

When words fail

The role of physical touch in the practice of spiritual care for people with an intellectual disability

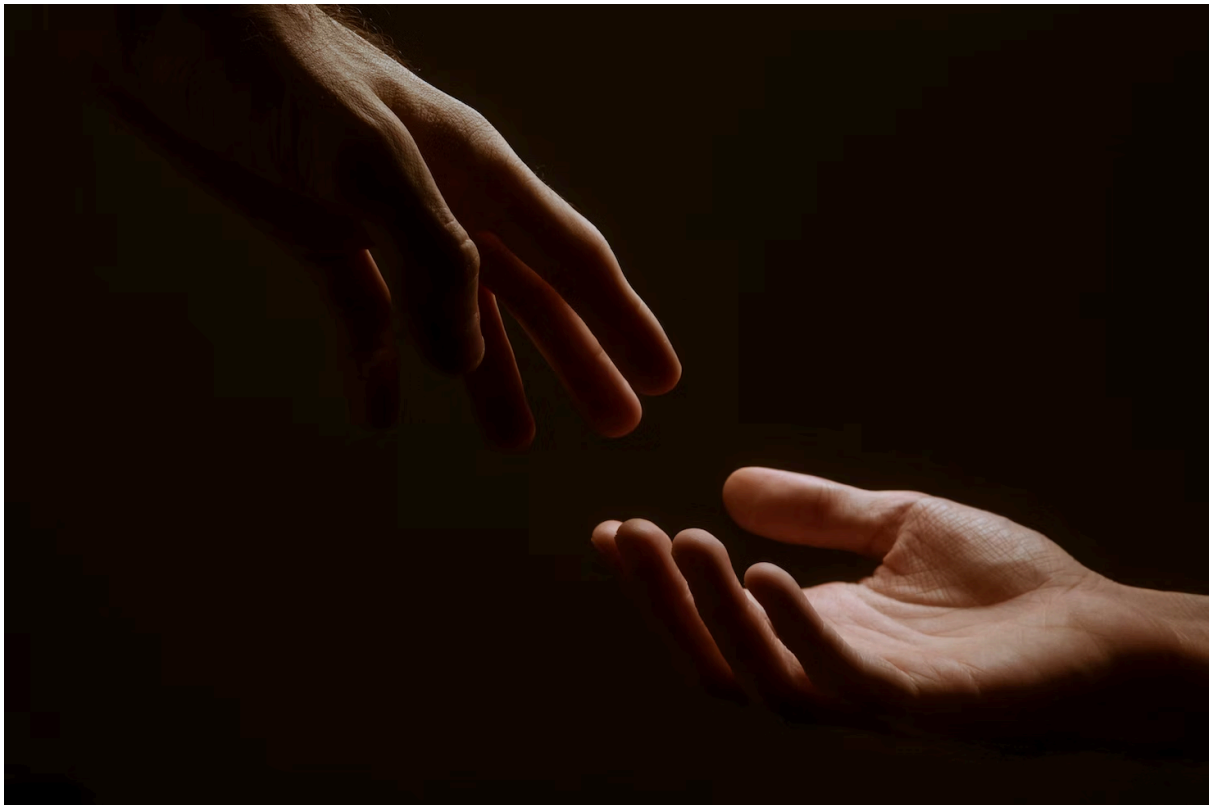


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Word count: 15619

Monday, the 22th of January 2024

Thesis to obtain the degree “Master of Arts” in Theology and Religious Studies

Faculty of Philosophy, Theology and Religious Studies

Radboud University Nijmegen

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Monday, the 22th of January 2024.

"there is no need
for half measures
when it comes to you
i cannot touch you
and feel nothing
i cannot touch you
and not feel like i am touching
everything that exists"

"To Touch the Sky" by Rupi Kaur

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Abstract

This study aims to explore the ways in which physical touch can be a professional tool for spiritual caretakers who work with people with an intellectual disability, which is a neglected research area. Through an interdisciplinary lens, it examines the nuanced ways in which physical touch can enhance the practice of spiritual care for people with an intellectual disability, while also acknowledging the challenges and ethical considerations associated. By shedding light on this underexplored research area, the research aims to contribute to improving spiritual care for people with an intellectual disability.

Acknowledgements

Writing a Master's thesis is not just an academic requirement. For me, it signifies the final moment of a degree that has been of incredible value to me, both professionally and personally. Four years ago, in the midst of the COVID-19 crisis, I was working as a market researcher for an international consultancy firm and asking myself: why am I doing this? In these moments of change and uncertainty I started to question the societal value and meaning of the work I was doing. Through a series of accidental events, I became acquainted with the profession of spiritual care and immediately knew that this was a profession I wanted to pursue. Fast forward to four years later, I am writing these words as I am finishing my Master's Thesis in Spiritual Care, which is both an academic and a personal achievement and moment of joy.

Writing this Master's Thesis would not have been possible without my dedicated supervisor dr. Joud Alkorani. Not only did you agree to my last-minute request of asking you to be my supervisor, you also challenged me and supported me throughout the writing process. You were always able to unravel the strings of my often knotted thoughts and after our meetings, I always felt clear-headed and ready to continue.

As the Beatles already famously sang, I got by with a little help from my friends. Janneke, you have been of enormous help throughout this process. From discussing my initial ideas to your thorough proof-reading of my entire thesis and challenging me in my thinking: you have been both academically and emphatically involved in this project, recognizing and agreeing on the importance of this topic in academia. Sanne, you inspire me through your pioneering work in challenging the norm surrounding the meaning of disability. Your critical and engaged points of view challenge me to look outside my academic bubble, to the 'real world' out there. Thijs, Kim and Marjon, you have always been lovingly walking next to me on my journey to become a spiritual caregiver, and have held space for me to discuss my thesis at length.

After finishing this degree, I cannot wait to integrate what I have learned in this Master's Thesis. I am grateful for my wonderful colleagues Manon and Joukje. I could not wish for two better companions on the road to becoming a better spiritual caregiver for my clients.

Looking back on the past four years, I am incredibly grateful for the events that have guided me to this profession. This degree and this job have brought meaning to my life in ways I have not experienced before: I feel like I have found the path that's meant for me to walk.

Introduction

It is autumn 2023 and I am driving back home after my first day working as a spiritual caregiver. I work for an organisation that houses and offers care to people with an intellectual disability. On this first day, I shook hands and elbows, held hands and touched the shoulders and arms of clients and residents. As the day progressed, I had to use body and sign language to express myself and converse with my clients, or to physically emphasise what I was verbally saying. I immediately realised that my practice working with these people was going to be quite different from what I learned at university. While driving, I reflected on my day, my experiences and how I felt. One question that kept coming back was: how do I manoeuvre this new, physical element of my job? As a ‘stereotypical’ university graduate, who studied philosophy and religious studies, I use words to express myself, and to connect with others. In my work, it is also the main way of communication I use to guide my clients in their self-reflection, existential exploration and meaning-making process. Rarely do I use non-verbal means of communication. At most, I use my hands to emphasise something when I express a thought. Encountering clients who find it hard to speak or express themselves verbally was therefore quite an eye-opener to me. Partly because of my own verbal preference and proficiency, but also because I saw how often my clients use physical means of communication, such as touch, directional and expressive movement. After seeing how my clients connected to me and one another and expressed themselves through physical communication, I felt like there was a lot to learn. These encounters resulted in two distinct realisations. Firstly, in a personal sense of awkwardness because I was not able to use my preferred, comfortable mode of communication. Secondly, in a feeling of failure because I felt like I lacked the professional competence that I needed to be a sufficient spiritual caregiver to my clients. But after a while, however, a question rose up: how do other spiritual caregivers navigate these obstacles? Other spiritual caregivers probably have a similar educational background. This means that they probably developed individual ways to navigate these challenges. I decided I needed to dive into the role of physical touch in the practice of spiritual care for people with an intellectual disability.

Aside from my personal interest in this topic, it is also a topic that is discussed by spiritual caretakers and academics alike. Spiritual caretaker and researcher Marieke Schoenmakers has written on the role of physical touch in the practice of spiritual care.¹ She found that both in practical courses and in academic and professional literature, physical touch in spiritual care is a neglected topic. This means that there is

¹ Marieke Schoenmakers and Carlo Leget, “Aanraken in de geestelijke verzorging. Een verkennend onderzoek met bijzondere aandacht voor mensen met dementie,” *Tijdschrift Geestelijke Verzorging* 17, no. 74 (December 2014): 1.

no theoretical framework or professional point of view that spiritual caretakers can fall back on. She states that this is unfortunate because spiritual caretakers often find themselves in situations in which touch can be of great value. She concludes that both training in and research on the use of physical touch in spiritual care are desirable.² Spiritual caretaker Riëtte Beurmanjer adds to this discussion by arguing that part of the set of competences of a spiritual caretaker is being sensitive to body language and being able to interpret its expressive power, and not to underestimate the role of the body in person-centred communication. She proposes to enrich the professional standard of the Dutch professional association of Spiritual Care (de VGVZ) by adding a ‘physical competence’³. This research shows that the topic of physicality and physical touch are relatively new research topics in spiritual care, but more importantly, that spiritual caretakers are actively looking for guidelines, frameworks, or other forms of theoretical documents to support their practice. Another element that is discussed in academic literature is the dominance of verbality in communication. Spiritual caretakers Gustaaf Bos and Susan Woelders wrote about the role of verbality and cognition in communication with people with an intellectual disability or aphasia, who cannot speak. They highlight the dominance of the verbal and cognitive mode of communication, originated in an academic setting, and its presence in healthcare organisations. This verbal and cognitive mode often is the base for how professionals think, talk and organise their everyday practice. They also state that the possibility of using other forms of communication is often limited or sometimes even impossible⁴. The dominance of this verbal and cognitive mode raises questions on the quality of the practice of spiritual caregivers, specifically in the context of people with an intellectual disability.

Considering the work of Schoenmakers, Beurmanjer, Bos and Woelders, this thesis aims to look at the possible role of physical touch in spiritual care for people with an intellectual disability. I thus hope to contribute to the development of a body of academic research on the role of physical touch in the practice of spiritual care. My focus will be on how physical touch can be a tool in working with people with an intellectual disability. Given that many people with an intellectual disability are not always able to express themselves verbally, I question if using solely verbal communication does justice to the needs of these people when it comes to spiritual care. As spiritual caretakers, we are supposed to be “capable of providing spiritual

² Schoenmakers and Leget, “Aanraken,” 3.

³ Riëtte Beurmanjer, “Betekenisvol lichaam. Lichaamstaal in de hermeneutische, spirituele en communicatieve competentie,” *Tijdschrift Geestelijke Verzorging* 24, no. 103 (December 2021): 19.

⁴ Gustaaf Bos & Susan Woelders, “Collaboratief onderzoek in het spanningsveld tussen verbaliteit, cognitie en lijfelijkheid: grensverkenningen van academische kennisproductie,” *Waardenwerk* 82-82 (December 2020): 64.

care to each client.”⁵ We therefore also hold a responsibility to be able to provide care to those who can’t communicate verbally. This means that other ways of communication should be part of the practice of a spiritual caretaker. Clearly, learning about using physical communication as a professional tool will strengthen my personal practice. Additionally, I hope that my research will shed a light on why physical touch is currently not part of the professional development of spiritual caregivers. Most importantly, I hope my research contributes to bettering the practice of spiritual care for people with an intellectual disability.

To understand how physical touch can be a tool in working with people with an intellectual disability, we first need to understand why this topic has been largely neglected. I will answer the question: how can physical touch be a professional tool for spiritual caretakers who work with people with an intellectual disability? Hereby, my research will in part be a reaction to the call for action voiced by Marieke Schoenmakers: to investigate how spiritual caregivers integrate physical touch into their work and how this is experienced by the people they accompany through further field research.⁶

The argument proceeds in three stages. In Chapter 1, I introduce the topic, methodology and a short discussion on the term ‘Disability’. In Chapter 2, the history and current status of using physical touch in both academic research, professional literature and practice of spiritual care are addressed. Chapter 3 builds on the insights of Chapter 2 and engages with spiritual caregivers who work with people with an intellectual disability. This chapter discusses their vision on using physical touch as a professional tool in their practice. In the Conclusion and Discussion section, I discuss theoretical and practical implications.

⁵ “Professional Standard VGVZ,” Professional Standard VGVZ, Accessed September 30, 2023, https://vgvz.nl/wp-content/uploads/2023/02/VGVZ_Professional_Standard_2015_Main_Text_EN_v03_WITH_APPENDICES.pdf

⁶ Schoenmakers and Leget, “Aanraken in de geestelijke verzorging,” 19.

Chapter 1. Theoretical framework

1.1. Methodology

This study employs a mixed-methods research design, which integrates theoretical and empirical research approaches to gain a comprehensive understanding of the use of physical touch in the practice of spiritual care for people with an intellectual disability. The research design consists of two main phases: a literature review and qualitative data collection through semi-structured interviews.

1.1.1. Literature review

The literature review serves as the foundational component of this thesis, aiming to provide an overview of the theoretical underpinnings, historical development, and contemporary perspectives on the use of physical touch in spiritual care in general, and specifically in the context of spiritual care for people with an intellectual disability. The following research questions guide the literature review:

- How has the use of physical touch in spiritual care been explored and defined within existing literature?
- What are the primary motivations and intentions behind using physical touch in spiritual care practices?
- Which academic disciplines have contributed the most to the study of physical touch in spiritual care, and what are the key findings from these disciplinary perspectives?
- What are gaps and areas of contention in the current literature on the use of physical touch in spiritual care?

The literature review draws upon a wide range of academic sources, including peer-reviewed journal articles, books, reports, news articles and grey literature. A systematic search strategy was employed to identify relevant literature, using online databases such as PubMed, Google Scholar and RUQuest, a database developed by Radboud University. These sources come from multiple disciplines, such as disability studies, religious studies, spiritual care studies, psychology, pedagogy, humanistics and philosophy.

The literature review data was analysed thematically. Key themes and concepts related to the use of physical touch in the practice of spiritual care were identified. These themes have informed the development of interview questions and guide the

qualitative phase of the research. Additionally, gaps and missing information in the theory on the use of physical touch have been explored during the interviews.

1.1.2. Qualitative research

Unlike more established aspects of spiritual care, such as verbal communication and emotional support, the use of physical touch in this context lacks a well-defined theoretical framework. Therefore, the primary aim of this section of the study is to gain insights into how spiritual caretakers have developed and incorporated the use of physical touch in their practice without the guidance of an established theoretical, practical or legal framework. The following research questions guide this qualitative phase:

- What are the motivations and intentions behind the use of physical touch in spiritual care for people with an intellectual disability?
- How have spiritual caretakers learned to navigate the ethical and professional boundaries associated with physical touch in their work?
- What challenges and opportunities have spiritual caretakers encountered in developing their own practice of physical touch in spiritual care for people with an intellectual disability?

Participants in the qualitative phase of this study will consist of spiritual caregivers working with people with an intellectual disability. Potential participants will be approached through a professional work group of VGVZ, consisting of spiritual caretakers working with people with an intellectual disability.⁷ Additionally, I will use my personal network to approach colleagues in the field. A purposive sampling strategy will be employed to ensure a diverse range of perspectives and experiences within the chosen population.

Semi-structured interviews will serve as the primary method of data collection. Interviews will be conducted face-to-face or via video conferencing, depending on participant preferences and logistical considerations. Four spiritual caregivers, comprising two male and two female participants⁸, will be interviewed to ascertain their perspectives on the role of physical touch within their professional practice when working with people with an intellectual disability. Recruitment of participants will be

⁷ “Werkvelden - Mensen met een beperking,” VGVZ Werkvelden - Mensen met een beperking, Accessed October 5, 2023, <https://vgvz.nl/werkvelden/mensen-met-een-beperking/>

⁸ The decision to include two male and two female participants was influenced by the fact that gender can play a significant role when it comes to physical touch in spiritual care. Cultural and societal norms often influence the ways in which people who identify as man or woman perceive touch, particularly in sensitive, professional contexts in which spiritual care finds itself. By including both male and female participants, potential gender-specific nuances in the context of physical touch in spiritual care can emerge.

facilitated through my professional network within the domain of spiritual care for people with an intellectual disability.

The interview guide will be developed based on the themes, concepts and theoretical gaps identified in the literature review, namely the nature of spiritual care for people with an intellectual disability, the complexity of verbal communication, the role of physical touch in spiritual care, and challenges that spiritual caregivers face in their practice. The interview guide will be designed to be open-ended, allowing for flexibility and responsiveness to the unique experiences and perspectives of each participant. The use of open questions should provide participants the opportunity to freely express their thoughts, feelings, and insights on the role of physical touch in their practice. The semi-structured nature of the interview guide aims to bring balance between predefined key topics surrounding physical touch, and the emergence of unexpected themes, hoping to ensure a comprehensive exploration of physical touch in spiritual care.

In conducting the analysis for this study, a cross-analysis approach will be employed, involving the examination and comparison of data obtained from four semi-structured interviews. The purpose of this method is to discern commonalities, divergences, and patterns across participants' responses, and previously written literature. A system of intuitive, open coding will be employed to identify overarching themes and patterns within each interview. Following this phase, themes and patterns from each interview will be systematically compared and contrasted with one another, and with insights gained in the literature review.

1.1.3. Ethical Considerations

Prior to participating in this study, all participants will be provided with clear and comprehensive information about the research objectives and procedures. Informed consent will be obtained from each participant, ensuring their voluntary and informed participation in the study. Participants will have the opportunity to ask questions and withdraw their consent at any time without consequences. Anonymity of all participants will be ensured. To protect the identities of individuals involved, personal information, including names and identifying details, will be replaced with unique identifiers or pseudonyms during data collection and analysis. Any potential identifying information inadvertently disclosed during interviews will also be removed or altered to preserve anonymity. Data collected, including interview transcripts and survey responses, will be stored in a password-protected and encrypted format. All research data will be securely stored on Radboud University servers.

These servers adhere to robust data security protocols and are subject to stringent access controls.

1.1.4. Summary

A mixed-methods approach, consisting of a literature review and qualitative research, fits best with the research question of this thesis. The literature review serves as a foundational step, critically assessing existing knowledge on physical touch in spiritual care to identify both the current status of the field, and gaps that invite further research. It helps to establish a theoretical framework, inspiring the focus points of the qualitative research phase.

Interviews are essential to complement the literature by capturing nuanced perspectives and lived experiences of spiritual caregivers who work with people with an intellectual disability. These interviews delve into personal motivations, cultural influences, and ethical considerations, providing a deeper understanding of the complexities surrounding physical touch in spiritual care. The qualitative data also enriches the interpretation of the literature review, aiming for an enriched and nuanced analysis. By combining these methods, the study aims to offer a multi-dimensional perspective by bridging theoretical insights from the literature with the lived realities of spiritual caregivers. This hopefully enhances our understanding of the role of physical touch in spiritual care for people with an intellectual disability.

1.2. On the term ‘Disability’

Before I discuss the findings of the literary review, I need to address the concept of 'disability' itself. 'Disability' after all, is by no means a clear concept, but rather one that is politically, morally, historically and culturally infused with a wide array of meanings. The concept is by no means a 'neutral' concept, which is why I need to be specific what its meaning and limitations are with respect to this research

1.2.1. Historical developments

The word ‘disability’ originates in the 1570s, meaning the “want of power, strength, or ability”. In the 1640s, the word also carried the meaning “incapacity in the eyes of the law”⁹. We therefore see that, historically, impairments of people who were labelled ‘disabled’ have been explained in terms of divine punishment, karma, or moral failing, and, post-Enlightenment, in terms of biological deficit. Even though these

⁹ “disability (n.),” Etymology of disability by etymonline, accessed on December 10, 2023, [https://www.etymonline.com/word/disability#:~:text=disability%20\(n.\),Related%3A%20Disabilities](https://www.etymonline.com/word/disability#:~:text=disability%20(n.),Related%3A%20Disabilities)

explanations have shifted from spiritual and/or religious in nature to ‘biological’ and medical in nature, they share the position that a disability is an individual ‘problem’. These explanations have resulted in a contemporary account of disability that is medicalised and individualistic: disability is a medical condition and an individual deficit that has to be cured.¹⁰ In the 1960s, a global movement arose, started by disabled people, in protests against this medicalisation of disability. This movement followed the same trajectory of previous movements: the Civil Rights movement, the women’s movement, and the lesbian and gay liberation movement.¹¹ People within this movement advocated for a different point of view on disability. Instead of perceiving disability as an individual medical problem that needed to be solved, activists argued that disability was something imposed on top of people’s impairments by the way people were unnecessarily isolated and excluded from society. They stated that disabled people were an oppressed group. This movement gave rise to the field of Disability Studies. Early scholarship in this field distinguishes the medical model of disability, which locates physical and mental impairments in individual bodies, from the social model, which identifies disability as a culturally and historically specific phenomenon. Additionally, the social model distinguishes between disabled people as an oppressed group and the non-disabled people that are the causes or contributors to that oppression.¹² One of the central notions in the social model is the difference between impairment and disability: “Impairment is the deficit of body or mind; disability is the social oppression and exclusion. The disability movement focused on de-naturalising forms of social oppression, demonstrating that what was believed to be biological and unchanging was actually a product of specific ways of thinking and responding to people with impairments.”¹³ Over the last few decades, the field has expanded to include individuals with a wide range of disabilities—not just physical conditions, but also mental and chronic ones.¹⁴ This is a very sparse overview of a complex and multi-faceted historical and contemporary movement and academic discipline. In this thesis, I cannot do justice to the important work pioneers in the global disabled people’s movement and in Disability Studies have done. As disability scholars have shown, disability is a multi-dimensional concept. There are many ways to be disabled. A disability affects people in different ways and to a greater or lesser extent, and the meaning of both disability and impairment change over time and place.

¹⁰ Tom Shakespeare, “The social model of disability,” in *The Disability Studies Reader*, ed. Lennard J. Davis (New York: Routledge, 2017), 195.

¹¹ Tom Shakespeare, *Disability: the basics* (London: Routledge, 2018), 12.

¹² Shakespeare, “The social model of disability,” 195.

¹³ Shakespeare, *Disability: the basics*, 13.

¹⁴ “Disability Studies: Foundations & Key Concepts,” Jstor Daily. Disability Studies: Foundations & Key Concepts, accessed on December 10, 2023, <https://daily.jstor.org/reading-list-disability-studies/>

1.2.2. Spiritual care for people with an ‘intellectual disability’

This thesis centres around people with an ‘intellectual disability’. The term is put between quotation marks because it immediately falls short: in practice it does not describe a homogenous group of people with an intellectual disability. An estimated fifteen percent of the global population is disabled in some way, which means there are at least a billion people with a form of disability on the planet.¹⁵ This is such a large number of people that it is impossible to say anything about them *as a ‘group’*. Additionally, the range of impairments is vast. Examples of impairments are visual impairments, auditory impairments, autism spectrum disorder, psychiatric symptoms, Down syndrome and developmental challenges. Since this is the case, it’s also impossible to formulate a ‘universal’ answer to the research question of this thesis. It is also unwanted to adopt a universalist approach because the nature of people’s impairments and the degree in which they experience themselves as disabled differs. Therefore, I hope to explore the ways in which physical touch can be a tool in spiritual care for people with an intellectual disability, and how to do justice to their own, *unique* preferences and needs. When I refer to the description ‘people with an intellectual disability’ in this thesis, I specifically refer to people who live in organised health care units based on their impairments, and have access to spiritual care. I’m aware that this categorization doesn’t always do justice to the multi-dimensionality of disability, and doesn’t take clients’ own perspective on their impairments and disability into consideration. Within these constraints, I hope to do justice to the sensitivity of this topic, while simultaneously knowing that this approach doesn’t solve the issue completely.

¹⁵ Shakespeare, *Disability: the basics*, 1.

Chapter 2. Literature review

This chapter provides an overview of the theoretical underpinnings, historical development, and contemporary perspectives on the use of physical touch in spiritual care in general, and, specifically, in the context of spiritual care for people with an intellectual disability. This chapter is divided into four sections. Firstly, I describe how the use of physical touch in spiritual care has been explored and defined within existing literature. Secondly, I delve into the motivations and intentions behind using physical touch in spiritual care practices. Thirdly, I put into frame existing criteria and guidelines for determining when and how physical touch should be employed in spiritual care. Combining the insights from the first three sections, the final part of this chapter indicates current gaps and areas of contention in academic and professional literature on physical touch in spiritual care. As such, it provides the basis for the third chapter, in which I explore the ways in which spiritual caregivers work with physical touch in their everyday practice.

2.1. Physical touch in spiritual care: its history and current developments

2.1.1. A short overview of the current field

The use of physical touch as a tool in spiritual care is increasingly becoming a topic of discussion. This discussion finds itself in a larger debate on the role of the body in spiritual care. For instance, spiritual caretakers write on embodied meaning-making,¹⁶ or the spiritual and/or religious meaning of the body.¹⁷ Others are known to look at body-oriented practices, such as haptonomy, gestalt therapy, yoga, dance or art therapy for inspiration for their own practice.¹⁸ Even the VGVZ showed interest in the topic

¹⁶ Isene et al., “Embodied Meaning-Making in the Experiences and Behaviours of Persons with Dementia,” *Dementia* 21, no. 2 (September 16, 2021): 442–56. <https://doi.org/10.1177/14713012211042979>; Captari et al., “Embodied Spirituality Following Disaster: Exploring Intersections of Religious and Place Attachment in Resilience and Meaning-Making,” *Springer eBooks*, 49–79, 2019 https://doi.org/10.1007/978-3-030-28848-8_4; Ryu and Price, “Embodied Storytelling and Meaning-Making at the End of Life: Voicing Han Avatar Life-Review for Palliative Care in Cancer Patients,” *Arts & Health* 14, no. 3 (June 23, 2021): 326–40. <https://doi.org/10.1080/17533015.2021.1942939>; Sietke Vandebriel, “Zingeving in meer dan alleen woorden,” Master thesis., Universiteit van Humanistiek, 2023; Corine Westerink, “Belichaamde zingeving bij pelgrimage,” Master thesis., Universiteit van Humanistiek, 2019.

¹⁷ Herman Coenen, “Lichamelijkheid in de geestelijke verzorging,” *Nieuw Handboek Geestelijke Verzorging*, ed. Jaap Doolaard (Kampen: Uitgeverij Kok, 2015), 909–915; Goedele van Edom, *Lichaam en levensadem. Pastorale zorg voor de hele mens* (Antwerpen: Halewijn, 2010); Ruud Ganzevoort, “De zin van het geschonden lichaam,” *Gereformeerd Theologisch Tijdschrift* 97, no. 4 (1997): 168–177; Eline Verbruggen, “Met aandacht en mildheid luisteren naar wat je lichaam je vertelt,” *Waardenwerk* 82–82 (December 2020): 183–195.

¹⁸ Schoenmakers and Leget, “Aanraken in de geestelijke verzorging,” 10–19; Verbruggen, “Aandacht,”; Vandebriel, “Zingeving,”; Elze Riemer, “Theologie en dans zijn niet twee verschillende werelden,” *Volzin*, November 10, 2022; Beurmanjer, “Betekenisvol lichaam,”; Gerarda van Moerik, “Het luistert nauw. Onderzoek naar aanraking in het pastoraat en de mogelijke bijdrage van haptonomie daaraan,” Master thesis., Tilburg University, 2018.

by organising a symposium on embodied spiritual care.¹⁹ Strikingly, most of the research that highlights the body as essential in the practice of spiritual care is produced at the University of Humanistics in Utrecht. Even more interesting is the fact that a substantial part of the research is the result of master's theses of students, presumably indicating that contemporary students increasingly value literature on the topic.

However, even though literature on the role of the body in spiritual care is abundant, literature on the use of physical touch in spiritual care is much slimmer. In the Netherlands, the main body of work on this topic is written by humanistic spiritual caregiver Marieke Schoenmakers and health care ethicist and theologian Axel Liégeois. Other authors are sociologist and humanist Herman Coenen, theologian Christoph Schneider Harpprecht and moral theologian Mariéle Wulf. In the few available articles and books on physical touch in spiritual care, Axel Liégeois was the first to develop a professional framework to ethically reflect on the use of physical touch in spiritual care.²⁰ His work has been foundational to multiple contemporary authors who focus on this topic, such as Marieke Schoenmakers²¹. The incentive of his research is rooted in the everyday practice of spiritual caregivers. In their practice, they noticed the benefits of physical touch and intuitively use it sometimes, but are unsure on how to professionally do this. Liégeois' aim is to offer a framework for ethical reflection on the use of physical touch in the practice of spiritual care. In this framework, he investigates when physical touch can be beneficial, and when the use of physical touch is irresponsible and possibly dangerous. He hopes to contribute to reducing uncertainty of action of spiritual caregivers and to offer points of reflection that help develop individual practices.²² Marieke Schoenmakers' work is inspired by the writing of Liégeois. She is currently the most prominent thinker on physical touch in spiritual care. Her work originated in the same way as Liégeois': based on her own professional experience. While working with people with dementia, she questioned the role physical touch should, or should not, have in her practice: "Whom do I touch? When do I touch? And for what purpose?"²³ Importantly, she emphasised that many spiritual caretakers touch spontaneously and intuitively, without a clear vision on which their touching is founded. She did an in-depth literature review on the topic and remarks that the body of literature she found, was found after an intensive search, "with some difficulty"²⁴ and that "a lack of a clear vision seems to be widespread

¹⁹ "Werkveld Psychiatrie: Dichter bij het lichaam "Studiedag over lichamelijkheid en geestelijke verzorging", VGVZ Agenda, accessed on September 30, 2023, <https://vgvz.nl/evenement/dichter-bij-het-lichaam-studiedag-over-lichamelijkheid-en-geestelijke-verzorging/>

²⁰ Axel Liégeois, "Een ethiek van de lichamelijke aanrakingen tijdens de pastorale begeleiding," *Lichaam en levensadem. Pastorale zorg voor de hele mens*, ed. Goedele van Edom (Antwerpen: Halewijn, 2010), 91-106.

²¹ Schoenmakers and Leget, "Aanraken".

²² Liégeois, "Ethiek," 91.

²³ Schoenmakers and Leget, "Aanraken," 1.

²⁴ Schoenmakers and Leget, "Aanraken," 13.

among the profession.”²⁵ She found two types of sources: peer supervision reports written by spiritual caregivers reflecting on the use of touch in their individual practice, and academic literature attempting to provide a theoretical foundation for the use of touch in spiritual care. In this second category, she mentions the work of Liégeois as central to theoretical developments on physical touch in spiritual care.²⁶

2.1.2. The definition of physical touch in the context of spiritual care

Liégeois distinguishes between a broad and a narrow definition of touching. The broad definition is as follows: “Any contact between two individuals in which a part of one person's body comes into contact with a part of the other person's body.”²⁷ This definition encompasses the entire range of touch, from accidental, unintentional touches to sexual, intimate touches. The narrow definition, then, does not include sexual touches. These touches are considered both inappropriate and unwanted from both ethical and professional perspectives. In the narrow definition, physical touch is understood as *any bodily contact that is unrelated to the expression or fulfilment of a sexual desire*. Liégeois does acknowledge that emotional and psychological circumstances may make it difficult to distinguish physical and sexual touches from each other.

Within the boundaries of this narrow definition, Liégeois makes a distinction between three possible types of touch between conversation partner and spiritual caregiver. Firstly, he mentions *accidental*, unintentional touch, that for example can occur while handing an object. Although this touch is not intended to convey a message, it can still be perceived as meaningful by the conversation partner. *Expressive touch* (intended and brief), has the purpose of communicating something, for example affection or encouragement, for example holding someone's hand or giving a pat on the shoulder. The third category contains purposeful *supportive* touches, expressing safety and protection in the face of unpleasant or confrontational experiences. Holding or embracing the conversation partner is an example of this.²⁸ These three categorisations clearly illustrate that the intensity, intentionality and context of the touch are significant factors to take into account. Both the conversation partner and spiritual caregiver can attribute meaning to touch. This highlights the complexity of using touch to communicate.

Schoenmakers formulates a definition similar to the narrow definition of touch, after comparing the available literature on the topic. She defines touch within the context of

²⁵ Schoenmakers and Leget, “Aanraken,” 14.

²⁶ Schoenmakers and Leget, “Aanraken,” 14.

²⁷ Liégeois, “Ethiek,” 92.

²⁸ Liégeois, “Ethiek,” 93.

spiritual care as “physical, non-necessary contact that is not focused on sexuality, with the purpose of meeting the other, through which they are strengthened, supported, and affirmed.”²⁹ This definition will be used throughout the rest of this thesis, because it defines physical touch within the context of spiritual care, and encompasses its possible benefits.

2.2. Benefits of physical touch in spiritual care

There are multiple benefits attributed to physical touch in spiritual care, by spiritual caregivers, pedagogues and haptonomic therapists. Physical touch is an integral contributor to mental and physical health, it is an alternative to verbal communication, it can deepen the process of meaning-making, and it can offer solace and be a pathway to spirituality. This section engages with each benefit separately.

2.2.1. Physical touch contributes to mental and physical health

The sense of touch is the first sense to develop, and as the external sensory organ, the skin is also the largest sense organ we possess. Studies from the beginning of the last century have shown that babies who are not touched face serious risks, such as stunted growth or development.³⁰ For a baby, not being touched can even mean death. The attachment theory of the English psychiatrist John Bowlby highlights the importance of touch in the emotional development of children. According to Bowlby, secure attachment is the foundation for healthy emotional development. Secure attachment occurs when parents or caregivers sensitively and responsively respond to the signals emitted by the young child.³¹ As a result, the child will feel safe and learn to trust their caregivers, establishing a foundation for their own identity and relationships with others.³² Touch also plays a significant role for adults. Research into the impact of touch on the health of AIDS, rheumatoid arthritis, cancer, and diabetes patients has shown that touch strengthens the immune system and reduces pain. The influence of touch in conveying emotions is demonstrated in the research conducted by Hertenstein et al.³³ Therefore, touch is of essential importance for both physical and psychological health for everyone, regardless of age. The appreciation and interpretation of touch varies greatly among individuals and is influenced by social and cultural factors.³⁴ Regardless, it is not exaggerated to state that touch should be part of good healthcare.

²⁹ Schoenmakers and Leget, “Aanraken,” 14.

³⁰ Marijke Sluijter, *Aanraken: een levensbehoefte. Aanraakspel in kinderopvang en school* (Amsterdam, SWP, 2017), 19.

³¹ L. Tavecchio en R. van IJzendoorn, “Niet alle banden binden even vast. De gehechtheidstheorie van John Bowlby,” *Psychologie* no 3, 11(1984): 22.

³² Gerarda van Moerik, “Het luistert nauw,” 22.

³³ Matthew J. Hertenstein et al., “Touch Communicates Distinct Emotions,” *Emotion* 6, no. 3 (January 1, 2006): 528–33, <https://doi.org/10.1037/1528-3542.6.3.528>.

³⁴ Gerarda van Moerik, “Het luistert nauw,” 22.

In the context of research on care for people with an intellectual disability, physical touch also seems to be an element that should not be underestimated. This reasoning is grounded in developmental psychology and has been extensively described by pedagogue and psychologist Dorothea Timmers-Huigens. Her work on the ways in which people are able to structure experiences has been foundational for developing a practice of care for people with an intellectual disability, specifically focused on the fact that each person has a unique set of needs and ways to communicate and express themselves. Timmers-Huigens' theory is based on the idea that people structure experiences in different ways. All experience that comes to a person through sensory processing is somehow processed in an organising way. People use an organisational system for this, which Timmers-Huigens calls *the structuring of experiences*: a way of structuring sensations and experiences in which feelings, emotions, relationships and existence influence cognitive understanding.³⁵ Experiences are therefore understood as resulting from connecting all sorts of relevant information and impressions from the environment to the self, which are then made into a coherent 'experience'³⁶.

Embodied structuring of experiences is one way to structure experiences and is often the dominant way in which people with an intellectual disability structure their experiences. This way of structuring experiences is focused on providing information about the safety of one's physical existence.³⁷ When the body is not experienced as safe, it will require more and more attention and embodied experience structuring becomes the dominant way. People with an intellectual disability often experience physical discomfort. This can lower the feeling of reliability and safety of one's own body. The more serious the physical dysfunction, the faster and the more frequently embodied experience structuring will become dominant. The fact that there are people with an intellectual disability who, as a result of their serious physical problems (often multiple complex disorders), are always closely connected to their physicality, means that some people experience embodied experience ordering as permanently dominant.

For these people, the body becomes *the* important source of information. Those who predominantly order reality like this, give meaning to situations and events in reality in an embodied way. Anyone who primarily uses embodied experience ordering, can't connect to people they cannot physically perceive. It also means that a response to a

³⁵ Dorothea Timmers-Huigens, *Ervaringsordening Mogelijkheden voor mensen met een verstandelijke handicap* (Maarssen: Elsevier Gezondheidszorg, 2005), 85.

³⁶ Timmers-Huigens, *Ervaringsordening*, 86.

³⁷ Timmers-Huigens describes four ways in which experiences are structured: 1) embodied experience structuring, which provides information about the safety of one's physical existence; 2) associative experience structuring, which provides information about the reliability of concrete and momentary reality; 3) structural experience structuring, which provides information about the coherence of events and episodes; and 4) formative experience structuring, which provides information about the individuality of the self and the extent to which one can be oneself. These ways of structuring experiences are always present and work simultaneously, instead of successively.

situation or event has to be a physical response. This asks for communication that does justice to this way of ordering experiences, having to find ways to recognize and respond to this embodied experience ordering dominance. Timmers-Huigens states that this often requires great empathy and a lot of inventiveness from parents, caregivers, teachers and supervisors.³⁸ In this context, physical touch is seen as one of the best ways for embodied communication.³⁹ Timmers-Huigens doesn't address spiritual care in her work. But since her theory talks about the foundational way in which people experience the world, spiritual care has to function within this framework. In a chapter of the Handbook of Spiritual Care on working with people with an intellectual disability, a similar approach is mentioned:

Every client has their own possibilities and limitations in voicing their needs. Often, spiritual caregivers have to rely to a certain degree on non-verbal communication, and are expected to have a broad repertoire in order to help clients in their meaning-making process.⁴⁰

Taking these works into account, it is surprising that physical touch in spiritual care has so far received little attention. In section 3.2.3, I address possible reasons for this absence.

2.2.2. Physical touch is an alternative to verbal communication

In certain situations of grief, anger or sadness, verbal communication is known to fall short in conveying the depth of empathy and comfort spiritual caregivers seek to express. Sometimes, especially in times of distress, physical presence and touch can be beneficial, offering a unique dimension of closeness, solace and connection that words cannot always replicate.⁴¹ Schoenmakers compares multiple peer supervision reports on physical touch written by spiritual caregivers and concludes that touch is used to express closeness, especially in situations when suffering is “too big to comprehend.”⁴² Touch can give a unique access to the experience of suffering, allowing this suffering to be transcended and put into perspective.⁴³ This can be partly linked back to the important role of physical touch in developmental psychology, as

³⁸ Timmers-Huigens, *Ervaringsordening*, 104.

³⁹ Timmers-Huigens, *Ervaringsordening*, 106.

⁴⁰ Werner van de Wouw, “Levensbeschouwelijke diagnostiek” *Nieuw Handboek Geestelijke Verzorging*, ed. Jaap Doolgaard (Kampen: Uitgeverij Kok, 2015), 597.

⁴¹ Liégeois, “Ethiek,” 91.

⁴² Schoenmakers and Leget, “Aanraken,” 14.

⁴³ Gaining direct access to this text was not possible. These quotes are found through the master thesis of Gerarda C. van Mourik: “Het luistert nauw,” published by Tilburg University in 2018.

described in section 2.2.1. Gestures such as embraces, holding and touching through hands, can be understood as signs of care, physical closeness, security and safety.⁴⁴

Because physical touch is a way to express closeness, solace and connection, it does not seem to be something that happens only in exceptional cases, but in fact belongs at the heart of spiritual care; providing closeness, solace and connection has traditionally been a central task of spiritual caregivers.⁴⁵ Sometimes, spiritual caregivers also use physical touch when their conversation partners can't speak.⁴⁶

2.2.3. Physical touch can deepen the process of meaning-making

According to Liégeois, physical touch can contribute to empowering the conversation partner, and to clarifying or deepening that person's meaning-making journey.⁴⁷ Often, physical touch does not directly contribute to meaning-making, but its strength lies in supporting and strengthening it. By using physical touch, the spiritual caregiver offers something, such as solace, strength, empathy, warmth, understanding, that can help the conversation partner to continue their exploration and meaning-making process. Especially when people get tied up because of the intensity of their feelings and cannot find words to express this, physical touch can help to 'unravel' the tension and continue.

2.2.4. Physical touch is a pathway to spirituality

In certain situations, physical touch can be a way of "giving depth to the soul, releasing it from rigidity and healing it"⁴⁸ and bring body, soul and spirit into harmony with each other. Someone who touches another reaches into an inner space where the other is not only profoundly themselves but also connected with something that transcends them.⁴⁹

⁴⁴ Mariële Wulf, "Jenseits der Haut," *Exploring Boundaries of Bodiliness. Theological and Interdisciplinary approaches to the Human Condition*, ed. S. Müller, G. Marschütz and S. Dlugos (Göttingen: Brill Deutschland, 2013), 136.

⁴⁵ Babet te Winkel & Carmen Schuhmann, "Het lichaam als grond, toegang en 'meer dan' in geestelijke verzorging," *Waardenwerk* 80 (April 2020): 87.

⁴⁶ Schoenmakers and Leget, "Aanraken," 13.

⁴⁷ Liégeois, "Ethiek," 98.

⁴⁸ Wulf, "Jenseits," 129.

⁴⁹ Wulf, "Jenseits," 137; Wulf uses the word 'God', but I choose to use a broader term that is applicable to people from multiple different cultural, religious, spiritual and existential backgrounds.

2.3. Criteria for the use of physical touch in spiritual care

In the small body of literature available, several authors have developed criteria for the use of physical touch in spiritual care. These criteria are based on professional reflective reports of spiritual caregivers, and academic literature attempting to provide a theoretical framework and foundation for the use of physical touch in spiritual care.

In summary, a spiritual caregiver should:

...be able to comprehend the other person's experience. By doing this, one should focus on the nature of the relationship between conversation partner and spiritual caregiver, factors such as age and gender, life story and future expectations, living situation and emotional state, and ethnic and cultural background.⁵⁰

...be sensitive to non-verbal communication. A spiritual caregiver should be sensitive to (bodily) signals and able to read 'between the lines'. This is accomplished by being connected to one's own body, not just to one's own mind. The underlying assumption here is that one is only able to communicate well (non-verbally) when one is in touch with one's own body.⁵¹

...be connected to oneself physically, mentally and spiritually.

This includes being aware of one's own position as a spiritual caretaker, and one's life story that could be of influence.⁵² Physical touch should be used with the *intention* to contribute to empowering the conversation partner, and to *clarifying* or *deepening* that person's meaning-making journey. However, intentions are often ambiguous and can be influenced or determined by many different motivations. Here, the concepts of transference and countertransference originating in one's own life story play an important role. Transference is a general term for conveying feelings and expectations onto others. When transference occurs, the conversation partner (unconsciously) transfers old feelings to the spiritual caregiver. Countertransference, as the term suggests, is the transference in the opposite direction: the spiritual caregiver (unconsciously), in their position as an authority, transfers their own (older) feelings onto the client. Often the (counter)transference of the spiritual caregiver is a reaction to the behaviour of the conversation partner: the spiritual caregiver reacts from their

⁵⁰ Polspoel et. al. "Leren uit ervaring," *Lichaam en levensadem. Pastorale zorg voor de hele mens*, ed. Goedele van Edom (Antwerpen: Halewijn, 2010), 212; Liégeois, "Ethiek", 104.

⁵¹ G Lambrechts. "Lichaam als mogelijkheid tot communicatie," *Met heel mijn lijf. Lichamelijke tussen hebben en zijn*, ed. L. Paeps and M. Robbroeckx (Den Bosch: Altiora, 1994); Andries Baart, *Een theorie van de presentie* (Den Haag: Lemma, 2016); Liégeois, "Ethiek", 104.

⁵² Lambrechts, "Lichaam als mogelijkheid tot communicatie."; Baart, *Presentie*; Liégeois, "Ethiek", 104; Schoenmakers and Leget, "Aanraken," 16.

own old (unconscious) feelings to behaviour of the conversation partner.⁵³

...be aware of the importance of consent from the conversation partner.

The relationship between spiritual caregiver and conversation partner is professional and therefore always asymmetrical. A spiritual caretaker fulfils a specific role and sometimes also holds a religious office. The conversation partner is dependent on the spiritual caretaker and shares vulnerable experiences, which makes this exchange, in this respect, a one-directional relation. This power imbalance is structurally present in the relationship between spiritual caregiver and conversation partner, and should therefore always be considered in the context of physical touch. Therefore, authors recommend to place the decisive criterion for the appropriateness of the touch with the conversation partner.⁵⁴ This is a way to try to avoid overruling the needs of a conversation partner, because of one's own interpretation: "The most important rule in touching is therefore that the initiative to touch has to come from the one being touched, not from the one who wants to touch."⁵⁵

...be aware of the inherent tension of using physical touch in spiritual care.

The use of physical touch in the practice of spiritual care finds itself in the tension between distance and closeness. Closeness in spiritual care has many benefits, such as expressing care and empathy and offering solace. It might even be described as vital to good spiritual care. However, being close to another person demands a careful approach, because of the risks involved. For example, in consoling a grieving person through a comforting touch, closeness is a strength, embodying empathy and solace. But when this touch lingers too long, it risks transgressing personal and professional boundaries. In spiritual care, navigating this balance means understanding that a hand on a shoulder can convey both comfort and discomfort. The spiritual caregiver must discern the moment when the strength of closeness risks becoming a pitfall, trying to hold space for individual sensitivities and cultural considerations.⁵⁶

2.4. Current gaps and contentions

This section addresses current gaps and contentions within the academic and professional literature on physical touch in spiritual care. While delving into the existing body of work, it becomes evident that while significant strides have been made on the role of physical touch in spiritual care, there remain notable gaps and

⁵³ Fee van Delft, *Overdracht en tegenoverdracht. Een therapeutisch fenomeen vertaald naar alledaagse psychosociale begeleiding* (Amsterdam: Boom Lemma, 2015), 15.

⁵⁴ Liégeois, "Ethiek," 102.

⁵⁵ Wulf, "Jenseits," 137.

⁵⁶ Liégeois, "Ethiek," 96.

areas of contention. These will be addressed one by one.

2.4.1. Strong focus on possible negative outcomes

Most literature described in the previous section emphasises the value of physical touch in spiritual care, but stresses, at the same time, the importance of caution. For example, most of the criteria described in section 2.3 focus on minimising the possible damage physical touch can do, instead of exploring how to increase the value of physical touch. To be sure, it is important to do justice to the delicate nature of physical touch, and be aware of what its possible negative effects could be. However, by *solely* focusing on the constraints, the literature fails to properly develop physical touch as part of spiritual care. This is a significant lack, as this literary review also clearly demonstrates the unique value to physical touch.

The aforementioned research is still based on the assumption that the use of touch could be beneficial in the practice of a spiritual caregiver, while simultaneously addressing possible risks. A clear example, unfortunately, is the practice of spiritual caregiving itself. Importantly, the idea that physical touch could be beneficial is not a widely shared viewpoint. The professional standard for spiritual caregivers, as developed by the VGVZ, states that “the spiritual caregiver shall not physically touch the client with sexual or erotic intentions, nor in a way that could be perceived as bearing sexual or erotic intentions. The spiritual caregiver shall not respond to sexual advances by the client.”⁵⁷ This is the only mention of the use of physical touch in spiritual care in the professional standard. There is no mention of how physical touch can be beneficial in spiritual care.

2.4.2. Non-verbal spiritual care

Spiritual care is often offered through a verbal exchange between spiritual caregiver and client. When it comes to spiritual care for people with an intellectual disability, this can cause challenges. Some clients are not able to express themselves verbally, or understand others. This raises questions on the shortcomings of verbal communication in spiritual care for people with an intellectual disability. These shortcomings are mentioned in literature on spiritual care for people with an intellectual disability, but are only mentioned once in literature on physical touch in spiritual care for people with an intellectual disability. This leaves questions unanswered about how physical touch can be a non-verbal way to communicate and offer spiritual care. Physical touch as part of an encompassing repertoire of communicative tools in spiritual care is therefore one of the central themes to be explored during the qualitative phase of this

⁵⁷ VGVZ, “Professional Standard”.

thesis. In the words of sociologist and humanist Herman Coenen: “How do spiritual caregivers deal with the body in a way that contributes to the task and role they are assigned to, namely to provide spiritual care to each client?”⁵⁸ The lack of literature on non-verbal spiritual care might be rooted in a cognitive-dominant field of work, where the spiritual is most often associated with a verbal or written formula. Spiritual care, then, becomes a transmission of that formula, the utterance of words containing the message's meaning. In this situation, the bodily aspect of spiritual care becomes nothing more than arranging a physical space where a conversation can take place. However, even if we prioritise the word, we will encounter the body at its centre repeatedly: speaking is a physical activity. To Coenen, the physical is not merely packaging for the words; it is the word we speak or write. The body is therefore not an incidental characteristic of spiritual care: it is not merely the non-verbal accompaniment to the 'essential' that should unfold in the spoken word. This point of view is crucial to take into consideration when researching the value of physical touch in spiritual care for people with an intellectual disability. It also ties in with Schoenmakers vision on spiritual care that focuses on body, mind and spirit.⁵⁹

In the next section of this thesis, I will conduct interviews with spiritual caregivers who work with people with an intellectual disability, to explore how they use touch in their practice.

⁵⁸ Coenen, “Lichamelijkheid in de geestelijke verzorging,” 910.

⁵⁹ Schoenmakers and Leget, “Aanraken,” 19.

Chapter 3. Qualitative research

This chapter explores the ways in which spiritual caretakers have developed and incorporated the use of physical touch in their practice without the guidance of an established theoretical, practical or legal framework.

3.1. Participant selection and inclusion

I asked four spiritual caregivers about their ideas on the role of physical touch in their practice working with people with an intellectual disability. Two of them identified as men, and the other two identified as women. One of them had less than a year's worth of experience in working with people with an intellectual disability. The other three have been working in this field for over ten years. Three of them have an educational background in pastoral care and one of them in Humanistics. They have all been approached through my professional network of spiritual caregivers who work with people with an intellectual disability. Their contributions to this thesis have been anonymised through the use of pseudonyms. The interviewees will be addressed by the names Dean, Marthe, Lily and James.

Even though none of the participants were previously acquainted with me, our conversations were influenced by the fact that we are 'colleagues': we work in the same field and roughly the same region of the Netherlands. This resulted in colloquial interviews. The topics we discussed were often illustrated by descriptions of individual clients. Sometimes, the participants would ask about my personal point of view, or would ask or assume that I recognize certain situations they described in my own practice. This familiarity contributed to a certain level of trust, understanding and safety during the conversation. However, even though we shared a certain professional familiarity, our expertise differed. The fact that I'm new to this profession brought a specific dynamic to the conversations. One participant explicitly mentioned that she enjoyed the idea of 'passing on' knowledge to a colleague who is just getting started. Another participant wanted to convey the passion he felt about his job to me and wished for me to experience the same in my own practice.

On some occasions the participants explicitly asked me for my point of view. In these instances I have shared some concrete situations from my own practice. This, of course, steered our conversation in a certain direction, but I have been conscientious about what I shared, as I was aware of the effects it could have on the conversation. In two interviews I mentioned which concrete situation at work inspired me to research physical touch in spiritual care for people with an intellectual disability. In one interview, my personal views on the value of physical touch aligned with those of

my participant. At the end of this interview, I therefore expressed these views as a reaction to her input. During two interviews, I voiced my concern about our professions' focus on verbal communication, while so many people are verbally challenged as input for the conversation. Even though I did express some of my personal thoughts on the subject, I tried to phrase them as questions, rather than statements. In this way, I hope they functioned as stimulating thoughts, rather than me trying to enforce my personal opinions. Looking back, I don't think that the way we conversed prevented my participants from expressing their own point of view. Of course, thoughts and opinions that are expressed during a conversation always inspire and direct this conversation in a certain way.

It is important to bear in mind that this qualitative research is exploratory in nature, meaning that the opinions expressed below are not representative of the profession of spiritual care as a whole. These interviews help to map views on the role of physical touch in the practice of spiritual caregivers who work with people with an intellectual disability. These insights are a contribution towards developing a sound body of academic literature on physical touch in spiritual care, and spiritual care for people with an intellectual disability.

3.2. Interview insights

In this thesis I address two main questions: How can physical touch be a professional tool for spiritual caretakers who work with people with an intellectual disability? And why has physical touch so far been neglected as a competence of spiritual caregivers? I consider both questions in this section of my thesis. There are three key points that came up during the interviews. Firstly, that physical touch offers something unique when words fall short. Secondly, that consent is a complex topic. Thirdly, that physical touch should/could be part of a repertoire of embodied competencies of a spiritual caregiver. I'll address each point separately.

3.2.1. Physical touch is a unique way to offer spiritual care when words fall short

All participants agree that physical touch can have multiple possible beneficial effects in their practice. The types of touch that express solace, comfort, warmth and being close, present and attentive can result in someone feeling seen, heard and supported. Dean says that he thinks every person sometimes needs a comforting touch: "At times when you're very deep in your grief, you often want to have someone nearby to embrace you for a moment. Why would that not be possible in healthcare?" Martha agrees on the importance of touching to comfort or offer solace, but mentions that she often sees that colleagues solely engage in 'functional touching', like washing,

carrying and lifting: “This type of touching is not wrong per se, but it is kind of like Senseo coffee: not very enjoyable. I sometimes think we also need to provide another type of touch.” The type of touch she alludes to, can also be described as functional, but the function it carries is different. Emphatically touching people to express closeness differs from practically oriented touching precisely in the results of the touch. In the latter, the result is also practical: someone is washed or transported. But in the former, physical touch can result in someone feeling physically and mentally supported and guided.

Physical touch is also of value when words fail to do justice to the gravity of the situation. Dean says the following:

You can say you are there for somebody, but they gain nothing from that. It's mainly about showing closeness and presence, demonstrating it. Touch is very functional in this regard. I hold your hand; you are not alone. Especially when people are in their final hours. In these moments, you don't say anything because there is nothing to say. I just hold someone's hand and convey the feeling that they are not alone. But I also want to convey that feeling in other situations: I am here for you. In situations where words fall short, we don't have much else.

This point of view aligns with the works of Liégeois and Schoenmakers, who both highlight how physical touch expresses closeness, solace and connection in a way that words cannot always express, or when suffering is too big to comprehend. The types of physical touch that are used in situations like these are in accordance with the two types of touch Liégeois describes. Expressive touches, which are intended but brief, in order to communicate something, and purposeful supportive touch, with the aim of providing support, and expressing safety and protection in the face of unpleasant or confrontational experiences.⁶⁰

Aside from stating that their clients find comfort and solace in being touched, two participants emphasise the need for physical touch is *necessary*. James describes how he sees this need in his clients:

In the presence of apparent physical distress, I often discern an underlying existential or spiritual dimension. Utilising physical touch in such moments, especially when people are in pain, holds the potential to provide solace. It becomes a means of acknowledgment, a way of truly 'seeing' and connecting with their inner struggles.

⁶⁰ Liégeois, “Ethiek”, 93.

Martha sees a similar need in her clients. She additionally describes how touch is a primary need for people:

When people go without physical touch for a while, complications may arise. Studies show that kids who miss out on physical touch are more likely to get sick. It's like a basic need for our bodies. And for some clients we work with, getting that physical touch is of vital importance.

By looking at the value of and need for physical touch in spiritual care from a developmental psychologist perspective, Marthe joins Timmers-Huigens, Schoenmakers and Wulf in their work on why physical touch is an element of (spiritual) care that should not be underestimated.

The insights offered above are all related to the role physical touch has in offering *good spiritual care*. Dean explicitly states that “there are plenty of times when physical touch is an integral part of offering good care.” We have seen this in the multiple beneficial and sometimes even necessary effects of the use of physical touch. Another element of offering good spiritual care, specifically for people with an intellectual disability, is offering *tailored* spiritual care. All participants mention how broad their field of work is. Each client is different, and in turn, what makes spiritual care ‘good’ for one client, does not always hold up for other clients. Lily describes how she has to adjust her practice everyday:

In this field, unlike other fields with more predictable routines, every interaction is unique due to the diverse combinations of physical and intellectual disabilities among my clients, as well as the varied contexts in which they live. When meeting a new client, I continually ask myself: how can we communicate effectively, and if we can, how can I provide meaningful support?

James expresses a similar perspective when he says that he needs a considerable repertoire of communication and meaning-making tools: “This group of people is so diverse. With each new contact, you have to figure out that repertoire all over again.” This means that for every client, spiritual caregivers have to discover how to communicate. One needs to take into consideration that these caretakers work with clients for whom verbal communication is challenging. The meaning of physical touch thus acquires a wholly different significance in this field. Next to expressive and supportive touch, which can still be understood as a benefit for all potential clients, physical touch becomes a *communicative tool* for people with an intellectual disability specifically. All participants confirm that for them, physical touch is an intrinsic element of communicating with people for whom verbal communication is difficult or

impossible. Referring back to the work of Dorothea Timmers-Huigens,⁶¹ for clients who order their experience solely through embodied structuring, physical touch is one of the most important ways to communicate.

The meaning of ‘when words fail’ encompasses multiple layers. Beyond situations where words fall short in capturing profound emotions like sadness, joy, or anger, it extends to instances where clients cannot communicate through verbal expression altogether. In such cases, physical touch is used as the primary mode of communication. This transforms the value and importance of physical touch. If physical touch is one of the ways to offer spiritual care, it is still part of a broader repertoire of a spiritual caregiver, next to for example verbal conversation or rituals. If this is the case, physical touch can be used expressively, with the purpose of communicating something, for example attentiveness, or supportively, with the purpose of providing support, and expressing safety and protection in the face of unpleasant or confrontational experiences.⁶² It is an alternative to other forms of spiritual care, or is integrated by for example holding someone’s hand during a conversation. However, if there is no other way to offer spiritual care than through physical touch, physical touch becomes not just *a* tool, but *the only* tool. Physical touch, then, is central to developing a good practice of spiritual care for people with an intellectual disability.

Despite physical touch being a unique and sometimes necessary aspect of good spiritual care, there are certain conditions that must be met. In the literature review, I summarised the main criteria for the use of physical touch in spiritual care that are currently available in professional literature. Each participant directly or indirectly mentioned corresponding criteria. The most frequently mentioned criterion is the *importance of knowing a client as well as one can, in order to estimate if physical touch is fitting*. An important element of this is having a *trustworthy relationship*. Dean describes how he truly developed deep connections with individuals in this work:

I know people whom I've known for 10 years. In such relationships, the way you interact is very different compared to a hospital setting, where you might see someone briefly, or encounter different people who come and go quickly. You don't form strong bonds with people in that context. In such situations, you are not as inclined to make physical contact; there really needs to be a foundation of trust to either initiate or accept physical touch.

⁶¹ Timmers-Huigens, *Ervaringsordening*, 106.

⁶² Liégeois, “Ethiek”, 93.

Another key criterion is the importance of knowing one's own boundaries regarding physical touch. Marthe called this *knowing one's own biography' surrounding physical touch*: "You should know what physical touch, and the lack of it, means to you personally." Iris has a similar point of view on this: "I believe you must know very well what belongs to yourself and what belongs to the other person. You need to have your own thoughts and feelings in order." This topic touches on which competences a spiritual caregiver needs in order to do one's job well (Section 3.2.3. further elaborates on this topic).

A third element regarding the use of physical touch is *taking the asymmetrical relationship between a client and a spiritual caregiver into account*. This power imbalance is present in every professional relationship a spiritual caregiver has, and asks for self-awareness and sometimes also caution. Lily says:

People often live in these facilities their whole life. They are always here, and also dependent on what happens here. You are at the mercy of the kindness, or absence of kindness, of the people around you. You can do little about it yourself. That's why I believe we should ensure that you are aware of their dependency, also when it comes to physical touch.

This theme touches upon the topic of consent, which I will address in the next section.

3.2.2. The complexity of consent

The previous section clearly demonstrates that physical touch is beneficial and sometimes even necessary in spiritual care for people with an intellectual disability. However, as Marthe points out: "Physical touch is an essential part of my work with people with an intellectual disability, but that doesn't mean I should casually touch everyone or accept that everyone touches me." Put differently: the benefits of physical touch should not result in a careless attitude towards its delicate nature and complexities. In other fields of caregiving there are clear rules that outline the boundaries for the appropriate care. This is no less true for spiritual care in general, let alone for people with a disability. Evidently, for them too their feelings concerning physical touch, specifically received from a caregiver, may differ tremendously. Two of the four participants underscore the possible salubrity of physical touch in spiritual care, but also immediately express their personal caution in incorporating physical touch into their own practice. The two other participants are less cautious, but also express multiple reasons to be careful when it comes to physical touch. There are multiple sides to this caution, each of which is addressed in this section.

One of the main reasons for caution is that clients are often seen as *vulnerable*. For instance, the risk of entering the sphere of sexual transgression is often seen as too high. James says he is very cautious when it comes to physical touch:

Physical contact is common here; clients, for example, warmly welcome you by hugging you. However, that's not the type of touch I mean. In certain situations, where I perceive a need, I try to suggest, if people are open to it, more physical forms of therapy, or specific massages. My colleagues already do a lot in this regard. Personally, I find it challenging to engage in that. My caution stems from the risk of sexual transgression, and this risk closes me off from using physical touch in my practice.

Importantly, James also specifically mentioned him being a man as an additional reason for caution:

I am very reluctant to use physical touch in my practice, but at the same time, it is something that could be hugely significant, especially in this day and age. However, I can't manage to integrate it into my work in a way that fits me personally. This may also have something to do with me being a man and not having specific training or education in that area.

For him, his caution is based on his gender. He is the only participant who mentions his gender specifically in relation to being cautious in using physical touch in his practice. Lily, who expresses a similar caution, doesn't base her argument on her gender. She perceives her clients as vulnerable, because they have often been victims of sexual transgression:

Physical touch is a tool you can use, but I don't know most of my clients well enough to know what the effect of touch will be. Often, it can be complex for them to say what they want and don't want. This is why I choose the safe route. I could ask their personal coaches how their clients feel about touch, but physical touch is such a personal topic. Clients might accept and enjoy being touched by one colleague, and feel uncomfortable being touched by other colleagues. It's often hard to explain why this is the case. And as a spiritual caregiver, I want to offer a safe space for clients. I do think physical touch has a lot to offer, but I'm always aware of the fact that these people often have been victimised by others, which I find really striking and very disturbing.

To summarise, clients are often perceived as vulnerable because they often have a complex history regarding physical touch. But more fundamentally, this perceived vulnerability of clients originates in the fact that they are dependent on professional caregivers. This dependency holds risks for (sexual) transgression. Being in a dependent relationship makes it harder to set boundaries, aside from any impairments that might complicate doing this.

Aside from the challenging nature of setting boundaries, Marthe argues that in the case of clients facing severe multiple disabilities, professionals sometimes have a tendency to cross their clients' physical boundaries too easily:

I think we always have to stay attuned and ask ourselves: why am I initiating physical contact? The client probably won't do that; they won't ask themselves that question. We often cross boundaries by always being the one talking, or determining the topic, the location, and who is present. We are always in the lead.

This quote highlights how the *inherent power imbalance* between client and caregiver easily grows when caregivers are not aware of their dominance. This perspective is similar to points made by Liégeois and Wulf on the inherent asymmetrical relationship between a spiritual caregiver and their client.⁶³ Because this power imbalance is structurally present, it should always be something that spiritual caregivers are mindful of when they use physical touch in their practice.⁶⁴

Central to the topic of physical touch is the concept of *consent*. Currently, consent is a relevant and hotly debated topic in, among others, feminist theory. The scholarship dealing with this issue is much too vast to include, but I do think it is important to highlight consent within this specific research field, as it is an integral part of physicality and touch. The influence of feminist scholarship is clearly visible, as we can no longer properly theorise physical touch without taking into account the importance and role of consent within this field. Additionally, the conversation on physical touch cannot be held without taking current and historical societal developments into consideration, because these influence how physical touch is perceived. This influence is also clearly reflected in the ideas expressed by all participants, as they mention either the #metoo discussion or the sexual transgressions that have taken place in the institute of the Roman Catholic church. Martha aptly summarises the impact of these events on her practice when she says that

[...] a lot has changed in terms of safety, partly also because of the me too discussion, the transgressions in the Church, and the gender identity discussion. This huge range of developments in the last 20 years have turned physical touch into an important topic, but it's still a topic that people don't know what to do with. So people then just become very careful and hesitant to touch.

⁶³ Wulf, "Jenseits", 137; Liégeois, "Ethiek", 102.

⁶⁴ This power imbalance is not exclusively present in the relationship between spiritual caregiver and client, but in any relationship between a healthcare professional and client. It is therefore also not a unique characteristic of the relationship between spiritual caregiver and client, but nevertheless an important element of this relationship that should always be taken into consideration.

The topic of consent becomes extra important when one considers that within the field of caretaking 1) there is often an asymmetrical power relation at work, and 2) verbal communication - the way most people express consent - is often impaired. James, when asked about consent, says that he finds consent to be a technical concept:

It, of course, pertains to what the other person wants. This is something you try to explore together, continually checking in. But in my opinion, the question ‘is it okay if I touch you?’ falls short. I wonder if a client can truly understand this question and oversee the results of their answer. Often, I think that this way of asking for consent doesn't work. The other person may not grasp what I'm asking when I seek consent. It's more concrete to ask: do you mind if I do this, or do you like it if I do that? But even if someone says yes, it may turn out differently. You need to always anticipate that someone can change their mind. If this happens, you can't say: but when I asked they said they consented.

Some participants have found ways to ask for consent that work for many of their clients. Marthe shares a practice of touch she has developed:

When people are grieving during a funeral, comfort becomes such a physical matter. After the funeral, I go to the family afterward and reach out my hands, palms facing upward. I let whatever happens happen. I present it as an invitation. This practice has grown intuitively, and it works. These outstretched hands, I do it very often, and they are often taken by others. And if they are not taken, that's okay too.

In this way, physical touch is an invitation, but the acceptance of that invitation is placed with the client. This example shows that through creative thinking and experimenting, it's possible to navigate the complexity of consent.

3.2.3. Physical touch should be a competency of spiritual caregivers

This thesis is a direct response to Schoenmakers' call for research on how spiritual caregivers integrate physical touch into their work. We've seen that physical touch holds a unique value in the practice of spiritual care for people with an intellectual disability. This value is acknowledged by every participant in this research project, but also by multiple scholars as shown in Chapter 2. However, because of the perceived vulnerability of clients and the complexity of consent in their professional context, many spiritual caregivers are cautious when it comes to physical touch. Participants also stated that physical touch is a neglected topic in spiritual care as a discipline, and in their own practice. This caution might partly explain why up until now, physical touch has not been developed as a competence of spiritual caregivers. This next section tries to shed a light on this neglect, and formulates opportunities for integrating physical touch in the practice of spiritual care.

Participants express that physical touch is a subject that has been written about far too little in spiritual care. The topic is not covered in education, and rarely discussed in peer-to-peer supervision or professional events. Dean perceives a tendency to only look at the mental domain, while the body is a crucial element in spiritual care because to Dean, the body is where the soul resides: “Many philosophical traditions have spoken extensively about this, but we have somehow diminished its importance in our profession.”

They also express how they increasingly experience the lack of physical touch in their practice as a deficiency. For example, James says he notices there is a need for it: “I think there are people locked inside their own bodies, whom you could offer relaxation through physical touch.” The interviewees do not always feel equipped to do anything with physical touch, partly because of their educational background. James says that “in my understanding of what spiritual caregiving means nowadays, it is mostly about conversation. That's how I've been trained. I often feel limited in providing good care to people who are verbally challenged.” Lily expresses something similar when she says that she is exploring a completely new area in her work:

I was trained in verbal communication during my ministry training, based on the idea that people need to be able to tell their story. However, that doesn't get me very far with many of my clients. I have to be creative. What can I do with what I know now, and what I know from my clients personal coach, who knows the clients much better, and what I learn from relatives? It's challenging because you first have to see if you can communicate, and if you can, what can someone take in and understand? That varies so much. What should I pull out of the toolbox to give someone what they need? It's really like starting anew.

Physical touch is thus perceived as valuable and important, but integrating it into everyday practice is difficult because of the verbally-oriented educational background of spiritual caregivers. This asks for improvisation and experimentation. Thoughts differ on *how* physical touch should be incorporated in spiritual care. Marthe argues that

Especially with our professional standard, that's currently being updated, I think it's a crucial competence to add. Call it an embodied competence, or the dimension of physical experience. I also believe that spiritual care beyond intellectual disability can benefit from this. Think about people with dementia, those in palliative care, or in youth care.

In contrast, James and Dean are more hesitant about formalising physical touch in spiritual care. Dean worried that developing rules and protocols stand in the way of developing a good practice:

When something happens in healthcare, all sorts of regulations are developed, and it becomes very instrumental. We need to be cautious about this. I think that our thinking on physical touch should be developed in the individual relationship you have with the other person, and in this relationship, you decide whether you'll touch somebody. Touch is functional when we use it to express our presence when words are absent, but if you develop rules and regulations, then it becomes instrumental. Then it needs to fit into a protocol and be part of the professional standard. You lose your own feelings and intuition when this happens. I hope every spiritual caregiver reflects on their own actions, but that's different from having to think about rules or protocols everytime you touch someone. Then you lose yourself and start thinking in a box. If there's one thing we, as spiritual caregivers, should not do, it's thinking inside a box.

James expresses a similar sentiment when he says he believes that embodiment shouldn't be developed as a separate aspect of spiritual care:

Before you know it, it becomes a new form of spiritual care. But it would be nice if there was perhaps more space to think about it and how to integrate it into your practice, building on what already exists. For me, it's a repertoire that you can deploy, rather than a distinct form.

There is no consensus on the way in which physical touch as a competence should be formalised. However, all participants state that it's impossible to design a general framework surrounding physical touch, because their clients differ so much:

I don't believe in general professional guidelines. I don't know how that should work. Everyone is so different, from verbally strong and assertive to not being verbal at all and not being able to hear or see. It's almost impossible to write guidelines for that.

They also agree on the fact that physical touch should be part of the repertoire of a spiritual caregiver, and that this can be developed in multiple ways. The first way is through *peer supervision and individual reflection, by focusing on why one would use physical touch in their practice*. For example, why would touch be considered as fitting in a specific situation? Does it originate in the spiritual caregivers mind, trying to know what a client needs, or does it come from other needs a spiritual caregiver might have, such as dealing with their own discomfort in painful situations? All participants emphasised that as a spiritual caregiver, your own background always influences your profession. Lily states:

I believe that as a spiritual caregiver, you are your own instrument. So, you have to listen very closely to your own feelings and tune in to someone else, and that is even more pronounced with these clients who may not always communicate or communicate differently. It's a different language. When I first started working here, I realised: I need to learn a new language to communicate beyond words. I find that very interesting.

This aligns with the work of Lambrechts, Baart, Liégeois and Schoenmakers on the importance of being connected to oneself physically and mentally, and underscores that one's life story could be of influence. The second way is through *collaborating with colleagues within and outside the organisation, to learn more about their clients, about how to communicate with them, and about how they might feel about physical touch*. Participants highlight that their colleagues are of vital importance for them to offer good spiritual care:

Recently, I visited a client whose personal coach mentioned that he enjoyed a hand massage, and then he handed me oil so I could do it. I wouldn't have done that on my own. Personal coaches are often the eyes and ears of clients. It's helpful to ask them questions when I don't know a client. Asking about what physical needs clients have is just as normal a question as asking how you communicate with that person.

This example shows that spiritual caregivers often need to collaborate with other disciplines in order to offer tailored spiritual care, as mentioned in section 3.2.1.

3.2.4. Summary

The interview findings shed light on the many-sided nature of physical touch in the practice of spiritual care and resulted in three key themes: physical touch as a unique mode of communication, the complexity of consent, and physical touch as a professional competence. The first key theme describes the value of physical touch as a *unique mode of communication*, especially in moments where verbal expressions may inadequately convey the depth of emotions or solace required for fitting support. Physical touch seems to have the capacity to bridge certain communication gaps that language sometimes fails to do. Physical touch thus offers an alternative, and sometimes the only possible, connection between the spiritual caregiver and the client. The second key theme delves into *the complex nature of consent in the context of physical touch*. The interviews reveal that navigating the boundaries of physical touch requires an understanding of individual preferences, cultural norms, and the evolving dynamics between the spiritual caregiver and client. This is specifically important because physical touch is such a delicate topic. Consent emerges as a crucial aspect of physical touch, specifically because clients are perceived as being in a dependent and

sometimes vulnerable position, and because non-verbal consent is challenging in its own way. The third key theme advocates for the *integration of physical touch into the repertoire of competencies for spiritual caregivers*. Recognizing touch as a potentially transformative tool in the repertoire of a spiritual caregiver, the findings suggest that caregivers should be equipped with a diverse set of skills, including an understanding of the emotional and spiritual significance of touch and the ability to navigate its complexities responsibly. These insights carry multiple theoretical implications that will be examined in the Discussion section below, next to practical implications such as potential adjustments to spiritual care practices and educational programs, in order to provide tailored and meaningful spiritual care for people with an intellectual disability.

Conclusion

This concluding section brings together the insights gained from the literature review, and the first-hand perspectives of spiritual caregivers obtained through interviews on the role of physical touch in spiritual care for people with an intellectual disability. The literature review serves as a theoretical anchor, providing a framework for further research. The interviews offer firsthand insights that bridge the gap between theoretical concepts and everyday practice of spiritual caregivers. The synthesis of these two chapters aims to present a more informed understanding of the significance of physical touch in spiritual care for people with an intellectual disability. In this section, the key findings and points of discussion will be discussed, while making connections between theoretical frameworks and lived experiences of spiritual caregivers.

This thesis aims to answer how physical touch can be a professional tool for spiritual caretakers who work with people with an intellectual disability. The preceding chapters have examined various facets of physical touch, including its historical underpinnings, inherent and unique value, and ethical considerations. Additionally, they highlight personal narratives that contribute depth and nuance to our understanding. These insights show that current scholarship on physical touch in spiritual care is present in everyday practice of spiritual caregivers. At the same time, however, all interviewees confirm that the topic of physical touch remains neglected, both in education for aspiring spiritual caregivers and in professional peer supervision. This holds for spiritual care in general, but also for spiritual care for people with an intellectual disability.

The interviews echo the significance of physical touch as a communicative tool in spiritual care, expressed in scholarship. The correspondence between the interviews and the scholarship becomes particularly clear in four key findings. Firstly, the notion that physical touch serves as a *means of communication when words fall short* resonates strongly with existing literature on the subject. The interviews underscore the value of both expressive touch and supportive touch, affirming the idea that physical touch can convey empathy, comfort, and understanding in ways that verbal communication alone cannot always capture. Secondly, emphasis on the *importance of understanding one's own biography concerning physical touch* aligns with the established literature. Recognizing the influence of personal experiences and beliefs about physical touch is seen as something that's needed to properly navigate the complexities that are inherent to physical touch in spiritual care. Thirdly, the interviews also align with research by *addressing possible risks inherent to physical touch in spiritual care*. Some participants express a cautious approach, acknowledging

the potential for misunderstandings or discomfort because of the asymmetrical, professional relationship and perceived vulnerability of their clients. This caution echoes the general careful tendency of academic literature on the topic. Finally, the interviews confirm the *underexplored nature of physical touch within both academic research and the professional field of spiritual care*. The consensus among participants that physical touch remains a neglected topic underscores the need for increased attention and exploration, and the call for action that served as the start of this thesis.

While multiple interview findings align with existing literature on physical touch in spiritual care, previously unexplored dimensions also came up. Interestingly, other aspects than the ones mentioned above were addressed when discussing the importance of physical touch in spiritual care for people with an intellectual disability specifically. In current scholarship there is no link between pedagogical theory on people with an intellectual disability and spiritual care. Interviewees referred back to pedagogical theory that shows that for some people with an intellectual disability, the body is *the* important source of information. This asks for embodied ways of communication, of which physical touch is seen as one of the best ways to do so. For some clients, verbal communication is meaningless or incomprehensible. Therefore, in order to be able to support clients in their meaning-making process, spiritual caregivers need a repertoire that includes non-verbal and physical communication skills.

Discussion

Although the previous section summarises multiple key findings and corresponding patterns, it is important to point out that this scholarship has only recently gained more recognition and is therefore still in development. The topic of physical touch alone is tremendously complex, let alone in the context of spiritual care *and* spiritual care for people with an intellectual disability. Evidently, this thesis is not the end of this development, but rather a way of mapping several pertinent directions that scholarship may pursue in order to improve spiritual care for people with an intellectual disability. In this vein, this section points to several critical reflections on the results, as well as recommendations for further research.

One of the similarities between the existing body of literature and the interview data is that spiritual caregivers are careful when it comes to physical touch, because they perceive their clients as being more vulnerable. The reason for this perceived vulnerability lies in the fact that clients are dependent on healthcare professionals when they live in a healthcare facility. In the context of spiritual care, there is a one-sided exchange of often intimate, personal experiences. The client is dependent on the spiritual caregiver for support and counselling regarding these experiences. These elements result in an asymmetrical relation between spiritual caregiver and client. This is important to highlight because they should be considered when spiritual caregivers want to use physical touch in their practice.

Another element to this perceived vulnerability seems to be caused by the fact that they are disabled. While it's of vital importance to do justice to each person's unique physical, mental and social situation and the ways in which they experience their impairments and disability, calling people vulnerable *only* because they are labelled 'disabled' is problematic. Disability scholars Stephanie Patterson and Pamela Block write on what happens when people with an intellectual disability are called vulnerable:

Traditionally, and particularly from the perspective of non-disabled people, the disabled community is considered a 'vulnerable' population. Merriam-Webster's dictionary defines the word vulnerable as "capable of being physically or emotionally wounded: open to attack or damage", and it naturally conjures up visions of helpless babies, neglected animals, children being bullied, and elderly people being abused. The word pulls on our heartstrings, our righteous sensibilities, and our beliefs about the right to be safe and protected. When used to describe (and label) an entire group, it suggests individuals that require utmost care, specific ancillary considerations and augmented protections. Rather than protecting disabled people, it can be argued

that the ‘vulnerable’ label actually causes what is known as ‘pathogenic vulnerability,’ a condition where harm is inflicted by injustice and repression stemming from systems that are devised to alleviate these situations.⁶⁵

They state that there are many people in the world, some with a disability, who need specialised attention and require cautious and thoughtful concern. There are also many circumstances in which people can feel intimidated and vulnerable, regardless of whether they are disabled or not.⁶⁶ Calling people with a disability vulnerable means thinking from a vulnerable/invulnerable categorization, which holds the risk of producing rigid social hierarchies, and stigmatising and regulating groups of people: “Taken to the extreme, it can even be considered a mechanism of discipline.”⁶⁷ This highlights the importance of reflecting on the effects of calling people with an intellectual disability vulnerable, and how it impacts the spiritual care that is offered.

Another result of labelling one’s clients as vulnerable in the context of physical touch is that consent becomes complex. As we’ve seen, spiritual caregivers doubt if consent is possible for someone with an intellectual disability living in a dependent care relationship. While this question is valid, it’s important to scrutinise the effect of the label ‘vulnerable’ in this discussion. The unique value that physical touch can bring in spiritual care for people with an intellectual disability is evident. The question of consent is complex because of possible communication barriers and asymmetrical power dynamics. That doesn’t mean that spiritual caregivers should not at least try to explore the ways in which physical touch can be integrated in their practice. If the complexity of consent is used as an argument against physical touch in spiritual care, while knowing how beneficial and necessary it can be, possible beneficial ways of offering care are neglected. The fact that consent is complex means that it should be navigated carefully, but closing the door because of this complexity does not do justice to the needs of some people with an intellectual disability.

Patterson and Block describe what happens when one’s impairment and perceived disability is used as an argument for the impossibility of consent. They say that it is an unsettling presumption that being diagnosed automatically diminishes an individual’s ability to provide consent, raising the probability of facing stigmatisation, stereotyping, and prejudice. Individuals with various disabilities may encounter diverse challenges in their lives, such as limited access, resources, employment opportunities, and educational options compared to the general population. However, these challenges are unrelated to their individual capability to give consent; rather,

⁶⁵ Stephanie Patterson & Pamela Block, “Disability, Vulnerability, and the Capacity to Consent,” in *Research Involving Participants with Cognitive Disability and Difference: Ethics, Autonomy, Inclusion, and Innovation*, ed. M. Ariel Cascio & Eric Racine (Oxford: Oxford University Press, 2019), 69.

⁶⁶ Patterson and Block, “Disability, Vulnerability, and the Capacity to Consent,” 69.

⁶⁷ Patterson and Block, “Disability, Vulnerability, and the Capacity to Consent,” 69.

they stem from environmental and attitudinal factors. The act of categorising this minority group is not only demoralising but also infantilizing.⁶⁸ They propose to focus on one's capacity to consent and one's power to resist manipulation as inputs for consent, instead of using disability labels and categories. While they developed this theory as a tool in obtaining informed consent in research projects, it would be interesting to explore the usability in the context of physical touch in spiritual care.

A final important point of discussion is that up until now, all research in this discourse is conducted by academics and spiritual caregivers. In this, they voice their views on what is important in spiritual care for people with an intellectual disability. Yet the people that this research primarily concerns, are rarely directly involved in doing the research. This is also the case in this thesis. Four spiritual caregivers were interviewed, who are hopefully able to partially convey the voices of their clients in a nuanced and respectful way. However, in the most ideal situation, their voices are still only interpreted by people who do not find themselves in the same, nor even a similar position as theirs. All research on this topic is thus, in effect, a conversation between people about *people with intellectual disabilities and not a direct conversation with them*. Because of practical restrictions, such as limited time and the complexity of obtaining informed consent from more 'vulnerable' participants, this thesis does not include data gathered from clients of spiritual caregivers. Therefore, this thesis only specifically contributes to scholarship on how spiritual caregivers integrate physical touch into their work. It does not investigate how physical touch is experienced by their clients.

As such, there is certainly more work to be done when it comes to including the people we write about, and representing their perspective. Because of the reasons mentioned above, this type of research can be challenging. Spiritual caregivers and academics Gustaaf Bos and Susan Woelders describe this tension aptly in their work on collaborative research with people with an intellectual disability. They both see it as a primary responsibility of researchers to bring together and keep together all parties relevant to a research practice, in order to arrive at outcomes in a joint process of 'knowledge-making' that does justice to all parties involved and that helps to further develop that practice.⁶⁹ However, conducting this is challenging because of the dominance of the verbal and cognitive mode of knowledge production in both an academic context and in healthcare organisations, as well as academic knowledge in healthcare practices determines how people think, talk and organise in everyday practice and legitimises why people do something. The authors describe the limited or even impossible act of bringing in other forms of knowledge, which are often

⁶⁸ Patterson and Block, "Disability, Vulnerability, and the Capacity to Consent," 70.

⁶⁹ Bos and Woelders, "Collaboratief onderzoek", 58.

disqualified before they are even considered to be included. The result of this is that collaborative research, which tries to voice all those who are part of the research topic, often meets with multiple obstacles, even when the research itself has been completed successfully. The main point that the authors make is that this focus on verbal, cognitive knowledge excludes certain people and certain types of knowledge.⁷⁰ This is thus clearly a form of epistemic injustice: wronging someone specifically in their capacity as a knower and being blocked from access to knowledge or communicating knowledge.⁷¹ In future research on this topic, it would be beneficial for spiritual caretakers to include clients, either as participants, or as collaborators, in the research process. More importantly, for clients themselves, it's necessary to be part of this research process, in order to make sure their voices are justly represented.

⁷⁰ Bos and Woelders, "Collaboratief onderzoek", 60.

⁷¹ Rachel McKinnon, "Epistemic injustice", *Philosophy Compass* 11, no.8 (2016): 439.

Afterword

This thesis started because of personal encounters with my clients. These encounters made me question the way healthcare professionals and society at large look at people with an intellectual disability, my own position as a spiritual caregiver within this framework and which responsibilities I experience because of my position. Before diving into the topic of physical touch in spiritual care, I primarily thought of physical touch as an enriching practice, next to conversations. Even though I already realised that verbal communication did not always do the trick, I was not aware of the importance of physical touch as a communicative tool. Writing this thesis made me realise that for some of my clients, physical touch is essential because without touching, they cannot properly communicate. This insight, combined with the fact that both physical touch and spiritual care for people with an intellectual disability are neglected topics in academic and professional research in spiritual care, clearly demonstrates the urgency of this topic.

During the writing process of this thesis, I noticed encounters in which physical touch played a role more clearly. Firstly, I became aware of my own ‘biography’ surrounding touch. I started to notice in which situations I wanted to touch somebody, and for what reason. At the same time, I became aware of situations in which clients wanted to touch me, and tried to reflect on their motivations and needs. While these reflections are certainly important and a start of growing awareness surrounding physical touch, it’s just the beginning. Any process of developing a more nuanced and inclusive awareness starts with personal reflection on concrete situations. These individual reflections then lead to organised, peer-to-peer reflections and ultimately to theorising physical touch in spiritual care. This means that the journey has only just begun. This holds for both spiritual care as an academic discipline and professional practice, as for my personal practice. After finishing this thesis, I still have many unanswered questions, maybe even more than before starting this thesis. I’m still uncomfortable when clients can’t verbally communicate and I lack professionally developed skills to find alternative ways to communicate. In these situations, I improvise to the best of my abilities, but there is much to learn before I can offer the type of spiritual care that my clients deserve. If there is one thing the writing of this thesis has shown me, it’s the responsibility to offer good, tailored spiritual care to people with an intellectual disability, taking into consideration that academic thinking on spiritual care for people with an intellectual disability is severely neglected. Because of this, the academic and professional field does not do justice to the diversity of clients we encounter in our practice. Moving forward, I hope to grow into a spiritual caregiver that honours the diversity of my clients to the best of her abilities, because each person deserves to be seen in light of their own, unique being.

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