

**Existential Issues and Existential  
Conversations in Old Age:  
A Diaconal Approach**

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Approach

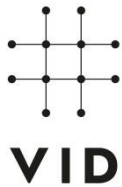
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Dissertation Submitted  
in Partial Fulfilment of the Requirements  
for the Degree of Philosophiae Doctor (Ph.D)

VID Specialized University

2023





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ISBN: 978-82-8456-053-3

ISSN: 2535-3071

*Dissertation Series for the Degree of Philosophiae Doctor (Ph.D.) at VID Specialized University No. 57*

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## ORD OVER GRIND

Du går fram til mi inste grind  
og eg går òg fram til di.  
Innanfor den er kvar av oss einsam,  
og det skal vi alltid bli.

Aldri trenge seg lenger fram,  
var lova som gjaldt oss to.  
Anten vi møttest titt eller sjeldan  
var møtet tillit og ro.

Står du der ikkje ein dag eg kjem  
fell det meg lett å snu  
når eg har stått litt og sett mot huset  
og tenkt på at der bur du.

Så lenge eg veit du vil kome iblant  
som no over knastrande grus  
og smile glad når du ser meg stå her,  
skal eg ha ein heim i mitt hus.

Halldis Moren Vesaas

## Preface

On the plane home from a weeklong PhD course on argumentation, I had a conversation with a woman. She asked me about my occupation, and I gladly told her about my PhD project on older people, existential questions and deacons as conversation partners. The issue of death emerged, and she shared her thoughts and experiences about the recent loss of her mother and of having been diagnosed with cancer, for which she was being treated. During the conversation, which seemed unusually open for two strangers on a plane, I was fortunate to talk about the deacons of my study and their ministry in being conversation partners for older people. The woman – who knew nothing about deacons – said: “The church has an important challenge in conveying what deacons can offer!” This gave me food for thought and motivation to continue working on my thesis.

An essential part of my thesis is interviews with older people. For as long as I can remember, I have enjoyed talking to older people. They possess so much experience and wisdom assembled through a long life. I feel humbled and lucky to metaphorically sit at their feet and listen to what they so generously share. As a deacon in a nursing home, I was fortunate to have many conversations of this kind. Sometimes they made me feel that I was standing on holy ground, getting a glimpse into another person’s private universe. My preconceptions were challenged, adjusted or sometimes confirmed. After such a conversation, I left the room feeling richer and thankful to the person who had shared personal, and often private, thoughts, feelings and experiences. It gave me a sense of being close to life and gaining valuable and important perspectives on my own life. It made me reflect on what was important in life.

Existential questions fascinate and engage me – and sometimes frustrate me. Questions like the essence of life, the meaning of death, and sources of hope have engaged people since the beginning of history. I seek good answers to these questions that will enable a fulfilled life, and I appreciate listening to others’ reflections. In meeting other people, I also meet myself. What other people narrate may resonate in my own life, or it may create dissonance. Either way, the other has opened me to something in my life that can give me new perspectives and thoughts for reflection. However, existential questions have no definitive answers. Sometimes it would have been nice to find a simple truth in all the difficult questions. At the same time, it would probably be boring and too predictable. Something about this dialectic is fascinating. It makes me curious about what people who have lived a long life are interested in and how they relate to existential questions.

Reflecting on such issues – preferably in dialogue with a trusted person – may be a toolbox for facing life’s many colours. This thesis is thus relevant for anyone willing to be open to reflection on questions with no definite answers. Getting old may cause existential issues to become more prominent. Even those of us who are not yet old usually have at least occasional interactions with seniors. Gaining insight into their reflections on death, meaning and loneliness may be enlightening.

Moreover, learning more about possible conversation partners as deacons can hopefully be of interest and value. Thus, I welcome you, reader, to my research universe.

Åsta Marie Olafsson,  
Bergen, 10.10.2023

## Anerkjennelser

Jeg dedikerer denne avhandlingen til min kjære og gode mann, som var den som oppdaget stipendiattutlysningen og som oppmuntret meg til å ta en doktorgrad. Du har hatt en urokkelig tro på meg og prosjektet mitt. Tusen takk, Suman! Nå kan jeg endelig svare ja på spørsmålet som du ofte har stilt i det siste: «Har du levert nå?»

Fra tid til annen leser jeg at mange som har tatt doktorgrad fraråder andre til å gjøre det, av ulike grunner. For min del har stipendiattiden vært et høydepunkt i utdanningen min, og et av høydepunktene i arbeidslivet. Å få tid – og lønn – til å fordype meg i noe jeg er interessert i har vært et stort privilegium. Jeg føler meg heldig og takknemlig, og har ikke angret et sekund på at jeg gikk i gang med forskerutdannelsen. Samtidig så har alt sin tid, og nå er jeg glad for at jeg er i havn. Nå er utdanningen ferdig, men jeg har innsett at jeg hele karrieren vil være som en student som stadig må lære noe nytt. Og det å utforske nye felt er jo så spennende! Selv om jeg har fått fordype meg faglig disse årene så innser jeg likevel at for hvert kapittel i avhandlingen så skulle jeg gjerne fordypet meg mer. Selveste Albert Einstein skal ha sagt noe sånn som: "Jo mer jeg lærer, jo mer innser jeg hvor mye jeg ikke vet." Det kjenner jeg meg veldig igjen i, uten sammenligning med Einstein for øvrig. Heldigvis får jeg fortsette med forskning og undervisning i min nye stilling på VID vitenskapelige høyskole.

Selv om jeg for det meste har jobbet alene med prosjektet har PhD-løpet ikke vært en ensom reise. Jeg har vært omgitt av mange mennesker som har heiet på meg, gitt meg råd og veiledning. For å ta det siste først; jeg startet med professor emerita Herdis Alvsvåg som hovedveileder. Takk for din rause og inviterende tilnærming, og for dine verdifulle innspill fra din omfattende forskningserfaring. Deretter professor Linda Rykkje, som tok over som hovedveileder og var medforfatter på min første artikkel. Takk for ditt engasjement, dine grundige lesninger og tilbakemeldinger som fikk tekstene mine til å bli tydeligere og bedre. Da jeg etter hvert la om på prosjektet og ga det en diakonal profil byttet jeg veiledere til to professorer innen diakoni og sjelesorg. Professor Anne Austad som hovedveileder og professor emeritus Hans Stifoss-Hanssen som biveileder. Veiledningsmøtene med dere har vært preget av grundig respons i en trygg og god tone. Hans, din omgjengelighet og ditt omfattende arbeid innen forskningsfeltet har vært uvurderlig. Det er mye takket være deg at VID vitenskapelige høyskole har et PhD-program innen diakoni. Takk for at du har banet vei for diakoniforskning generelt, og min spesielt. Anne, takk for din mildhet, dine grundige tilbakemeldinger og for at du har støttet meg hele veien. Du har vært god på å gi meg tilbakemeldinger både på detaljnivå og mer overordnet, noe jeg har satt veldig stor pris på. Så tusen takk, alle fire! Jeg kunne virkelig ikke ha gjort dette uten dere.

Alle deltakere i prosjektet fortjener en stor takk; dere eldre som så sjenerøst delte av deres refleksjoner og erfaringer omkring det eksistensielle, og dere diakoner som delte av deres

profesjonshverdag, kunnskap, erfaringer og refleksjoner. Takk også til min venninne Gerd, som lot meg utføre et pilotintervju før jeg gikk i gang med de «ordentlige» intervjuene.

Jeg vil videre rekke en stor takk til mine medstipendiater i Bergen for et støttende og heiende miljø. Dere var med på å gjøre reisen gøy og lærerik! Jeg savner allerede å være i stipendiatboblen med dere. En spesiell takk til Helene som på en særlig måte har vært en god samtalepartner – ja, av de sjeldne. Jeg savner å ha deg ved min side! Takk også til Marianne, Stine, og Camilla. Å ha andre stipendiater som jobbet innen det eksistensielle og åndelige var veldig lærerikt og verdifullt. Reisene og kursene med forskergruppen Religions, Values and Society (RVS) vil stå som store lyspunkt langs PhD-veien, og ikke minst med dere medstipendiater som jeg fikk bli kjent med der. For noen gøy, kloke og dyktige mennesker dere er!

Å få delta i forskningsgruppene EXIST og DIAPP har vært inspirerende og lærerikt, og jeg er glad for å kunne fortsette med å delta i disse gruppene. Takk til bibliotekarene Anna Kirsten og Irene som er oraklene mine i referansebruk og litteratursøk. Takk også til VID vitenskapelige høgskole som ga meg muligheten og tilliten til å ta en doktorgrad. Øvrig familie og venner: Takk for at dere har heiet fra sidelinjen. Til slutt, mine tre døtre, Sara, Lina og Maya: Takk for at dere er de dere er! Nå er jeg endelig ferdig!



## Sammendrag

Avhandlingen utforsker kvalitativt eksistensielle problemstillinger og eksistensielle samtaler i alderdommen fra et diakonalt perspektiv. Den er plassert innenfor diakonivitenskapen, og inkluderer religionspsykologi og eksistensiell psykologi. Studiet er delt inn i tre hermeneutiske delstudier. Det første er basert på individuelle intervjuer med 11 eldre i alderen 73 til 91 år, mens de to andre er basert på tre fokusgruppeintervjuer med 18 diakoner i Den norske kirke. Når det gjelder analyse er delstudium 1 og 2 basert på tematisk analyse, mens delstudium 3 er inspirert av kvalitativ innholdsanalyse.

Delstudium 1 utforsker Eldres refleksjoner rundt eksistensielle spørsmål og deres mulige behov for å snakke om dette med andre, og tilfører ny kunnskap til empirisk forskning i en norsk kontekst. Det teoretiske rammeverket inkluderer Yaloms grunnleggende vilkår og Tornstams teori om gerotranscendens. Funn fra delstudium 1 viser at deltakerne var stort sett fornøyde med livet, noen var ensomme, og de fleste var ikke redd for døden. Mening ble først og fremst opplevd på et horisontalt nivå mer enn vertikalt nivå. På grunn av livshendelser og sykdom opplevde noen økt interesse for eksistensielle spørsmål i alderdommen, og noen ønsket å snakke om disse spørsmålene med andre.

I delstudium 2 utforsker diakoners konseptuelle forståelse av eksistensielle samtaler med eldre mennesker og hvilke begreper de bruker for disse samtaler. Vi fant at diakonene opplevde en glidende overgang mellom eksistensielle samtaler (EC) og sjelesorgsamtaler (PCC). EC ble oppfattet som bredere enn PCC. Diakonene foretok også en avgrensning mellom sjelesorg på den ene siden og åndelig og eksistensiell omsorg på den andre, særlig når det gjaldt personer med demens. Diakonene brukte ulike begreper for sine samtaler med eldre mennesker, avhengig av hvem de snakket med. Vi tolket derfor at diakonene var strategiske og pragmatiske i sin språkbruk.

I tredje delstudium utforsket vi diakonenes opplevde kompetanse som samtalepartnere med eldre mennesker. Diakonene la vekt på relasjonelle ferdigheter og samtaleevner, eksistensiell og religiøs «leseferdighet» og det å ha tid som ressurs. Vi introduserte begrepet "tilnærmelige diakoner" som en analytisk innovasjon. Med utgangspunkt i det empiriske materialet og perspektivene fra diakoni og religionspsykologi, argumenteres det for diakonprofesjonens samfunnsbidrag til offentlig psykisk helse.

Avhandlingen møter etterspørselen etter empirisk forskning innen diakonivitenskap. Det finnes knapt noen skandinavisk empirisk forskning på diakoner som eksistensielle samtalepartnere, og heller ikke på Eldres refleksjoner og opplevelser av eksistensielle spørsmål. Videre er mye av diakonal forskning fokusert på sosialt arbeid, menighetsarbeid eller institusjonsarbeid, mens mitt bidrag er på service- og profesjonsnivå fremfor organisasjonsnivå. Innovasjonen i denne oppgaven er dens klare eksistensielle helseperspektiv i kombinasjon med diakoni og heterotopi.

## Abstract

The thesis qualitatively explores existential issues and existential conversations in old age from a diaconal perspective. It is placed within the science of diaconia, with the psychology of religion and existential psychology as its main perspectives. The study is divided into three hermeneutical sub-studies. The first is based on individual interviews with 11 older people aged 73 to 91 years, while the two others are based on three focus group interviews with 18 deacons within the Church of Norway. Regarding analysis, Sub-studies 1 and 2 are based on thematic analysis, while Sub-study 3 is inspired by qualitative content analysis.

Sub-study 1 explores older people's reflections on existential issues and their possible need to discuss them with others, adding new knowledge to empirical research in a Norwegian context. The theoretical framework includes Yalom's ultimate concerns and Tornstam's theory of gerotranscendence. Findings from Sub-study 1 show that the participants were mostly satisfied with life, a few were lonely, and most were not afraid of death. Meaning was primarily experienced on a horizontal rather than a vertical level. Due to life events and illness, a few of the participants experienced an increased interest in existential issues in old age, and a few wanted to talk about existential issues with others.

The second sub-study explores deacons' conceptual understandings of existential conversations with older people and what terms they use for these conversations. We found that the deacons experienced a gradual transition between existential conversations (ECs) and pastoral care conversations (PCCs). ECs were perceived as broader than PCCs. The deacons also made a demarcation between pastoral care on the one hand and existential and spiritual care on the other, especially for people with dementia. Lastly, the deacons used different terms for their conversations with older people depending on whom they talked to. We thus interpreted the deacons to use language strategically and pragmatically.

In Sub-study 3, we explored the deacons' perceived competence as conversation partners with older people. The deacons emphasised their relational skills and conversation skills, existential and religious literacy and having time as a resource. We introduced the term "approachable deacons" as an analytical innovation. Based on the empirical material and the perspectives from diaconia and the psychology of religion, arguments are made for how the deacon profession can contribute to societal mental health.

The dissertation meets the demand for empirical research into the science of diaconia. There is scant Scandinavian empirical research on deacons as existential conversation partners, nor on older people's reflections and experiences of existential issues. Furthermore, much of diaconal research is focused on social work, congregational work or institutional work, whereas my contribution is at the

service and professional levels rather than the organisational level. The innovation of this thesis is its clear existential health perspective in combination with diaconia and heterotopia.

## Clarifications of Terms and Abbreviations

The following abbreviations are used in this thesis:

Existential conversation: EC

Spiritual care: SP

Pastoral care: PC

Pastoral care conversation/counselling: PCC

Diaconia is spelt differently in this thesis: diaconia and diakonia. I use the first version, except in citations where the latter is used.

I use the pronoun “she” to refer to “deacon” as a linguistic variation. This is justified by the fact that there is a large preponderance of women in the profession of deacon. Furthermore, I alternate between using “thesis”, “study”, and “dissertation” for my work. Lastly, I alter between using “I” and “we” in the text. “We” refers to my supervisors and me.

## List of Publications

### Article 1

Olafsson, Å. M., & Rykkje, L. (2022). Existential Issues in Old Age as Narrated by Older People – An Interview Study from Norway. *Religions, 13*(3), 259.

### Article 2

Olafsson, Å. M., Stifoss-Hanssen, H., & Austad, A. Deacons' perspectives on "the existential" and existential conversations with older people. (Submitted to *Diaconia. Journal for the Study of Christian Social Practice* September 2023).

### Article 3

Olafsson, Å. M., Stifoss-Hanssen, H., & Austad, A. (2022). Deacons as conversation partners on existential issues with older people. *Tidsskrift for praktisk teologi, 39*(2), 21–36. doi:<https://doi.org/10.48626/tpt.v39i2.5499>

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Article 1: Existential Issues in Old Age as Narrated by Older People – An Interview Study from Norway.

Article 2: Deacons’ perspectives on “the existential” and existential conversations with older people.

Article 3: Deacons as conversation partners on existential issues with older people.

Interview guide study individual interviews sample 1

Interview guide study individual interviews sample 2

Interview guide deacons

Approvals from NSD

# 1 Introduction

## 1.1 Short Presentation of the Thesis

Briefly, this thesis explores older people’s experiences and thoughts on existential issues, reflections on existential conversations with older people by deacons within the Church of Norway, and their perceived competence as existential conversation partners of older people. The thesis draws on the scientific fields of diaconia, the psychology of religion and existential psychology. Research questions, samples and methods used in the three articles are shown in Table 1.

	<b>Research question</b>	<b>Sample</b>	<b>Methods</b>
<b>Article 1</b>	What are older people’s reflections on their thoughts and feelings about existential issues, and do they possibly want to talk about this with others?	11 home-dwelling older people aged 73 to 91 years	Individual interviews
<b>Article 2</b>	What are deacons’ conceptual understandings of existential conversations with older people and what terms do they use for these conversations?	18 deacons within the Church of Norway	Focus group interviews
<b>Article 3</b>	What characterises deacons’ perceived competence as existential conversation partners with older people?	18 deacons within the Church of Norway	Focus group interviews

**Table 1:** Research questions, samples and methods for the three articles.

I will elaborate on the concepts of “the existential” and “existential health” later in this thesis, but will here only refer to Nygaard et al.’s (2022) description to clarify what I mean by the existential:

The term ‘existential’ related to health refers to the fundamental, basic condition of being a human. The existential is based on the irrefutable fact that we live and will die, facing conditions and uncertainties along the way beyond our control. The existential is expressed primarily through a quest for making and seeking meaning in life in general, as well as in demanding life situations. This may involve movements between suffering and re-orientation and meaning and meaninglessness. Existential concerns can be integrated into both religious, secular, and spiritual worldviews. (p. 16)

“The existential” in this thesis thus relies on this description.



## 1.2 Background

Part of the reasoning for my thesis is based on Norwegian public policies that aim to secure rights for older people concerning existential issues. According to the dignity guarantee *Regulations on dignified older people care* (Verdighetsgarantiforskriften, 2010), conversations about existential issues are meant to secure a dignified, safe and meaningful old age. Further, the Norwegian Ministry of Health and Welfare (Helse- og omsorgsdepartementet, 2009) emphasise that those who are dependent on practical and personal assistance from the municipal health and care services have the right to practice their faith, and that spiritual needs are to be met, including the opportunity for existential conversations. The quality reform for older people, *Live the whole life* (Meld. St. 15 (2017–2018)), also says that “when life becomes extra vulnerable, older people should have the opportunity for conversation, motivation, and support” (p. 13. My translation). However, according to this quality reform, there is a lack of care for social, cultural and existential needs (p. 14). Healthcare professionals are expected to provide holistic and existential care (p. 88), but for different reasons, as I shall come back to, they often do not fulfil this demand. Furthermore, in the same reform, the Norwegian government states that all sectors, not just the healthcare sector, must create a society where older people can stay active and act independently (p. 10). This includes the volunteer sector, encompassing different religious and philosophical organisations. Here, the Church of Norway, with its deacons and pastors, is an important partner.

Historically, diaconal engagement and diaconal institutional work have led to the development of the welfare state in Norway, and over time, diaconal institutions have changed from being pioneers in healthcare to being integrated into the state’s welfare provision (Nordstokke, 2011, p. 30; Wyller, 2022; Aadland, 2012, p. 10). Today, hospitals, institutions, nursing homes and home nursing care are concrete welfare services provided by the public authorities. The Church of Norway also sees people’s health as one of its responsibilities, and the document “Church and health” (Kirkerådet, 2015) emphasises a broad understanding of the church’s health mission “as health promotion work, as help to cope with life, as medical treatment and as care for the sick and frail” (p. 9. My translation). Furthermore, the church has a special calling to meet the spiritual needs of people (Den norske kirke, 2020, p. 8).

When existential needs are accepted and included as a responsibility of society, and are even institutionalised, one might think that these rights have been fulfilled, with the primary obligation belonging to the state and the welfare system. That is not the case, however. For instance, as of 31 December 2022, one pastor has a 30% part-time position as nursing home pastor for all the 2,386 public nursing home residents in the municipality of Bergen, Norway (<https://www.bergen.kommune.no/omkommunen/fakta-om-bergen/hverdag/gir-helsehjelp-og->

omsorg, retrieved April 24, 2023). Needless to say, this pastor cannot offer existential/spiritual conversations and support to all who want it. The authorities are dependent on the third sector, for instance, the churches. The congregations in the different dioceses offer some ministries, such as devotionals or pastoral care conversations by the pastor or the deacon, or they can be contacted if necessary. However, congregational clergypersons also do not have time in abundance.

### 1.2.1 Sociological Perspectives: Post-Secular and Postmodern Scandinavia

Sociologically, Norway can be described as a post-secular society, meaning secularisation is ongoing but religion is also present (Habermas, 2008; Hovdelien, 2019, p. 62; Johannessen-Henry & Iversen, 2019, p. 27). The sociologist of religion Pål Repstad described three main strategies for meeting religious and ideological diversity (2018, pp. 51-53). The first is characterised by maintaining the dominant role of the majority religion (as in Russia and Greece). The second excludes religious expressions from the public sphere and creates a strict division between religion and the state (as in France). The third strategy can be found in Norway, according to Repstad, in which the public sphere is allowed to reflect the diversity in society. Norway is often called “det livssynsåpne samfunnet”<sup>1</sup> (Tjørhom et al., 2018), defined as a type of soft secularisation where the public sphere is characterised by a multitude of religions and philosophies of life (Hovdelien, 2019, p. 66). All religious or ideological organisations can claim grants from the Norwegian state, but the Religious Communities Act (Trossamfunnsloven, 2020) requires at least 50 grant-paying members. Furthermore, shared values, such as human and constitutional rights, are emphasised. A historic event took place in 2012 when the Norwegian Parliament passed two crucial amendments to the Constitution: The Church of Norway ceased to be the state church, and the Evangelical-Lutheran faith was no longer the official state religion (Hovdelien, 2019, p. 67). This is an example of formal secularisation on a societal level (Repstad, 2020, p. 26).

At an institutional level, the Church of Norway has the main responsibility for religious service in public institutions such as the military, hospitals and prisons. However, some institutions also have professionals from other religious or ideological communities. There is a principle in the government document *Det livssynsåpne samfunn* that everyone should agree to be exposed to other people's beliefs and faith practices in the public realm as well as in daily life within institutions (NOU 2013:1, p. 168). This contributes to ensuring religious diversity.

Valerie DeMarinis, a Swedish psychology of religion professor, portrays Sweden as a postmodern society (2003). Scandinavian countries share many similarities, so this portrayal may also

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<sup>1</sup> “Det livssynsåpne samfunnet” means a society open to different kinds of philosophies of life.

fit Norwegian society to a certain extent. I will use the term postmodern as DeMarinis understands it in the context of her case study (the function of pastoral care in relation to existential healthcare):

Postmodern, as used here, is understood as an aggregate of perspectives and philosophies that hold in common the idea that 'there are no metaphysical absolutes; no fundamental and abstract truths, laws, or principles that determine what the world is like and what happens in it' (Slife & Williams, 1995:54). Postmodernists have questioned and have deconstructed "the deterministic, reductionistic, mechanistic, and positivistic assumptions of mainstream science and psychology" (Richards & Bergin, 1997:37; and see also Gergen, 1982; Faulconer & Williams, 1985; Packer, 1985; Kvale, 1992). (2003, p. 26)

Furthermore, according to theorist David Wulff (1997), "all beliefs, religious and scientific alike, are *social constructions*, linguistic products of negotiation among persons living at a particular time and place" (p. 9). DeMarinis also asserts that the postmodern paradigm has grasped the process of deconstruction, the "deconstruction of absolutes" (pp. 26-27), tearing down the structures, demarcations and absolutes characterised by modernism. At the individual level, then, this leaves everyone to make their own choices because nothing is indisputable: There is no truth with a capital "T". DeMarinis refers to Bauman, who calls postmodern people *choosers* (p. 30).

In the context of the existential – when postmodernism's relativism is taken to its most extreme form, without religion, ideologies or philosophies of life as frameworks – there is a lack of foundation upon which to ground one's existential position and choices. This, according to DeMarinis (2003), is a fundamental challenge for the individual.

### 1.2.2 Some Aspects of Older People's Current Situation in Norway

As the West has industrialised, older people have lost importance and value, overshadowed by material productivity, science, technology and individualism (Moberg, 2012, p. 23). Furthermore, the trend of placing older people in institutions reduces fellowship and communication across generations and essentially holds older people apart from the rest of society. Haukelien (2021) describes a new approach offering alternative service provision solutions that are less binding and burdensome for public authorities and service-providing institutions, such as investment in welfare technology, everyday rehabilitation and the increased involvement of volunteers and relatives (p. 192). This is one way of meeting the demographic challenges of increasing life expectancy and falling birth rates.

Munkejord, Schönfelder, et al. (2018) asserted that with home-based care for older people in Norway, health-related services have long been the focus at the expense of other services. In addition, healthcare workers have little time, and those working in home services experience increasing fatigue, less room for person-oriented services and a high level of sickness absence, as found in the municipality of Bergen (Førland et al., 2017, p. 11). Older people who receive in-home care also meet a high number of busy workers who do not necessarily perceive it as their responsibility to address the loneliness and

unmet social needs often experienced by home-dwelling older people. However, there are regional and local differences in both time and flexibility in meeting social needs.

Under the municipal authority of home services, social care is generally not an employee duty (Munkejord et al., 2017). However, Munkejord, Schönfelder, et al. (2018) argued that social care should be a foundational aspect of caring for older people. The term “social care” includes both a structural and a relational dimension between the caregiver and the receiver, which they defined as “to recognise the user as a whole person, as well as to facilitate or create conditions for meaningful activities and social relationships” (p. 304. My translation). This can help prevent isolation and loneliness and imbue the lives of older people with activity and meaning.

Through interviews with representatives of the majority church, the public welfare sector and other local informants in a municipality in Norway, Angell and Wyller (2006) found that even though church representatives “in general approve of public welfare services” (p. 116), their main objection is the challenging issue of caring for older people. Recently, there has been a social debate in Norway surrounding the lives of older people that indicates that their situations have not improved. The NRK TV documentary programme *Brennpunkt* revealed that in some municipalities, the care provided for older adults is terrible. The programme revealed a number of troubling details, including a lack of nursing home facilities, the fact that some home-dwelling older adults are lonely and too sick to be living alone, how older adults with dementia are confused in their own homes and that some healthcare workers are rude and do not give older adults the help and service their jobs require. Consequently, not all home-dwelling seniors receive the support, service and care they are entitled to. The programme ignited several debates in both TV and newspapers and highlighted the growing challenge society faces in looking after the older generation more effectively. In this context, the question is raised: How will society meet the existential needs of older people if it cannot even care for their most basic physical needs?

Independent of the debate initiated by *Brennpunkt*, both the public discourse on the care of older people and that care itself has evolved over the last two decades to focus on the consequences of the economic challenges of the so-called “age wave” (Haukelien, 2021). The Norwegian graphic designer Hermund Storsæter made a digital drawing of this concept in 2022:



### Eldrebølgen

Hermund Storsæter © 1999. Eldrebølgen i tegning 2002.  
 Foto: H. Storsæter. Illustrasjon: H. Storsæter. 2002. 40x60 cm.  
 Pris: 120,-

Alle rettigheter forbeholdt. Ingen deling eller utlåning av bildet er tillatt uten tillatelse fra utgiveren. Dette er et bilde som er beskyttet av opphavsrett. For mer informasjon, se www.storsæter.no

**Figure 1:** “Eldrebølgen”: Reproduced with permission of the artist, Hermund Storsæter.

The text beneath the picture says:

An enormous wave of older and sick people and people with disabilities is about to wash over a small nursing home like a tsunami wave. The age wave is a term used to describe the development and change in the age and composition of the population. Higher life expectancy due to, among other things, better health service provision as well as high birth rates after the Second World War, combined with falling birth rates in recent years, means that there are constantly more old-age pensioners and pension recipients and fewer people working and paying taxes.

Against this background characterised by insufficient attention to the existential needs of older people, and in a post-secular and postmodern society with a growing population of older people where the Church of Norway and its deacons are important partners of public health services, my thesis explores the perspectives of older people and deacons on existential issues and ECs.

### 1.3 Diaconia

The thesis is placed within the science of diaconia, and since there are differences in the theology of diaconia between the Nordic countries (Leis-Peters & Middlemiss Le Mon, 2024), I will elaborate on diaconia and the science of diaconia in the Norwegian context. Then, I will briefly include a few Nordic researchers relevant to this thesis.

In *Plan for diaconia* (Den norske kirke, 2020) the Church of Norway defines diaconia as “the church's care service. It is the gospel in action and is expressed through charity, inclusive communities, protection of creation and struggle for justice”<sup>2</sup> (p. 4. My translation). In the plan, diaconia is not reduced to measures and activities, but is also considered a dimension that can be expressed through, for instance, values and identity. In deacons’ meetings and conversations with older people, the diaconal dimension can be expressed through respectful and trusting relationships as well as through rituals and devotions. Furthermore, according to the plan, the church “has been given a special mission to serve people, and to share community and resources with marginalised, sick, hungry, thirsty and isolated (Matthew 25, 35ff)” (Den norske kirke, 2020, p. 6. My translation). *Diaconia in Context* (Nordstokke & Lutheran World, 2009) also underlines the diaconal responsibility for and with the marginalised. The latter document furthermore emphasises taking the perspective of the marginalised and giving them a voice.

The diaconal view of human life is a holistic one; that is, that man consists of body, soul and spirit. This means that when meeting people, one must take into account that they consist of physical, psychological, social and existential needs, and that they mutually influence one another (Austad et al., 2020, p. 12). In diaconal work, people are to be seen and listened to because they are fellow humans with infinite value (Nissen, 2008, p. 245). Moreover, the diaconal view of man is based on a Christian foundation, where each person has an intrinsic value as a being created in the image of God. External characteristics, such as gender or nationality, do not affect value (Nissen, 2008, p. 248; Bibelen 2011, Galaterne 3:28), nor can old age diminish a person’s worth, according to the biblical perspective. Older people are mentioned and described throughout the Bible. For instance, old age is portrayed as a flourishing time (Psalm 92, 12–15) and the Fifth Commandment urges people to honour their parents (Ex. 20, 12), which also safeguards the basis of life. Thus, the Bible promoted the care and support of older people in what can be a challenging phase of life long before modern welfare systems were established.

Lastly, human beings have physical, psychological, social and spiritual/existential needs. These different aspects have a mutual influence on each other. Religion can, for instance, affect our physical and mental health, and social life can impact our physical and psychological health (Hvidt et al., 2017; Sørensen & Kvande, 2014). With this as a backdrop, conversations on existential issues may influence people’s social, mental and physical health, thus giving rise to the concept of existential health. I will return to the existential as it relates to health in Chapter 2.2.

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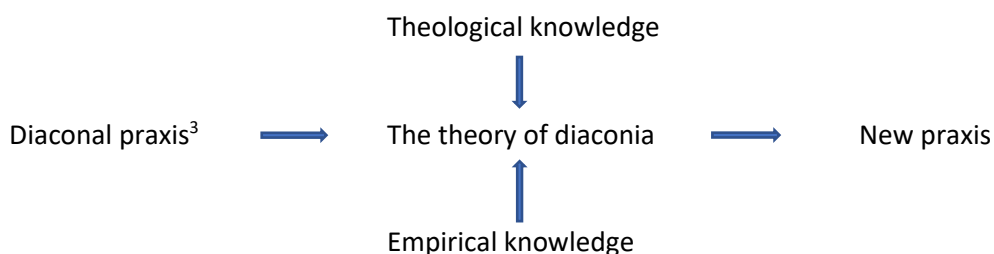
<sup>2</sup> “kirkens omsorgstjeneste. Den er evangeliet i handling og uttrykkes gjennom nestekjærlighet, inkluderende fellesskap, vern om skaperverket og kamp for rettferdighet.”

### 1.3.1 The Science of Diaconia in the Norwegian Context

The science of diaconia has undergone development, and the theologian and psychologist of religion, professor emer. Hans Stifoss-Hanssen, has contributed significantly to the advancement of the field. He led the work on developing the diaconal discipline in educational institutions, establishing the PhD programme Diaconia, Values and Professional Practice at VID Specialised University (Diakonhjemmet University College at the time). One of the aims of forming the PhD programme was to ground diaconia on its own foundation with its own practice, theory and research in the practice field. The programme aimed at “contributing towards the expansion and development of the diaconal sciences through studies with a focus on professional practice in health and social services, and churches and other faith communities” (Stifoss-Hanssen, 2014, p. 63). Furthermore, the PhD programme highlights the need for a broader consideration of how to shape diaconal studies, emphasising diaconia as a professional practice with empirical investigations into diaconal practices as its central component (Stifoss-Hanssen, 2014, p. 63).

Before diaconia started its development as a scientific discipline in Norway, it was an academic subject treated as a sub-theme of theology (Kleiven, 2015; Stifoss-Hanssen, 2014). The notion of diaconia as a category under (practical) theology still exists in some contexts, and Grevbo (2018) even placed diaconia under pastoral care (p. 39). However, the theologian and professor emer. of diaconia Kjell Nordstokke is another scholar who has contributed greatly to expanding the diaconal scientific field into more than a theological sub-discipline by opening it up to empirical and interdisciplinary work.

In arguing for the *raison d’être* for the science of diaconia, Nordstokke considered two main approaches: theology and the social sciences. Because Nordstokke felt neither could offer a convincing relationship between church and society on their own, he developed a theoretical framework for the science of diaconia (Model 1).



**Model 1:** The framework of the theory of diaconia according to Nordstokke (2011, p. 36).

<sup>3</sup> Nordstokke uses the term “praxis” for “social action that is planned and goal oriented” and is thus not to be interpreted as any type of practice (Nordstokke, 2021, p. 29).

With this figure and his elaboration on it in his book *Liberating Diakonia* (2011), Nordstokke's main point is that the science of diaconia is interdisciplinary in nature and epistemologically draws on theology and the social sciences as well as theory and empirical knowledge. Such a combination is needed to develop diaconal theories.

His model contributes significantly to the science of diaconia. Still, it calls for reflection. One aspect concerns theology, as the model itself does not portray the diversity of theological traditions or which theological branch it refers to. In his writings, however, Nordstokke advocated Latin American liberation theology, whose inductive approach has methodological implications, as opposed to the traditional theology freed from time and space that favours deductive methods (see for instance Nordstokke (2011, pp. 34, 59)). Nordstokke (2011) also asserted that praxis comes before theory and that theory must be rooted in praxis (pp. 34-35), a principle found in the theology of liberation (p. 59). At the same time, he referred to theology as theory: "the theoretical framework for the science of diakonia cannot be exclusively theological" (p. 35).

Another issue is that the social sciences are not explicitly included in the model, although Nordstokke emphasised that interdisciplinarity means giving equal importance to theology and social sciences in a dialectic process (p. 35). I find that the model's design does not fully capture the interdisciplinarity that Nordstokke described, for instance in his book chapter "Theoretical Framework of the Science of Diakonia" (2011).

The third aspect of Nordstokke's model worth noting is that the arrows in the epistemological axis could preferably go both ways. Diaconal theory is not only formed by theological and empirical knowledge. Diaconal theory and practice can and should influence theological knowledge (Stålsett, 2021, p. 95). I believe that for professional deacons, in many cases there is an *interaction* between theological knowledge (both theoretical and lived), empirical knowledge from different scientific fields, and theories of diaconia. Hence, the model is served by the arrows pointing in both directions. Nonetheless, Nordstokke's model is excellent for reflecting on theology, diaconal methodology, epistemology and praxis. Nordstokke thus provided a substantial contribution to the science of diaconia as well as its explicit development as an interdisciplinary field. Moreover, he contributed to emphasising influences from liberation theology into diaconia, such as participation, empowerment and the focus on oppressive structures and the element of power imbalances (Nordstokke, 2011; Nordstokke & Lutheran World, 2009).

For this thesis, then, even though Nordstokke seems to equate empirical knowledge and social sciences in his model, I choose to interpret the model as open to scientific disciplines besides social sciences. Therefore, as an illustration relevant to my dissertation, diaconal theory on how to address existential issues with older people would include, for instance, theological reflection on the Christian view of older people juxtaposed with psychological sciences on existential conversations. It is



important to point out that I consider both theology and psychological sciences as sources of both theoretical and empirical knowledge.

### 1.3.2 Some Relevant Nordic Contributors

In this section, I will present some Nordic researchers relevant to this thesis.

Dr. theol. and professor emer. Trygve Wyller has influenced the Norwegian diaconal field by, for instance, introducing and applying the French philosopher Michel Foucault's concept of heterotopia (1986), initially with his book chapter "Heterotopisk diakoni: diakoni i spenningen mellom kall og profetisme"<sup>4</sup> (2006). Heterotopia is not an original diaconal concept, but through Wyller's work it has become an important perspective in the diaconal discourse. This is a good example of diaconal-scientific interdisciplinarity, as he applied heterotopia in dialogue with theology in the discussion of diaconia. Wyller thus deepened and broadened the interpretation of diaconia and expanded the diaconal interlocutors mainly from theology and social sciences to philosophy. He also argued that if the prophetic and ecclesiastical-based diaconia is to become interesting and important, the practice and theory must be heterotopic (2006, pp. 274-275). I will return to the concept of heterotopia in Chapter 3.

Dr. theol. and professor Sturla Stålsett is another Norwegian theologian who has contributed to the diaconal research field. Like Nordstokke, he is rooted in Latin American liberation theology (Stålsett, 1997; Stålsett et al., 2018). Regarding diaconal research, Stålsett et al. (2018) emphasised that this is not only research *on* diaconal practice, but that research should be seen as diaconal practice in its own right. Thus, it is essential to integrate the efforts of individuals and communities through collaborative and participatory involvement (2018, p. 166). In other words, they bring in methodological aspects on how to conduct diaconal research. This emphasis on diaconal research as research *with* people, not *on* people, shows commonalities with Nordstokke and Wyller, who also pointed out that diaconia is not working *for* but *with* people (Nordstokke, 2011, p. 60; Wyller, 2006, p. 282). Another resemblance to Wyller is that Stålsett contributed to incorporating perspectives from outside theology and social work. For instance, he used the work of the philosophers Giorgio Agamben and Judith Butler in his analysis of the gradation of the human dignity of asylum children (2012).

A commonality of Nordstokke, Wyller and Stålsett is that they describe diaconia as Christian *social* practice (Dietrich et al., 2014, p. 1; Stålsett, 2021, p. 95; Wyller, 2009, p. 206). What they seem to lack in their diaconal research, and what this thesis contributes to, is diaconia as Christian health practice at the service level, as a mentioned aspect in the development of the PhD programme (Stifoss-Hanssen, 2014, p. 63). There are different branches within the Nordic science of diaconia, with the

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<sup>4</sup> In English: "Heterotopic diakonia: diakonia in the tension between vocation and prophetism".

major branch focusing on diaconia as social work. However, some Norwegian researchers in the field of psychology of religion – including Marianne Rodriguez Nygaard, Hans Stifoss-Hanssen, Lars Danbolt, Anne Austad and Tormod Kleiven – sometimes employ a diaconal perspective. Nygaard, who is a deacon as well as a researcher, also provided important research on deacons’ professional knowledge and knowledge-formation processes within the Church of Norway. In addition, in her doctoral thesis, she developed a model of deacons’ empirical knowledge creation and care in interactions with participants (Nygaard, 2015). In Norway, she has made the most substantial contribution to Stifoss-Hansen’s request for research on the professional practice of the deacon (2014, p. 62). Furthermore, through her empirical research, she found that deacons’ work transcends the traditional dichotomy between the logic of word and the logic of action. This suggests an expanded definition of diaconia that does not confine the work of deacons to mere actions but rather acknowledges the importance of the interplay between words and actions (Nygaard, 2017).

In her article “Reflective Diaconia from the Margins”, Nygaard also addressed power structures and the marginalisation of deacons (2017). She found only one deacon among the 21 committee members of the General Synod (Kirkemøtet) in 2011, the highest representative body for the CofN. This deacon was also the only deacon among the 115 voting members of the General Synod that determined “The Deacon Ministry in the Church Ministry Structure”, one of the essential documents on deacon ministry in the CofN (Nygaard, 2017, p. 167). In the article, Nygaard reflected on how deacons are on the periphery of the decision-making structure in the church. Moreover, she highlighted the clear division between the centre and periphery: The centre is inhabited by bishops, the General Synod, pastors, word and sacraments; while on the periphery are deacons, diaconia, suffering and actions. Consequently, there is an imbalance of power. Nygaard further argued that deacons in the Church of Norway face double marginalisation, in that their ministries are relegated to the periphery and they are excluded from decisions regarding their roles in the Church of Norway.<sup>5</sup>

Even more important is her – and other deacons’ – research in evening out the heavy influence of theologians in diaconal science. Theologians and deacons have different educational backgrounds, and this thesis aligns with Nygaard, who asserted that “deacons themselves should research their own professional practices” (2017, p. 183). She also highlighted that theologians lack the relational aspects in favour of an emphasis on the word, whereas the relational approach is central in diaconia (2017, p. 184).

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<sup>5</sup> By marginalised/margins, Nygaard refers to Nissen’s definition: “The term ‘marginalized’ designates various groups that social discrimination processes have excluded from the decision-making processes”. Nissen, J. (2014). Creating a space for the others: The marginalized as a challenge to Diaconia and Church-a theological perspective. *Diaconia*, 5(1), 31-46.

Though Nygaard did not touch upon the question of gender in her article “Reflective Diaconia from the Margins” (2017), the issue of power structure resembles what the Swedish professor emer. in ecclesiology Ninna Edgardh worked on. Together with Erik Lundström (2017), Edgardh researched prophetic diaconia and gender power structures in churches. Based on interviews with deacons in the Church of Sweden, they found that inside the Church, deacons are predominantly women but face resistance from predominantly male decision-makers. Outside the Church, they face critics in their efforts to help vulnerable people. Thus, they are in a role that faces criticism from both directions. Along these lines, Edgardh was the first to evolve a feminist ecclesiology of diaconia (Leis-Peters & Middlemiss Le Mon, 2024, p. 18). The Norwegian feminist theologian and associate professor Gyrid Gunnes expanded this perspective into queer theology (2020), and conducted critical observations of diaconal practices in the Lutheran church Our Lady in Trondheim, with a theoretical basis in Hethrington’s use of heterotopia combined with a diaconal and ecclesial discourse on heterotopia (2017).

The Swedish dr. theol. and deacon Charlotte Engel made an essential contribution with her doctoral thesis *Svenska kyrkans sociala arbete - för vem och varför? En religionssociologisk studie av ett diakonalt dilemma*<sup>6</sup> (2006). She focused on diaconal work in six congregations with the aim of investigating how well it corresponded to the Church of Sweden’s goal of directing diaconal work towards the most disadvantaged and/or marginalised groups in society. She found that the congregations she studied did not prioritise people in particularly vulnerable positions and/or in marginalised life situations. Rather, the diaconal work often took on an entertaining aspect for “energetic and better-off pensioners” (p. 163).

The Danish theologian Johannes Nissen has written extensively on diaconia, including the theology of diaconia, diaconia in relation to pastoral care and diaconal values in social and health work (Nissen, 2008, 2019, 2022). He also wrote the article “The Marginalized as a Challenge to Diaconia and Church – A Theological Perspective” (2014), in which he suggested that “the elderly” be added to the account of “the others” listed in the document *Jesus Christ Heals and Reconciles: Our Witness in Europe* issued by the Conference of European Churches (Church of England & Chartres, 2003), even though his article focused on migrants, the poor and people with mental disabilities.

Diaconia has thus undergone a transformation from a sub-discipline of theology to a scientific field characterised by interdisciplinarity, drawing on theology, diaconal praxis/theory and other relevant empirical or theoretical scientific fields. Several Norwegian and Nordic diaconia researchers

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<sup>6</sup> In English: The Church of Sweden's social work - for whom and why? A religious sociological study of a diaconal dilemma

have contributed to a growing interest in diaconia and an increasing research field, which will be interesting to follow in the future.

#### 1.4 The Psychology of Religion and Existential Psychology

The other major disciplines that I draw on in this thesis are the psychology of religion and existential psychology. The former is a sub-discipline of psychology, which in a Nordic context is described as:

a field of study and research where different kinds of psychological theories and methods are used to study beliefs and worldviews such as experience, behaviour and function. The exploration of the individual's meaning-making is central. In this context, *meaning* means far more than the purely cognitive and is about *a pervasive experience of trust, belonging and coherence in life*. (Danbolt, 2014, p. 18. My translation)

This quotation conveys at least two essential aspects. First, the field uses theories, methods and perspectives from psychology, not religion. Psychology is thus the onset. Second, it clearly states that beliefs, worldviews and meaning-making are not restricted to the cognitive dimension but open to activity and the experiential dimension, which may be expressed through participation in different types of communities, rituals, aesthetics, prayer, meditation or ethics. Furthermore, the discipline strives for religious and ideological neutrality but is diverse in terms of theoretical traditions and scientific ideals (Engedal, 2014, pp. 46–47). Therefore, although the term “psychology of religion” may indicate that religion is the main focus, according to the previous citation<sup>7</sup>, the discipline is not restricted to traditional religious worldviews but includes secular outlooks as well. However, there are other perspectives on what the psychology of religion should be, including Belzen’s (2010). He asserted that to understand religious phenomena from a psychological perspective, one must utilise the scientific disciplines of religion. Psychology is concerned with psychic functioning, and Belzen stated that “at best, most of the psychology of religion is about religiosity, about the individual-personal counterpart of some type of religion” (p. 9), but that religion is a cultural phenomenon (p. 11) which must be included within this branch of psychology.

Religion can be understood or studied from different angles, and there has been a movement from a substantial understanding of religion towards a functional understanding. A functional approach asks what religion does to and for people. A classic definition of religion within the psychology of religion that initiated the move to a functional perspective is the one by Batson et al. (1993):

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<sup>7</sup> “Worldviews (‘livssyn’ in Norwegian) include the individual’s basic attitude, assessment system and image of people and the world. ... These can be more or less inspired by religious or secular ideas and traditions or combinations of such” (Danbolt, L. J. 2014, p. 18).

whatever we as individuals do to come to grips personally with the questions that confront us because we are aware that we and others like us are alive and that we will die. Such questions we shall call existential questions. (p. 8)

Dealing with such questions brings up religion (Batson et al., 1993). With this definition, the existential, understood as the fundamental conditions of human existence in the world, takes on a central role, including in the psychology of religion.

The issue of existential questions leads us to another related sub-discipline of psychology: existential psychology. This discipline has its roots in philosophy, arts and literature, and concerns exploring the existential affairs of human life, both in health and sickness (Binder, 2020, pp. 11–13). Existential anxiety and pain are recurring themes, and the aim is to analyse and describe the basic conditions of human life and to raise the big existential questions, such as: What is the meaning of life? Who am I? What happens after death? The questions raised by existentialists are also found within the different world religions, but existentialists do not provide answers, and the interpretations of existence vary (Austad, 2014). For instance, the philosopher Søren Kierkegaard (1813–1855) paved the way for existentialism. To him, existential philosophy had a religious foundation, with God holding a central place. In his view, human beings can establish a personal connection with God and possess free will (Binder, 2020, p. 14). Other religious existential philosophers include Emmanuel Levinas and Martin Buber. A contemporary of Kierkegaard, atheist and existentialist Friedrich Nietzsche, lived, like Kierkegaard, during a time when religion was gradually losing its authority. Human beings thus became free to choose their worldview and which values to build their lives on (Binder, 2020, p. 14), with the freedom to create values and meaning becoming central issues (Binder, 2020, p. 15). Today, the term “existentialism” usually refers to the philosophy of Jean-Paul Sartre and the philosophers in his circle, which was founded on atheism (Austad, 2014, p. 146). This thesis will also adopt this interpretation of the term.

The psychiatrist and writer Irvin D. Yalom is affiliated with both existential psychology and existentialism, focusing on human beings’ existence in the world and the conflicts that emerge when confronted with the ‘givens of existence’ (1980, p. 8). According to atheism, there is no God or Creator, and according to existential philosophy, the universe has come into being by chance. Thus, life has no predetermined meaning; each human must find their place in the world and search for and create meaning. This is in line with Yalom’s thinking (1980). In the philosophy of existentialism, existence is the naked start, and existence precedes essence. Man is born into the world without an intrinsic nature or a predefined purpose. Man’s identity, his essence, is created through the choices he makes (Martinsen, 1991). Life has no inherent meaning, but every person can *create* meaning (Austad, 2014, pp. 143–144; Binder, 2020, p. 15; Yalom, 1980, p. 9). According to the basic existentialist view, values

and meaning are constructive, and thus belong to “the meaning-making paradigm” (Hansen, 2016, p. 65).

This existentialistic worldview contrasts with religious and spiritual worldviews, where God/a higher power is the Creator, and man’s life on earth has a purpose. According to the Jewish Christian tradition, a person’s goal is to realise their destiny (Austad, 2014, p. 143). This may be seen as a meaning-*receiving* perspective (Hansen, 2016, p. 68), as opposed to the meaning-making perspective. Being born into this world by a Creator may be perceived as giving meaning in itself and may give the religious or spiritual-oriented person a sense of meaning and direction in life. From such a perspective, the existentialist viewpoint that existence precedes essence may be turned around; if God created man with a purpose, essence precedes existence. It may even be the meaning *of* life; that life is a gift, and its meaning is to live it in accordance with the will of the Creator. However, these perspectives are not necessarily opposing. A religious person may have both a sense of a universal meaning *of* life and search for meaning *in* life. The first article of this thesis will delve more deeply into this issue.

A core concept within these fields of psychology is existentiality. A discussion of the concept appeared in the late 1990s. As a response to Pargament (1999) concerning the discipline of the psychology of religion, Stifoss-Hanssen (1999) suggested using “existentiality” instead of Pargament’s “sacredness” as the heart of “spirituality”. Stifoss-Hanssen saw spirituality as to a large extent overlapping with religiosity but extending slightly beyond its boundaries. More importantly, existentiality would include both religious and secular dimensions of spirituality. In the almost 25 years since then, one can see that “the existential” has established itself as the overarching term in the Scandinavian context, though the concept is understood in various ways. Nygaard et al. (2022) contributed essential research in this respect by studying how the term has been used in Scandinavian healthcare journals. Based on this extensive research, they formulated a description of the concept, which forms the foundation of this thesis and is also referred to in Section 1.1:

The term ‘existential’ related to health refers to the fundamental, basic condition of being a human. The existential is based on the irrefutable fact that we live and will die, facing conditions and uncertainties along the way beyond our control. The existential is expressed primarily through a quest for making and seeking meaning in life in general, as well as in demanding life situations. This may involve movements between suffering and re-orientation and meaning and meaninglessness. Existential concerns can be integrated into both religious, secular, and spiritual worldviews. (p. 16)

Therefore, existential issues concern the human being’s basic conditions in this world regardless of religion or outlook on life. Thus, I have chosen to use “existential” instead of “spiritual” in the title of this thesis, as it is not primarily concerned with religion or spirituality but rather existential questions and how older people experience and reflect on them. Moreover, the thesis explores how deacons, who are ecclesiastically educated, meet older people’s existential challenges.

## 1.5 Contextualisation within the PhD Programme

This thesis is placed within the PhD programme Diaconia, Values and Professional Practice at VID Specialized University in Norway, a programme “with an interdisciplinary approach as an innovative contribution to the research field of diaconal studies”<sup>8</sup>. The thesis deals with all three dimensions of the programme – diaconia, values and professional practice – to a greater or lesser extent.

Diaconal research can focus on diaconia understood as diaconal work/activities/organisations on the one hand and deacons’ professional practice on the other (Stifoss-Hanssen, 2014, p. 62). The practice field needs a theoretical foundation from educational institutions, but educational institutions also need contributions and experiences from praxis to develop diaconal knowledge and theories. In other words, an exchange of knowledge is required between the two fields, and empirical research on deacons’ professional practice is thus an essential source for the science of diaconia. This also lies at the heart of the development of diaconal theory (Nordstokke, 2011, pp. 29–39). Furthermore, it is in line with the PhD programme Diaconia, Values and Professional Practice: “The PhD programme points to a general reflection on how diaconal studies could preferably be shaped with an increased focus on *diakonia* as a professional practice and on empirical studies of diaconal practice as the core element” (Stifoss-Hanssen, 2014, p. 63). Stifoss-Hanssen also pointed to an essential aspect: “Systematic studies of practices can also contribute towards improving strategies, developing a reflection on practice (= theory), and establishing links between theory and practice” (2014, p. 64).

Based on Stifoss-Hanssen’s aspects, I aim to develop reflection on practice. Additionally, my thesis meets the need for more empirical research on diaconia as professional practice, as it is an empirical study of deacons as existential conversation partners with older people. Finally, my work is interdisciplinary, as requested in the PhD programme. I have combined healthcare, the psychology of religion, the science of diaconia and existential psychology/philosophy.

## 1.6 Aim and Research Question

The mentioned dignity guarantee and quality reform for older people inspired me first to explore older people’s reflections and experiences concerning existential issues and whether they need to discuss them. The second was to explore deacons as existential conversation partners for older people.

Diaconal work and research must always adopt the perspective of people’s needs, especially vulnerable groups (Kleiven, 2015; Nordstokke et al., 2010). This lies at the heart of diaconia. Therefore, the aim is also to explore the thoughts and experiences of older people, a group often not listened to

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<sup>8</sup> [Studieplan-ph.d-i-diakoni-verdier-og-profesjonell-praksis-engelsk-2018-2019-vid.pdf](#)

and that, to some extent, is treated as a marginal group and subjected to ageism<sup>9</sup>. Additionally, I want to highlight deacons' perspectives – a group of professionals not well-known in Norwegian society and not extensively researched. Finally, the aim is to contribute empirical insights into deacons' experiences and reflections, which can be valuable in further diaconal research work and diaconal practice.

The aim of this thesis is to explore older people's reflections on existential issues and deacons' perspectives on existential conversations with older people. The overall research question is: "What are older people's reflections concerning existential issues and how do deacons within the Church of Norway interpret and respond to older people's needs through existential conversations?"

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<sup>9</sup> "Ageism refers to the stereotypes (how we think), prejudice (how we feel) and discrimination (how we act) towards others or oneself based on age." WHO <https://www.who.int/news-room/questions-and-answers/item/ageing-ageism>



## 2 Research Front and Research Gaps

In this chapter, I will present research relevant to this thesis and the gaps I aim to contribute to filling.

Existential issues in old age from the perspective of older people and existential conversations between older people and deacons are largely unexplored empirical research fields in the Scandinavian context. In the following presentation of the research front, I will divide the research field into two sections, each devoted to one of the aforementioned aspects. While there may be some overlap between what follows and what I have already presented in the articles, I will also present supplementary and updated research. Thirdly, I will present research on existential language and existential health in a Scandinavian setting, as this is closely linked to talking about existential issues.

As for databases, relevant research was conducted using Academic Search Elite, Atla Religion Database with AtlaSerials and SocINDEX with full text, Cinahl and Medline. Literature and research were also identified through reference lists in articles and books and recommendations from others.

### 2.1 Existential Issues and Older People

Do older people relate differently to existential issues than younger people? In a Norwegian quantitative study by Sørensen et al. (2021), people in late adulthood ( $\geq 65$  years) scored significantly higher than younger adults (18–64) in meaningfulness, including vertical transcendence. In the same study, unselfish engagement with others and generativity emerged as important sources of meaning for people aged 65 and older. This may not be surprising, as old age may be a time for maturation and growth, transcendent thinking, existential and spiritual orientations and practices, and reflections on existential issues such as death, meaning, loneliness and coherence (Binder, 2018, pp. 317–327; Binder & Nielsen, 2005; Erikson, 1997; Levin et al., 2011; Stripp et al., 2022; Tornstam, 2011). At the same time, it may also be a period of physical decline and loss, which may prompt some people to ask existential questions. This is confirmed by an increasing amount of research indicating that existential issues can be essential for older people in healthcare services (van Der Vaart & van Oudenaarden, 2018). For instance, a Norwegian interview study with older, cognitively healthy nursing home patients conducted before the coronavirus pandemic found that almost 50% of the participants reported being lonely (Kuvein et al., 2023).

Some studies from Finland have examined older people and existential issues. Pirhonen et al. (2023) researched the religiousness of people with severe dementia through interviews with Lutheran chaplains and nurses. They found that people with dementia expressed religiousness to the chaplains through their bodies, emotions and rituals and also that the chaplains influenced the older people's religiousness through the body. Saarelainen et al. (2022) found that among older people, relationships

are key to experiencing meaning in life. In another study, Saarelainen et al. (2020) interviewed five older people who were dying. The researchers identified that the older people's religious experiences were often shared with others, giving them a relational aspect, and that religious experiences could be sources of both comfort and challenge. Spännäri and Laceulle (2021) found that religion and spirituality were present in the lives of Finnish retirement migrants in Spain, with meaning-making emerging not only as a result of facing crises such as ill-health or death but also through mundane activities. Spirituality may be an important source of hope and meaning, and Malone and Dadswell (2018) found that older adults longed for a holistic approach to their health and well-being, including religion and/or spirituality<sup>10</sup>. Furthermore, Thauvoye et al. (2018) found a positive relation between well-being and experiencing spirituality, and Brémault-Phillips et al. (2015) determined that spirituality is essential in coping with distress at the end of life. In a quantitative study on terminally ill (although not specifically older) patients, "spirituality, especially its existential or 'sense of meaning and purpose' dimension, was associated with less distress" (Chochinov et al., 2009). However, in the Norwegian context, where this thesis is situated, there is little research on older people's experiences and reflections regarding spirituality, according to Rykkje et al. (2013). Updated searches confirm this gap, which my thesis aims to fill.

Although most older people are not patients, most patients are older people (Bondevik, 2009), and as patients, they encounter many different healthcare professionals. Serious illness can lead to existential concern and reflection that for some may be alleviated by having a conversation partner. However, both international and Nordic studies indicate that healthcare professionals avoid talking about existential or spiritual issues with patients (Bailey & Cogle, 2018; Giske & Cone, 2020; Kaspersen, 2020; Kuven & Giske, 2019; Wright et al., 2008). In a Finnish study, Saarelainen et al. (2020) found that religious or spiritual support was not provided by healthcare services. In Denmark, Søndergaard et al. (2017) found that many general practitioners (GPs) even understood themselves as barriers to existential conversations. These research findings may be anticipated, as discussing existential issues is often regarded as a private matter in Scandinavia (Giske & Cone, 2020; Hvidt et al., 2020; Jensen & Mørk, 2016; la Cour & Hvidt, 2010; Nissen & Andersen, 2021; Rykkje et al., 2013; Viftrup et al., 2020).

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<sup>10</sup> In the research literature, "spirituality" tends to be understood as a collective designation for the interior life with its convictions, practices, emotions and sources of meaning that are present as a source of hope and energy in every person. SC, on the other hand, is broadly understood as a type of care that addresses and seeks to meet existential and spiritual needs and challenges in connection with illness and crisis. Hvidt, N. C., Nielsen, K. T., Kørup, A. K., Prinds, C., Hansen, D. G., Viftrup, D. T., Assing Hvidt, E., Hammer, E. R., Falkø, E., Locher, F., Boelsbjerg, H. B., Wallin, J. A., Thomsen, K. F., Schrøder, K., Moestrup, L., Nissen, R. D., Stewart-Ferrer, S., Stripp, T. K., Steinfeldt, V. Ø., . . . Wæhrens, E. E. (2020). What is spiritual care? Professional perspectives on the concept of spiritual care identified through group concept mapping. *BMJ Open*, *10*(12), e042142-e042142. <https://doi.org/10.1136/bmjopen-2020-042142> .

Although many healthcare professionals may provide satisfactory existential and spiritual care, by their own admission their contribution is not sufficient due to various reasons, including lack of time and/or competence or a feeling of being out of their comfort level (Balboni et al., 2014; Giske & Cone, 2020; Kuven & Giske, 2019; Steinfeldt et al., 2019, p. 90; Strang et al., 2014). For instance, Balboni et al. (2014) found that 40% of nurses and doctors provide less SC than desired because of a lack of private space and time, respectively. In addition, a Swedish study by Strang et al. (2014) describing nurses' reflections on existential issues in communication with patients close to death found that some nurses stressed prioritisation as a reason for not entering existential conversations and that "routines and knowledge about existential questions were insufficient" (p. 566). Moreover, there were no procedures for documenting conversations. In focus group interviews with 61 healthcare professionals, Sundström et al. (2018) determined that the participants found it challenging to talk about existential issues, as it also affected them personally and professionally.

Finally, Scandinavian countries are highly secularised (Hovdelien, 2019; Nissen & Andersen, 2021, p. 1; Repstad, 2020; Urstad, 2017). This may lead healthcare professionals to believe that most patients have secular values, which could make them less likely to bring up the topic of religion. Furthermore, according to Stripp et al. (2023)<sup>11</sup>, research on spiritual needs and experiences in secular societies is essentially non-existent. As the first large-scale study on spiritual needs in Denmark – with 26,678 participants – their study is therefore a compelling contribution that will be of great significance for further research on spiritual needs in secularised countries, for healthcare professionals and policymakers alike. As the largest study to examine spiritual needs to date, it provides long-awaited insight into the spiritual needs of people in post-secular societies. Therefore, studies on spirituality and religion based in Scandinavia are essential, and of great value for this thesis. Their results showed that of the 23,863 participants who completed the survey, 81.9% reported having at least one spiritual need the previous month (p. 13). Of interest for this thesis, Stripp et al. also found that being older (age 65+) was one of several factors that "predicted a greater likelihood of having existential needs" (p. 9). The researchers interpreted the results as pointing to two issues. One is that there is a need for heightened attention to spiritual needs in healthcare settings, and the other is "the need for future research to guide spiritual care interventions as part of a holistic approach to healthcare in post-secular cultures" (p. 13). Worth noting is that though Denmark is largely non-religious, almost one in five citizens experience religious needs, suggesting that assessments and interventions in post-secular settings should also include attention to religious needs if present. Based on their study, Stripp et al. concluded that there is a need for holistic clinical care that includes the spiritual needs of patients (p. 12).

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<sup>11</sup> They used the Spiritual Needs Questionnaire (SpNQ), which measures spiritual needs in four dimensions: 1) religious needs, 2) existential needs, 3) generativity needs and 4) inner peace needs.

The article “Defining pastoral care for older people in residential care” (Wilkes et al., 2011) thematises the characteristics and meanings of PC based on the perspectives of PC providers, older recipients and their family members in an Australian setting. The study highlighted “the characteristics of pastoral care and typified the role of the pastoral care worker as spiritual guide, confidante, emotional and practical supporter acting within a trusting relationship” (p. 220). The study participants emphasised the need for a trusting relationship and spiritual support. Likewise, the PC providers and older people expressed that building this trust often takes time. The participants further conveyed the value of having someone outside the family or institution with whom to discuss deeper issues.

## 2.2 Deacons as Existential Conversation Partners with Older People

Existential conversations may be understood as dialogues between two or more people around existential issues such as the meaning and purpose of life, death, loneliness and freedom (Bunkholt, 2022, p. 151). Deacons are educated conversation partners: They are individual Christians who are called, trained and recognised by the church to diaconal ministry, responsible for caring for the needs of their community members. Research shows that Norwegian deacons have many weekly conversations (Grung et al., 2016). However, the science of diaconia is a young and quite small research discipline in the Norwegian context, and even smaller in the professional practice of deacons<sup>12</sup>. Narrowing diaconal research to existential health in the Norwegian context, we find very few research publications in international databases, as confirmed by DeMarinis (2022, p. 61). Furthermore, as presented in our article on deacons as existential conversation partners with older people, I have not found any studies that discuss older people and existential issues *and* deacons as existential conversation partners/PC providers (Olafsson et al., 2022). Furthermore, there seem to be more theoretical research publications than empirical ones on PCCs (Danbolt et al., 2021). There are a few empirical and newly published articles on pastors and deacons as PC providers in the Norwegian context;<sup>13</sup> however, none focus on older people as pastoral care recipients or the deacons’ professional competence. This is a clear signal that this thesis belongs to a new research field.

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<sup>12</sup> I have not included research on Catholic deacons or deacons from traditions other than the Lutheran.

<sup>13</sup> Danbolt, L. J., Stokka, E., Sandsmark, A., & Stålsett, G. (2022). Sjelesorg med ungdom. Hva snakkes det om og hva er rammene? *Tidsskrift for praktisk teologi*, 39(1). <https://doi.org/https://doi.org/10.48626/tpt.v39i1.5478>

, Grung, A. H., Danbolt, L. J., & Stifoss-Hanssen, H. (2016). Sjelesorg på plass: på sporet av dagens sjelesorgpraksis i Den norske kirke. *Ibid.*, 33. , Stifoss-Hanssen, H., Grung, A. H., Austad, A., & Danbolt, L. J. (2019). Sjelesorg i bevegelse : kerygmatiske, konfidentorientert, dialogisk sjelesorg - møte mellom teoretiske posisjoner og et empirisk materiale. *Tidsskrift for sjelesorg*, 39(1), 75–95. , Stokka, E., Stålsett, G., Sandsmark, A., & Danbolt, L. J. (2022). Sjelesorg i farta. *Tidsskrift for praktisk teologi*, 39(1). <https://doi.org/https://doi.org/10.48626/tpt.v39i1.5480>

### 2.3 Existential Language and Existential Health in a Scandinavian Setting

As already mentioned, DeMarinis (2003) asserted that the loss of religious framework in the postmodern society poses a threat to healthcare on the one hand, where the most extreme consequence is “the inability to articulate a philosophy of health and of care, the inability to create a system of orientation necessary for the mental health professional’s ability to diagnose and treat” (p. 29). On the other hand, it poses a threat to individuals by depriving them of a framework to understand their situation in the world. This may lead to a lack of language for communicating their existential thoughts, experiences and feelings. The aforementioned understanding is confirmed in a Danish qualitative study by Viftrup et al. (2020), who pointed out that “Danes have few linguistic resources for dealing with existential thoughts and feelings, and medical languages are increasingly being implemented in the general language” (p. 161).

In the same study, Viftrup et al. also identified support for the idea that terminal illness can lead to intensified existential, spiritual and/or religious considerations. The patients’ existential language<sup>14</sup> is strengthened and developed when healthcare professionals use an existential rather than medical language (p. 170). The following extract from Hvidtjørn et al. (2014) may thus call for reflection:

If Danish society does indeed become more secularized, it is possible that spiritual struggles will increasingly become commonplace among patients dealing with life-threatening diseases as their religious belief systems becomes more fragmented, less integrated, and less helpful. As religious upbringing becomes less common among younger generations (Ausker & Mørk, 2007) younger patients in secular societies may become more vulnerable to spiritual struggles because they lack concepts and language to deal with existential, religious, and spiritual questions (la Cour, 2008) and as a result grasp for whatever existential, spiritual, or religious meaning-making systems (Park, 2005) they believe may help them cope. The question is whether they will succeed in constructing a new system of religious or spiritual meaning or whether their struggles will lead to frustration, confusion, and despair. (p. 200)

Regardless of religious/existential literacy, international and Scandinavian studies indicate that talking about death and life can improve quality of life for terminally ill patients (Balboni et al., 2010; la Cour, 2008). La Cour (2008) even found that the youngest age group (<36 years) seemed to be the most active in the existential, religious and practice domains, and writes concerning clinical perspectives:

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<sup>14</sup> Viftrup et al. (2020) define existential language as “words, concepts and understandings within the three existential meaning domains: the secular ... the spiritual ... and/or the religious” (p. 162, my translation).

In a secular setting, this group will often have been raised in a non-religious way and may therefore have special needs regarding development of words and concepts dealing with their changed life conditions, especially if illness is experienced as a life threat. If patients are non-religious, previous clinical studies with non-religious patients have stressed the necessity of time to mutual exchanges of thoughts and natural development of suitable language (McGrath, 2005; McGrath & Clarke, 2003). (pp. 779–780)

Moreover, Bolmsjö (2000) found indications that patients want to discuss existential issues with somebody, and when end-of-life discussions are provided, less aggressive medical care near death is needed and hospice referrals are conducted earlier (Wright et al., 2008). Such findings suggest that existential conversation partners are needed.

The World Health Organization (WHO) describes health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, n.d.). This understanding does not include pain as a normal aspect of life, but rather as a sign of disease. Esdaile et al. (2021) suggested that this description be expanded to include an existential dimension. They explained the concept of “existential health” as incorporating “aspects as faith, experience of dignity, hope, meaning, attachment, spirituality and ability to handle crisis situations”. Existential health is more than a mere bio-medical condition, and Esdaile et al. highlighted that salutogenetic perspectives – that which induces health – such as reasons to live and hope for the future, should be included in the health definition. They furthermore suggested that faith and belief communities can play a significant part in providing these conversations.

Hvidt et al. (2017) found that according to a body of research on religion, spirituality and health, faith moves mountains and mountains move faith, meaning that faith can have a positive influence on physical and mental health and that illness can give rise to faith. They furthermore asserted that the extensive research on religion and health shows an undisputed positive association between health and religion. Furthermore, the comprehensive research on religion, ageing and health also shows that religious participation is essential to psychosocial and related outcomes (Levin et al., 2011, p. 390).

Nevertheless, the picture is not entirely clear. For instance, there are different kinds of religiosity. Hvidt et al. (2017) used the terms “crisis religiosity” and “restful religiosity”, with the former referring to an experience of crisis that triggers religious seeking and the latter characterised by resting securely in one’s faith. In post-secular countries such as Norway, crisis religiosity is predominant. Interestingly, international studies indicate that people tending towards crisis religiosity often “develop negative religious coping patterns that actually increase the risk of disease-related depression” because they do not possess established coping resources (Hvidt et al., 2017, p. 301). This suggests that to strengthen people’s existential health, having available existential conversation partners should be a high priority in post-secular societies.

Given the importance of existential issues for older people and the dearth of research focused on older people, this thesis aims to explore older people's reflections and experiences on existential issues. Furthermore, the thesis contributes to the almost non-existent empirical research on deacons as existential conversation partners with older people. In the context of post-secularism and postmodernism, the thesis presents research on deacons as professionals who understand and speak existential language and thus contribute to existential health.

### 3 Theoretical Frameworks

I place my study within the field of the science of diaconia, which is an interdisciplinary field (Nordstokke, 2011, p. 35). In this thesis, I use the science of diaconia as an umbrella for an interdisciplinary approach combining theology, the psychology of religion and existential psychology. The psychology of religion and existential psychology provide insights into the human mind and human being in the world, which are valuable for deacons' approach to people and ECs. This is combined with theological aspects, such as view of man, and theoretical and practical aspects of pastoral care and ECs. Furthermore, the empirical experiences and perspectives of deacons are important contributions, and diaconal theory is, as addressed in Chapter 1.3.1, a result of theological knowledge, empirical knowledge and diaconal praxis.

In the following, I will present the theoretical frameworks for the discussion in this extended introduction. On the one hand, I use Foucault's concept of heterotopia as well as the diaconal perspective on heterotopia, mainly through Wyller's work. For the concept of heterotopia, I lean on Gunnes (2017), who argued that because of the vast and varied use of the term in different academic disciplines, it "may be understood as a complex of ideas, metaphors and sensitizing devices rather than as a theory in the strict understanding of scientific theory and no single use can claim to be comprehensive" (p. 54). I therefore acknowledge that the way I use and understand the concept may differ from other understandings. On the other hand, I utilise Yalom's ultimate concerns as a universal condition. Heterotopia as dealing with differences, and Yalom's ultimate concerns, which are regarded as common for all humans, are used as two complementary perspectives.

I find two theoretical perspectives sufficient for this overarching discussion, and thus Tornstam's theory of gerotranscendence, which was also used in Article 1, will only be included in a few cases where it is relevant.

#### 3.1 Heterotopia

It was the French philosopher Michel Foucault (1926–1984) who introduced the term heterotopia, first through a lecture in 1967, and then in an English published version called "Of Other Spaces" (1986). Central to the theory of heterotopia is using space rather than time as a way of understanding society and otherness (Wyller, 2006). Other terms used for space in this context are place and room, with heterotopic places characterised as different from so-called normal places but still actual places. Kaia Rønsdal (2018a) made a demarcation between space and place, with place being a geographical location and space referring to the social, formative spaces that arise where people are gathered



(p. 58). Another distinct difference between the two is that the former exists in itself while the latter is created by the involved persons (Rønnsdal, 2018b).

According to Foucault (1986), there are heterotopias in every culture; places that are real, in contrast to utopias, which are “sites with no real place” (p. 24). While utopias are imaginary places, heterotopias are *counter-sites*, according to Foucault. He further explained:

“places of this kind are outside of all places, even though it may be possible to indicate their location in reality. Because these places are absolutely different from all the sites that they reflect and speak about, I shall call them, by way of contrast to utopias, heterotopias”. (p. 24)

According to Foucault, “heterotopias of crisis” in so-called primitive cultures are being replaced by “heterotopias of deviation”, where individuals have behaviour that diverges from the norm. Out of interest for this thesis, he mentions rest homes and retirement homes, what we today call nursing homes, where older people often reside. The older people in these facilities may be in crisis, as may be common in old age, and also in heterotopia of deviation because older people are deviant to the working, productive and active population. Foucault therefore described such institutions as “the borderline between the heterotopia of crisis and the heterotopia of deviation” (1986, p. 25).

In political science, the centre and periphery refer to two opposing sides of a conflict. Belonging to the centre provides privileges, whereas being situated on the periphery equates to marginalisation. Though Foucault (1986) does not use the concepts of marginalised or marginalisation with the heterotopia concept, they are relatable. Being in the other room – in heterotopia – can be associated with being in the margins. Furthermore, marginalisation leads to loss of power, as power, production and crucial tasks lie in the centre rather than the periphery. Being in a heterotopic space thus means being deviant, less important and less influential. It may also signal a lack of material goods, dignity, attention and future prospects. Marginalised people are on the outskirts of society. However, people in heterotopia are not without power. By being deviant and different from the norms of society, the other room “can cross the border, return and at least mirror the normal discourse so that it almost collapses” (Wyller, 2006, p. 274. My translation).

Wyller made an interesting point in his first writing on heterotopia (2006, p. 274), which is that Foucault does not mention religion, the church or rituals in his list of examples of types of other rooms. However, in post-secularised societies, such as the Scandinavian countries, issues such as religion, faith, existential questions and spirituality are to a large extent reserved for private spheres, as mentioned earlier in this thesis. They are taboo, belonging to the periphery and not the centre of what people talk about. They have a central place in the church, though, which may be denoted as a heterotopic room in a secularised society.

In recent times, some have argued that diaconia is reserved for marginalised groups in society (Ham, 2012; Nygaard, 2014; Nygaard, 2017; Wyller, 2010). Stories of marginalisation are also found throughout the Bible, and the Scripture reveals a God who sides with the marginalised (Nissen, 2014). This was also a vantage point at the World Council of Churches conference on Theological Perspectives on Diakonia in the Twenty-First Century in Colombo, Sri Lanka, in June 2012. The conference saw diaconia of the marginalised as crucial for the church's engagement (Ham, 2012, p. 388).

By introducing heterotopia in the diaconal discourse, Wyller challenged the Lutheran World Federation's (LWF) focus on prophetic diaconia. He argued that according to LWF, the church is the subject of the diaconal action. Wyller's (2006) point, on the contrary, is that when bringing the theory of heterotopia into diaconia, diaconia must take place in "the other room", *with* and not *for* the people in the other room. Drawing from the Brazilian liturgical heterotopia, it is the people in the other room that both call and act in the sacred room, not the church. He goes as far as saying that the others give me the bread (p. 282), not the opposite. According to Wyller, then: "Turning the poor into ecclesiastical subjects is the sum of heterotopic diaconia" (p. 286. My translation).

In the book *Heterotopic Citizen: New Research on Religious Work for the Disadvantaged* (2009), Wyller elaborated on the two "waves" in the history of research in the heterotopic (pp. 8–16). The first wave is the tradition of a concrete, limited space, such as safe spaces for persons living with HIV in South Africa, or City Mission work for drug addicts in Norway. The second wave focuses on describing heterotopic spaces and their relationship to society. Here, the heterotopic is not a specific and limited building, institution or practice. On the contrary, otherness and marginalisation in general, and the normative demand from heterotopia (p. 13) are of interest in this context.

### 3.2 Yalom's Ultimate Concerns

In the first article of this dissertation, I used Yalom's four ultimate concerns as a conceptual theory for understanding existential issues. The following section will expound on these concerns.

In his book *Existential Psychotherapy* (1980), Yalom described death, isolation, meaninglessness and freedom as ultimate concerns and as a source of basic conflict for the human being (pp. 8–9). He describes them as "givens of existence" or an "inescapable part" of being human, which create a conflict for the individual: The existential position emphasises

*a conflict that flows from the individual's confrontation with the givens of existence. And I mean by "givens" of existence certain ultimate concerns, certain intrinsic properties that are a part, and an inescapable part, of the human being's existence in the world. (1980, p. 8)*

Every human being faces these conflicts, according to Yalom: “An existential paradigm assumes that anxiety emanates from the individual’s confrontation with the ultimate concerns in existence” (1980, p. 110). His existential psychodynamic is that awareness of ultimate concerns leads to anxiety, which again leads to defence mechanisms (1980, p. 10).

The first existential concern is death. No one can escape death, and Yalom portrays the human being as afraid to die. Death constantly “itches”, he claimed (1980, p. 29). Therefore, the individual builds defence mechanisms to keep anxiety about death at bay, for instance through repression, and develops different coping strategies based on denial (1980, pp. 110–111). However, when crises in life occur, anxiety about death can surface:

A “boundary situation” is an event, an urgent experience, that propels one into a confrontation with one’s existential “situation” in the world. A confrontation with one’s personal death (“my death”) is the nonpareil boundary situation and has the power to provide a massive shift in the way one lives in the world. (1980, p. 159)

Second, we all have the freedom to make choices in our lives. This freedom is linked to the mentioned idea that we as human beings are thrown into a world without meaning. Human beings cannot be accountable to a non-existent Creator but are rather responsible for creating a life of their own. Freedom and responsibility are closely connected, and Yalom uses the concept “responsibility” in line with Sartre’s use: “To be responsible is to be ‘the uncontested author of an event or a thing’” (1980, p. 218). The individual has the freedom to create their own self and destiny, and the freedom to make choices and determine how to justify those choices. Freedom may be perceived as a positively charged word, but it can also be experienced as a burden. Structures and frameworks may be of great help and comfort. However, Yalom states that “we cannot escape our freedom” (1980, p. 353).

Third, every individual is existentially isolated in the sense that one’s subjective perspective cannot be fully shared with others, and we can never be *fully* understood by another human being. The latter is poetically described in Halldis Moren Vesaas’ poem “Ord over grind”, cited at the beginning of this thesis. Yalom differentiated between interpersonal, intrapersonal and existential isolation. Interpersonal isolation equates to loneliness as the term is used in everyday language and relates to isolation from other people. Intrapersonal isolation is when a person splits up parts of oneself, for instance when excluding experiences or thoughts from one’s consciousness. “Intrapersonal isolation results whenever one stifles one’s own feelings or desires, accepts “oughts” or “shoulds” as one’s own wishes, distrusts one’s own judgement, or buries one’s own potential” (1980, p. 354). In essence, it is losing or cutting off contact with parts of oneself. So, when Yalom speaks about existential loneliness, it must not be confused with inter- and intrapersonal isolation, though he emphasises that the boundaries between them are semipermeable.

Finally, according to the existentialist Yalom, meaninglessness is a fundamental condition because the world is without inherent meaning or preordained design, and thus individuals must create meaning for themselves (1980, p. 9). The conflict consists of making meaning in a meaningless world. Existential questions follow in the wake of the realisation of meaninglessness such as, “What is the meaning of life?”, “What is the meaning of *my* life?” or “Why do we exist?”. Yalom proposed that the problem with meaning is that a) the human being seems to require meaning, but b) according to the philosophy of existentialism, the universe has no meaning (1980, pp. 422–423). Yalom referred to Viktor Frankl, who asserted that the human being’s basic motivation is a “will to meaning”. However, according to Frankl’s logotherapy, which is more optimistic than most existentialistic schools of thought, there is always a meaning to life (Frankl, 2007).

All four ultimate concerns are intertwined, as illustrated by the following: The fact that we are all going to die is related to the issues of existential isolation in the sense that we face death alone. Existential isolation implies that even though we have family and friends who love us and know us well, no one fully knows how we are or can fully understand the complexities of our being. We seek community because we fear death and isolation, but deep down – according to existentialism and Yalom – we are on our own. This entails that even though we have the freedom to choose how to live life, individuals must take full responsibility for the choices they make. We can seek advice from other people, but nobody can make choices for others or take another person’s place in case of guilt. Further, existential isolation is also related to meaninglessness. Being alone in a world without intrinsic meaning, and without a safety net or without a divine task to fulfil, means that individuals must make meaning for themselves.

Yalom’s main point is that “we are all in the same boat” (2007, p. 38), in the sense that we are subject to the vulnerabilities of life. We all face some universal conditions, regardless of socioeconomic or cultural contexts, age, gender or faith, which can initiate us to reflect on existential questions.

## 4 Research Process

In this chapter, I will present the research process, design and position within the philosophy of science, data and methods. First, however, I will explain the partially winding road this PhD process has been.

When I applied for the PhD position in 2019, VID Specialized University requested research on existential group conversations offered to nursing home residents connected to Diakonhjemmet Omsorg (<https://www.diakonhjemmet.no/omsorg/om-diakonhjemmet-omsorg/>). The framework for the conversations was determined by a psychologist and a philosophic practitioner, using the existentialists Heidegger and Yalom and the philosophers Nelson and Heckman as a theoretical foundation. Moreover, they made use of Socratic dialogue as a conversation frame. For me, the study's initial aim was to explore the experiences of older people with group conversations around existential questions. However, COVID-19 prevented me from visiting the nursing home, so I had to change my project plans and let go of the existential group conversations at Diakonhjemmet Omsorg. I kept to the overall theme – existential issues/conversations and older people – but saw myself having to recruit home-dwelling older people. The manager of a senior centre helped me recruit participants, and they even had a conversation group around existential issues. My hope was thus to write two articles, one on older people and existential issues and one on experiences from the conversation group. Unfortunately, I did not get enough participants from the conversation group, and consequently had only enough data for one article, though the data for the first article included the experiences of two participants from the conversation group (a few of the questions). The article based on the interviews with older people was still somewhat influenced by the theoretical basis of the original project, with Yalom's ultimate concerns persisting in my consciousness.

The first article had, to a large extent, a clear existential health perspective. My supervisor, Linda Rykkje, who was my co-author on this article, is a geriatric nurse, which again influenced the analysis. However, as a deacon, I gradually saw a golden opportunity to anchor the new project more clearly in the science of diaconia. As diaconia is an interdisciplinary field and can be effectively combined with health sciences, I chose to include deacons as participants, with having conversation experience with older people as the inclusion criterion.

If the COVID-19 pandemic had not occurred, I think I would have tried to do more interviews with older people, preferably nursing home residents, and thus have two articles about older people and one on deacons. However, with the pandemic as a barrier, it was easier and less time-consuming to recruit and interview deacons.

Finally, it has been a challenge to keep the threads together and ensure an interdisciplinary thesis. It was thus important for me to combine the health perspective and the diaconal perspective

in the discussion of this extended abstract. The solution was to combine the diaconal perspective of heterotopia with existential psychology.

## 4.1 Research Design

Since my primary purpose was to explore and seek to understand the experiences, thoughts and opinions of my participants, I chose a qualitative research design (Denzin & Lincoln, 2013, pp. 26–29). Furthermore, as I consider interpretation to be a prerequisite for understanding (Thomassen, 2006, p. 163), I chose an interpretive paradigm. Finally, as research questions and the unit of analysis determine which method is best suited for a specific study, I found the interview a suitable method to elicit the required empirical material (Creswell, 2018; Fog, 2004, p. 11). Interviews give insight into people's life worlds and provide the opportunity to be more open to narratives and stories from the perspectives of the interviewees.

Phenomena as existential themes are complex, and qualitative interviews make it possible for complexities and nuances to emerge. I chose a hermeneutic approach to gain understanding, and by carefully studying the data through systematised analysis, I aimed to gain scientific insight.

## 4.2 Philosophy of Science

The philosophy of science is concerned with the assumptions that govern scientific activity (Brottveit, 2018, p. 24). The type of research undertaken, the research question(s) that guide it and how it is conducted rely on a certain ontology, that is, the nature of what is to be studied. Furthermore, a central concern within the philosophy of science is the question of knowledge; what can we know and how do we gain knowledge, what type of knowledge do we aim to obtain and the relationship between the researcher and who or what is being researched (Brottveit, 2018, p. 23; Krumsvik, 2016). The type of phenomena and research question(s) also guide which methods to choose (Thornquist, 2018, pp. 16–17). In the following, I will elaborate on these aspects of my thesis.

### 4.2.1 Ontology and Epistemology

An ontological view of science may be differentiated into two main paradigms. On the one hand, there is the objective paradigm, in which the world is seen as objective: It can be explained and measured and it exists without human constructions. On the other hand, there is the subjective paradigm, where reality is seen as constructed between people. Within this paradigm, the aim is to seek to understand

reality by acknowledging that reality is a result of the individual's experiences and perceptions of it (Crotty, 1998, pp. 1–17). This thesis is situated in the latter paradigm.

As mentioned, the aim of the interviews was to explore and understand the participants. Specifically and overarching, to explore and understand their reflections, experiences and opinions concerning existential issues, existential conversations and professional competence. The participants' subjective points of view guide the ontology of the thesis, in that the subjective position in interpreting the world and being in the world means that reality is multiple and individually constructed and not the result of cause and effect (Creswell, 2018, pp. 6–8; Krumsvik, 2016, p. 96, as cited in Polit and Beck, 2012)<sup>15</sup>. Hence, the aim was not to find an objective truth about the reality or the world per se but to explore the participants' multitude of perspectives on the mentioned topics. The interpretations and reflections of the participants differed in part based on factors including culture, history, experiences and personality. The older participants in my first article gave me meaningful but different responses to my questions. For example, I interviewed a married couple where one of them saw life as full of coincidences, while the other saw life as a matter of adjustments. Also, one of them was an atheist while the other was inspired by anthroposophy. They had different worldviews and divergent perceptions and interpretations of what it is like to be in this world.

Epistemology is another central aspect of the philosophy of science. To gain knowledge about how the participants thought, understood and reflected, I needed to communicate with them; therefore, the findings are the result of an interactive process between the participants and me as a researcher (Krumsvik, 2016, p. 96). In the interview settings, the participants' perceptions were presented through their answers to my questions and our dialogue. Through these conversations, we were able to co-construct meaningful knowledge together. For example, some of the participants stated that they had not reflected thoroughly on existential questions before, but that now – through our conversation – they were able to. The dialectical form of the interviews made this possible. After creating transcripts of the interviews, I performed several rounds of data interpretation.

To promote understanding, I chose a hermeneutic approach, where the aim is to gain understanding through a dialectic and circular relation between parts of a text and the text as a whole (Gadamer, 2003, p. 33). Hermeneutics is not one particular methodology or philosophy, but is described as an interpretive science (Brottveit, 2018, p. 29). Moreover, according to Alvesson & Sköldberg (2017, p. 206), there are two main orientations. One is *objective hermeneutics*, where there is a clear distinction between a researching subject and a researched object, and where the basis is the movement between the whole and the parts. The other is *alethic hermeneutics*, where the distinction

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<sup>15</sup> Creswell and Creswell do not use the term “interpretive paradigm”. Their corresponding term would be “social constructivism”, which, according to them, is often combined with “interpretivism”. Creswell, J. W. (2018). *Research design : qualitative, quantitative & mixed methods approaches* (5th ed.). Sage.

between object and subject is blurred and the basis is the dialectic movement between preconceptions and understanding, in addition to the whole and the parts. The ontological basis for the alethic hermeneutics methodology is that the human being is existentially an understanding and interpretive being (Alvesson & Sköldbberg, 2017, p. 139). The hermeneutic work in this thesis is characterised as the alethic type (Alvesson & Sköldbberg, 2017, p. 162).

Practising hermeneutics required me to be aware of my preconceptions and prejudices (see Chapter 4.6). In addition, I had to ascertain what the text or the person communicated by focusing “on the things themselves” (Gadamer, 2013, p. 279) and being willing to change or adjust my preconceptions during my spiral of understanding. Furthermore, I had to act dialectically towards the text and attempt to be part of it rather than standing on the outside as an observer; to be open and sensitive to the perceptions of the text and the text’s alterity to my fore-meanings, as Gadamer points out (2013, pp. 281–282). The understanding of the researcher is always based on preconceptions and previous experiences. This is in line with Gadamer’s thinking, where understanding never starts from scratch but rather depends on a person’s preconceptions and horizon of understanding based on the time and culture in which they find themselves (Gadamer, 2013, p. 317).

A person who is trying to understand a text is always projecting. He projects a meaning for the text as a whole as soon as some initial meaning emerges in the text. Again, the initial meaning emerges only because he is reading the text with particular expectations in regard to a certain meaning. Working out this fore-projection, which is constantly revised in terms of what emerges as he penetrates into the meaning, is understanding what is there. (Gadamer, 2013, p. 279)

Hence, as a researcher, I came with preconceptions, but I tried to be conscious of them on the one hand and keep an open mind on the other.

Alethic hermeneutics is concerned with the revelation of something hidden (Alvesson & Sköldbberg, 2017, pp. 140–141). Moreover, it sees understanding as something existential for all human beings rather than something exceptional attained through scientific work. Humans need understanding to live their lives, and this basic understanding must be the starting point for exploration (Alvesson & Sköldbberg, 2017, p. 139). Thus, alethic hermeneutics, with its focus on both interpretations and the collaboration between the researcher and the text/interviewees, can easily be placed in the interpretive paradigm. As a researcher, I am part of the historical and cultural conditioned “life world” of my participants, and both my participants and I have preconceptions. Through dialogue and analytical work, these can develop into new understandings, which is what Gadamer called the fusion of horizons (2013, p. 317).



#### 4.2.2 Method – Individual Interviews

To elicit the participants' reflections and experiences and existential issues seen from their point of view, I found the qualitative interview to be an appropriate method (Kvale & Brinkmann, 2018, p. 20). This approach would enable me to ask questions, listen to the answers, and delve more deeply into the answer if necessary or to clarify whether I had understood the participants correctly. I chose individual interviews with the older people because I wanted thick descriptions of the participants' understandings, feelings, experiences and reflections related to existential questions and conversations. This form of interview is also useful when the topic is intimate, personal and private. Focus group interviews were therefore not suitable in this case, as participants may be less inclined to speak openly in a group setting.

Nine of the participants were interviewed individually and two participants who were married to each other were interviewed together. The interviews lasted from 45 to 105 minutes.

#### 4.2.3 Method – Focus Group Interviews

The focus group interview is a research method where data is produced through group interaction around a predetermined topic chosen by the researcher (Halkier, 2016, pp. 9–10). When a group of people gather to talk about a specific topic, they share thoughts, opinions and experiences, and listen to each other. Through this dialogue, the participants may be challenged to reconsider their opinions, and new associations and reflections can arise through the listening process. This can produce both convergent and divergent views, and with a good moderator, data can be produced on a collective level (Halkier, 2016, p. 13). A disadvantage is that data production on a more individual level is weakened due to the time limit. There is no time to go deeply into the life world of each of the participants. However, the primary focus is on the interaction between the participants (Halkier, 2016, p. 14).

Deacons are professionals with formal education in diaconia, though their foundational educational backgrounds may vary. Thus, it can be argued that deacons as a professional group have a more heterogeneous education than many other professional groups. However, one of the prerequisites for choosing the focus group interview method is that the participants have something in common (Krueger, 2015, p. 5) and what the deacons shared, in addition to diaconia, was their experience of talking with older people about existential issues. Gathering them in focus groups was a way of facilitating opinion formation where they could exchange thoughts and experiences. By reflecting on experience, known and unknown knowledge can come to the surface, which was also mentioned in one of the interviews:

But for me, this has been very interesting – to become more conscious about what are existential needs and what are spiritual needs? I haven't thought very clearly into the various ... words. ... So, I'm very excited now, about what we're going to talk about, because it teaches me quite a lot too. (Deacon O)

Through dialogue, the deacons were given the opportunity to explain their opinions and perceptions explicitly, which aligns with the aim of a focus group interview, which is not to achieve consensus but to illuminate the perspectives of the participants (Krueger, 2015, p. 7). Through the focus group interviews, the deacons' norms for practice and interpretation could become visible, either explicitly, implicitly or both (Halkier, 2016, p. 11), and their implicit values could surface.

Finally, the aim was to understand – and gain knowledge about – how deacons understand their competence and existential conversations with older people. Focus group interviews were thus an academically sensible choice (Halkier, 2016, p. 16).

## 4.3 Recruitment and Sample

In what follows, I will present the recruitment process for the two groups of participants.

### 4.3.1 Older People

In May 2020, I invited organisations that did social work for home-dwelling older people in a town in Western Norway to help recruit older adults through their networks. One senior centre responded positively, and from August to September 2020, participants were recruited from among the visitors to the centre. The leader distributed information sheets with consent forms, and 11 people accepted. Because of COVID-19 restrictions, the senior centre had to stop its activities, and its localities could not be used for interviews in the initial phases of the pandemic. However, a few older people welcomed me into their homes. Some interviews were thus conducted in homes, and when the senior centre re-opened, some interviews were conducted there.

### 4.3.2 Deacons

In the fall of 2021, diaconia counsellors in five dioceses in Norway were asked via e-mail to help recruit deacons for focus group interviews. Because the ecclesiastical landscape varies by region, I wanted to recruit deacons from different parts of Norway. I ended up with convenience sampling, choosing dioceses from Eastern and Western Norway based on the places of residence of my supervisor/co-interviewer and myself. Interested deacons were asked to contact me directly.

One focus group from Eastern Norway and one from Western Norway were formed, as well as one mixed group with deacons from three different dioceses. The mixed group was a result of too few volunteers in each of the three dioceses.

The interviews were conducted in January and February 2022. Initially, I wished to do all the interviews physically because I prefer talking to people in person rather than via a screen. Meeting and sitting in a circle when sharing experiences creates a good basis for dialogue, as communication is more than mere words. However, COVID-19 and geography prevented us from doing this in two of the three interviews. In retrospect, I see that the digital interviews turned out much better than expected, and the data generated from the three interviews were just as rich. This may be because the COVID-19 pandemic made people more comfortable interacting via digital platforms. In addition, the deacons had many experiences and reflections on the topics for the interviews.

## 4.4 Description of the Study Participants

### 4.4.1 Older People

Based on the Norwegian retirement age, which is normally 67, and that all the nursing homes were closed to visitors at the time of recruitment due to the pandemic, inclusion criteria were home-dwelling people aged 67 or older. The exclusion criteria were dementia/cognitive impairment, and illness or health conditions that would make a conversation ethically or medically unsound. The ages of the participants ranged from 73 to 91 years, and there were five men and six women.

### 4.4.2 Deacons

As for the deacons of this study, their primary educations were educators/teachers (eight), nurses (five), social workers (two), Christianity studies and pastoral care courses (one), occupational therapists (one), and a business school degree and pastoral care courses (one). Some had a master's degree, whilst others had a so-called former diaconia education<sup>16</sup>. One of the deacons worked only as

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<sup>16</sup> The deacon education is interdisciplinary, and deacons combine knowledge and reflection from their vocational education and diaconia. Since 2005, the deacon education within the Church of Norway has consisted of a bachelor's degree in health, social or pedagogical studies and a master's degree in diaconia. The former diaconia education consisted of a bachelor's degree plus a year of diaconal studies. The diaconia master's programme for the 2023–2024 academic year at VID Specialized University consists of the following subjects: science of diaconia; diaconal ministry; leadership in the church and non-profit organisations; outlooks on life, values and relationships in professional practice; pastoral care; co-creation and social innovation; crises in a diaconal and pastoral care perspective; internship; and religion, poverty and development (<https://www.vid.no/planer/studieplan-master-i-diakoni-2023-2024/>). In other words, these or similar topics are part of a deacon's knowledge base and competence.

a hospital deacon, while the rest worked as parish deacons. However, for most of the parish deacons, their work included ministry in nursing homes or other institutions. Inclusion criteria for the deacons were that they were educated as deacons and that they had experience talking to older people about existential issues. I had no exclusion criteria. As for gender distribution, there were 17 women and one man. While these numbers are quite skewed, they are representative of the occupation.

## 4.5 Data Analysis

The following sections will elaborate on the analysis methods for all three articles.

### 4.5.1 Article 1: Thematic Analysis

According to Braun and Clarke (2006), thematic analysis (TA) “should be seen as a foundational method for qualitative analysis” (p. 78). It is a method for identifying, analysing and depicting patterns and themes in the data, which I found expedient in analysing my material. Creating categories is a way of comparing when looking for similarities and differences, and even though my study does not have a comparative design, it still contains elements of comparison.

The 11 older participants were asked what existential issues were important to them in old age and about their thoughts and feelings around them. They were also asked if they felt a need to talk about them or not and/or if they had someone to talk to about these issues.

The interviews were audio-recorded and transcribed, followed by proofreading, before being imported to Nvivo. The transcripts were read through several times to obtain an overview and sense of the whole. They were then coded inductively, initially into 59 main codes. Next, I conducted more coding rounds to sort and structure the material and lower the number of main codes to a more manageable amount. Finally, I gathered different codes from a common and more abstract code. This resulted in 16 main codes with several sub-codes.

Coding is not just an organising tool; it is also an initial stage of analysis, as it requires understanding and interpretation to code the material. Coding and categorising make a large amount of data more accessible, which may increase the quality of the analysis (Linneberg & Korsgaard, 2019, p. 3). After several rounds of coding, I copied the quotes under each main code into Word documents and named them “existential themes”, “religion – outlook on life”, and so on. When reading through the documents, I wrote memos – “sites of conversation with ourselves about our data” (Saldaña, 2016, p. 44) – on the side. To gather the quotes in a categorical and clear way, I rearranged the quotes into sub-codes. For instance, under the main code “religion and outlook on life” I gathered quotes concerning the participants’ personal faith or outlook on life under the sub-code “outlook

on/philosophy of life”, and their thoughts about religion under the sub-code “thoughts about religion”. This made it easier to obtain an overview and look for similarities and differences.

The next step was to select which codes to include in my further analysis and which to exclude. The main codes I chose to include in the first round were “existential themes”, “existential conversations” and “religion and outlook on life”. The choice was based on my overall impression and the fact that these categories were the largest and most relevant to answering the research questions. The codes then served as a framework for further analysis (Linneberg & Korsgaard, 2019). Within the main code, “existential themes”, the following sub-codes were the “thickest” and most frequently answered: “death”, “meaning” and “loneliness”. To continue the analysis, I asked questions and found quotes in the material that answered them. I used the document with quotes and notes concerning death to look for differences and similarities and began to write out the findings within these sub-codes.

Questions to the main code “existential conversations”
Do they need to talk about deeper topics?
Do they have someone to talk to? If so, who?
What do they talk about/like to talk about?
Do they have any general thoughts on (existential) conversations?
Have they been in situations where it would be preferable to have a conversation partner?
Are they used to talking about existential issues?
What is it like to talk about these existential issues now, in the interview?

**Table 2:** Example of questions to a main code

One of the challenges in TA is that categorising the material can lead to decontextualising because the categorising is made across cases and not within a single case, as with case studies (Maxwell & Chmiel, 2014, p. 26). Extracting quotes from the context in which they were conveyed can be a threat to the interpretation. To meet this challenge, I went back to the interview where a quote was extracted to read it in context and try to ensure that the quote was interpreted accordingly. I started the analysis with an inductive strategy, although with my preconceptions. However, as I immersed myself in interpretations and included theories, the strategy became more abductive. In this process, themes were developed in dialogue with the theories of the existential psychiatrist Yalom and the sociologist Lars Tornstam as part of the hermeneutical process: Yalom’s four ultimate concerns were used as a conceptual theory for understanding existential issues (Yalom, 1980, 1998), and the data were further interpreted in light of sociologist Tornstam’s theory of gerotranscendence

(Tornstam, 1996, 1997, 2011) and Yalom's ultimate concerns. To ensure transparency and trustworthiness, I included several citations from the participants as examples in the article.

#### 4.5.2 Article 2: Reflexive Thematic Analysis

Braun and Clarke (2022) noted that some analytical skills and ways of working with data require training to develop (p. 37). Therefore, for the second article, I wanted to acquire a more comprehensive understanding of TA than I had for my first article. However, TA is not a single approach (Braun & Clarke, 2021b), and between the analysis of the data for Articles 1 and 2, Braun and Clarke had published a new book, *Thematic Analysis: A Practical Guide* (2022). This inspired me to try "reflexive thematic analysis" (RTA) as described in this book.

By adding the adjective "reflexive" to TA, Braun and Clarke wanted to emphasise that the RTA researcher is "a subjective, situated, aware and questioning researcher, a *reflexive* researcher" (2022, p. 5). I will elaborate more on the concept of reflexivity in Chapters 4.5.4 and 4.6, while here, in relation to the process with this particular article, I will limit reflexivity to the necessity of the researcher to think and reflect critically on their role as a researcher and the research process (p. 5).

Braun and Clarke (2022) presented six phases of RTA that are not to be perceived as rules or a method but rather guidelines (pp. 35–36). I was inspired by these and will present my analysis work according to them. As the authors emphasised, they are not steps, but phases that are not necessarily strictly linear, as was also my experience.

The 18 deacons were asked about their conceptual understandings of existential conversations with older people and what terms they used for these conversations. In phase one, I needed to familiarise myself with their reflections, so I listened carefully to the recordings as I transcribed them. I also read the transcripts several times and wrote some initial notes. In phase two, I started the coding process. This resulted in three main codes: "the existential", "the name of the conversation" and "character of the conversation". Within each of these, I coded descriptive codes such as "family", "pastoral care" and "conversations (about life)". I then started systematic, detailed and inductive coding to capture single concepts or meanings on a semantic level. In RTA, coding is a systematic *process*, and several rounds of coding are needed to obtain insight into the material and ensure nuanced coding (Braun & Clarke, 2022, pp. 53–55). Hence, I performed more rounds of coding in Nvivo, and summarised or rearranged some codes into sub-codes under the aforementioned main codes.

In phases 3–5, I began to write texts based on the coding and generate initial themes across the dataset. In RTA, a theme "is a pattern of shared meaning organised around a central concept" (Braun & Clarke, 2022, p. 77) across the dataset. In the beginning, I found it difficult to generate themes. I had asked the deacons some concrete questions, and I found it challenging to develop themes across the dataset rather than just presenting their answers. Therefore, to engage further with

the data, I began to write down how the deacons talked about the character of the conversation and saw that I needed to read between the lines. Writing helped me verbalise thoughts and reflections that could be used in the last phase. Finally, by devoting time and focus to theme development, I found that there was something in the way the deacons expressed themselves concerning conversations with older people. The way they reflected and talked about their ministry was embedded with diaconal values, such as autonomy, respect, mutuality, interdependency, empowerment (Dietrich, 2014) and a consciousness around power balance. This helped me generate the different themes presented in the article, although it required several rounds, as with the rounds of coding, to develop, review and define the themes as a way of working hermeneutically. In this rather long process, I wrote drafts that formed a scaffold for the sixth phase. In this final phase, called “writing up”, I gathered the different “threads” and rewrote them into the format of a formal article.

#### 4.5.3 Article 3: Qualitative Content Analysis

For me, as a research student, it has been important to learn different analysis methods, so for the data analysis for Article 3, I decided to use QCA (Bengtsson, 2016; Graneheim et al., 2017; Graneheim & Lundman, 2004). QCA “focuses on subject and context and emphasizes variation, e.g. similarities within and differences between parts of the text” (Graneheim et al., 2017, p. 29), and one can choose between analysing manifest and descriptive content close to the text or latent and interpretative content that highlights the underlying meanings of the text. We aimed for a more latent than manifest level of analysis.

The interviews were audio-recorded and transcribed, proofread and imported to Nvivo. To familiarise myself with the material, I read through and listened to all the transcripts several times. Then they were coded inductively in Nvivo with seven main codes: existential, significance for the older persons, experiences, competence, partners and health professionals, conversation settings, and the deacons’ career choice. There were also several sub-codes. After completing the coding, I wrote some overall reflections based on my impressions from the interviews to try to capture what the deacons were sharing both on the manifest and latent levels and to reach an abstract degree of analysis. It was also a way of gaining a general overview and impression. The next step was to dive into the codes in Nvivo and work directly with the material inspired by QCA. Meaning units were extracted and analysed as suggested by Graneheim and Lundman (2004):

Meaning unit	Condensed meaning unit; Description close to text	Condensed meaning unit; Interpretation of the underlying meaning	Sub-theme	Theme
And unlike people who work in home nursing, we are people who can perhaps set aside a little more time. And preferably from time to time. So, several visits, not just once. So that is perhaps the most important resource, i.e. being a fellow human being who can take time. And if you have the opportunity to do that, it is often what you need more, not necessarily so much what we say, but that we have the opportunity to be there and listen and to see them. That is almost the most important thing.	We can set aside a little more time. And preferably from time to time. So, several visits, not just once. So that is perhaps the most important resource, i.e. being a fellow human being who can take time. Not necessarily so much what we say, but that we have the opportunity to be there and listen and see them is almost most important.	Time as an important and unique professional resource for providing follow-up in the form of watching and listening	Time as a unique resource	Time as counter-culture.

**Table 3:** Example of the data analysis process

The meaning unit, which is in the first column, is a direct extract from the interview transcript. In the next column, I condensed the meaning unit, shortening the text while still preserving the core meaning (Graneheim & Lundman, 2004, p. 106). Then, in the third column, I attempted to interpret the underlying meaning, while in the fourth and fifth columns, I interpreted sub-themes and themes. Graneheim and Lundman (2004) explained a theme as “a thread of an underlying meaning through, condensed meaning units, codes or categories, on an interpretative level. A theme can be seen as an expression of the latent content of the text” (p. 107).

I did not use a specific theory in the analysis of the data but rather discussed the findings with extant literature from the field of diaconia and the psychology of religion, which may be seen as empirical theories (Anker, 2020, p. 58).

#### 4.5.4 Overall Presentation of the Analysis

I utilised two different analysis strategies, TA and QCA. However, as employed in this thesis, they are not very different strategies, and QCA and RTA are very similar (Braun & Clarke, 2021a, p. 39). For the sake of simplicity, I use TA in this section for both TA and RTA, since they are closely related. QCA also consists of different sub-versions, according to Braun and Clarke (2021a, pp. 39–40). In both methods, however, there are some similarities: there are coding and theme development processes, one can



choose between focusing on a semantic or latent level, and both are flexible concerning using inductive and deductive coding approaches or a combination. Still, QCA has most in common with the TA versions called codebook and coding reliability TA, while I used reflexive approaches (Braun & Clarke, 2006, 2022). Lastly, they are both either atheoretical or theoretically flexible, but in their study context, they are infused with theoretical assumptions (Braun & Clarke, 2021a).

Independent of the analysis method for each sub-study, the aim was to explore and describe similarities and differences and search for patterns and themes across the dataset. This requires interpretation work. Analysis was used to divide transcriptions into smaller units and interpret and find the (underlying) meaning (Vaismoradi & Snelgrove, 2019). Regarding the reflexivity of the researcher, Braun and Clarke (2022) referred to the American social worker and researcher Roni Berger's definition of reflexivity:

It means turning of the researcher lens back onto oneself to recognize and take responsibility for one's own situatedness within the research and the effect that it may have on the setting and people being studied, questions being asked, data being collected and its interpretation. As such, the idea of reflexivity challenges the view of knowledge production as independent of the researcher producing it and of knowledge as objective (2015, p. 220). (p. 13)

The researcher is thus subjective and situated, but this is not seen as a weakness but rather a value and resource, as long as one reflects critically on one's role as a researcher. This subjectivity and the researcher's engagement with the data material is the most important tool for RTA (Braun & Clarke, 2022, pp. 5, 8). QCA does not stress researcher subjectivity, and sometimes even downplays it by relying on inter-coder agreement to minimise subjectivity in pursuit of coding "accuracy" (Braun & Clarke, 2021a, p. 40). However, this again depends on which type of QCA is used.

Finally, the reflexivity and subjectivity of the researcher correspond well with a hermeneutic approach, which highlights the preunderstanding of the researcher.

#### 4.6 Reflexivity

"Data never speak for themselves" (Dressman, 2008, p. 57), and a researcher is never tabula rasa (Alvesson & Skoldberg, 2017, p. 155) but brings experience, preunderstandings and personality to the work. In every step of the analytical process, more or less conscious assumptions and biases influence the researcher's analysis (Dressman, 2008, p. 57). This is far from a detriment. In fact, if a researcher has no experience in the field of study, the interviews will usually be worthless as empirical data, according to Gubrium and Holstein (2001, p. 106). In addition, according to Braun and Clarke (2022), analysis may be seen as a process of meaning-making rather than finding the truth, thus, subjectivity can be a source of strength rather than a weakness or "bias" (p. 55). To establish credibility with the

reader, my reflexivity is therefore important and a way to be transparent. I will elaborate on my reflexivity below.

My education at the teacher training college and my master's degree in diaconia have contributed not only to my knowledge base but also my values. For example, my view of man is characterised by my education in diaconia and my Christian faith. In my opinion, all humans are equal and have the same value by virtue of being created by God, regardless of categorisations such as gender, age, culture, sexual orientation and other factors. One's personal attributes can neither add to nor subtract anything from one's value. This means, for instance, that I find marginalisation and ageism provocative and react when older people experience being devalued, deprioritised or not listened to. Furthermore, as a trained deacon with experience in nursing homes, I see great value in the deacon profession and the opportunity for older people to have existential conversations.

Part of my preunderstanding is that older people are heterogeneous. I know that some need or enjoy existential conversations while others prefer more mundane conversational topics. I also know from experience that what gives meaning to a person can change through the different phases of life. Spirituality or religious faith can be a major resource, but I have also met older patients who struggled in this area. Still, I was a bit surprised that many of the older participants of this study reflected very little on death in old age.

A challenge for me as a new researcher was to remember that the meetings with the older participants were interviews for a PhD project and not PCCs. I mention this because I have had many ECs and PCCs in the nursing home where I worked. On the other hand, when doing interviews on ECs, I saw it as an advantage that I was no stranger to talking about these issues with older people. Prior to the interviews, I therefore reflected on the following: I must be aware of what the informants are telling me, how they tell it (what tone of language and feelings they show), and what is not said. Are they saying something between the lines? What do I pay more attention to? What might I be missing due to my inherent tendency to emphasise some types of utterances over others? With a large data collection, this inherent tendency is often the case (Hardy & Bryman, 2004, p. 533). In other words, the interviews were not only dependent on my preparations but also on how sensitive I was in the interview setting, what I interpreted and what I asked the interviewees to elaborate on.

In retrospect, I see that the interviews with the older participants for my thesis could to some extent be closer to a conversation than an interview, as I occasionally confirmed what the older people said or shared my own perspectives. This has been an important lesson for me, which I kept in mind when interviewing the deacons. At the same time, the word "interview" implies that there is an exchange of views, which Kvale and Brinkmann (2018) thematised, and there are many forms of conversation. However, the research interview has a concrete goal of producing knowledge (Kvale & Brinkmann, 2018, pp. 21–22). Still, an interview will always be characterised by the two (or more)

participants, what they say and the non-verbal communication that takes place. The latter can have a major influence on whether interviewees feel safe sharing their thoughts and opinions, which I tried to be conscious of during the interviews. I draw this perspective from my experience as a conversation partner for older people, which is part of my reflexivity.

In my meetings with the deacons, the interviews to a greater extent than in the individual interviews were characterised by me as a researcher asking questions while the deacons answered. Here, I held back so as not to enter into the conversation as an equal interlocutor. As a former nursing home deacon, I had experience from and preunderstandings of the deacon ministry, and what the deacons shared was very recognisable. I thus had good prerequisites for understanding what the deacons were talking about. On the other hand, my insider knowledge probably also influenced my questions consciously and unconsciously. My supervisor, Anne Austad, with whom I discussed the interview guide and who participated in the focus group interviews, is a theologian with in-depth expertise in PC and experience teaching diaconia students in PC, so we were both familiar with the field.

How has my status as a deacon influenced the questions asked of the deacons, the selection of topics for the article and the interpretation of the data material? First, I chose to interview deacons because there is little research on the profession, experiences and reflections of Norwegian deacons, as addressed in Chapter 2 of this thesis. Belonging to a small occupational group that is barely researched made me want to explore their thoughts and experiences. I could have chosen to interview nurses, doctors or psychologists about their experiences discussing existential issues with older people, but I wanted to interview deacons because I know they have a great deal of experience in the field.

Another experience that has influenced me is the downsizing process in a diaconal foundation I worked in, where the priest and deacon department was hit hard. As head of the department, I fought for our service and survival. I felt that our expertise was not fully recognised and that the importance and uniqueness of our work was not fully comprehended by the top management. This has prompted me to conduct research on the deacon profession and convey some of its characteristics. This means that I am biased. Still, as mentioned, Braun and Clarke (2022, p. 12) emphasised that the researcher's subjectivity must not be seen as something exclusively negative in qualitative research, but as something valuable. Furthermore, I have been conscious of my bias throughout the process, and of not embellishing the results. In the focus group interviews, I therefore asked the deacons about where they felt a lack of competence or where they fell short to ensure a more balanced presentation. I could of course have pushed them more on their perceived deficiencies; however, the aim of the study was to explore what they perceived as their competence in the specific field, which had not been researched previously. Against this backdrop, I would argue that their competence is more valuable and interesting than their lack of competence.

## 4.7 Ethical Considerations

Ethics are crucial throughout the research process (Creswell, 2018, p. 90). As a researcher, I am responsible for how I collect and process data, and my responsibility is primarily to my interviewees (Denzin & Lincoln, 2013, p. 47). Ethics in research is about assessing research in relation to norms and values in society and has to do with the planning, conducting and reporting of research. Thus, I tried to think ethically throughout the whole process. Values and ethics are closely linked, and my diaconal background has strongly influenced my ethics. Diaconal values coincide with what is called a sacred, existential epistemology: “This sacred epistemology stresses the values of empowerment, shared governance, care, solidarity, love, community, covenant, morally involved observers, and civic transformation” (Denzin & Lincoln, 2013, pp. 46–47). These values constitute the backbone of my work and a foundation for my research.

When it comes to ethics in research, one of the first steps is to seek necessary ethical approvals. The Norwegian Centre for Research Data (NSD) approved the projects (projects 861100, 155899 and project 824483)<sup>17</sup>. Approval from the manager at the senior centre to recruit residents and guests was also given. The NSD approvals can be found as attachments to this thesis.

The next step in terms of ethical requirements is to ensure voluntary, informed consent from the participants. To maintain a distance from the participants during the recruitment process and avoid making them feel compelled to join the project (Creswell, 2018, p. 93), I asked for recruitment assistance. For the older people, I asked the manager at the senior centre to hand out the information letters. For the deacons, I asked the diaconate advisors in the dioceses to distribute the information letters by email to their deacons. In the letters, I emphasised that the invitation to join my research project was voluntary and that if they accepted, they could withdraw without having to give any reason, and that they would experience no negative consequences as a result of the withdrawal (Hvinden et al., 2016, p. 15).

The most important ethical issue is to do no harm. Privacy, confidentiality and anonymity must be thoroughly addressed, and I was conscious not to exploit my participants (Miles et al., 2020, pp. 49, 56). During the interviews, I strove to show the participants respect and ensure dignity and integrity. This was especially essential in the individual interviews, where personal and private issues were shared. To avoid the misuse of results, I tried to ensure I understood what the participants told me by asking for clarification when things were unclear to me (Miles et al., 2020, p. 59). Ensuring the accuracy of the data is crucial for good research, and trustworthiness and authenticity are important criteria

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<sup>17</sup> Originally, I planned to write one article based on interviews with older people who attended group conversations, but due to too few participants I mixed the participants from both projects in Article 1)

(Denzin & Lincoln, 2013, pp. 136, 191) and an ethical concern. Finally, in the articles, I was conscious to anonymise the individuals and the data.

A dilemma that emerged when preparing for the individual interviews with the older people was where to meet them in light of the risk of COVID-19 transmission. The participants appeared to deal calmly with the risk of infection. Some invited me to their homes, others wanted to meet me at the senior centre. One participant was anxious about travelling by bus or taxi and was very unsure of where it would be wise to encounter. After a discussion, we agreed to meet at the senior centre.

## 5 Findings

In what follows, I will present the findings of each study, compile the findings and highlight the coherence between them.

### 5.1 Article 1

The first article is based on individual interviews with 11 older people aged 73 to 91, five men and six women. The research question was: “What are older people’s reflections on their thoughts and feelings about existential issues, and do they possibly want to talk about this with others?” An overall finding was that the responses from the 11 older persons showed great variation and is a reminder that older people constitute a heterogeneous group of people.

We interpreted the following themes:

#### 5.1.1 “Loneliness as part of everyday life”

Some participants did not feel lonely, probably because they sought community and activities through the senior centre and met with family members and others. Other participants reported feeling lonely in different ways. These feelings of loneliness had developed in old age as friends and spouses died, and a few conveyed that the COVID-19 pandemic had led to more isolation. Existential isolation – the feeling of being lonely on both a horizontal and a vertical level – was experienced by a participant suffering from anxiety and depression. Also, the experience of being more on the periphery in old age, in the sense that older people were not asked for their opinions, was reported.

However, an important contextual aspect is that all the participants lived at home and visited the senior centre. Thus, they were not frail and used the senior centre to socialise, stay active and avoid loneliness.

#### 5.1.2 “Death as part of everyday life”

The participants’ reflections on death varied. For some, death as a theme had become more prominent in old age. A few participants had experienced life events that led to thoughts around death and others had experienced severe illness. However, some participants did not reflect more on death even though they had experienced severe illness: a few pushed thoughts of death away, and one participant was indifferent to death. Accepting death was also found to make life easier. Only one participant reported a fear of death, but a few feared the pain that might accompany death. One participant saw death as a liberation. The participants portrayed different views on death, from the end of life to a transition to an afterlife or something ungraspable or mysterious. No one conveyed fear of hell.

### 5.1.3 “Meaning in life – or meaning of life”

At least two aspects of meaning were found in the interviews. One was whether life has a higher meaning, the other was more contextual and individual, linked to what can be meaningful in daily life. A few participants found it difficult to distinguish the two types of meaning or did not see any difference between them. Meaning was primarily experienced on a horizontal level – through actions, activities, or relationships – rather than by meditation and religious rituals, and was thus perceived more on the physical than the transcendent level.

### 5.1.4 “Talking about existential issues – or not”

Three categories regarding the participants’ needs or desire for the opportunity to talk about existential issues were categorised; some wanted it, some did not want it, and some discovered that talking about existential issues in the interview was good even though they were not used to talking about these topics in depth with other people. Some of the participants even wanted to talk about death. One participant also conveyed that talking about death was a good experience.

## 5.2 Article 2

This article is based on focus group interviews with 18 deacons within the Church of Norway, a Lutheran church. The research question was: “What are deacons’ conceptual understandings of existential conversations with older people and what terms do they use for these conversations?”

### 5.2.1 Inclusive Understanding of the Existential

A main finding was that the deacons had a broad understanding of the concept of “the existential”, as something all people have in common regardless of their outlooks on life. The existential was seen as broader than the spiritual. Furthermore, on the one hand, it concerned cognitive reflection on basic human questions in life such as questions of meaning, theodicy, faith and doubt, and on the other, as experiential phenomena such as relationships, freedom, dependency, confusion, safety, guilt and shame, grief and dignity. However, the deacons had to some extent different perceptions of the concept of the existential, from “almost everything that isn’t about the weather, I think” to essential questions in life that require deep pondering. They also reported that many seniors needed to talk about faith when approaching death and place their life story within a greater story. Finally, some older people suffered from poor or challenging family relationships and wished for reconciliation.

### 5.2.2 Gradual Transitions and Overlapping Conversations

We found that the deacons experienced a gradual transition between ECs and PCCs. ECs were perceived as broader than PCCs. The latter was explained as including aspects of faith, while ECs could encompass anything, regardless of whether faith was included or excluded. Often, a secular conversation with an older person would turn to spiritual issues over time as the relationship developed. They also conveyed that often, older people did not wish to talk about spiritual issues with family members.

The deacons also made a demarcation between PC on the one hand and existential care and SC on the other, especially concerning older people with dementia. Music, nature, holding hands, saying a prayer, or just sitting together were mentioned as alternatives to deeper cognitive conversations.

### 5.2.3 Contextual Use of Terms

Lastly, the deacons used different terms for their conversations with older people depending on whom they talked to. In conversations with older people, the deacons would avoid ecclesiastical and unfamiliar terms, instead using common language. Some were concerned about lowering the threshold for coming to church and discussing relevant issues. However, in settings among colleagues or professional collaboration partners in healthcare who were sceptical of church and concerned about neutrality, the deacons would use more professional terms, such as existential and spiritual.

An interesting question that was raised among the deacons, was: “Who defines the conversation?” Maybe deacons are quick to define a conversation as a type of PCC, while the other person has a different experience, one deacon reflected. We discussed this finding in light of diaconal values, which indicate that diaconal work should minimise power imbalances between the helper and the receiver or the different participants.

## 5.3 Article 3

This article is also based on focus group interviews with 18 deacons within the Church of Norway. The research question was: “What characterises deacons’ perceived competence as existential conversation partners with older people?” The main findings were that the deacons perceived themselves as 1) approachable and 2) professional, 3) they positioned themselves in relation to other professionals and 4) their understanding of their ministry could represent a counterculture to society and healthcare, as the deacons reported having time as a resource and did not deprioritise older



people. Based on the findings and relevant research, we thus discussed their possible societal contribution as complementary to healthcare professionals and pastors.

### 5.3.1 Deacons as Approachable

When analysing the empirical data, we perceived that the deacons talked about themselves and their ministry in a way that could be described by the term “approachable”. However, they did not use this term themselves. We thus introduced the term “approachable deacons” as an analytical innovation. We understand an approachable person as friendly, available and easy to approach and talk to<sup>18</sup>. Furthermore, we consider being approachable as more than being available. Having an open door may be interpreted as being available. Approachability is more of an individual characteristic that makes it easier for another person to make contact and refers to the quality of being available.

### 5.3.2 Deacons as Professionals

The deacons in this study talked about themselves and their ministry by using metaphors as being a fellow traveller, a mirror, a wailing wall, a fellow human, a representative of God and the church, a bridge builder, an interlocutor, one who endures, and one who has time. These were linked to their professional identity. The deacons also shared reflections on seeing older people finding peace and experiencing alleviation and relief after the conversations. Furthermore, they highlighted relational competence and conversation skills as essential professional competencies: tuning in, active listening, seeing the person, and being attentive to nonverbal communication. They also found liturgies, rituals and time as important resources in their ministry. However, psychiatry was the most frequently mentioned challenge for the deacons because of the lack of psychiatric competence. Meeting with suicidal people was also demanding.

### 5.3.3 Deacons’ Positioning in Relation to Other Professions

Sometimes, the deacons explained their occupation in relation to other professions, such as health workers and pastors – not to put their competence in a better light but to promote their specific contribution; for instance, in explaining how their existential and religious competence can complement the competence of health workers. The participants conveyed that determining when to use religious resources is unique for deacons, unlike most health professionals. The deacons explained that they had more time than pastors for existential conversations. Also, conversations with a deacon could sometimes serve as an alternative to a consultation with a psychologist or GP. Thus, the deacons filled the gap between healthcare workers and psychologists.

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<sup>18</sup> [Approachable Definition & Meaning - Merriam-Webster](#)

#### 5.3.4 Counterculture to Society and Healthcare

Through the analysis process, we found that much of the deacons' understanding of their ministry for seniors could be portrayed as a counterculture to society and healthcare, where time is short and older people may feel degraded, although the deacons did not use the term counterculture themselves. The deacons spoke warmly and respectfully of older people and wanted to contribute to making their days meaningful instead of them having to "sit at a waiting station" in their last phase of life. The deacons thus took the seniors seriously and spent time with them. We interpreted time as both Chronos (chronological time) and Kairos (understood as being present in the situation and the encounter)<sup>19</sup>. Finally, some deacons talked about being a voice for voiceless older people, even in demanding situations with other professionals. We interpreted this as political diaconia or advocacy.

#### 5.4 Overall Findings

The findings are based on two groups of participants – older people and deacons who are accustomed to talking with older people about existential issues – and are related to their reflections on existential issues and ECs. It is not possible to discuss all the main findings in this section, so the criterion has been to discuss issues that can be found across the three articles and that will be included in the discussion. I will here briefly present the overall findings.

Marginalisation and being on the periphery can be found on an overall and interpretive level, which are intertwined with the issue of power. In Article 2, we discerned that the deacons tried to minimise power imbalances by using language strategically. The power issue was also implicitly raised by a deacon's question of who defines the conversation.

A finding among the older participants was that existential questions are something only some older people are used to talking about. This finding confirms the Scandinavian culture's characteristic of being private, with existential and religious issues reserved for private spaces. However, for some of the older participants in the study, existential issues had become more salient in old age, and some wanted to talk about these concerns with someone. The need for conversations was confirmed in the interviews with the deacons.

The deacons conveyed that they had time and competencies to meet the existential needs of older people. Being interpreted as approachable, deacons can be trustworthy existential conversation partners for older people, as seen in Article 3. They shared reflections on how they met or could meet older people through metaphors emphasising the qualities of the relationship between the deacon

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<sup>19</sup> Kairos is seen as a qualitative character of time and Chronos as chronological time Smith, J. E. (1986). Time and qualitative time. *The Review of metaphysics*, 40(1), 3–16.

and the older person and their competencies as professional conversation partners. An important – but not surprising – finding was that deacons are available to talk about anything with older people, from the weather to religious and private concerns, as presented in Article 2. The deacons also saw themselves as flexible in that they were concerned with what the individual wanted to talk about rather than having an agenda. This suggests the values of respect and autonomy and indicates that their service was not limited to individuals who wanted to discuss existential, spiritual or religious questions. The deacons could converse about spiritual/religious issues as well as secular concerns.

In Article 1, we also found that older people are not asked for their opinions. Without being explicitly asked, the deacons confirmed this in Article 3, conveying that older people consider themselves outdated and sometimes feel downgraded. We furthermore interpreted that older people are subject to ageism. We thus perceived some older people as being on the fringes of society and feeling sidelined by rapid social and technological developments.

Based on the above, the main findings in the three articles of this study can be characterised as belonging to the periphery in society, making it natural to discuss them in light of the phenomenon of heterotopia, specifically the diaconal heterotopia discourse. Based on the data obtained for this thesis, I cannot and do not assert that older people are a marginalised group per se. However, aspects of marginalisation were found in my study, and the issue will be discussed in what follows. Furthermore, I will discuss marginalisation and heterotopia – theories of differences – in relation to what unites people across boundaries, as Yalom's ultimate concerns and of existential issues, as it is a central topic for the dissertation as a whole.

## 6 Discussion

“A large acquaintance with particulars often makes us wiser than the possession of abstract formulas” (James, 1902, p. xiii). This short quote, from the preface of *The Varieties of Religious Experience* by the American philosopher and psychologist William James (1842–1910), serves as a reminder to use a variety of empirical knowledge and not get too abstract and general in our thinking. That is also my aim for the following discussion – to stay close to the empirical findings and the perspective of the individual, despite discussing them in light of theoretical perspectives.

Based on our empirical findings and other research, I aim to discuss my overall research question along two lines: First, in light of marginalisation and heterotopia, and second, in light of the existential understood as a universal condition. In other words, I use the concept of heterotopia according to Foucault and Wyller on the one hand and Yalom’s theory of the four ultimate concerns on the other. These theoretical perspectives are used as overall orienting lenses that shape my focus and inform the analysis by guiding what issues I should explore and elaborate on (Creswell, 2014, pp. 51, 64). Furthermore, I discuss what I consider the limitations of the theories in terms of the material for this thesis and how they complement each other. In the final section, I discuss approachability as a diaconal response. After the discussion, I will argue for the relevance of the thesis in the diaconal research field before I reflect on the strengths and limitations of the work.

As presented in Chapter 1.6, the overall research question is: “What are older people’s reflections concerning existential issues and how do deacons within the Church of Norway interpret and respond to older people’s needs through existential conversations?”

### 6.1 Are Older People in a Heterotopic Space?

A question that emerged from the overall findings was whether older people are marginalised. The reasons for bringing in the question of marginalisation and heterotopia are because 1) there are clear traces of marginalisation in the data material and 2) because an essential question in diaconia is: Who are the marginalised?

In the diaconal discourse, Wyller (2006) argued for making heterotopic spaces the centre of diaconia, that diaconia should take place in heterotopic spaces. In this discourse, Wyller is concerned with undocumented migrants, homeless people, prostitutes, illegal immigrants and mentally ill people with severe substance abuse problems (Wyller, 2006, 2013). Lid is concerned with people with disabilities (Lid, 2012, 2019) and Stålsett et al. with asylum children, refugees, ethnic minorities, the poor and the exploited (Stålsett, 2012). None focus primarily on older people as a possibly marginalised group, as this thesis does. In both samples of my material, some older people appeared downgraded,

outdated and not listened to. Both samples also showed traces of ageism, in that older people are not consulted or invited to share their opinions or ideas. Being excluded from discussions and conversations and thus perceived as unimportant and without valid contributions is an example of devaluation and marginalisation. Furthermore, many older people live in nursing homes, which are examples of heterotopic spaces, or “heterotopias of deviation”, according to Foucault (1986). When heterotopic spaces are characterised as “other spaces” different from the spaces they reflect (Foucault, 1986), older people who experience being outdated and not included and/or being nursing home residents may be seen as being in a heterotopic space.

In the Norwegian diaconal discourse, Korslien and Notland (2011) are, to my knowledge, the only ones who have opposed Wyller by advocating that diaconia is for *all* people, not only the most marginalised. They also criticised Engel’s (2006) assessment of older people as not in a heterotopic space without having solicited their thoughts on the issue. Engel (2008) emphasised that the diaconal mission has two sides: one is to assist people in particularly vulnerable life situations and the other is to speak out on and work for change to the conditions that create vulnerability (p. 234). Questions that emerge then, are: What characterises “vulnerable life situations” and why is old age not considered a vulnerable time in life? Korslien and Notland, referencing Foucault (1986), asserted that older people may actually be in a heterotopic space for two reasons; ageing may be seen as a crisis, and older people deviate from the norm by virtue of their lack of employment. Being in a situation of crisis or deviation, I would like to note, is closely linked to vulnerability. Finally, Korslien and Notland asserted that diaconal work for older people may serve a purpose in that it may be preventative and can be one of few social meeting points. However, while their agenda is not to define older people as being in a heterotopic space, they miss a more nuanced categorisation and highlight the ambiguity associated with it. Nevertheless, they indicate that older people are subject to increased marginalisation in society.

A key goal for the Norwegian government is to enable older people who can and wish to live at home to do so for as long as possible. The Ministry of Health and Welfare has therefore started working on a reform that will help older people live at home longer and more safely (Regjeringen, 10.11.2022). This is in many ways a good thing for healthy, social older people. Being able to live in familiar housing can strengthen feelings of mastery, independence and freedom. However, old age is also a time when people experience losing friends and family members due to illness or death. Munkejord, Eggebø, et al. (2018) found that not all older people who receive extensive home services feel safe in their home, and for some, moving to a care home or an adapted apartment in the centre of the municipality can contribute to increased well-being, security and physical and psychosocial health (p. 17). Saarelainen et al. (2022) found in their study that older home-dwelling people faced existential struggles related to loneliness (p. 1045). Consequently, being old and living at home – perhaps alone – can lead to increased loneliness and thus more marginalisation. In Sub-study 1 of this

thesis, some of the participants reported an increase in loneliness, partly because of the COVID-19 pandemic and partly due to the loss of loved ones. However, in general, loneliness is not more prevalent among older than younger people (Meld. St. 15 (2017–2018), p. 81; Slagsvold & Solem, 2005), but many older people report that they do not get enough offers of varied and adapted activities (Meld. St. 15 (2017–2018), p. 79). Decreased mobility due to old age and reduced health can cause more isolation, and increased loneliness can cause impaired functionality, both physically and mentally, and reduced quality of life (Meld. St. 15 (2017–2018), p. 82). Loneliness may also be extra challenging in late old age, according to Binder (2018, p. 321), when even younger family members and friends may be ageing and losing mobility. So, without family members to look after them at home, who is responsible for older people who receive home care?

## 6.2 The Existential as a Universal Condition: We Are All in the Same Boat

Heterotopia is concerned with differences, different rooms or spaces, and distribution of power. It is a concept that depicts the distinctions between groups of people, emphasising that some people are in the centre and others on the periphery or outside. However, when consulting another element of this thesis, the concept of the existential, that concept may be understood as something that unites people across gender, age, culture, nationality and worldview. According to Binder (2020), the existence of human beings is characterised by the fact that we reflect and ask philosophical questions such as “Who are we?” and “Why do we exist?” (p. 11). The existential is thus a universal condition and a phenomenon we all face, both inside and outside heterotopia. Thus, we are all in the same boat. Sub-study 2 revealed that the deacons had a broad understanding of the existential. They understood the concept “as something that embraces all people regardless of one’s outlook on life”. In other words, they saw the existential as a universal concept, as Yalom does (1980, p. 8).

One may, as seen in the preceding section, describe some older people as being in a heterotopic space, but that is not the whole picture. When Yalom elaborated on the four ultimate concerns, he emphasised that they are universal. One example of Yalom’s universal existential concerns is that as social creatures, we seek community (1980, p. 363). This was confirmed by the older participants in Sub-study 1, who sought fellowship with other people at the senior centre and in some cases disliked being alone. For others, the need for alone time can increase in old age, as Tornstam (2011) suggested. However, this was not a finding among the older participants of this study. A plausible explanation may be that all the participants were conscious about avoiding loneliness and thus sought community through the senior centre.

Even though we all face existential issues or the ultimate concerns, according to Yalom, individuals have varying thoughts and feelings about them. According to Binder (2018), an individual's personal identity is a unique means of making sense of experiences and is central and important to who the individual is (p. 33). Two people facing the same situation can thus understand and react to the situation in different ways. Moreover, a person's outlook on life is a relevant frame of reference (Stifoss-Hanssen & Kallenberg, 1998, p. 82; Sørensen & Kvande, 2014, p. 305), with some needing professional help to cope with existential crises or feelings while others manage with varying degrees of help from family or friends (Saarelainen et al., 2020).

Yalom's universal aspect includes the fact that we are all going to die. Nobody can escape death. This fact is not exclusive to older people. Still, statistically speaking, being old means that death is likely closer, which can lead to greater awareness about mortality, as partly indicated by my findings. This awareness of our mortality may be crucial, according to Yalom, as expounded in Chapter 3.2. According to the cultural anthropologist Ernest Becker (1973), man refuses to acknowledge his own mortality, and the fear of death leads to denial of it. This aligns with Yalom's thinking (2007, p. 49). However, in our material from Sub-study 1, we saw little fear of death. One objection could be that the older people were not completely honest or that they were not conscious of the fear. As a researcher, I can neither confirm nor reject this, but choose to assume that the participants' statements are authentic.

The religious perspective is not obvious in Yalom's existential psychotherapy, as he mainly draws on the existentialist philosophy where the human being is perceived as being thrown into this world with no inherent meaning and that at our core, we are alone in the world (1980, p. 355). He starts from meaninglessness rather than meaning and takes an atheistic ontological position. If a therapist conveys scepticism towards religiosity, it might turn out to be a weakness or a problem for the other person, considering that religion can serve as a framework in life and be of great support to some individuals. However, though Yalom stressed his atheistic ontological position in his books (1980, 2007), he also stated that his intention was not to impose his view but rather to be empathetic and to offer help (2007, p. 51). As mentioned in Chapter 2.3, DeMarinis (2003) considered the loss of religious frameworks a hazard to public and individual mental health (p. 29), and Hvidt et al. (2017) highlighted that religion and spirituality can have a positive effect on mental and physical health. As mentioned in Chapter 2.3, they furthermore asserted that extensive research on religion and health points undisputedly to a positive correlation between health and religion. On the other hand, through a meta-analysis of 84 empirical studies that addressed the relationship between religiosity and fear of death, Ellis and Wahab (2013) discovered that the findings were contradictory and inconsistent, with 40 studies finding an inverse correlation and 32 studies finding no significant correlation (p. 154). However, they found that intrinsic religiosity or strong private beliefs and practices showed inverse

correlation between religiosity and fear of death (p. 164). Saarelainen et al. (2020) found that religious experiences could provide both struggles and comfort in the final stage of life. These considerations are, in my opinion, crucial to be aware of for deacons dealing with older people who struggle with existential issues.

Another finding in my study that opposes Yalom was that a participant who suffered from anxiety saw death as a liberation. Tatjana Schnell, who researches meaning in life, asserted that when experiencing crises of meaning, feelings of isolation can occur, along with suicidal thoughts (2020, p. 105). The mentioned participant experienced existential isolation and had tried to commit suicide several times. He had no wish to live any longer and welcomed death rather than feared it.

According to Yalom (1980), however, a confrontation with death may also lead to personal changes and liberation from anxieties (p. 160). The recognition of death is simultaneously a recognition of the limits of freedom and its possibilities (Binder, 2020, p. 46). Knowing that death will eventually come made some of the older participants in Sub-study 1 focus on living while they still could. In addition, some conveyed that accepting death made life easier. Being aware of death, then, may increase the awareness of life, and even fuel it. The deacons also shared stories of older people who struggled with existential issues or crises, but when the deacon was there to listen, converse and perform rituals with them, they could lower their shoulders and feel alleviated and relieved. However, this was not always the case.

So, findings from Sub-study 1 showed that the participants had different thoughts about death, from pushing thoughts of death away to reflecting on them, from being indifferent to the theme to finding it liberating to talk about. This confirms that older people are a heterogeneous group. As expected, this was also evident in the two other main categories of existential issues in the same sub-study. Although, according to existentialist philosophy, we are all in one sense alone and solely responsible for our choices and actions (Binder, 2020, p. 83), we reflect upon and deal with this in many different ways. This was also mirrored in the older participants' views on meaning, ranging from something you need to find for yourself to a notion of a cosmic meaning given by God, as the meaning-receiving perspective of Chapter 1.4.

We found that existential issues were salient for some of the older participants, which was also conveyed by the deacons. For instance, thoughts about death and feelings of loneliness were reported to increase in old age. Some people who enter old age or approach death tend to turn to existential and spiritual orientations and practices, and for some, transcendent thinking increases (Binder, 2018, pp. 317–327; Binder & Nielsen, 2005; Erikson, 1997; Levin et al., 2011; Stripp et al., 2022; Tornstam, 2011).

As seen in Article 3, some older people experience challenging relationships with their families and/or themselves. Combined with deteriorating health, grief in life and losing independence, this



increases existential pressure. Still, some older people who feel this existential pressure may leave their existential thoughts and experiences to the periphery, as seen in the first article. In Article 2, we saw that, according to the deacons, older people often do not want to speak to their families about existential issues, a finding that was confirmed by Wilkes et al. (2011). There may be different reasons for this reluctance, including not wanting to be a burden and not having the type of close and open relationship that makes such discussions possible. Therefore, they keep their worries to themselves.

### 6.3 The Human Being as Being Like and Unlike Others

As expounded in the previous two sections, people can be in different spaces because they are different from one another in terms of – in this case – age. At the same time, all people, across all ages and cultures, are subject to the life conditions that belong to this world, which Yalom calls ultimate concerns, indicating that there are some things that make all people alike. The professor of pastoral theology, Emmanuel Y. Lartey, addressed the aspects of human beings as being simultaneously different and alike by referring to the “trinitarian” formulation of human personhood by Kluckhohn and Murray from 1948: “Every human person is in certain respects: 1) Like all others, 2) Like some others, and 3) Like no other” (2003, p. 34). The first assertion may be related to the existential and universal conditions as discussed. Furthermore, it includes physiological, cognitive and psychological capabilities. The second assertion acknowledges that human beings are also shaped by the values, beliefs and customs of the culture in which they live, and refers to “characteristic ways of knowing, interpreting and valuing the world which we receive through the socialization processes we go through in our social groupings” (pp. 171–172). This also includes sociocultural and socioeconomic aspects and differences. A finding that may serve as an example here is that some older people view themselves as downgraded or outdated as a result of how they experience their position in their family, culture and/or social class. Thirdly, the trinitarian formulation recognises that every human being is unique, for instance with their unique genetic code, but also psychosocially. The uniqueness is moreover reflected in the person’s lifestyle, life experiences and feelings (pp. 34–35, 172), and the participants in Sub-study 1 shared their unique experiences, thoughts and reflections concerning existential issues. Finally, regarding the three characteristics, Lartey emphasised that they are interrelated (p. 34). This three-dimensional understanding of human personhood is elaborated on by Lartey within the field of PC and PCC and is an important consideration for the PC giver. This understanding also brings out both the differences related to the concept of heterotopia and the universal aspect, as represented by Yalom, for instance, with the theoretical perspectives complementing each other.

## 6.4 Approachability as a Diaconal Response?

One way of describing diaconia is that it is a response to the needs in society (Nordstokke, 2011, p. 15) – either groups of people, individuals or systemic injustice – and all diaconal care is based on the values of reciprocity, equality and respect (Den norske kirke, 2020, p. 6).

In the following, I will discuss the response to older people and existential issues as found in the data. This examination will be conducted in the context of the science of diaconia and relevant research, using the concept of approachability as a guiding compass. Approachability is central in responding to the call from the margins, being a good conversation partner and the question of power relations.

### 6.4.1 Call from the Margins

As mentioned in Section 1.3, both the Church of Norway's *Plan for diakoni* (Den norske kirke, 2020) and *Diaconia in Context* (Nordstokke & Lutheran World, 2009) emphasise the diaconal responsibility for and with the marginalised. A question that arises then, is: If we assess older people as being in a heterotopic space, how can we address it?

In Article 3 of this thesis, we interpreted the deacons' self-perception to be approachable, meaning friendly, available and easy to approach and talk to. It included individual characteristics and the quality of being available. When approachability leads to contact with marginalised people or groups of people, it may be seen as a way of bridging the gap between church and society and between the centre and the margins. An approachable person, in this case the deacon, is a professional and, in that sense, placed in the centre from a heterotopic perspective. She is part of working life, but through her ministry, she is also situated amid heterotopic citizens, such as marginalised older people. There is thus a movement between the first room (the normality/familiar room) and the other rooms (the marginalised/strange rooms) (Wyller, 2006). Wyller (2006) argued that diaconia should take place *in* heterotopia instead of inviting heterotopic citizens to the "familiar" or "normal" rooms. The call comes from the other, from the margins (p. 282), and Wyller describes heterotopic diaconia in the following manner:

It is about making the strange spaces the centre of diaconia, not the familiar spaces. When the heterotopia is put at the centre, diaconia can easily be called prophetic, not least because the classic vocation stench in that case also regains relevance. And it can, in a certain sense, also belong to the ecclesiastical office. (2006, p. 275. My translation)

From a diaconal perspective, the periphery may regard physical distance from the church community. Nygaard (2014) points out that siding with the marginalised "may facilitate belonging and/or participating in the community and/or the inner church tradition outside the community as

Holy Communion at home” (p. 17). Further, in the mentioned Australian study by Wilkes et al. (2011), an older person expressed that the pastoral care workers brought the church to them, as they could not attend it themselves (p. 219). The pastoral care workers in the same study explained their service as “going on a journey with the older person by being a friend and actively listening and sharing with them” (p. 218). These perspectives were also found in our material from the focus group interviews with deacons, as detailed in Article 3. They reported that many older people felt seen, met and acknowledged through the conversations with the deacons. This bringing of the church to people – and the opposite: bringing people to church – resembles the bridge-builder metaphor in diaconia, where the deacon builds a bridge, a connection, between church and society. The expression “go-between” is also used by deacons (Jordheim, 2014). This function is described by Collins (2002) in that whenever the deacons are mentioned in the New Testament, “somewhere in the background there is a person or a group of people to whom the *diakonos* is responsible in the carrying out of a task” (p. 89). However, Wyller (2006) advocated that diaconia take place *in* heterotopia, and *by* the heterotopic citizens. According to him, church employees can then facilitate heterotopic diaconia but not be in the lead. They should instead leave space for the people to empower themselves and seek justice (Wyller, 2022). One can, of course, debate whether that is always possible in practice, or to what extent.

That said, older people, generally speaking, are not on the periphery or outside the church. Neither my material nor other research makes this claim, though the feeling of being on the periphery was found in Article 1. When Christian older people cannot go to church for various reasons, they are still part of the assembly of believers. However, they are physically on the periphery. So, I would say that in terms of ecclesiology, older people can concurrently be placed in the margins or a heterotopic space in physical and social means and still be in the centre by being a believer, a seeker or a member of the church. The congregation is not restrained to the church building or the churchgoers. To prioritise older people is a way of announcing their dignity rooted in God’s love for all people. Moreover, whose viewpoint one takes is also an essential aspect here. A group of people who are defined as marginalised in society or church may not experience themselves as on the periphery. Conversely, some may feel like outsiders without being considered outsiders by others. There are no clear-cut distinctions here, which challenges the diaconal discourse on heterotopia.

The deacons in this thesis conveyed that time was one of their resources (Article 3). Having the time to spend with older people, both for single discussions and over time, was valuable to the deacons. A former bishop even said that deacons should have time in their calendar. Time is a rare resource in a society where efficiency and productivity are favoured, and being busy is understood as a sign of importance. Having time is also linked to approachability, as it is easier to approach a person who does not radiate busyness. Therefore, approachability can also be seen as a counterpart to being busy with important and high-priority matters, and it does not fit the New Public Management (NPM)

thinking, with its particular emphasis on target and results management. Thus, approachability and having time may be vulnerable and signal less urgent and crucial tasks. In church, the deacons usually do not posit statutory duties as the priests, and Nygaard (2015) found that colleagues may ask the deacon to perform tasks that they themselves do not have time for (p. 1). Consequently, in downsizing situations, the deacons must go first, both in healthcare institutions and in churches, as found in Sweden (Leis-Peters & Middlemiss Le Mon, 2024, p. 12). Hence, being an approachable deacon may be a vulnerable position at risk for negative changes.

#### 6.4.2 Existential Conversations and Pastoral Care (Conversations)

Diaconia is a response to people's sufferings and needs, "particularly as death-dealing forces and realities threaten life" (Stålsett, 2021, p. 96). How can deacons respond to older people and their existential issues? When existential issues are taboo, pressing and unmet in healthcare, who can and will meet older people who are in need of existential conversations?

One way of responding is to offer ECs. We found that the deacons of this study met with older people in church, bereavement groups, in their homes, nursing homes or hospitals. They offered ECs, PCCs that sometimes would include rituals and liturgies, and spiritual and existential care through devotions or non-verbal communication with people with dementia, as seen in Article 2. The deacons had time for and showed respect to older people, and we interpreted this as being approachable and as presenting a counterculture to society and healthcare (Article 3). When the deacons had time for people with dementia, stories could sometimes come to the surface. Being able to bring up old memories, or being reminded of the era from which one has the most autobiographical memories, will, for many people, strengthen the experience of being in contact with who they are (Binder, 2018, p. 324). In a Finnish study on religiousness in people with severe dementia in nursing homes, Pirhonen et al. (2023) found that individuals expressed religiousness physically, emotionally and through fumbling liturgical movements, which shows how religiousness is not limited to cognitive functions. Furthermore, in Article 2 the deacons conveyed that some older people need to place their life story into a greater story, and the opportunity to tell one's life story to another person can be a way to create or (re)discover coherence in life (Nielsen, 2010, p. 34).

Betty from Sub-study 1 discovered that the interview conversation on existential issues, in which she shared crucial stories from her life, made her feel good even though she characterised herself as not being philosophical or reflective. A few participants also experienced ECs to be liberating and make death seem more harmless. Such findings suggest that there may be many older people who could benefit from an EC. The deacons also expressed that many older people needed to talk about existential issues. They received help in ordering their thoughts and unhealthy belief systems, and some experienced relief, alleviation, forgiveness and peace through conversations (Article 3). Further,

the deacons conveyed that many older people needed to talk about faith when approaching death (Article 2). In a Norwegian study conducted by Senter for omsorgsforskning<sup>20</sup> (Disch, 2022), the informants<sup>21</sup> pointed out that several of the people they encounter miss individual conversations of an existential, spiritual and cultural character; having individual conversations with representatives of their faith community; and someone who has the time to sit down to listen to and converse with them. However, some respondents report that in some places, the follow-up is to a large extent left to the next of kin (p. XI).

These findings are not surprising. People prepare themselves for many occasions and situations, and one might say that preparing oneself for dying is similarly wise. Part of preparing for death may be looking back on life, reflecting and talking about how life turned out – for good and for bad – and sorting events, feelings and relationships in a search for meaning and coherence. This may also involve reconciling with others or asking for forgiveness. These issues were often part of conversations with older people, as reported by the deacons. When people are uncomfortable discussing existential matters with family members or friends but need someone to talk to, they may experience a feeling of otherness and loneliness. They may feel they are the only ones with these special needs, and no one asks them how they are. They are marginalised with their existential thoughts.

Sometimes, existential crises cannot be met only on a cognitive or rational level, and the deacons of this study would use rituals and liturgies when it felt natural. Through ritualisation, the individual may experience coherence in life, and ritualisation provides room for processing challenges and creating meaning (Danbolt & Stifoss-Hanssen, 2014). Stripp et al. (2023) found through their survey that “increasing age was positively associated with having more spiritual needs across all dimensions except for inner peace” (p. 12). Ergo, older people may need someone who can meet their existential and spiritual needs. Deacons form a professional group that can – and already do – meet these needs.

One might object that older people do not necessarily want to talk about existential issues, which is a fair and true criticism. Older people are not a homogenous group but have different preferences concerning conversation topics and social activities. For instance, bingo and devotions – two common activities in elder care – are not preferred activities by all older people (Meld. St. 15 (2017–2018), pp. 79–80). However, as presented earlier in this thesis, old age is a period in which existential issues and transcendent thinking emerge for some people. Thus, having the opportunity to

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<sup>20</sup> Centre for care research

<sup>21</sup> Employees from a selection of Norwegian municipalities, as well as interviews with leaders from religious and ideological organisations at national level and priests, pastors, deacons and lifestyle counsellors at regional and local levels.

talk about these reflections may be valuable. However, as a heterogeneous group, older people have different worldviews, and some may be critical towards deacons – as they represent the church and a specific religious faith – and assess them not to be neutral conversation partners. This aspect was found in Article 2, where one deacon experienced significant prejudice towards the church’s agenda and that public collaboration partners were preoccupied with neutrality. This objection must be respected. At the same time, in Article 3 we argue that deacons fill a gap between healthcare professionals and pastors and thus make a distinct societal contribution. They have time as a resource and competence in talking about existential issues on the other person’s premises, regardless of their outlooks on life. Additionally, older people may be more concerned with having an adequate conversation partner than the person’s worldview. Austad and Johannessen-Henry (2020) found that Norwegian pastors’ language moves between secular and religious, which enables them to talk about existential and religious issues in a secular context (p. 73). It is likely that deacons also have this competence, as they work in the same context and have even more PCCs than pastors (Grung et al., 2016). The deacons in our study confirmed this.

The deacons conveyed that their ministry was not limited to PC understood as Christian counselling but could also concern mundane or secular issues. This may be understood as an influence from the chaplaincy ministry. The clergy is there to be a fellow human traveller and to assist based on the needs of the other, regardless of faith or outlook on life. From a psychological perspective and according to Binder (2018, p. 312), having a fellow traveller to whom one can tell stories from life is important and requires trust. It also calls for a listener who can meet the person with acceptance and empathy. Deacons are thus suitable fellow travellers, as they are flexible in terms of conversational topics and worldviews. As mentioned in Article 2, Doehring (2015) distinguished between PC and SC, where the former concerns Jewish and Christian leaders’ and lay people’s spiritual care for their community members (p. xxii). SC, on the other hand, respects and deals with religious differences (p. xxiii). The deacons in this study emphasised that conversations should be on the other person’s terms, and that they respected that not all people want to discuss spiritual issues (Article 2). Grung (2021) also highlighted that within the professional paradigm for institutional chaplains, meeting the needs of the other is central, irrespective of their faith or outlook on life.

As noted, we also found that thoughts about death were avoided by some participants. As a consequence, some of them did not normally talk about the issue with others. Similar findings were identified by Saarelainen et al. (2020) in their research on the religious experiences of older people in home-based palliative care. However, ECs may be highly important for older people, and studies have found that terminal patients who have the opportunity to talk about reflections and feelings concerning death have a higher quality of life (Viftrup et al., 2020, p. 161). Viftrup et al. also found that the patients (who were not necessarily older people) lacked an existential language and thus used

more medical and fewer existential concepts when talking about death. This can be interpreted as a consequence of a secular society. However, older people belong to generations not used to talking about personal thoughts and feelings. Betty (Article 1) is a good example. As mentioned, she did not characterise herself as philosophical and was not used to talking about existential issues. As existential and religious issues are often taboo in a Norwegian/Scandinavian setting, they are marginalised and left to the private sphere (Giske & Cone, 2020; Hvidt et al., 2020; Jensen & Mørk, 2016; Nissen & Andersen, 2021; Rykkje et al., 2013; Viftrup et al., 2020). However, in the past, Christianity was part of many people's understandings of life to a completely different degree than it is today. Hence, a religious or spiritual language may be more familiar to older people than to younger. Still, some may need help from a conversation partner to express what is on their minds concerning existential, spiritual and religious topics. Furthermore, some older people may have been secularised over the decades and may be confused when it comes to their beliefs or identities in old age. Approaching death may, as seen in Article 2, cause existential questions to arise. Saarelainen et al. (2020) found that the closer the participants were to death, the more likely they were to talk about death. They also found that older people who had a clear religious identity seemed to talk about death more easily. Still, as we have seen in Article 2 of this thesis and the study of Wilkes et al. (2011), family and friends are not necessarily preferred conversation partners. Furthermore, the lack of religious and existential language as found by DeMarinis (2003; 2008) and Viftrup et al. (2020) as a result of the secularisation process may suggest a need for professional conversation partners, such as deacons. They are trained in providing existential/spiritual/pastoral care and are literate in existential and religious issues.

#### 6.4.3 The Issue of Power

Both within the fields of PCCs/ECs and heterotopia, there is the issue of power and asymmetry. In the introduction of the book *Makt, motmakt og praksis. Bidrag til kritisk refleksjon innen diakoni og velferd*<sup>22</sup>, Lid and Wyller (2022) presented Foucault's concept of "pastoral power" as the power priests and church leadership have over the individual person's salvation. However, Foucault believed that in modern secular society, a similar exercise of power also occurs, albeit focused not on salvation but rather on quality of life, health and autonomy. This perspective is echoed in the secular versions of modern welfare professions as discussed by Lid and Wyller (2022, pp. 10–11). The aspects presented in Section 1.2.2, where some older people in Norway suffer from insufficient or unacceptable home care, may serve as one example of how older people can experience powerlessness and lack of autonomy in the face of the authorities. Moreover, downgrading the importance of the existential

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<sup>22</sup> In English: *Power, counter-power and practice  
Contribution to critical reflection within diakonia and welfare*

needs of older people is another way of exercising this power. Older people who suffer from such policies are then robbed of their rights and indirectly left to the periphery and a heterotopic space. However, as touched upon in Chapter 3.1, heterotopic citizens are not without power – their reflection of the first room (the normality) always includes a critique and counter-power (Wyller, 2006, p. 274).

Professional deacons sometimes encounter older people who are in a heterotopic space. The deacons then represent the first room and would not be characterised as in heterotopia, as they come as professionals, and professionalism is power. Knowledge use and professional language are examples of the exercise of power (Lid & Wyller, 2022, p. 13). However, we found that by being strategic in their use of language, the deacons avoided professional terms and thus contributed to bridging the power gaps. One may interpret the deacons' use of language as a mediating tool (Nygaard, 2014) to convey specific values. We interpreted the deacons' language use to convey diaconal values as reciprocity and equality to reduce power imbalances (Article 2). Furthermore, refraining from using professional language in favour of everyday terms is a way of being approachable and entering the other room – to adjust to the other's way of talking and acting. According to Dietrich (2014), such a power imbalance is not necessarily a problem if there is a conscious and critical reflection on it. However, the diaconal value of reciprocity and the idea that we all have the same value does not eradicate the issue of power. In some situations, there are clear traces of marginality, asymmetry and power. Thus, there may be tension between reciprocity and equality on the one hand and power asymmetry on the other.

Nordstokke and Collins (2011) are concerned with inclusion: "When new mechanisms of exclusion are at work in both church and society, diakonia has a special mandate to identify mechanisms of inclusion" (p. 47). However, the deacons in Sub-study 3 did not explicitly talk about inclusion. Rather, they were concerned with tuning in and integrating into the other's world. In the Church of Norway's diakonia definition, "inclusive communities" is one expression of diakonia (Den norske kirke, 2020, p. 13). However, in that context, the church is the subject, in that it is the church or congregation that is expected to create inclusive communities. The heterotopic aspect is absent in that definition. The definition and the elaboration on inclusive communities are from the perspective of the church. Wyller (2009) pointed out that diaconal work is often characterised as places where "people have been included ('disciplined') into the large community of a nation or of a local municipality" (p. 209). However, heterotopic diakonia inverts the positions by taking place in the other room and with the others as subjects.

Consciousness concerning power was found in the interviews with the deacons. For instance, a rhetorical question was also posed by Deacon J (Article 2): "Who has the power to define a conversation?". A legitimate follow-up question to this is: "Who has the power to define who is in a heterotopic space or not?" This kind of critical reflection on diaconal practice is crucial to avoid running the risk of using the same pastoral power one criticises.



## 6.5 Closing Reflections

In this chapter, I have discussed the overall findings of my study through two theoretical perspectives: heterotopia and the universal aspects of Yalom's ultimate concerns. There may be tension between concepts that emphasise divisions between people and theories that focus on what is universal to all people. However, I do not find these apparently opposing perspectives to be in conflict. Heterotopia may be used to illuminate that even though we all have the same value as human beings, society does not reflect this. Some individuals and groups are disregarded and marginalised, while others have power and prestige: this is an important aspect to address. Hence, it can be helpful to use these perspectives to help us understand older people's situations. The diaconal values of reciprocity and interdependency convey that, as fellow human beings, we face life's challenges and are mutually dependent on each other. We all need help occasionally; at other times, we can be helpers. In other words, we are all in the same boat but occasionally take different positions. In addition, we face the same ultimate concerns but deal with them differently. Feeling lonely and on the outside may be interpreted as being in a heterotopic space, but we may all experience outsidership at times, so maybe we are all examples of heterotopic citizens. Or maybe none of us is either in a heterotopic space or at the centre; it always depends on the context. Still, in practice some suffer more from marginalisation than others, in that inequality in power and resources are fundamental issues in society.

Considering everything discussed here about heterotopia and the importance of ensuring that diaconal work is in the heterotopic spaces and with the marginalised, another question for reflection arises: When the church has to set priorities, is it older people or other societal groups who need diaconal services the most? While this question has value, pitting groups against each other is not always the most fruitful or constructive way of answering it. Diaconal ministry must answer the call from the other, whoever that may be and whatever the need is. Another relevant question is whether diaconal work is *only* for the marginalised. This subject raises several more questions, such as: What criteria should be used to define who is in the margins? How can we know if the right groups are being addressed, especially since marginalised groups or individuals may not be visible? Moreover, and maybe even more crucially: Who has the power to assess who is "inside" or "outside?". Nordstokke suggested using hermeneutics of suspicion by asking whose interests are underlying (2011, p. 61).

Through the participants of this thesis, we found that some older people feel outdated and de-prioritised. They feel set aside. One of the deacons put it this way: "I'm thinking, who takes seriously these old, anxious ladies who are perhaps really struggling with their big life crises?" (Olafsson et al., 2022, p. 31). This a powerful reflection that reminds me that people – including older people – need people. I am convinced that many individuals who are seen as among the privileged feel outside and alienated from others. Marginalisation is not always visible to the naked eye. Hence, we must be

careful not to think we know who needs diaconal ministry the most, but rather be alert and listen to the needs in our society. Moreover, the theory of heterotopia is quite dichotomous when people are either in the first room or the heterotopic room. However, heterotopic diaconia is about meeting the marginalised where they are in their heterotopic space and is imbued with values of respect, equality, empowerment and reciprocity.

Finally, can approachability be a way to minimise polarities and break down the barriers between inside and outside, centre and periphery? The deacons conveyed that many older people need someone to talk to about life and death and that, for some, there is also a need for prayer, blessing and communion. A diaconal church is responsible for listening to those who do not necessarily shout the loudest and asking the diaconal question that Jesus asked Bartimaeus: “What do you want me to do for you?” (Mark 10, 51). I believe that approachability, as in deacons who are present among groups or individuals, helps fill these gaps and testifies that we are all alike to some extent. The idea of a society without differences may be utopic. In that case, building bridges and practising the gradual movement that we found in the deacons in this study is essential.

Based on the above, I argue that older people suffer a double marginalisation: On the one hand, they are subject to ageism and unsatisfactory healthcare in society. Politics and social institutions tend to see old age as a problem to be solved and consider older people as “patients” rather than individuals. That might lead to a perception of ageing as decay (Binder, 2018, p. 325). On the other hand, in Norwegian diaconal research, older people have not been prioritised. As diaconal researchers, we have a responsibility to give voice to them through research projects, not only those traditionally described as recipients of diaconal ministry, as the most marginalised and mentioned by Stålsett et al. (2018). That said, an essential point is that “giving voice to” may be perceived as a more paternalistic perspective, where researchers or diaconal workers are the ones in a position to – so generously – hand the microphone to those in the margins. That may, of course, sometimes be the case. The power imbalance is then fairly clear. Still, this may sometimes be unavoidable, as groups may need assistance raising their voices. One way of meeting this challenge is to conduct diaconal participatory action research as both Lid and Stålsett advocated (2019; 2021; Stålsett et al., 2018). As Stålsett et al. (2018) pointed out, diaconal research has traditionally been researching *on* diaconal practice, and they legitimately ask: “*Whose science, whose practice? Whose experience, whose worlds?*” This is also in line with Wyller (2006) who stressed that the marginalised must be ecclesiastical subjects in heterotopic diaconia (2006, p. 286).

## 6.6 How This Thesis Contributes to the Research Field

Research is about obtaining the most reliable knowledge within a specific field, and we need theoretical and empirical research. Within the science of diaconia, there is an explicit demand for more empirical studies (Stifoss-Hanssen, 2014), and my thesis meets this demand. Specifically, my thesis contributes to one of Stifoss-Hanssen's three suggestions on diaconal research fields: "Mapping out exploratory studies in the field of church and society" (2014, p. 71), where he proposes studying marginalised groups in society to "see to what extent and in which ways churches, deacons and parishes serve or interact with those people" (p. 71). Research on deacons as existential conversation partners with older people is, as far as I can see, non-existent. This study furthermore contributes to the PhD programme Diaconia, Values and Professional Practice with its attention to "professional practice in health and social services, and churches and other faith communities" (Stifoss-Hanssen, 2014, p. 63).

The most reliable data concerning understanding older people and existential issues are the ones based on their direct voices. Research grounded in professionals who work with them is valuable, yet insufficient, as they will always function as a secondary source. To improve existential/spiritual care for older people, knowledge based on older people's voices is needed. The mentioned study by Sørensen et al. (2021) is quantitative and an important contribution to older people's experience of meaning. My contribution provides qualitative perspectives on how some older people reflect on and experience meaning. Regarding ageism, research based on older people is one way of empowering them to convey what is important to them and allowing them to engage as collaboration partners in research. Researchers within the science of diaconia have a responsibility to help marginalised people raise their voices, and my thesis is partly a response to this challenge. Given that little Norwegian research is based on older people's voices regarding their spirituality (Rykkje et al., 2013), this dissertation provides an essential contribution.

Much of diaconal research is focused on social work, congregational work or institutional work. The innovation of this thesis is its clear existential health perspective in combination with diaconia and heterotopia. A number of studies investigate diaconal healthcare organisations. However, my contribution is at the service and professional levels rather than the organisational level.

Almost 10 years ago, Nygaard (2014) pointed out that research on deacons' everyday practice is scarce, and this is still the case. My study will thus contribute to the field of professional deacons, specifically their perceived competencies as existential conversation partners for older people. Moreover, the study contributes empirical bottom-up research on the concept of "the existential" through focus group interviews with deacons. There is a lack of such research on the concept,

especially when compared to research on the concepts of spirituality and religion (Hvidt et al., 2022, p. 3280).

Concerning the diaconal discourse on heterotopia, older people are mostly not seen as marginalised, a position I have challenged through this thesis. I fear, and assert, that the heterotopic diaconal research and discourse has to a large extent forgotten older people in favour of undocumented migrants, drug addicts, people with disabilities and other outcasts, and has therefore turned out to be too schematic in its focus on the most visible marginalised groups. Consequently, older people seem to have slipped under the radar in the eagerness to focus on the most marginalised. This thesis is partly a response to this.

## 6.7 Strengths and Limitations

A major strength of this thesis is its mentioned innovation in the broad and interdisciplinary theoretical framework and its rare data in the Scandinavian context. However, qualitative research such as this thesis has its limitations. For instance, it does not fully capture the complexity and diversity in the participants' reflections and experiences. Still, it provides more in-depth and nuanced knowledge than a quantitative study. Furthermore, the inclusion of quotations from the participants invites readers to interpret and understand for themselves and to assess our interpretations.

One limitation of the study is that the older participants were all engaged socially at a senior centre. Data from older people who are more isolated and/or in poorer health, or nursing home residents, would have added other experiences, reflections and perspectives. On the other hand, a strength is that this sample can convey important aspects from active, home-dwelling older people, though not generalisable due to the study's size and qualitative design. The more qualitative research on the issue of older people and existential issues, however, the more knowledge we will have, both as researchers and as practitioners. This study contributes in that respect.

A limitation concerning the article with deacons as conversation partners (Article 3) is that we only interviewed deacons about *their* reflections and opinions but did not ask recipients of the deacon ministry about how they experienced the deacon's competence – or lack thereof. That would have provided a needed and long-awaited perspective.

## 7 Conclusion, Implications and Further Research

### 7.1 Conclusion

The overall research question was “What are older people’s reflections concerning existential issues and how do deacons within the Church of Norway interpret and respond to older people’s needs through existential conversations?” I will conclude with the following.

As found through the participants of this study, some older people experience that existential issues become more salient and challenging in old age. Society is obliged to meet the existential needs of older people. However, healthcare workers report that they lack time or are mostly uncomfortable or unqualified in meeting patients’ existential needs. Furthermore, many older home-dwelling people do not even encounter healthcare workers. Some older people want to talk about existential issues but often prefer not to have these conversations with family members. Thus, they may need competent conversation partners. As seen in Chapter 2.3, talking about existential issues when seriously ill is needed by many patients, even though they may not have an existential or religious language. If Norwegian society becomes even more secularised than it is today, the need for competent existential conversation partners will increase. Therefore, I argue for the importance of deacons. As approachable professionals who represent a counterculture in society with resources such as time, conversation skills, religious and existential literacy and who can perform religious rituals, deacons can respond to the challenges associated with older people, existential issues and existential conversations. As professionals, and with their awareness concerning power imbalances and diaconal values such as reciprocity, empowerment and respect for older people, they make an important societal contribution. These values highlight the “trinitarian” formulation of human personhood: that older people are simultaneously like all other people, like some other and like no other, all aspects that need to be considered in ECs, PCCs and PC. Finally, this combines both the heterotopic aspect and the universal conditions of human beings.

### 7.2 Implications

Concerning the research field as presented in Chapter 2, older people’s need for existential conversations is not being sufficiently met by healthcare professionals due to lack of time and perceived competence. Older people have a right to such conversations. In healthcare, it would be significant if existential and spiritual care were incorporated into the curriculum and education of nurses and doctors to increase their awareness and competence around existential caregiving. In

Norway, there is a group of healthcare professionals, “helsefagarbeidere”, with health education from upper secondary school. These workers usually spend more time with patients than doctors and nurses; therefore, strengthening their existential competence would also favour older patients.

From the deacons’ perspective, there seems to be a lack of competence in meeting more severe mental health issues, as suggested in Article 2. Not all deacons have been trained in dealing with people who have suicidal thoughts, for instance. This could preferably be strengthened in the master’s programme in diaconia.

I have argued that older people suffer a double marginalisation: one way of addressing this is to employ deacons (or chaplains) both in churches and institutions for older people to ensure they have access to existential conversation partners. Deacons can also assess whether existential group conversations could both save time for the deacon and facilitate older people coming together to share experiences and reflections. When people in post-secular societies experience crisis religiosity, they may need existentially, spiritually and religiously literate people who can meet them in urgent or difficult situations. This is not only a prediction for the future. In addition, older people are not used to discussing existential issues with family or friends, and religious older people may want a deacon to converse with.

To see a psychologist, you either must get a referral from your GP and pay a deductible or pay full price to see a private psychologist, for which the waiting list may be long. Conversations with deacons are free. Still, these conversations are not therapy and cannot be expected to treat deeper psychological issues.

Finally, the population of older people is growing and the average life expectancy is increasing, so we must take older people’s existential needs seriously and work preventively. Offering existential conversations is one of several such measures, and through group conversations, more people can be reached. Cooperation between healthcare professionals and deacons is of great importance. For nursing home patients, healthcare personnel should be attentive to their existential needs and initiate contact with the deacon/chaplain when the patient wants it.

### 7.3 Further Research

In the research field within PC and the psychology of religion, there is a lack of research based on older people’s experiences of existential conversations and pastoral care provided by pastors and deacons. In this discussion, I claimed that older people suffer a double marginalisation through ageism and unsatisfactory healthcare in society on the one hand and that the diaconal research discourse has failed to prioritise older people on the other. Therefore, we should conduct more diaconal research on

the well-being of older people, especially concerning their existential well-being and how the church can contribute to meeting those needs. We need research, both qualitative and quantitative, based on Nordic older people's voices. We need more empirical research on older people's perspectives in different fields, with existential conversations just one of those fields. The need for research within the religious, spiritual and existential dimensions, with reference to the work of DeMarinis (2003) is also stressed by Stifoss-Hanssen (2014, p. 71).

Moreover, there is a need for more research on older people's experiences from ECs or PCCs and nursing home chaplains' and deacons' work in a Norwegian or Scandinavian setting, since the PC research is mainly based on the perspectives of the PCC providers rather than the receivers. This lack calls for both qualitative and quantitative studies. To fully defend the deacons' ministry in the care of older people, older recipients' experiences are valuable and needed.

Additional research on deacons' professional practice is in demand; for instance, what they experience as their lack of competence. This was only briefly dealt with in Article 3 of this thesis. Experienced deficiencies in a professional group are essential to research and report to educational institutions to improve the educational training of deacons.

Finally, from a heterotopic–diaconal point of view, diaconal participatory research with older people is also in need.

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### Article 1

Olafsson, Å. M., & Rykkje, L. (2022). Existential Issues in Old Age as Narrated by Older People – An Interview Study from Norway. *Religions*, 13(3), 259.

<https://doi.org/10.3390/rel13030259>

### Abstract

Background: Research about the importance of existential issues and individuals' responses to them in old age is growing. This study aimed to explore older Norwegians' thoughts and experiences related to existential issues and whether or not they wanted to talk about existential concerns with others. The theoretical framework includes Yalom's ultimate concerns and Tornstam's theory of gerotranscendence. Methods: Individual semi-structured interviews were conducted with eleven home-dwelling older persons, five men and six women aged 73–91 years, all residing in a larger Norwegian town. The data were analysed using thematic analysis. Results: Four main themes and two subthemes regarding the participants' existential reflections emerged concerning loneliness, death, and meaning. Some participants increased their interest in existential issues in old age, and only a few participants desired deeper conversations about existential issues. Conclusions: The participants were mostly satisfied with life, mainly did not feel lonely and were not afraid of death. Existential meaning was experienced on a horizontal level rather than a transcendent level. Although few openly wanted existential conversations, most participants conveyed a positive interview experience, suggesting that if existential conversations were offered, they would be valuable to older people.

## Article 2

Olafsson, Å. M., Stifoss-Hanssen, H., & Austad, A. Deacons' perspectives on "the existential" and existential conversations with older people. (Submitted to *Diaconia. Journal for the Study of Christian Social Practice* September 2023).

### **Abstract**

The article contributes to the conceptual discussions on what "the existential" and "existential conversations" (ECs) may be, providing empirical research on the perspectives of deacons within The Church of Norway (CofN) on specified terms and ECs between deacons and older people. The article then explores how the deacons approach ECs with older people. Data were sampled through focus group interviews with 18 deacons and were analyzed by drawing on pastoral care literature and other relevant research. Findings show that the deacons understand "the existential" as more inclusive than "the spiritual", involving cognitive thinking and experiential phenomena. Moreover, they perceive ECs as broader and less private than pastoral care conversations (PCCs). Finally, to reduce thresholds, distance and scepticism towards the church, the deacons use terms for their conversations pragmatically and strategically according to the specific context.

*Article 3*

Olafsson, Å. M., Stifoss-Hanssen, H., & Austad, A. (2022). Deacons as conversation partners on existential issues with older people. *Tidsskrift for praktisk teologi*, 39(2), 21–36.

doi: <https://doi.org/10.48626/tpt.v39i2.5499>

**Abstract**

Deacons within the Church of Norway constitute a professional group that can encounter older people's need for existential conversations, but empirical research in this field is scarce. This study aims to explore professional deacons' perceived competence in the field of older people and existential issues. Three focus group interviews with 18 deacons and an inductive qualitative content analysis were used to answer the inquiry. We introduce the term "approachable deacons" as an analytical innovation. Based on the empirical material and the perspectives from diaconia and the psychology of religion, arguments are made for the societal contribution of the deacon profession. As approachable existential conversation partners, deacons may make an essential contribution to public mental health. We assert that the deacon profession represents a counterculture to society and healthcare, where time is short, older people may feel downgraded, and existential and religious literacy is limited.

## Interview guide sample 1

First phase: Framing	<p><b>Informal chat (5 min)</b></p> <hr/> <p><b>Information (5-10 min)</b></p> <ul style="list-style-type: none"> <li>• Inform about the topic of the conversation (background, purpose).</li> <li>• Explain what we will use the interview for.</li> <li>• Explain confidentiality and anonymity.</li> <li>• Ask if anything is unclear and if the respondent has any questions.</li> <li>• Inform about audio recording and ask for consent to it.</li> <li>• Start recording.</li> </ul>
Second phase: Experiences	<p><b>3. Transition questions: (15 min)</b></p> <p>A bit about the interviewee's background</p> <ul style="list-style-type: none"> <li>• Would you like to say a little about yourself, very briefly, so I can at least get to know you a little?</li> <li>• Possible follow-up questions.</li> </ul>
Third phase: Focusing	<p><b>4. Key questions: (50-60 min)</b></p> <ul style="list-style-type: none"> <li>• What is important to you in the life phase you are in now? What gives you meaning in life?</li> <li>• Are there any significant life questions that have become more prominent in old age? If so, can you tell me a little about it?</li> <li>• What is it like to be you now?</li> <li>• Do you have someone to talk to about these things? Is it important for you to speak to others about this?</li> <li>• Are there contexts where you feel there is room to talk about this? Where/with whom would you like to have the opportunity to discuss these topics?</li> <li>• What do you need to feel good? / What gives meaning to you?</li> <li>• Possible follow-up questions.</li> </ul>
Fourth phase: Retrospect	<p><b>5. Summary (approx. 15 min)</b></p> <ul style="list-style-type: none"> <li>• Summarise the conversation to ensure a common understanding.</li> <li>• Have I understood you correctly?</li> <li>• Is there anything you would like to add?</li> <li>• Would you like to say something about how you experienced this interview situation (taking care of the interviewee)?</li> </ul>



## Interview guide sample 2

First phase: Framing	Informal chat (5 min)
	<p><b>Information (5-10 min)</b></p> <ul style="list-style-type: none"> <li>• Inform about the topic of the conversation (background, purpose).</li> <li>• Explain what we will use the interview for.</li> <li>• Explain confidentiality and anonymity.</li> <li>• Ask if anything is unclear and if the respondent has any questions.</li> <li>• Inform about audio recording and ask for consent to it.</li> <li>• Start recording.</li> </ul>
Second phase: Experiences	<p><b>3. Transition questions: (15 min)</b></p> <ul style="list-style-type: none"> <li>• A bit about the interviewee's background</li> <li>• What made you join the dialogue group, with thoughts about being on the way in life?</li> <li>• How long have you been involved?</li> <li>• Possible follow-up questions.</li> </ul>
Third phase: Focusing	<p><b>4. Key questions: (50-60 min)</b></p> <p><b>A bit about the interviewee's experiences from the conversation group</b></p> <ul style="list-style-type: none"> <li>• Can you tell us a little about your experiences from the group discussions?</li> <li>• What do you think is essential to talk about with others?</li> <li>• Do you feel there is room to discuss this in the conversation group?</li> <li>• What do you need to feel good?</li> </ul> <p><b>A bit about the interviewee's reflections afterwards</b></p> <ul style="list-style-type: none"> <li>• How long have you been involved?</li> <li>• Would you say the group discussions have been vital to you afterwards? Can you tell us a little bit about it?</li> <li>• Possible follow-up questions.</li> </ul>
Fourth phase: Retrospect	<p><b>5. Summary (approx. 15 min)</b></p> <ul style="list-style-type: none"> <li>• Summarise the conversation to ensure a common understanding.</li> <li>• Have I understood you correctly?</li> <li>• Is there anything you would like to add?</li> <li>• Would you like to say something about how you experienced this interview situation (taking care of the interviewee).</li> </ul>

## Interview guide deacons

### *Opening question:*

Please tell us your name, where you work as a deacon, and what you like to do most when you are not at work.

### *Introductory questions:*

What made you choose to become a deacon?

### *Transition questions:*

In what contexts do you talk to older people about existential questions? Home visit? Church coffee? Group calls? Other?

### *Key questions:*

1. "The existential" is a term that we can add different content to or understand in different ways. How do you understand the concept?
  - a) Possibly: Is there a difference between the existential and the spiritual, for example?
  - b) Can you tell us about an episode where you talked about something existential?
2. How do you understand an existential conversation in relation to a pastoral care conversation?
3. Can you tell us about your experiences talking to older people about existential topics?
4. Can you tell us about a situation when you felt you had something to contribute to a conversation about existential questions? In what way did you think that you had something to contribute?
5. Can you tell us about a situation when you felt you fell short in a conversation about existential questions? In what way(s) did you think you fell short?
6. Which competencies do you consider the most important when dealing with older people and existential conversations? Professional? Personal characteristics? Life experience? Something else?
7. Do you feel that your deacon training has given you concrete help in conversations about existential questions?

### *Closing questions:*

1. What would you say if you were to advise the educational institutions on what should be emphasised in the education of deacons in terms of pastoral care/existential conversations?
2. If you were to single out three things you think are the most important things we've discussed, what would they be?
3. Is there something you think we should have discussed within the topic of existential conversations with older people that we have not touched on?

# Vurdering av behandling av personopplysninger

**Referansenummer**

155899

**Vurderingstype**

Standard

**Dato**

09.07.2020

**Prosjekttittel**

Dialoggrupper

**Behandlingsansvarlig institusjon**

VID vitenskapelige høgskole / Fakultet for helsefag / Fakultet for helsefag Bergen

**Prosjektansvarlig**

Åsta Marie Olafsson

**Prosjektperiode**

01.06.2020 - 15.11.2023

**Kategorier personopplysninger**

Alminnelige

Særlige

**Lovlig grunnlag**

Samtykke (Personvernforordningen art. 6 nr. 1 bokstav a)

Uttrykkelig samtykke (Personvernforordningen art. 9 nr. 2 bokstav a)

Behandlingen av personopplysningene er lovlig så fremt den gjennomføres som oppgitt i meldeskjemaet. Det lovlige grunnlaget gjelder til 15.11.2023.

[Meldeskjema](#) **Kommentar**

Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet 09.07.2020 med vedlegg, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

**MELD VESENTLIGE ENDRINGER**

Dersom det skjer vesentlige endringer i behandlingen av personopplysninger, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. Før du melder inn en endring, oppfordrer vi deg til å lese om hvilke type endringer det er nødvendig å melde: [https://nsd.no/personvernombud/meld\\_prosjekt/meld\\_endringer.html](https://nsd.no/personvernombud/meld_prosjekt/meld_endringer.html)

Du må vente på svar fra NSD før endringen gjennomføres.

**TYPE OPPLYSNINGER OG VARIGHET**

Prosjektet vil behandle særlige kategorier av personopplysninger om religion, filosofisk overbevisning og helseforhold og alminnelige kategorier av personopplysninger frem til 15.11.2023.

**LOVLIG GRUNNLAG**

Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og art. 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte kan trekke tilbake.

Lovlig grunnlag for behandlingen vil dermed være den registrertes uttrykkelige samtykke, jf. personvernforordningen art. 6 nr. 1 bokstav a, jf. art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2).

**PERSONVERNPRINSIPPER**

NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen om:

- lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen
- formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke viderebehandles til nye uforenlige formål
- dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med

prosjektet

- lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet

#### DE REGISTRERTES RETTIGHETER

Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20).

NSD vurderer at informasjonen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

#### FØLG DIN INSTITUSJONS RETNINGSLINJER

NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og eventuelt rådføre dere med behandlingsansvarlig institusjon.

#### OPPFØLGING AV PROSJEKTET

NSD vil følge opp underveis (hvert annet år) og ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet/pågår i tråd med den behandlingen som er dokumentert.

Lykke til med prosjektet!

Kontaktperson hos NSD: Kajsa Amundsen

Tlf. Personverntjenester: 55 58 21 17 (tast 1)

# Vurdering av behandling av personopplysninger

**Referansenummer**

824483

**Vurderingstype**

Standard

**Dato**

23.09.2021

**Prosjektittel**

Diakoners erfaringer med eksistensielle samtaler med eldre

**Behandlingsansvarlig institusjon**

VID vitenskapelige høgskole / Fakultet for helsefag / Fakultet for helsefag Bergen

**Prosjektansvarlig**

Åsta Marie Olafsson

**Prosjektperiode**

01.09.2021 - 15.11.2024

**Kategorier personopplysninger**

Alminnelige

Særlige

**Lovlig grunnlag**

Samtykke (Personvernforordningen art. 6 nr. 1 bokstav a)

Uttrykkelig samtykke (Personvernforordningen art. 9 nr. 2 bokstav a)

Behandlingen av personopplysningene er lovlig så fremt den gjennomføres som oppgitt i meldeskjemaet. Det lovlige grunnlaget gjelder til 15.11.2024.

[Meldeskjema](#) **Kommentar**

Det er vår vurdering at behandlingen vil være i samsvar med personvernlovgivningen, så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet den dagens dato med vedlegg, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

**TYPE OPPLYSNINGER OG VARIGHET**

Prosjektet vil behandle alminnelige personopplysninger, særlige kategorier av personopplysninger om religion og filosofisk frem til 15.11.2024.

**LOVLIG GRUNNLAG**

Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte kan trekke tilbake.

For alminnelige personopplysninger vil lovlig grunnlag for behandlingen være den registrertes samtykke, jf. personvernforordningen art. 6 nr. 1 a.

For særlige kategorier av personopplysninger vil lovlig grunnlag for behandlingen være den registrertes uttrykkelige samtykke, jf. personvernforordningen art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2).

**PERSONVERNPRINSIPPER**

NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen:

- om lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen
- formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke viderebehandles til nye uforenlige formål
- dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet
- lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet.

## DE REGISTRERTE RETTIGHETER

NSD vurderer at informasjonen om behandlingen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18) og dataportabilitet (art. 20).

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

## FØLG DIN INSTITUSJONS RETNINGSLINJER

NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

Zoom og Microsoft Teams er databehandler i prosjektet. NSD legger til grunn at behandlingen oppfyller kravene til bruk av databehandler, jf. art 28 og 29.

For å forsikre dere om at kravene oppfylles, må prosjektansvarlig følge interne retningslinjer/rådføre dere med behandlingsansvarlig institusjon.

## MELD VESENTLIGE ENDRINGER

Dersom det skjer vesentlige endringer i behandlingen av personopplysninger, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. Før du melder inn en endring, oppfordrer vi deg til å lese om hvilken type endringer det er nødvendig å melde:

<https://www.nsd.no/personverntjenester/fylle-ut-meldeskjema-for-personopplysninger/melde-endringer-i-meldeskjema>

Du må vente på svar fra NSD før endringen gjennomføres.

## OPPFØLGING AV PROSJEKTET

NSD vil følge opp underveis (hvert annet år) og ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet i tråd med den behandlingen som er dokumentert.

Kontaktperson hos NSD: Olav Rosness, rådgiver.

Lykke til med prosjektet!

# Vurdering av behandling av personopplysninger

**Referansenummer**

861100

**Vurderingstype**

Standard

**Dato**

09.03.2020

**Prosjektittel**

Eksistensielle samtaler i eldreomsorgen

**Behandlingsansvarlig institusjon**

VID vitenskapelige høgskole / Fakultet for helsefag / Fakultet for helsefag Bergen

**Prosjektansvarlig**

Åsta Marie Olafsson

**Prosjektperiode**

15.08.2019 - 15.11.2023

**Kategorier personopplysninger**

Alminnelige

Særlige

**Lovlig grunnlag**

Samtykke (Personvernforordningen art. 6 nr. 1 bokstav a)

Uttrykkelig samtykke (Personvernforordningen art. 9 nr. 2 bokstav a)

Behandlingen av personopplysningene er lovlig så fremt den gjennomføres som oppgitt i meldeskjemaet. Det lovlige grunnlaget gjelder til 15.11.2023.

[Meldeskjema](#) **Kommentar**

Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet den 09.03.2020 med vedlegg, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

**MELD VESENTLIGE ENDRINGER**

Dersom det skjer vesentlige endringer i behandlingen av personopplysninger, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. Før du melder inn en endring, oppfordrer vi deg til å lese om hvilke type endringer det er nødvendig å melde: [https://nsd.no/personvernombud/meld\\_prosjekt/meld\\_endringer.html](https://nsd.no/personvernombud/meld_prosjekt/meld_endringer.html)

Du må vente på svar fra NSD før endringen gjennomføres.

**TYPE OPPLYSNINGER OG VARIGHET**

Prosjektet vil behandle særlige kategorier av personopplysninger om religion, filosofisk ovebevisning og helseforhold, samt alminnelige kategorier av personopplysninger frem til 15.11.2023.

**LOVLIG GRUNNLAG**

Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og art. 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte kan trekke tilbake.

Lovlig grunnlag for behandlingen vil dermed være den registrertes uttrykkelige samtykke, jf. personvernforordningen art. 6 nr. 1 bokstav a, jf. art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2).

**PERSONVERNPRINSIPPER**

NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen om:

- lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen
- formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke viderebehandles til nye uforenlige formål
- dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med

prosjektet

- lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet

#### DE REGISTRERTES RETTIGHETER

Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20).

NSD vurderer at informasjonen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

#### FØLG DIN INSTITUSJONS RETNINGSLINJER

NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og eventuelt rådføre dere med behandlingsansvarlig institusjon.

#### OPPFØLGING AV PROSJEKTET

NSD vil følge opp underveis (hvert annet år) og ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet/pågår i tråd med den behandlingen som er dokumentert.

Lykke til med prosjektet!

Kontaktperson hos NSD: Jørgen Wincentsen

Tlf. Personverntjenester: 55 58 21 17 (tast 1)



