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Article

# Religious Experiences of Older People Receiving Palliative Care at Home

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**Abstract:** Increasingly more older people are now being cared for in their own homes. Furthermore, it has become more common that people stay at home to receive end-of-life care. Using interpretative phenomenological analysis (IPA), we analyzed the religious experiences of older people (aged 65+). We answered these questions: What kind of religious experiences do older people have when death is approaching? What does this tell us about their religious coping? As IPA is based on the in-depth analysis of small amounts of homogenous data, we analyzed five interviews with older people who were dying. We identified three main themes. First, religious experiences are relational, that is, deeply rooted in personal relationships. Second, religious experiences are real and can provide both struggles and comfort in the last stage of life. Third, the experience of encountering one's mortality and planning for one's death was calming; while many had unclear views on the afterlife, the idea of continuing bonds after death was comforting. More open discussion on religious matters, death, and dying would be welcomed as part of home-based end-of-life care.

**Keywords:** palliative care; older people; home care; religious experiences; interpretative phenomenological analysis

## 1. Introduction

In theory, the number of patients in home-based palliative and end-of-life care in Finland is likely to increase as, according to current care policy and legislation, older people should mainly be cared for in their own homes (Outila et al. 2019; Ministry of Social Affairs and Health 2012). Palliative care refers to care given to patients that cannot be healed from their life-limiting disease; yet, the timing of death cannot exactly be stated. Making the palliative care decision is part of an advanced care plan. The palliative care decision should be made together with the patient and their carer. In this process, death is seen as part of normal life, and therefore, the aim of palliative care is not to influence the length of life. When the palliative care decision has been made, all unnecessary treatments are ended and the focus is shifted to enhancing the quality of life for the patient and the carer. End-of-life (EoL) care refers to the last phase of palliative care, which is given during the last weeks and days of life (Palliatiivinen hoito ja saattohoito 2019). Although it is widely recognized that care in the last stages of life is a multidisciplinary undertaking, there is no formal consensus on the optimal composition of support in home-based palliative care in Finland (Outila et al. 2019; Aaltonen 2015). Currently, Finland is only ranked twentieth in international research comparing the quality of death in fifty countries (Murray 2015). When looking at the quality of the last stages of life, the greatest challenges in the Finnish context are the quality of palliative care, the availability of care personnel, and the capacity to provide palliative care (Murray 2015; Saarto and Finne-Soveri 2019). Furthermore, there are strong regional

differences, for instance, in the availability of home-based palliative care (Saarto and Finne-Soveri 2019, p. 95).

Despite these challenges in palliative care at home, the elderly in Finland see continuing to live at home as an important part of aging and death (Pursiainen and Seppälä 2013). Most Finns wish to die in their own homes, yet only a few percent have been able to do so; more than 70 percent end up dying in hospital (Aaltonen 2015; Broad et al. 2013). Furthermore, EoL care at home increases holistic well-being; it enables calm surroundings and a more intimate focus on the losses related to approaching death (Higginson et al. 2013).

Holistic palliative and EoL care integrate a firmly spiritual dimension into the care: existential questions, things that an individual discovers as the most important, and religious aspects (WHO 2018; Nolan et al. 2011; also noted in (Saarto and Finne-Soveri 2019)). From the Finnish perspective, religiosity has been highly homogenous for many years (Seppo 1998; Bruce 2000). Even today, 68.6% of the Finnish population are members of the Evangelical Lutheran Church of Finland (ELCF Statistics 2020). Generational differences in religiosity are well known: older generations are more religious than younger ones (Niemelä 2011, p. 42). Young adults (aged under 29) are the generation leaving the ELCF the fastest (ELCF Membership 2020). Furthermore, there are gender differences: in the capital area, in all age groups, more women are registered members of the ELCF, and the group leaving the church the fastest is working-age men (Rytkönen 2019). Older people are more committed to the ELCF, both in terms of higher membership and greater participation in church activities (Salomäki 2014, p. 15). One in four older adults (aged 65+) identify as particularly strongly committed to the ELCF (ELCF Membership 2020). Although membership has decreased in recent years, the ELCF still has a strong influence on religious traditions, especially at the end of life: nearly 90 percent of Finns have a Lutheran funeral (Sohlberg and Ketola 2016, p. 31; Hautaustoimen Tilasto 2019).

In a religious context and among religious people, life events are likely to receive a religious explanation. In this paper, religious experience is understood as a religious interpretation of an event (Pargament 1997; Ganzevoort 1998b). In his diamond model of religious coping, Ganzevoort (1998b) maps religion, context, identity, and coping as interdependent dimensions that are constantly impacting each other. Personal identity becomes structured within surrounding cultural forms and norms. Furthermore, personal religious identity can be seen as an outcome of building and constructing a personal worldview within the cultural setting and people around an individual. (Ganzevoort 1998b; Saarelainen 2019). In this personal life context, individually meaningful lived religion is negotiated and constructed to assist with making sense of daily life (McGuire 2008, p. 209; Ammerman 2013; Ganzevoort and Roeland 2014).

From a psychological viewpoint, religious explanations can be seen through a schema that activates when individuals try to interpret their surroundings and life events (Ganzevoort 1998a; Saarelainen 2012; Eysenck 1998, p. 199; Lyons 1998). Three types of religious orientations impact this interpretation process: different schemata activate for individuals who see themselves as believers, unbelievers, or nonbelievers. For believers and religiously oriented people, events often receive a religious explanation. Unbelievers do not know what to believe or how to believe. Some unbelievers do not want to believe; yet, they have difficulty distancing themselves from religiousness such that for them, religion arouses many thoughts, emotions, and activations. Nonbelievers do not have any active religious orientation and may be neutral toward religiousness; religion is not a part of their meaning system, it does not arouse any specific thoughts or explanation models. (Scobie 1994, pp. 87–89; Ganzevoort 1998b, pp. 278–81). Any individual's religious orientation is constantly in flux with life events modifying it (Ganzevoort 1998a, 1998b).

Pargament (1997) defines religion as “a process, search for significance in ways related to the sacred” (p. 32). God or an Ultimate Being is always involved in this search process. Experience is an inevitable element of religion, which is also made up of cognitions and actions (Pargament 1997, pp. 33–39). Yet, it must be noted that religion is always more than institutional religiosity or official teaching. In their search for the sacred, people build a myriad of religious practices that are found to

be personally meaningful. Through these practices of lived religion, people interpret their religious experiences (McGuire 2008; Ganzevoort and Roeland 2014).

Based on the above-mentioned viewpoints, we analyzed the religious experiences of older people in home-based palliative care using interpretative phenomenological analysis (IPA). This study aimed to answer the following question: What kind of religious experiences do older people have when death is approaching? Furthermore, we explore what this tells us about the participants' religious coping.

### *Religiosity of Older People*

Affirmative religion may be positively correlated with experiencing aging positively (Fortuin et al. 2018). In old age, people have an intrinsic need to find life as “meaningful coherence of the world” (Ganzevoort 2010, pp. 333–34). Meaningfulness in life is linked to experiencing life as safe, which may include acceptance of the divine. If an individual is faced with a threatening life situation and the balance of that person's life is shaken, this may shake their image of a God who protects life and them personally. Especially when an individual encounters death, oppressive questions may emerge (e.g., Ganzevoort 2010). In times of struggle, spirituality and religion provide a source of resilience for older people (Manning 2012) as religion may provide personal stability. Furthermore, when personal strength is tailing off, religion may be a source of power and control (Emery and Pargament 2004).

For older people with chronic or serious illness, religion and religiosity may play a significant role. God may provide comfort and safety in daily life, which may make a personal relationship with God essential. A relationship with God can be seen as an intimate relationship that confirms the experience of meaning in life (Grant et al. 2013). Older people can turn to the Supreme Being of their religious traditions for spiritual support. Furthermore, the “religious systems of belief can affirm the significance, and indeed sacredness, of the individual and life, in spite of social, physical, and psychological change and loss” (Emery and Pargament 2004, p. 7).

There seems to be a link between religion and belonging. For older people, practicing religion has been shown to alleviate loneliness (Wijesiri et al. 2019). Religious groups provide older people with a strong sense of belonging (Saarelainen et al. forthcoming a, forthcoming b). According to Emery and Pargament (2004), religion has key functions in the coping process of older people as a source of intimacy and belonging. In old age, death becomes a frequent visitor in people's lives. Loneliness becomes a harsh reality for many, as they lose partners, siblings, friends, even children. When losing significant others, older people lose their trusted sharers of life experiences and daily lives. In the confusion aroused by death and bereavement, religious explanations and rituals offer sense and a route to coherence and continuity from here to the thereafter (Ganzevoort 2010).

Finnish care during the last stages of life provides little space for the dying to talk about spiritual and religious issues (Kuuppelomäki 2001). Furthermore, approaching spirituality as such appears to be difficult within the Finnish healthcare system and themes of spirituality are rarely openly discussed (Saarelainen 2020; Saarelainen et al. 2019; Karvinen 2012). The research on palliative care is more focused on a medical perspective (see, e.g., (Haltia et al. 2017)).

## **2. Materials and Methods**

### *2.1. Ethical Procedure*

This study is part of a wider project on home-based palliative care. This project aimed to investigate how personal relations influence the palliative care of older adults and their family carers (*omaishoitaja*, a recognized role in Finland, see (Family care 2020)) in the older person's own home. The focus on this age group is based on the home-based care policy for older adults in Finland; furthermore, previous research shows older people face age-specific questions in the last stage of life (e.g., (Gott et al. 2011)). In the project, we studied patients and their family carers during the palliative care process, as well as family carers after bereavement. The whole project was approved by the Ethical Review Board in the Humanities and Social and Behavioural Sciences at the University of Helsinki.

At the beginning of each interview, participants were told about the purposes of the study, ethical viewpoints, and compliance with data protection legislation (General Data Protection Regulation, GDPR in EU). As local care providers assisted with recruitment, it was important to make it clear to participants that they were free to express their thoughts openly and the interview would not impact the way they received care or support in their daily lives. Furthermore, they were given the option to leave questions unanswered and the visual assignment that was part of the data gathering was presented as optional. Participants were able to withdraw from the research at any stage.

The researchers were constantly aware of protecting the wellbeing of the participants. Visual elicitation methods can be helpful in research dealing with sensitive topics (e.g., Saarelainen 2015; Katz and Hamama 2013; Pain 2012; Lev-Wiesel and Liraz 2007). After considering different visual methods and pilot testing life tree drawings, as well as Pictor, the team chose the latter method as a visual tool for the project. Pictor was utilized in a hospice study in which participants did not find it too difficult to deal with (e.g., Hardy et al. 2012)). Pictor is a simple method that guides the participant to map their personal life situation, key people, and authorities involved on a large sheet of paper, using arrow-shaped sticky notes in three different colors. Participants were told that they could use the colors and arrow directions to show details on their maps if they so wished. The only ground rule was that participants had to use at least one sticky note; otherwise, they were free to choose how to make their map. After the arrows were placed, the interviewee was asked to describe the chart, the relationship between the arrows, and their placement (e.g., King et al. 2013)).

Beforehand, it was agreed that interviews could not last longer than two hours to avoid draining the participants' energy. For the same reason, the participants were interviewed once; one participant (Aune) was interviewed twice as there were so many topics she wanted to share that she requested a second meeting. On one occasion, interviewers decided not to introduce Pictor because of the physical condition of the participant. The researchers made sure to ask if participants wanted to pause or end the interview before covering all themes. Some took breaks but it seemed important to the participants to finish the interview.

At the end of each interview, the participants were asked if a researcher could make a follow-up call a week later to ask how they were doing. The idea of the phone call was to confirm whether the interview had caused emotional distress and find support for the participant if needed. Some interviewees found encouragement to seek more support after the interview but that seemed more likely to be becoming aware of an existing support system than due to increased anxiety after the interview.

Interviewing in pairs was found to be an ethical selection for this project. Conducting interviews with death on a horizon might become emotionally draining for the interviewers and the pairs of interviewers debriefed after each interview using a small reflection discussion. Each researcher also wrote a diary after the interviews to follow their thoughts and capacity during the process. Only in the few cases where one interviewer got suddenly ill or could not fit the schedule proposed by the participant, one researcher conducted the interview. In the team meetings, researchers were able to share their experiences of the interviews.

## 2.2. Data Collection

The participants were found with the help of private hospices in southern Finland and a public at-home hospital network in the Helsinki area. Contact persons at each hospital searched for possible participants and asked about their initial interest to take part in a one-time interview. If people were interested, a nurse asked their permission to pass on their contact details to the research group. After receiving contact information, a researcher phoned the potential participant to share more information and discuss being interviewed. Furthermore, an ELCF newspaper for the Helsinki area published an announcement about the study, both online and in print. This allowed possible participants to reach the research team. Additionally, some participants were contacted using the snowball method.

A semi-structured interview guide was planned to serve the needs of the multidisciplinary research team. Conducting the interviews in pairs also enabled researchers with different disciplinary backgrounds to interview the same person. As the aim was to integrate aspects of theology, nursing, social sciences, and law in the interview, the team representing all these disciplines carefully searched for common ground. Interviews began by introducing the idea of making a Pictor chart, after which, each interview covered the main themes: life here and now with the palliative care decision, home as an environment (including relations and restrictions), life before the illness, services and support, values and worldview (including religiosity and spirituality), personal rights, and a narrative of the future. To be able to cover these multidisciplinary themes in the interview, key questions were formed from each theme and voluntary prompting questions were formulated in advance in joint team meetings. In advance, it was decided which one of the two interviewers would be leading the interview: the second interviewer would also ask prompting questions when needed. When the interviewee formed a more talkative connection to the second interviewer, roles were changed to serve the flow of the interview. The idea was to have conversational interviews that would allow enough room for participants to express their thoughts.

### 2.3. Participants

Altogether, 32 interviews were conducted for the research project; in five of these, both the patient and their carer were interviewed together. Overall, 12 interviews were conducted with palliative care patients and 10 interviews with family carers. A further 15 interviews were conducted with bereaved carers whose spouse/family member had already passed away. From those twelve volunteers that signed up to be interviewed and identified themselves as a dying person, all chose to have the meeting in their own homes. The participants were also given the choice of being interviewed alone or with their significant others. To protect the anonymity of the participants, they were given pseudonyms, and any details that could jeopardize their anonymity are left out of the research reports and articles. Table 1 presents participants' demographic variables, ages, given pseudonyms, and significant others with whom they were interviewed, if they chose to do so. The pseudonyms in bold indicate participants whose interviews are analyzed in this paper (see next section).

**Table 1.** Background information of the participants. Bold indicates participants whose interviews are analyzed in this paper.

Pseudonym	Age	Health Condition	Religious Affiliation
<b>Aino</b> (female), interviewed with her sister <b>Arja</b>	74, 79	Lung stenosis, palliative care decision	Active member of the Evangelical Lutheran Church of Finland (ELCF)
Aleksi (male), interviewed with his wife, Reetta	78, 82	Chronic obstructive pulmonary disease and colon cancer, palliative care decision	Passive member of the ELCF, said that religion is not important
Anja (female)	77	Various long-term illnesses, no palliative care decision	Member of the ELCF
<b>Aune</b> (female)	85	Chronic obstructive pulmonary disease, palliative care decision	Active member and former employee of a minority Protestant community (within the ELCF)
<b>Henrik</b> (male)	70	Chronic obstructive pulmonary disease and bowel cancer.	Rejoined the ELCF as an older adult
Juhani (male)	76	Bowel cancer, recent palliative care decision, life expectancy: 2 months	Not a member of the ELCF
Maili (female)	83	Memory issues, no other physical illnesses, no palliative care decision	Used to be an active member of the ELCF
<b>Maria</b> (female)	81	Was given a palliative care decision two years ago for lung cancer but the cancer had not progressed as fast as expected	Passive member of the ELCF



Table 1. Cont.

Pseudonym	Age	Health Condition	Religious Affiliation
Olli (male), interviewed with his wife, Marja	85, 86	Stenosis in lungs, urological cancer, palliative care decision was a few months prior	Passive member of the ELCF, did not talk about his religiosity
Reijo (male), interviewed with his wife, Rebecca	70, 63	Lung cancer, additionally diabetes and heart problems, palliative care decision was a few months prior; Reijo died a week after the interview	Passive member of the ELCF, did not discuss religion explicitly
<b>Tapio</b> (male), interviewed with his wife, <b>Leena</b>	67, 61	Pancreatic cancer, diagnosed 18 months ago, experimental treatment ended recently	Passive member of the ELCF
Tyney (female)	79	Various long-term illnesses, no palliative care decision	Active member of the ELCF

#### 2.4. Analysis

It became crucial to delimit the participant sample for this paper to use our chosen approach of interpretative phenomenological analysis. IPA is based on in-depth engagement with a small and homogeneous sample (see e.g., (Smith et al. 2009)); therefore, we identified five cases for closer analysis. After careful reading of the data on dying patients, we identified two inclusion criteria that helped us to form a more homogenous sample. We decided to focus on those interviews in which, first, the participant had a palliative care decision, and second, the narration of religiosity was found to be meaningful, one way or the other. This excluded those participant interviews that described experiences of living with other types of long-term illnesses, such as Alzheimer's disease, or a chronic illness, which were not found to be leading to death any time soon. Furthermore, interviews where the participant directly stated that religiosity was irrelevant to them or religious issues remained unspoken about were excluded. Based on these criteria, the cases of Aino, Aune, Henrik, Maria, and Tapio were chosen for this article. As Aino and Tapio were interviewed with their close relatives, Arja and Leena, respectively, what these women said in the interviews was also analyzed as part of the data. For these two significant others, we focused on their narration when their thoughts brought more clarification to the experience of the dying participant.

For the selected cases, the interviews lasted from 62 to 122 min (81 min on average). All the interviews were transcribed by professional transcribing services and checked by the research group. Phenomenological approaches were chosen to analyze the data. In the first phase, the multidisciplinary team jointly used template analysis (TeA) as a thematic method (King 2017). During the process, researchers got to know the data thoroughly. Atlas.ti (version 8, User License Agreement of ATLAS.ti Scientific Software Development GmbH) was utilized for the coding.

At the beginning of the IPA analysis, the first and second authors independently coded the data. As instructed by Smith et al. (2009), the transcripts were first read several times to be sure of the familiarity with the data. The left-hand margin was used for free comments and thoughts formed by the researcher, and the right-hand margin was for codes and initial themes. After identifying the initial themes, it was possible to select key themes from each case. After that, the researchers began to compare their findings and agree on the main themes overarching the data. In this phase, the third author was invited to comment and double-check the reliability of the analysis.

Three main themes arose from the IPA analysis: relationality in religious experience, the reality of religious experience, and the experience of encountering mortality. In the results section, these themes are introduced one by one.

### 3. Results

#### 3.1. Relationality in Religious Experience

Relationality was an important part of the daily lives of our participants. Both men in our sample, Henrik and Tapio, were cared for by their wives and discussed the spousal bond in connection to

their religious experiences. Aino lived in the same household with her two elderly sisters, one of whom was her official family carer. Aune and Maria lived on their own but both had people who helped them practically and psychologically. Aune was surrounded by her neighbors and Maria was cared for by her daughter and family. The impact of close relationships is clear in this main theme of relationality in religious experience. This includes the following subthemes: biographical lenses on religious experience, shared belief, and comparison of religious connections.

Biographical lenses on religious experience indicate that relationality impacts religious experiences in multiple ways. The strong positive aspect of relationality is expressed in the interview with Aino and Aune. Aino's sister Arja depicted this vividly:

*When we were little, our mom used to gather us around the table and together we sang psalms and spiritual songs every Saturday. . . In those days, we sang a lot. It is really a good thing that sometimes we still sing together.*

Aino agreed and the sisters led the interviewers to understand that their religious upbringing was especially their mother's legacy. Singing together formed an important channel to express their common conviction. Decades after gathering to sing in their childhood, the sisters sang together at home. Aune shared similar thoughts about how her religious community provided her with support in life changes during her youth. Through her community, Aune found religious belonging and comfort. In the hardships of life, the community provided shelter and direction. Further, Aune's father had an important role in her religious formation; she told us with strong emotions about how her father was happy to see her "on that road" of believers. These expressions can be interpreted to suggest that religious experiences from their childhood and youth provided roots for religious experiences in later life. Comfort and belonging discovered in early religious experiences remained a lived reality for Aune, Aino, and Arja.

Biographical lenses on religious experience show that religion was not always seen as supportive. Henrik explained religious experiences in his youth by talking about his teacher. His relationship with the teacher gave him a strong distaste toward religion. He said:

*I was very much against religion during my school years. Our teacher of religion in lyceum was very strict and harsh. He/she talked so much rubbish that we boys did not accept that. Sometimes we even played some practical jokes and quite soon after finishing my matriculation examination, I resigned [from the church].*

This extract shows relationality from two aspects. First, the teacher's strictness aroused strong resistance. Second, Henrik shared his thoughts with his friends. The impact of the teacher and rebellion toward his teacher's beliefs was evident, but he also shared, with a neutral tone: "I wasn't any habitual believer in my youth either. But at that time, in youth, we [with the family] went to church at Christmas together and it did not feel bad." The biographical viewpoint leads us to interpret that religiousness has never been simple for Henrik. He expressed his current state of belief saying: "I am mild, mild—not a devoted believer—yet, there is a small sprout in that direction." It seems that Henrik was struggling to discover his true and balanced attitude toward his conviction. Religiousness is an ongoing process, as seen in Henrik's narration.

The subtheme of shared belief shows how important it is that religious experiences are common experiences. Aino and her sister shared their religious convictions and discussed "being on the side of the faith" from their youth. They added that their third sister, who was not present during the interview, was a believer as well. They explained that faith brought them joy and that they were able to practice their faith regularly when a diaconia worker (social and welfare worker for the church) from their Lutheran home parish visited. The diaconia worker came every other week and brought them holy communion regularly. Arja and their third sister were physically fit and could go to the local church; yet, they chose to receive communion as three sisters together, with Aino. When asked about the significance of communion, they briefly explain, complementing each other's words:



*Arja: It [communion] brings restfulness.*

*Aino: [It means that] Jesus has died for me.*

In these few words, religious experience was described in a very condensed manner. Through communion, they found comfort and balance in their daily life; furthermore, communion provided hope for eternal life. Aino and her sister were recruited via the snowball method; the diaconia worker asked them to join our study. This interview was conducted by the two theologians of our team (the first and second author of this paper). This might have affected how Aino and Arja stressed the diaconia worker's visits and partly took a shared understanding of religiousness for granted. Still, the diaconia worker's regular visits were clearly important to these women and they would have likely emphasized them to other interviewees.

Aune was a widow who was cared for by her neighbors. She lived in her own apartment but the whole building belonged to her religious community, in which she had previously worked. Therefore, she was surrounded by the members of her religious community. Aune shared that she had close friends and they had been helping each other through different life stages. It also seems that helping and doing favors was rooted in her religious community: it was expected that they share neighborly love in a very concrete manner. Aune's experience shows how the community was based on mutual relationality and helped each other weekly. Shared belief and religious community provide structures that support people in old age.

Based on a shared belief, the comparison of religious connection takes on an interesting tone in Aune's interview, in which she is eager to learn from the religious conviction of the interviewer. First, Aune hinted: "well, I don't know about your personal connection with God. . ." When the interviewer led Aune to understand that she believed in God, Aune wished to know "which congregation you belong to." Knowing these facts were important to Aune as, from sharing her religious experiences in the past, she knew that there were people who did not take her seriously. It can be interpreted that Aune posed these questions at the beginning of the interview to make sure that she would be understood correctly. She felt that the care staff had not understood her religious experiences. Even though the interviewer was not a member of the same community as Aune, at the end of the interview, Aune put her hand on the interviewer's shoulder and said, "you would fit in our community." This can be interpreted as a connection of trust having been formed between Aune and the interviewer. In the interview with Tapio and his wife, religious themes were also discussed with the understanding that one of the interviewers was a theologian, and communication around religious themes was more directed to her than the other interviewer. When sharing religious experiences with the interviewer, it seemed that having some common ground in terms of their belief was important for participants.

The comparison of religious connection became vivid in the religious struggles of Tapio. He compared his lack of religious connection to his wife Leena's connection through prayer. Tapio commented to Leena in the middle of the interview, "you've been able to pray better, perhaps you've been able to find connection better." This led Leena to explain that she had "turned back to being like a child" and refer to her evening prayers. She also shared that praying was an important coping tool for her, as it had been in earlier crises.

When comparing their religious stance, Tapio and Leena discovered a shared thought: they were looking for a minister to turn to. Tapio wanted a spiritual guide to support him. Leena explained that they wanted to meet someone who would then later conduct Tapio's funeral and perhaps support Leena in her grieving process. Both of them hoped to have a close relationship with the minister. In the follow-up phone call a week later, the researcher told Tapio that his private hospital had a chaplain. Tapio sounded settled with this idea. As he had a phone call appointment with the hospital on the same day, he said that he would ask to meet the chaplain.

### *3.2. Reality of Religious Experience*

As a major theme, the reality of religious experiences considers how religiosity was found in the daily lives of the participants. The theme builds on two subthemes: joy and meaningfulness found in

religious rituals, and religious seeking. Religious rituals are important for coping with anxiety and providing comfort. Religious seeking includes the struggles to find peace and safety in God. In sum, the reality of religious experience includes manifold layers of experience.

For both Aune and Aino, religiousness provided a firm basis for joy and meaningfulness in life. Aune explained the significance of her conviction by saying:

*I trust that the one who once has taken me under his care, will take care of me until the end. That is the best. When I have inner peace and tranquility, I have strength to smile.*

Aune's words reflect how her personal belief provided her with the basic trust to live. For her, strong religious guidance is lived in everyday life as her positive attitude grows from her faith. Amid her multitude of health problems, she found special comfort in the power of healing prayer: "When the headaches come, it is so horrible. But then I put my hands there [touching her head where the ache often emerges] and begin to pray and it stops." Aune shared this story of how her headaches have been healed by prayer a couple of times in her interviews with amazement and a smile on her face. For Aune, prayer was a significant route to God, and through it, God acted in her life. She shared other occasions in her life that reflected this.

Aino was less talkative than Aune; when asked what brings meaning or joy to her life, she answered with a couple of words and her sister confirmed what she said:

*Aino: Well, from faith [I find meaning and joy into my life].*

*Arja: Yes, from her youth she has been on the side of faith.*

*Aino: I have been [in faith] ever since my youth.*

Even at the stage in her life when Aino was not able to leave home, religious rituals played an important role: reading the bible and spiritual literature was part of her daily life. Regular visits from the diaconia worker bringing holy communion were also important to her, as we have seen. Singing psalms now and then with her sisters was part of their religious activities. Religious experiences are often shared, which gives them a relational aspect.

For Maria, the official teaching of the ELCF did not fully match her worldview. Her religious seeking became clear when she explored her religious commitment to ELCF's teaching and Finnish cultural history, and explained her position toward religion:

*I have this type of god, who is. . . I do not. . . Children are baptized, we have been married in the church. . . God is like a gray-haired old man who sits up there. . . This is just like a fairy tale but when there is trouble, I fold my hands in the evening and ask for something. . . I am not at all. . . I am not an atheist but God is like that. God does exist.*

Maria continued to explain her ideas with a long speech on the importance of Christianity in Finnish culture and history. For her, the ECLF seemed to be an important institution that brought literary and moral teachings into the country; the church needed to continue to function even though Maria did not feel that the teachings connected with this were meaningful for her.

Religious seeking had another tone in Tapio's case, as he was going through intense religious struggles and framed the lack of connection through prayer as "one of the challenges." He explained:

*I appreciate church very much. We belong to the church and we will belong to the church for all of our lives. . . I appreciate the word of the Bible and I've been trying to pray. But I just can't find [the connection]. I had a moment... [at his sister's summer cottage], when sitting there at the waterfront alone I found a sort of connection. I looked over the lake and tried to pray and wondered. That is the only time [when the connection was formed], that was a good experience. Therefore, it makes me sad that how come I haven't been able to reach that for a second time? I've been trying to.*

Tapio's words reflected that his connection through prayer was strong once. In nature, he found a connection to God and longed for this at the time of the interview. It could be interpreted that this

one-time touch through prayer awoke two conflicting ideas. On the one hand, Tapio knew that he had had this fulfilling connection with God and it brought him hope that this connection would be possible again. On the other hand, the experience reminded him that his current prayer life was not fulfilling. In the interview, he said that “I want to humble myself” and seemed to refer to a wish to surrender to God’s comfort and care, but did not know how to do this. In his search for peace of mind, Tapio had over 50 meetings with a psychologist. He framed the psychologist as “God’s gift,” as for him, these meetings were like “a medication that has effect for three days.” Yet, the interviewers had the impression that religious struggles are hardly discussed in these meetings.

Aspects of religious struggles and comfort are blended in Henrik’s religious seeking. He stresses that religion is not that central to his life and it is important for him to be understood correctly as having a sprout of religion. Henrik expressed rejoining the ELCF as follows:

*For decades, I was a pagan. In the last stage of life, for some reason, I converted or went back to the church membership. . . I thought, am I so poor. . . so if I were a member of the church, I wouldn't go to Hell.*

It seems that Henrik had difficulties verbalizing his reasons for rejoining the ELCF; yet, he made a clear connection between membership of the church and Hell. It remained unclear whether he was really afraid of going to Hell as he soon continued: “well I don’t believe in that kind of dualism,” and explained that in his thoughts, the afterlife was more like the “intermediate state expressed by Dante.” As Dante’s *Divina commedia* narrates a journey through Hell and Purgatory to Heaven, it seems that somehow Henrik believed that people are punished for their deeds; the afterlife is more than just Hell and Heaven. Yet, Henrik found that church membership might provide a safety net in death. Membership is a counterforce to his glimpses of fear of Hell that could provide him with eternal life without punishment. From the perspective of religious seeking, Henrik seems to seek peace of mind and security through his religious commitment. Some other participants also found it important to discuss the afterlife, as the next section will show.

### 3.3. Experience of Encountering Mortality

The experience of encountering mortality is formed from two closely interlinked subthemes: first, plans for dying alleviate the emotional pain of death, and second, beliefs about the afterlife and understandings of continuing bonds. The participants’ religious stances were directly linked to preparations for dying. Religiousness was not always depicted explicitly; rather, the significance of religion and religious experiences are implicitly present.

#### 3.3.1. Plans for Dying Alleviate the Emotional Pain of Death

The relationality and reality of religious experience affected how the participants viewed their approaching death. It seemed much easier to discuss death for those who had a clear religious identity. The length of time since the participant had been referred to palliative care also seemed to influence how able they were to talk about their death, both during the interview and with their loved ones. The third influencing factor seemed to be how much experience of death the participant had in their family or work. The subtheme “plans for dying” can be further divided into talking about one’s death and the influence of one’s worldview on attitudes to death and dying.

Some participants found it rather easy to talk about their approaching death in the interview, including Henrik. He had a long family history of caring for dying family members at home. He and his wife, who was a nurse, had taken care of both of their parents in their home during their palliative and EoL care. Henrik explained his present situation:

*I have done my own personal grief work. I have had long talks with my wife and she is not at all shocked at these discussions, she has seen so much death in her life. No, there should not be any surprises.*

Henrik used the concept of grief work during his process of getting ready for death. Part of this process has been talking frequently with his wife to prepare her for bereavement. Among our participants, Henrik was in many ways an exception in his preparedness to talk about death during the interview.

Like Henrik, Maria had personal experience of palliative care at home. Eight years ago, Maria had taken care of her husband in their home at the end of his life. Maria's husband also had cancer and had died at home. Maria explained how important it was to see a good death without pain. She had seen this many times during her career as a nurse. She explained how she had folded the hands of dead patients and how peaceful they looked. She reflected on how one dying patient remembered that there is a Creator who helps at the moment of death. This was important for Maria when she was thinking of her approaching death. Still, her disease had not progressed as fast as was expected when the palliative care decision was made. Maria talked openly about how she was living "on extra time that the Creator has given her." Her daughter was her family carer, even though Maria lived on her own. When Maria's condition was worse, she lived with her daughter's family for several months. Maria explained that since she and her daughter were both trained medical personnel, it was easy for them to talk about death. Even though the first shock for Maria was strong, they did not cry anymore because of the cancer but talked straightforwardly about the situation.

Most of the patients wanted to talk about practical arrangements, such as where they would die and be buried. For instance, Aino had been thinking of her burial and did not want to have a traditional grave. She pointed out that she did not have children who would visit the grave; therefore, it made more sense to have just a memorial plaque in a graveyard. Aino talked openly about death and life after death but concrete plans connected with dying and burial were not central for her. Her most important relations, her sisters, would be with her until her death, but since they were both old themselves, they would not live for very long after her. Aino's plans showed how far she had come in preparing for her death. She had been thinking of this a lot and in her typical brief manner, narrated these plans openly.

Relations to previous and future generations are the reason Henrik wanted to have his grave next to his parents. Henrik explained his plans:

*My next visit to the church might be my own funeral. They have never been really important to me. But the family wants to organize a proper funeral and we have to get somebody there to officiate at the funeral service. And I have a place ready in the urn cemetery in which I will be next to my parents. But also those who do not belong to the church will nowadays get there.*

Henrik had rejoined the ELCF in adulthood but reflected on his years without religious affiliation during which he was thinking what it would mean not to be getting, as he calls it, a "proper funeral" officiated by a Lutheran pastor. This idea that a pastor makes a proper funeral is very common in Finland. One reason might be that humanist funerals are not yet common in Finland, and apart from other Christian pastors and imams who serve the Muslim community, there are not many other people qualified to officiate at funerals (see (Butters 2017)).

Religion and spirituality are interwoven in the participants' discussion of their concrete plans for death and dying, even though these are mostly not expressed in strongly religious words. This is in line with the wider phenomenon that religion is practiced more in private than in public: religion seems to belong more to the private sphere of people's lives (see (Ketola 2016)). This indirect way of talking about religious ideas is connected with how participants talked about the afterlife.

### 3.3.2. Beliefs about the Afterlife and Understandings of Continuing Bonds

Henrik, Tapio, and Maria, who belong to the ELCF but do not have a strong connection to the church, do not personally believe in what the ELCF teaches regarding the afterlife. They do not know what they actually believe will happen to them after death and how they will continue the emotional bond with their loved ones.

Henrik had been receiving palliative care for some time and knew that he would die rather soon after his interview. Tapio's case was rather different; he had been recently transferred from experimental treatment at a cancer clinic to being an outpatient of a hospice and was not yet that used to thinking of himself as dying. Tapio and his wife Leena were a close couple who actively shared their ideas and emotions with each other. One issue that seemed to complicate the approaching death for them was that at least Tapio had difficulty knowing what happens after death. The couple discussed his death as follows:

*Tapio: The view of death and dying has been difficult for me to grasp. I am not bitter but the thing that I grieve the most is that the unity of two of us will be disrupted and I worry how the other one will be able to cope. I have started from a point of view that life will be finished and there is nothing after it.*

*Leena: But we have agreed that you will be with me whole the time.*

*Tapio: Yes, this is how we have agreed.*

*Leena: I just have to believe that you are somewhere.*

*Tapio: I will try to be somewhere.*

The above discussion shows that neither of them had a clear belief about the afterlife but they had agreed to rely on an understanding of a continuing bond between them even after Tapio dies. However, they could not explain where Tapio would be and how his wife could keep in touch with him. This thought that Tapio would not completely disappear brought them consolation in distress and showed how their spousal relationship was central for this couple. Since they did not have children, Tapio could not rely on them to be with Leena after his death, but instead imagined continuing their relationship. They did not know whether the bond would be concrete or only in memories, but the idea of having a bond brought them hope, even though the "biggest sorrow in this whole process and in approaching death is how Leena will cope."

Tapio was more skeptical here about life after death than he had been earlier in the interview. His wife's approaching bereavement was very hard to accept. Tapio was the youngest participant discussed in this paper and his wife Leena was even younger, just over 60 years of age and not yet retired. This couple would have wanted years of retirement together and suddenly had to face death and separation from each other. They had missed a future together because of severe illness and approaching death.

Maria shared Tapio's hesitation to believe in an afterlife. She identified as spiritual but not very religious and negotiated with the interviewer whether her ideas on what happens after death fit into Lutheran theology:

*I mean that I might be hard but I do not say that the Creator invites me with these good people into Heaven. This might be quite cruel talk but this is how it is. For some others, it is easier to think that Jesus brings you to the Heaven, invites all. Today many people are cremated. This suits me, my ashes could be distributed in nature as well. I think that we join the natural cycle without denying that the Lutheran religion exists and God and Jesus exist and everything.*

Maria did not group herself among the good people who go to Heaven. During her interview, she mainly showed strong self-confidence and seemed proud of herself and the life she had lived. Maria returned to the idea of life after death in her interview and explained: "Heaven would [not] be a place which helps me while I die." Maria did not explain where she goes when life ends, nor did she talk of a reunion with her late husband. It seems that the afterlife was such a big mystery for her that she did not know how to think about it; it certainly was not central to her spirituality.

Other participants in our study connected the discussion on the afterlife closely to their religiosity. A strong religious conviction seemed to make it easier to talk about life after death. For example, Aune seemed to know what would happen to her in death:

*Then they asked if I am afraid. I responded, I do not have fear. I am thanking God that I have survived without it. I have peace inside. I do not live with fear.*

Aino shared Aune's strong faith: "I have been many times on the border [of life and death]. But I do not get away [from this life]." Aino expressed her wish to die with even stronger words in the phone call a week after her interview. During the intervening week, Aino had been hospitalized because of very poor health and still felt very weak when she discussed her situation on the phone. For Aino, death seemed like a possibility of letting go and getting away from the suffering that she experienced in this world. Aino had been close to death frequently and she did not fear it.

The closer to death the participants were, the more likely they were to start talking about death and the afterlife. The more religious ones, Aino and Aune, talked more openly about this, but their personalities made a difference in how they expressed things. Aino seemed shy and spoke for a short time, while Aune wanted to express herself with long narratives. Tapio, Henrik, and Maria, who were less religious than Aino and Aune, also wanted to reflect on life after death, even though this was not easy for them to do.

#### 4. Discussion

The religious experiences of the participants are now discussed from the perspective of religious coping and Finnish religiosity. The three main themes, relationality and reality of religious experience and experience of encountering mortality, are closely connected. The findings illustrate key elements of religiosity among older Finns.

Many earlier studies show the positive effects (e.g., (Coleman et al. 2011)) and stability (e.g., (Emery and Pargament 2004)) that religion may bring older people. The participants in this study sought stability, both in general and through religion. This is especially true for Aune and Aino, whose religious identity can be seen as firm, where they utilized their religiousness and religious rituals (praying, bible reading, singing, holy communion) to strengthen themselves in their daily lives. Furthermore, their religious views of the afterlife provided a strong source of hope when facing death. These findings are in line with earlier studies suggesting that people who have a secure relationship with God are more likely to discover a benevolent religious reframing of difficulties in life than people whose relationship with God is less stable (see e.g., (Emery and Pargament 2004; Koenig et al. 1998)).

Both Aune and Aino seemed to rely on a collaborative religious coping style, in which difficulties in life are dealt with together with God (Pargament 1997, p. 181). For older people, a collaborative coping style is beneficial from at least three different perspectives: they can still experience having control in their own lives although their active agency is narrowing; when their relational networks are shrinking, relationship with God remains; and when social roles are lost, "God may also provide a secure social role" (Emery and Pargament 2004, p. 14).

Difficulties arising from the unsettled relationship with God were expressed by the men interviewed, especially by Tapio but also by Henrik, whose difficulties could be seen as violating his stability of life. Religious struggles could illustrate a "shaky relationship with God" (Emery and Pargament 2004, p. 11). Still, religious struggles can be seen as religious reframing and an attempt to discover meaning in a difficult life phase (Emery and Pargament 2004, p. 9; Ganzevoort 1998a, 1998b). Yet, older people's religious and spiritual struggles were found to be related to mental health issues, depression, and mortality (Murphy et al. 2016; Braam et al. 2014; Pirutinsky et al. 2011). These struggles are experienced by older people with a religious affiliation, but also those who identify themselves as an atheist (Exline et al. 2011; Weber et al. 2012).

Tapio felt that his search for spiritual support from his conviction and his means to reach toward God were deficient: praying did not bring him the needed experience of religious connection. His need to experience closeness with God and means to do so were mismatched. Tapio was undergoing divine struggles that involved distress when a personal relationship with God was not formed. His experience is close to that of people in the midlife crises who discover that God is not answering their prayers and therefore question God's love. Furthermore, Tapio is facing doubt-related struggles as he is troubled



with his personal beliefs (see (Abu-Raiya et al. 2015; Exline et al. 2014; Exline 2013)). Tapio wanted to give up on collaborative coping, in which problems are solved together with God. He hoped for a deferring model in which he could leave his problems to God to solve (see (Pargament 1997, p. 181)).

Henrik's struggles with religion are more related to problems of fit as he seems to have unsettled thoughts related to Hell, the ELCF teaching, and "earning" the afterlife. A discrepancy between one's personal religious views and views of what is socially acceptable give rise to interpersonal religious struggles (Abu-Raiya et al. 2015, p. 127; Exline et al. 2014; Exline 2013; Pargament 1997, p. 334). Overall, Henrik did not talk much about his religious views but he did express conflict within them. His coping style seems self-directed; he did not say that God was responsible for his coping but instead seemed to feel that this was his own business. Yet, in the face of death, membership of the ELCF provided a shelter that might save him from Hell. A social role in terms of being a member of the church became a significant aspect of Henrik's religious coping. Spreitzer et al. (1979) showed that, decades ago, church membership correlated significantly with the general wellbeing of the individual. This correlation is likely to remain relevant for older Finns as, in their largely homogeneous religious context (see (Heino 2002, pp. 23–24)), several generations of Finns grew up with close ties to the ELCF and with the idea of "believing in belonging" (Niemelä 2015; see also (Niemelä 2011; Sohlberg and Ketola 2016, p. 29)). For "believers in belonging," church membership is important and closely tied to personal identity (Day 2011).

Social connections are highly significant to the religiosity and spirituality of older people (McFadden 2013): relationality is connected to both gratitude to God and to finding life meaningful (Krause 2007; Saarelainen et al. forthcoming b). The search for intimacy and belonging were more explicitly seen within the subthemes of shared belief, comparison of religious connection, and beliefs about the afterlife and understandings of continuing bonds. When participants found that shared belief brought consolation, this was not located in larger congregational networks as proposed in earlier research (Emery and Pargament 2004; McFadden and Levin 1996), but rather in relationships with the people closest to them. For Aune, these were the people from her congregation, which is not surprising as church relationships are likely to become more important for older people when their social networks shrink (see (McFadden and Levin 1996)). For Tapio and Leena, this was their hope of continuing their bond after his death.

Older Finns seem to think that religiosity belongs to the private sphere and only refer to these issues indirectly (Saarelainen et al. forthcoming a). This may be why those interviewees who did not have clear religious convictions did not want to talk openly about their religious views. This distinction between public and private was seen in the discussion on burial rituals, which were grouped under public religion and openly discussed in the interviews. Some participants even said that a burial is "proper" when a Lutheran pastor officiates. The ELCF remains responsible for maintaining most of the cemeteries in the country (Hautauostoimilaki 457/2003 2003; Kasselstrand and Eltanani 2013, pp. 106–107; Furseth 2018). The 2019 burial statistics show that even most people who did not belong to the ELCF had still been buried by Lutheran pastors (Hautauostoimen Tilasto 2019). This could be partly because Finnish religiosity combines traditional Lutheran elements with other spiritualities (Saarelainen 2017; Vähäkangas forthcoming 2020).

This combination of selected elements from Lutheran and other spiritual traditions seems to create the lived religion of many older people in Finland. Maria was baptized into the Lutheran church and wants a Lutheran burial but does not agree with some of the teachings connected with these practices. As a result, she does not view herself as very religious but her values and worldviews are at least spiritual. This seems to be Maria's way of negotiating meaningful lived religion and making sense of daily life (McGuire 2008, p. 209; Ammerman 2013; Ganzevoort and Roeland 2014).

Awareness of approaching death changes close relationships. This is seen in Tapio's and Leena's interview in the discussion about how to continue their bond after Tapio's death. For the past twenty years, grief research has focused on continuing emotional bonds between the deceased and the bereaved (Klass et al. 1996; Valentine 2008; Klass 2006). However, this research has mainly considered the

experiences of the bereaved, rather than how a dying person narrates the future bond, which we have addressed in this paper. There are some recent studies on the relations between a dying person and their loved ones during end-of-life care (Borgstrom et al. 2019; Ellis 2013), but even these only touch on how to continue this bond after death.

Gender explains some differences in our participants' religiosity. Earlier literature on affiliation and religious practice in Finland shows that more women than men belong to religious communities and are active churchgoers (Rytkönen 2019). This was the case for the participants in our study. The most religious ones, Aino and Aune, are both women and of the other three participants who identify as not very religious, only one is a woman, Maria. Two interviews were excluded from the sample because, although their wives were religious, the male participants were not. Age is another factor in Finnish religiosity (Salomäki 2014), but the age range of study participants was only twenty years, which is not enough to show a generational difference.

Relationships, with both significant others and the transcendent, were found to be central for older people in home-based palliative care. This confirms previous research findings showing that thoughts and values are tested in a personal web of relations and self-image is constructed in a negotiation process with close people (e.g., Ganzevoort 1998a; 1998b; Miller-McLemore 2005). Amid despair, religious communities can provide a strong anchor through relationships and bring direction to life when everything else is lost (Moltmann 1993; see also (Saarelainen 2019; Park 2013)). Important life decisions are made within and are affected by a personally significant web of relations (e.g., (MacKenzie and Stoljar 2000; Nedelsky 1989, 2011)).

## 5. Conclusions

In this paper, we studied the religious experiences of older people in home-based palliative care. The results of the IPA analysis revealed three main themes: relationality in religious experience, the reality of religious experience, and the experience of encountering mortality. Some of the participants openly talked about their religiosity and views on approaching death but others preferred to discuss these issues more indirectly. Interviewees highlighted the importance of close relationships in terms of coping, support, and belonging.

The results show that older Finns in palliative care constructed their religiosity from a traditional Lutheran worldview with some modern spiritual twist, which can be interpreted as Finnish lived religiosity. In the last stages of their lives, lived religiosity was manifested in the importance of Lutheran burial rituals but some participants seemed to find the Lutheran teachings on the afterlife quite hard to understand. Religiosity included both religious struggles and comfort from personal conviction. Yet, health care services did not provide religious or spiritual support. There seems to be a clear need to discuss issues of death and dying more openly, including the religious and spiritual aspects.

As the IPA was selected to enable a deeper understanding of religious experiences, the data set is rather limited, and thus, the results cannot be generalized, although the discussion has shown that the results are in line with previous research. Instead, this paper provides viewpoints and offers an in-depth analysis and description of some religious experiences at the end of life. The strength of IPA is that it enables a close look at the experience of certain phenomena; in this case, it offers insight into religious experiences lived in home-based palliative care.

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