about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in a PhD thesis and may be submitted for publication in an academic or professional journal. The results will be presented at the annual symposium at the (in your hospital) and they may be presented at professional conferences.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform me and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University. It was also approved by the Slovene National Medical Ethics Committee and by the

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact me as the main researcher:

Branka Červ Tel: 01 522 22 07 (in the morning) or 01 427 26 67 (in the afternoon)

Email: b.cerv@lancaster.ac.uk

Or my supervisors at Lancaster University:

Dr Catherine Walshe Tel: +44(0)1524 510124

Reader in Palliative Care; Email: c.walshe@lancaster.ac.uk

Division of Health Research

Appendix 8: Consent form

Consent Form

Study title: The meaning of family meeting and its consequences for patients

We are asking if you would like to take part in a research project with an aim to understand patients' experience of participation in a family meeting and consequent experiences concerning this participation.

Before you consent to participating in the study we ask that you read the *Participant Information Sheet* and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Branka Červ.

Please initial each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study.
2. I confirm that I have had the opportunity to ask any questions and to have them answered.
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript (typed interview version).
4. I understand that audio recordings will be stored encrypted on researcher's password protected computer.
5. I consent to University Medical Centre Ljubljana keeping written transcriptions of the interview for 10 years after the study has finished.
6. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
7. I understand that my data can be withdrawn upon my request within two weeks time after the interview.

8. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.
9. I consent to information and quotations from my interview being used in reports, conferences and training events.
10. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with her research supervisor.
11. I consent to take part in the above study.

Name of Participant _____ Signature _____ Date _____

Name of Researcher _____ Signature _____ Date _____

Note:

- 1 copy to the participant
- 1 copy to the researcher
- 1 copy to the participant's medical notes

Appendix 9: Question and prompts guide

Questions and Prompts Guide

Main questions:

Can you describe a family meeting you have participated in recently?	Can you tell me what it was like participating in the family meeting?	Can you tell me what it has been like since you participated in the family meeting?
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Possible prompts:

Who was present at the family meeting?	How would you assess the family meeting?	How did participation in the family meeting influence you?
What did you talk about?	What did you like about it?	Was participation in the family meeting of any help for you?
	What did you dislike about it?	
	What did you feel during the family meeting discussion?	

Possible general clarifying questions:

Can you tell me more about this?
What gave you that impression?
Can you tell me what you meant by this?
Can you tell me what this mean for you?