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A population-based survey linked to Danish nationwide registers

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The Research Unit for General Practice
Department of Public Health
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Spiritual needs in Denmark

A population-based survey linked to Danish nationwide registers

PhD Thesis

January 2024

Spiritual Needs in Denmark

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PhD Thesis

by

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To all my teachers and masters who have taught me well, inspired me to become myself, and supported me compassionately along the way. I am honored to have met and learnt from you.

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01 PREFACE

The final mystery is oneself. When one has weighed the sun in the balance, and measured the steps of the moon, and mapped out the seven heavens star by star, there still remains oneself. Who can calculate the orbit of his own soul? — Oscar Wilde

When I had about two years left of medical school, something happened. It was not a specific external event as much as it was an intangible process slowly revealing two existential conditions in my core that I had left unnoticed my entire life. The first was a sensation that my life was meaningless and without purpose; the second was that I had been uncritically following a laid-out path from kindergarten through university without ever consulting my heart. Consequently, I felt a strong existential longing towards finding my true self. These conditions led me on a long, tedious, and enriching journey in the outer and inner worlds – two distinct perspectives that mutually benefitted and stimulated each other.

Simultaneously to feeling an inner existential yearning directed at discovering my full potential and purpose in life – it became apparent that people in my vicinity and, most importantly, the patients I met during my clinical education and work as a medical doctor had the same yearnings too. Furthermore, it became clear that the existential and spiritual elements of life I had struggled with were shared with my fellow human beings – both in my personal life and in my vocation as a doctor. Even though existential and spiritual events were happening daily in the clinic, this was not something that I had been taught anything about or prepared for at medical school. Nor was it given much attention in the healthcare settings where I worked. But it was present every day: patients were told about severe diagnoses that pivoted their lives, relatives lost loved ones, and healthcare professionals were trying to find meaning and purpose in a revved-up work life where genuine compassion for patients was not prioritized.

My journey led to an internal conflict: on one side, I observed that existential and spiritual matters of life were essential – to myself and my patients. On the other side, I had spent seven years studying and training to become a medical doctor. I had been trained in a biomedical “body-as-machine”-paradigm where psychological, social, and spiritual factors did not *really* exist. Even if they did, they were not something that I should be concerned with because they didn’t represent objects of “real science”.

The solution to this unsolvable conflict became apparent when my older brother told me about a professor whom he had heard lecturing (who should later become my principal supervisor during my doctoral studies). The professor was Dr.theol. Niels Christian Hvidt, professor of Spiritual Care, who had studied the relationship between existential and spiritual factors and health for over a decade! My eyes opened; this “existential and spiritual stuff” can be researched and examined academically. Perhaps, I thought, this area of research could be a way to build bridges between my seemingly unbridgeable interests. And so, with my heart in

my hands, I wrote Niels Christian. The rest is history, and you are currently holding the product of this unsolicited e-mail in your hands.

I am optimistic that the EXICODE study will continue to prosper well beyond the content of this thesis. EXICODE is already a remarkable Danish study, and the cohort has the potential for longitudinal internationally unique data on the complex, important, and essential aspects of the innermost human conditions that are important for all of us to flourish through our lives. In the future, EXICODE may provide valuable insights that may help shape the health care system of tomorrow – a health care system sensitive to all the dimensions of human health that we may flourish physically, mentally, socially, and spiritually.

First, I hope this dissertation may be a brick in the imaginary bridge between the biomedical paradigm and life's existential and spiritual domains. Both worlds are equally important, and I believe they hold infinite potential by working together rather than opposing each other. Secondly, I hope my story might be an inspiration – that I may shine a light for others who have lost their way or are considering swimming against the main current of their profession like I did. Finally, I am proud that I followed my heart and I have been rewarded for my courage. I have found significant meaning and purpose in my life, partly because of the wonderful time I have spent researching as a PhD fellow. Some of that research is a part of this thesis. I hope that it will be well received.

Slagersköp, Sweden | *July 2023*

Tobias Anker Stripp

02 ACKNOWLEDGMENTS

Wear gratitude like a cloak and it will feed every corner of your life. — Rumi

First and foremost, my thanks go to all the study participants of my works. People who willingly and without remuneration gave a bit of their life (i.e. time) to support my research. I am forever grateful and will do my best to honour your contribution: without you, I would not have been able to conduct my research.

Secondly, I thank my academic supervisors and mentors. A special thanks goes to my principal supervisor Professor Niels Christian Hvidt. I am grateful for his confidence and trust as he allowed me to prove my worth under his skillful and compassionate guidance. He has become not only a valued colleague but also a dear friend. I am also grateful to my co-supervisors, Professor Jens Søndergaard and statistician Sonja Wehberg. You both have been incremental to the success of this doctoral project. I am grateful and honoured by your words, time, and belief in me. I look forward to many more years of collaboration.

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Thirdly, I thank my many wonderful colleagues at the Research Unit for General Practice, Department of Public Health, University of Southern Denmark, Odense. You have all helped make the days fun and interesting. Special thanks to my office-mate Alex Hoffmann Kørup for critical conversations and great humour that made me laugh many times – both are essential to a successful doctoral project. I am also thankful to Sebastian Bloch and Sara Stage Voetmann for their kindness and fellowship.

Next, I extend my gratitude to my friends and colleagues at the Human Flourishing Program at Harvard University, Cambridge, Massachusetts, the United States. They invited me into their offices and homes during my half-year-long exchange visit. A huge thank you goes to Professor Tyler J.VanderWeele for inviting me as a visiting research fellow to the T.H. Chan School of Public Health at Harvard University. That was an experience I will never forget. Further, I am grateful to Richard Cowden, Jonathan Teubner, Jeffrey Hanson, Pedro de la Rosa, and, last but not least, Ewa Mlynarczyk and Wojciech Kaftanski. You all welcomed me with warmth and kindness.

Fifth, I am thankful to the funding organizations that enabled this doctoral project to come to life, allowing me to learn and train to become a researcher.

Sixth, I am grateful to my friends, no one mentioned no one forgotten, who supported and encouraged me all the way. I am also indebted to my wonderful family; Tommy Stripp (MD), Jonna Kvist Stripp, Rasmus Kvist Bonde (MD), Luise Kvist Bonde, Nete Kvist Bonde and Eskild Kvist Bonde for sustaining a loving, compassionate, and motivating environment for me. You were all essential for the success of my doctoral project, and especially for helping me retain my sanity through long days of working from home during the Covid-19 pandemic. Thank you for that.

Lastly, and most importantly, I extend my most humble and heartfelt gratitude and thanks to my wife, Cecilie Anker Stripp. She has been a mountain to lean on and the best of friends through all these years of me being consumed by research, coming home late, checking emails too often, talking to news journalists on holidays, or being overtly obsessed with my academic performance. She and my daughter Saga Anker Stripp (born in the final year of my doctoral project) were crucial in showing me one of the most important things a researcher can try to master: how to treat oneself with mildness and live a balanced life while fulfilling one's purpose. I am forever grateful to you both and honoured that you are willing to share your journeys with me. You are my greatest successes.

03 INTRODUCTION

It is the time you have wasted for your rose that makes your rose so important. — Antoine de Saint-Exupéry

03.01 Structure and content

To begin, the front matter contains the preface (01), acknowledgments (02), and introduction (03). The introduction will describe the structure and content of the thesis, followed by an autoethnographic note on the author's observed ontology and epistemology and lastly the glossary containing definitions and abbreviations. 04 contains the summaries in English and Danish. In the body of the thesis, I shall start in section 05 by providing background to the field, demonstrating the rationale for my research. Then, in 06, I shall list the formal aims and objectives. Section 07 contains the methods section, which will give an overview of the applied methods, and 08 the results. Then, 09 is used to discuss the findings and their implications, before I conclude in 10, highlighting my most important insights. The thesis' back matter contains the sections 11 and 12 – constituting the references and appendices respectively.

I have built the thesis around the following three peer-reviewed published papers, which are also found in appendix A, B, and C:

1. Stripp TA, Viftrup DT, Nissen RD, Wehberg S, Sondergaard J, Hvidt NC. Testing the acceptability and comprehensibility of a questionnaire on existential and spiritual constructs in a secular culture through cognitive interviews. Survey Research Methods. 2022; 17(1): 75-89. DOI: 10.18148/srm/2023.v17i1.7971.
Cited in text as: (T. A. Stripp, D. T. Viftrup, et al., 2022)

2. Stripp, T. K., Büssing, A., Wehberg, S., Andersen, H. S., Kørup, A. K., Pedersen, H. F., Søndergaard, J., and Hvidt, N. C. (2022), "Measuring Spiritual Needs in a Secular Society: Validation and Clinimetric Properties of the Danish 20-Item Spiritual Needs Questionnaire". J Relig Health. 2022; 61(4): 3542-3565. DOI: 10.1007/s10943-022-01533-5.
Cited in text as: (T. K. Stripp, A. Büssing, et al., 2022)

3. Stripp TA, Wehberg S, Büssing A, et al. Spiritual needs in Denmark: a population-based cross-sectional survey linked to Danish national registers. The Lancet Regional Health – Europe. 2023; 28: 100602. DOI: 10.1016/j.lanepe.2023.100602.
Cited in text as: (T. A. Stripp, S. Wehberg, et al., 2023)

03.02 Ontology and epistemology

The awareness and critical appraisal of one’s presumptions as a researcher are paramount to achieve high scientific quality. This is the case because without such reflection researchers can be unaware of their own biases or limitations which may ultimately tamper with any part of the research process – from research question to conclusion. Although reflection and transparency about presumptions does not entirely remove the risk that such presumptions can affect the research process, it is the only way to make the process as transparent as possible – and transparency is one of the markers of scientific quality.

Transparency of presumptions is often left unrecognized in the biomedical academic literature, where many premises are often taken for granted, e.g. a premise that “true” science is concerned with things that by nature are collectible or measurable (positivism), and that science is a process driven primarily by the principles of logic and rationality (epistemological normativity). While this understanding most certainly is also science, other approaches and sources of knowledge can be equally as scientific in my opinion.

I acknowledge that I am writing this thesis as a white, male, heterosexual medical doctor. Such position is structurally and historically a highly privileged one. This understanding has been a critical component of my research and will continue to stimulate my reflection about my profession.

My intuition about the structure of the world is that it consists of objects that are physical and non-physical in nature (in the sense of natural sciences). However, as I am well aware, a commitment to such a non-physicalist ontology poses some challenges to empirical research. I consider health to be a matter of optimal function(ing) physically, psychologically, socially, and spiritually; I consider care for these four dimensions essential for holistic, patient-oriented healthcare (see “Dimensions of health” in the terminology section). I am a man of faith. However, I do not affiliate myself with a particular religion. I believe in a universal experience of the sacred and transcendent – in the sense that such experience, to a certain degree, is available to all, but not in a single universal theology – in the sense that I do not consider a single theology to be the “only true” theology.

Apart from being a medical doctor, I am also trained as a Reiki master. Reiki (a complementary / alternative treatment method) is considered a universal life force that can be channeled to a client to achieve healing; physical, psychological, or spiritual. My practice and 5-year long training with Reiki have influenced me

tremendously. I genuinely believe that my first-person experiences of the transcendent and my knowledge of the holy texts of multiple religions have made it possible to retain a very nuanced and sensitive yet open view of belief and non-belief in my research.

I am of the opinion that a complete objectivity in research cannot be achieved as humans cannot ascertain a complete objective view of the world and as humans always engage their subjectivity engaging with the world (Stripp, 2022). We will always be in a relationship with whatever subject we study (irrespective of how this subject is examined) (cf. Heidegger's term '*Dasein'*) – thereby rendering complete objectivity impossible. Even when using technical man-made tools – which is often considered the gold standard for objective science – e.g. a weight or a blood sample, conclusions will often invite a degree of subjectivity in the understanding that humans have decided the possible range of values for x. Rather than aiming futilely at being completely objective and neutral as a researcher, I find it better to openly disclose whatever beliefs we as scientists may have and instead "own our subjectivity". I consider good science to be something then achieved by reflecting on and being transparent about own presumptions and understandings.

As a researcher I am pragmatic, and hence my epistemological stance is dynamic and relates to the methods used in the respective studies. When using qualitative methods, I observe a humanistic epistemology: data are considered to be co-created between the interviewer and interviewee, and knowledge is considered something that cannot be "picked up", weighted, or replicated, but instead, it is generated in the research process. Conversely, an empiricist epistemology guides my epidemiological studies utilizing questionnaires. In this paradigm, knowledge is considered something that can be captured with the right tools (e.g. through a questionnaire), weighted, and replicated – an approach that tries to minimize the influence of the researcher (in an attempt to obtain objectivity).

Although two of the main papers of this thesis use the term "secular" in their titles to denote the Danish culture, I have changed my view on this understanding since these papers were published. For the purpose of this thesis I consider Denmark a "post-secular" culture. In short, secularism advocates for the separation of religion and government (including public institutions), whereas post-secularism acknowledges the continued influence of religion and spirituality in public life and explores how different worldviews can coexist and interact in a pluralistic society. See "Terminology and definitions" below for an expansion of what I mean by "post-secular" and the implications of this.

The above presented position and affiliation as well as epistemological commitments have unquestionably affected my research in numerous ways. Although I by training came from a strict empiricist biomedical paradigm, it was intuitively (and theoretically) important for me to mix my questionnaire research with some form of qualitative interviewing. The result is the first paper of this thesis. Further, I guess it is fair to say that my positionality has been paramount in deciding which research questions I would be pursuing. As I am fundamentally interested in the principal fabrics of human health and the universe I am naturally drawn towards the "big questions" of humanity. The methods that I have used, however, adhere strictly to the theoretical and methodological expectations as they related to their research disciplines and a relevant to the research questions within each of the papers included in the thesis. Thus, I have tried to the best of my capabilities and with the guidance that was provided me, to use my own enthusiasm and interest as fuel for my work while having the methodological inquiries follow the utmost best practices.

03.03 Terminology and definitions

First, Table 1 contains the abbreviations used throughout the thesis.

Table 1 - Abbreviations used throughout the thesis.

Abbreviation		Meaning
CFA	–	Confirmatory Factor Analysis
CFI	–	Comparative Fit Index
COSMIN	–	COnsensus-based Standards for the selection of health Measurement Instruments
CR	–	Coefficient of Repeatability
DA-SpNQ-20	–	Danish Spiritual Needs Questionnaire (20 items version)
DI	–	Discrimination Index
DMP	–	Data Management Plan
EAPC	–	European Association for Palliative Care
EFA	–	Exploratory Factor Analysis
EXICODE	–	EXIstential health COhort DEnmark
GDPR	–	General Data Protection Regulation
ICC	–	Intra Class Correlation
ISCED	–	International Standard Classification of Education
KMO	–	Kaiser-Meyer-Olkin
OR	–	Odds Ratio
R / S	–	Religious / Spiritual
RMSEA	–	Root Mean Squared Error of Approximation
SD	–	Standard Deviation
SEM	–	Structural Equation Model
SEM-agreement	–	Standard Error of Measurement-agreement
SES	–	Socioeconomic Status
SpNQ	–	The Spiritual Needs Questionnaire
SRMR	–	Standard Root Mean Residual
TLI	–	Tucker-Lewis Index

In the following, I shall define and demarcate specific constructs, concepts, and terms to clarify how they are used throughout the thesis.

Bias: Denotes a systematic skewness in the research process potentially leading to spurious conclusions. E.g. *Information bias*: respondents are unlikely to provide truthful responses. *Sample bias:* the method of sampling causes some members of the intended population to have a higher or lower sampling probability. *Selection bias:* respondents are selected due to specific traits that are not randomly distributed in the population representativeness. *Recall bias:* when the variable of interest is probed with a long temporal delay.

Burnout: Burnout syndrome is constituted of three main factors: depersonalization, emotional exhaustion, and low level of personal accomplishment (Maslach et al., 1997).

COSMIN: The COSMIN terminology refers to a consensus-based taxonomy of psychometric measurement properties (see figure 1). Since much heterogeneity has been found in the field of measurement validation, this taxonomy is an attempt to streamline the definitions used. This thesis follows the COMIN taxonomy for measurement properties.

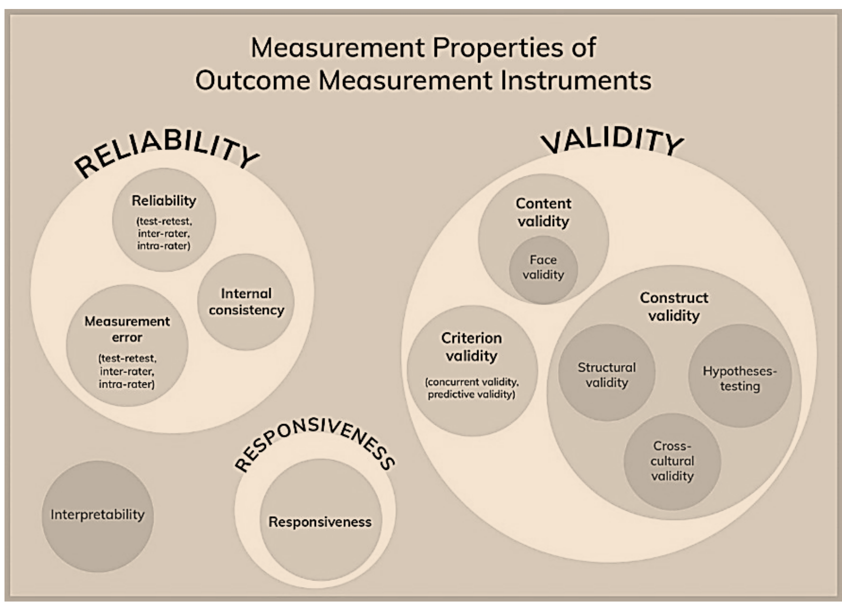

Figure 1 - The COSMIN taxonomy.

From www.cosmin.nl, accessed on the 12/12/22.

Danes: I use the term "Danes" to denote individuals living in Denmark with a valid Danish Central Personal Register (CPR) number. I understand that this notion might be considered normative, as some individuals living in Denmark with a valid Danish CPR-number, might not consider themselves Danes, but of a different ethnic affiliation. I am sorry if this use of wording causes any sorrow for my readers. It was a term used to increase readability of the text, although it has its limitations. Please forgive me.

Dimensions of health: The World Health Organization (WHO) defines health as "a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity" (a definition conduced in 1946 and which is still in place today) (World Health Organization, 1946). It has numerous times been suggested that a fourth spiritual dimension of health should be included in the WHO conceptualization (Cloninger et al., 2010; Larson, 1996; Peng-Keller et al., 2022). Based on the "total pain model" of Cicely Saunders among other things (Richmond, 2005), the WHO did themselves include a spiritual dimension of health in their understanding of palliative care (World Health Organization). Since then, other stakeholders have incorporated this notion of four distinct dimensions of health e.g. the Lancet Commission of the "Value of Death" (Sallnow et al., 2022) and the international association of family doctors – WONCA (Allen et al., 2011). The four dimensions can be understood as being four distinct ontological dimensions of health, where physical means *one's physical existence*, mental/psychological *one's psychological existence*, social *one's social existence*, and spiritual *one's spiritual existence* (see definition of "spirituality" below). Examples that clearly identify as belonging primarily to a specific dimension could be a broken leg (physical), anxiety (psychological), ostracism (social), and existential crisis (spiritual). However, other phenomena such as grief from losing a beloved relative, depression, or the experience of vitality, are much more difficult to clearly identify as belonging to one dimension only. The plot further thickens when each dimension is understood as encompassing both objective (physical/neurological/physiological) and subjective (mental experience, qualia) states. The complete taxonomy is beyond this thesis, but it becomes obvious that although this four-dimensional understanding of health might help to clarify a broad understanding of health, some nuances and granularity are (as always) lost when making strict demarcations.

EXICODE: EXICODE refers to EXIstential health COhort DEnmark, but the name bears more meaning than such. The project is also named thus as we are attempting to put the difficult to grasp constructs of the existential and spiritual

dimension on some sort of “code”. Such code may enable us to address these issues and their impact on society quantitatively. This is done with the utmost respect that such concepts will for some people always remain larger than what may be embedded in even the most comprehensive survey (T. K. Stripp, S. Wehberg, et al., 2022).

Existential (existentiality): The “existential” is, considering classical secular existential philosophy, used to refer to the ultimate human conditions as probed without relation to a transcendent reality. Concerns are matters of free will, meaning in life, questions of mortality etc. As such, the existential is part of “spirituality” as it pertains to the EAPC definition of spirituality (see below), at least as how an individual (as self or community) “*seek meaning, purpose”,* and *“the way they connect to the moment, to self, to others, to nature, to the significant”* (Nolan et al., 2011).

Generativity: Is related to the concern of others and the wish to do good extending beyond one’s own immediate environment. It is built on the work by Erik Erikson (Erikson, 1950) and arguably aligns with other described phenomena of (horizontal) self-transcendence as described by e.g. Tatjana Schnell (Schnell, 2009). In this understanding, generativity is part of “spirituality” as it relates to the EAPC definition of spirituality (see below) in the sense that it, at least, relates to how “*persons (individual and community) experience, express and/or seek meaning, purpose”,* and *“the way they connect to the moment, to self, to others, to nature, to the significant”* (Nolan et al., 2011).

Post-secular: I consider Denmark a “post-secular” culture. The “post-secular” is generally used to refer to the era following the “secular age”, as an indication that the hegemonial secular theories have failed (Parmaksız, 2016). These theories, which have dominated many European cultures, including the Danish, postulated that with increasing Enlightenment, modernization, and scientific knowledge, religion would dissipate (Taylor, 2007). This did not happen. Quite the contrary, in fact (Korup et al., 2020). By using the term “post-secular” to denote Danish society, I acknowledge that the traditional secular and non-secular spheres are constantly mixed at micro- and macro levels and that spirituality and religion did not dissipate with increased modernization (Balboni & Balboni, 2019; Beaumont et al., 2020; Berger, 2014; Habermas, 2008). A vast body of literature during the last decades has expanded the concept of the post-secular to examine the sociological and theological implications of the failed secularization theories (Berger, 1999; Geeraerts & Nynäs, 2012; Taylor, 2007). Central to this is the acknowledgement that the spiritual domain is important and central in the human

experience, despite the taboo surrounding such topics in Denmark – a country which by many has been considered one of the most secular cultures in the world (Zuckerman, 2008). The presence of hospital chaplains could be an example of how a non-secular institution is mixed with an institution that in modern times is considered a highly secular one.

Religion (religiosity): Religion is the search for significance that occurs within the context of established institutions that are designed to facilitate spirituality (Hill et al., 2001). It is a part of "spirituality" in the sense that it relates to how *"persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred*." (Nolan et al., 2011).

Secularism (secular): Secularism is used to describe the separation of religious and spiritual matters from government, where the government and its institutions are expected to remain neutral on religious and/or spiritual matters. Further, secular activities, structures, or phenomena are considered to denote such without any transcendent orientation or possibility (as opposed to spiritual activities, structures, or phenomena).

Sex and gender: I use the term 'sex' to denominate the biological sex. Gender (as a social construction) is, if used, intended to denominate the (fluid) subjective experience of (not) identifying with a specific sex.

Spirituality (spiritual): For this thesis, I use the European (European Association for Palliative Care) version of the U.S. consensus definition (Puchalski et al., 2014) of 'spirituality':

"Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred." (Nolan et al., 2011)

I use this definition as an umbrella term inclusive of theistic (e.g. religious), nontheistic, and atheistic (e.g., classic secular existential) aspects of the human condition. Spirituality in this understanding is thus inclusive of religiosity (see above) and the existential (see above).

It should be noted that the Danish National Health Data Authority translates the English word "spiritual" to "eksistentiel og åndelig" in Danish (en: existential and

spiritual) in their guidelines on spiritual care (spiritual care in Danish: Eksistentiel og åndelig omsorg) (Sundhedsstyrelsen, 2017). Thus, when writing in Danish I always write it out as “Eksistentiel og åndelig” and when writing in English I use the word “spiritual. The reason for this “double-word-translation” was that the word “eksistentiel” has a risk of leaving out the transcendent aspect of whichever word is used as the umbrella term, while the word “spirituel” in Danish has strong connotations to New Age philosophy etc. which was also sought to be avoided. Hence, the English term “spiritual” became “eksistentiel og åndelig” in Danish rather than just “eksistentiel” or “spirituel”.

Spiritual needs: ‘Spiritual needs’ are considered needs, concerns, or suffering related to the above understanding of spirituality *(T. A. Stripp, S. Wehberg, et al., 2023)*.

Spiritual aspects: I use this notion to mark specific parts of the spiritual dimension of health. E.g. can “prayer” be an aspect of the spiritual dimension.

Spiritual dimension: I use this notion to describe the dimension of health that is considered “spiritual”, in contrast to the physical, psychological, and social. See above “Dimensions of health”.

Spiritual care: Spiritual care is a type of care concerned with providing support for needs and struggles emanating from the spiritual dimension of the human condition (Hvidt et al., 2020).

Total pain: I use the Total Pain model of Dame Cicely Saunders (Richmond, 2005) and the conceptualizations of the WHO (World Health Organization) to understand and describe how pain has four distinct dimensions that align with the “dimensions of health”: the physical, psychological, social, and spiritual.

Validity: That a measure, estimate etc. does indeed reflect the true construct or value in the population. Internal validity refers to the internal methodology, rigorousness and strength of a study while external validity refers to how the study estimates or results relate to other studies’ findings on the same topic, theoretical knowledge, and how well the results can be used “outside” of the study itself.

03.04 Conflict of interests

I declare no interests which can be construed as conflicts of interest with the contents of this thesis.

03.05 Funding

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04 SUMMARIES

Make everything as simple as possible, but not simpler. — Albert Einstein

04.01 Abstract (english)

This thesis contains information on an extensive study on spiritual needs in a population random sample. Various international and national guidelines on health care at both primary (general practice) and secondary (hospital) levels emphasize a holistic and patient-centred approach where care is delivered to alleviate and prevent physical, psychological, social, and spiritual suffering. This latter spiritual dimension has received relatively little attention in care and research but is gaining attention due to amounting robust evidence documenting protective health effects of spiritual factors such as affiliations, beliefs, and practices. In addition, needs related to spiritual aspects (called 'spiritual needs') might increase as a person ages, gets severely ill, or approaches death. Research shows that attention to such spiritual needs might improve patients' health outcomes and health care professionals' well-being and reduce the overall cost of care. However, knowledge of spiritual needs in supposedly secular cultures, such as the Danish, is sparse, limiting clinical administration and political attention to care that addresses spiritual needs. Increased knowledge of spiritual needs in the population is thus needed. Consequently, the purpose of this thesis was to examine the spiritual needs of adult Danes.

The EXIstential health COhort DEnmark (EXICODE) questionnaire was developed as a compiled questionnaire containing various validated translated instruments measuring existential and spiritual constructs. The EXICODE questionnaire was tested qualitatively through cognitive interviews (n=14) where good acceptability and comprehensibility were found. Further, testing showed decreasing issues with the questionnaire across iterative rounds hinting at questionnaire maturation. Some questions/scales were adjusted or omitted because of interviewee feedback and issues found.

The Danish Spiritual Needs Questionnaire (DA-SpNQ-20) (a 20-item instrument part of the EXICODE questionnaire) was then psychometrically tested in a test-retest setup in a convenience sample of relatively healthy and young adult Danes (n=345). The instrument showed acceptable structural validity through both exploratory and confirmatory factor analysis, the latter within a structural equation model framework. However, model fit estimations failed to reach the level for a good fit. The DA-SpNQ-20 was established with four dimensions: Religious Needs, Existential Needs, Generativity Needs, and Inner Peace Needs. Cronbach's alphas as a measure of internal consistency were acceptable, good, or very good across dimensions and overall, with values between 0.73-0.93. Skewness and kurtosis analyses indicated some risk of floor effects, as expected

with this ordinal scale designed primarily as a clinical tool, although the distribution was heterogenous across items. Repeatability was high with an ICC of 0.86 and low systematic error was shown in a Bland Altman plot. It was different from the WHO-5 Well-being index, providing evidence for discriminant validity. In conclusion, the DA-SpNQ-20 showed acceptable but not perfect validity and reliability in a sample of healthy and relatively young adult Danes. More research is needed to further establish psychometric validity of the DA-SpNQ-20.

A random sample of 104,137 adult Danes was invited to participate in Wave I of the EXICODE study. In total, 26,678 randomly selected Danes participated (25.6%). Survey data was then linked to national health register data at an individual level. It was found, measured with the DA-SpNQ-20, that 81.9% of respondents reported at least one strong or very strong spiritual need. Inner peace needs were the most prevalent spiritual need in Danes, followed in rank by generativity needs, existential needs, and religious needs. In addition, existential and spiritual factors, low well-being, life satisfaction, and physical health were associated with positive OR for having spiritual needs. Responders and non-responders differed significantly on all measured variables indicating a selection bias. Findings were in line with theoretical understandings and expectations.

In conclusion, an instrument to measure spiritual needs was translated into Danish, qualitatively and quantitatively tested, and used to examine spiritual needs in a randomly selected sample of adult Danes. The thesis provides evidence for spiritual needs in Danes, although with limitations. This finding provides some support that Danes live in a post-secular culture, and thus supports that spiritual matters are salient for Danes.

Future research is needed to establish the clinical importance of spiritual needs, the link between spiritual needs and the actual need for spiritual care, and lastly the optimal way to address spiritual needs when people become patients.

04.02 Resumé (dansk)

Denne afhandling indeholder data på en omfattende undersøgelse af eksistentielle og åndelige behov i et tilfældigt udsnit af en befolkning. Forskellige internationale og nationale retningslinjer for sundhedsarbejde på både primært (almen praksis) og sekundært (hospital) niveau anbefaler en holistisk og patientcentreret tilgang, hvor pleje leveres for at lindre og forebygge lidelse på et fysisk, psykologisk, socialt og eksistentielt/åndeligt niveau. Sidstnævnte eksistentielle og åndelige niveau har fået begrænset opmærksomhed inden for pleje og forskning, men får nu tiltagende opmærksomhed fordi robuste studier har vist beskyttende sundhedseffekter af eksistentielle og åndelige faktorer som tilhørsforhold, tro og praksis. Behov relateret til sådanne eksistentielle og åndelige faktorer (kaldet 'eksistentielle og åndelige behov') kan stige, når en person aldres, bliver alvorligt syg eller nærmer sig døden. Forskning viser, at opmærksomhed på sådanne eksistentielle og åndelige behov er associeret med forbedret patienthelbred, sundhedspersonales trivsel og reducerede samlede omkostninger ved pleje. Viden om eksistentielle og åndelige behov i tilsyneladende sekulære kulturer, som den danske, er imidlertid sparsom, hvilket begrænser klinisk administration og politisk opmærksomhed på omsorg, der inkluderer opmærksomheden på eksistentielle og åndelige behov. Der savnes således viden om eksistentielle og åndelige behov i befolkningen. Derfor var formålet med denne afhandling at undersøge tilfældigt udvalgte voksne danskeres eksistentielle og åndelige behov.

EXIstential health COhort DEnmark (EXICODE) spørgeskemaet blev udviklet som et sammensat spørgeskema indeholdende forskellige validerede oversatte instrumenter, der måler eksistentielle og åndelige faktorer. EXICODE-spørgeskemaet blev testet kvalitativt gennem kognitive interviews (n=14), hvor der blev fundet god acceptabilitet og forståelighed. Desuden viste testen faldende problemer med spørgeskemaet på tværs af iterative runder. Enkelte spørgsmål eller skalaer blev fjernet grundet respons fra interviewdeltagere og opdagede fejl.

Den danske version af Spiritual Needs Questionnaire (DA-SpNQ-20) (et 20-spørgsmål langt instrument i EXICODE-spørgeskemaet) blev herefter psykometrisk testet i et test-retest setup med et convenience sample af relativt raske og unge voksne danskere (n=345). Instrumentet viste acceptabel strukturel validitet gennem både eksplorativ og konfirmatorisk faktoranalyse, sidstnævnte ved brug af structural equation model. Model-tilpasning-estimater i den konfirmatoriske faktoranalyse opnåede ikke det fremsatte niveau for en god model. DA-SpNQ-20 blev etableret med fire dimensioner: religiøse behov,

eksistentielle behov, generativitetsbehov og indre fredsbehov. Cronbachs alfa, som en måling af intern konsistens, var acceptabel, god eller meget god på tværs af dimensioner og generelt, med værdier mellem 0,73-0,93. Skævhed og kurtoseanalyser indikerede nogen risiko for gulveffekter, selvom distributionen var heterogen på tværs af spørgsmål. Repeterbarheden var høj med en ICC på 0,86, og der blev vist lav systematisk fejl i en Bland Altman-plot. Den adskilte sig fra WHO-5 Wellbeing-indekset, hvilket indikerede diskriminantvaliditet. Sammenlagt opnåede DA-SpNQ-20 en acceptabel om end ikke perfekt validitet og pålidelighed i en stikprøve med sunde og relativt unge voksne danskere. Yderligere forskning er nødvendig for videre at etablere validiteten af DA-SpNQ-20.

Et tilfældig udsnit på 104.137 voksne danskere blev inviteret til at deltage i Wave I af EXICODE-studiet. I alt deltog 26.678 (25.6%). Spørgeskemadata blev koblet med data fra de danske nationale sundhedsregistre på individniveau. Jeg fandt, målt med DA-SpNQ-20, at 81.9% af respondenterne rapporterede mindst ét stærkt eller meget stærkt eksistentielt eller åndeligt behov. Behov relateret til indre fred var det mest udbredte eksistentielle eller åndelige behov hos danskerne, efterfulgt (rangeret) af behov for generøsitet, eksistentielle behov og religiøse behov. Eksistentielle og åndelige faktorer samt lavt velvære, livstilfredshed og fysisk sundhed var forbundet med positiv odds ratio for at have eksistentielle eller åndelige behov. Respondenter og ikke-respondenter var signifikant forskellige fra hinanden på alle målte parametre, hvilket indikerer en selektionsbias. Resultaterne var i overensstemmelse med teoretiske forhold.

Sammenlagt, blev et instrument til at måle eksistentielle og åndelige behov oversat til dansk, kvalitativt og kvantitativt testet, og anvendt til at undersøge eksistentielle og åndelige behov i et tilfældigt udsnit af voksne danskere. Afhandlingen bidrager overordnet set med noget evidens, om end begrænset, for at danskere har eksistentielle og åndelige behov. Denne konklusion giver en vis støtte til, at danskere lever i en postsekulær kultur, og understøtter, at eksistentielle og åndelige anliggender er væsentlige for danskere.

Fremtidig forskning skal fastslå den kliniske betydning af eksistentielle og åndelige behov, forbindelsen mellem eksistentielle og åndelige behov og det faktiske behov for eksistentiel og åndelig omsorg, og den optimale måde at imødekomme eksistentielle og åndelige behov på, når folk bliver patienter.

05 BACKGROUND

Research is formalized curiosity. It is poking and prying with a purpose. — Zora Neale Hurston

Through secularization processes and discourses reinforcing logic and natural sciences, spirituality was (to a great extent) removed from public spheres, including health care (Balboni & Balboni, 2019). It was thought that through secularization and increasing knowledge, spirituality (and thus spiritual needs) would disappear altogether (Geeraerts & Nynäs, 2012). However, spirituality as a common human phenomenon always has been, still is, and probably always will be part of the human condition (Pew Research Center, 2017). This is acknowledge in the consideration of Denmark (and other countries) as a post-secular culture (Habermas, 2008). In addition, much research now documents favorable health effects of spirituality (Balboni et al., 2022). Illness (as well as aging and other crises) may stimulate needs related to one's spirituality i.e. spiritual needs (Kimble, 1995). Such spiritual needs can give rise to suffering but also to comfort (Pargament et al., 1998). Care for spiritual needs i.e. spiritual care, may support people in obtaining a comforting spirituality (Hvidt et al., 2020), thus perhaps harnessing some of the health benefits that research documents can be ascribed to spirituality. However, knowledge of spiritual needs in (post-)secular cultures is spare. Thus, a clarification of peoples' spiritual needs (Büssing, 2021) might then be at the center of spiritual care, and paramount to potentially harnessing the benefits spirituality has for health (Koenig et al., 2012; Stripp, 2023) and health economy (Balboni et al., 2011). Consequently, examining the spiritual needs of adult Danes is the objective of my thesis.

In contrast to the above line of argumentation, it has influentially also been argued that spiritual matters should not be part of health care (Sloan et al., 1999). Much research reporting that spirituality is associated with favorable health outcomes are based on cross-sectional data and tautological conclusions as a result of unclear measurement tools among other things (Koenig, 2008). Spiritual care, albeit based on a compassionate wish to perform holistic patient-centered care is arguably just another mechanistic, reductionist tool with which we unconsciously objectify the patient (Bishop, 2011). In addition to this, there is a persistent challenge in the academic literature to reach any (inter)national consensus on the various definitions, interrelationships, and wordings used in the field (e.g. spiritual, religious, existential, meaning, purpose, hope etc.) (la Cour, Ausker, et al., 2012; la Cour & Hvidt, 2010; Schnell, 2009) despite prominent efforts made to this end (Nolan et al., 2011; Puchalski et al., 2014).

The research field of spirituality and health, and hence spiritual needs, is a complex one. In the following I shall try to expand the above line of argumentation in a nuanced and reflective way, to arrive at the rationale for examining spiritual needs in the adult Danish population.

05.01 The history of spirituality and health

The modern healthcare system is historically rooted in spiritual thought and practice (Stripp, 2023). Modern day hospitals (at least in the West) stand on the shoulders of the monasteries and the diaconal service established by the Christian church. This idea is illustrated in the story of the Good Samaritan – the spiritual practice of the outcast Samaritan beckons him to care for his wounded neighbor. However, the historic bond between spirituality and health care has been severed during the past centuries. It was thought that spirituality and peoples' need for spirituality would diminish or disappear through secularization processes and the increase of (scientific) knowledge (Habermas, 2008). However, in a seminal paper J. Habermas concludes that this theory has indeed failed, and instead of having a secular society, we are entering the post-secular (Habermas, 2008). I refer to the "Terminology and definitions" for a further clarification of the post-secular. Be that as it may, Denmark has been through a strong secularization process leading to a situation where spiritual orientations, needs, and values have been severed from public spheres – including the healthcare system (Andersen & Lüchau, 2011; Andersen & Riis, 2002; Gregory, 2012; Kennedy, 2006; Stephenson, 1981; Sulmasy, 2002).

In a recent monograph Balboni and Balboni argue, based on Peter Berger's "plausibility structures"[1] (Berger, 1967), that the separation of spiritual matters from the healthcare system (at least in the US, but suspectedly also in Denmark) is based on three such "plausibility structures": 1) Hospitals are technological institutions (not primarily care institutions as they used to be), 2) doctors are primarily scientists (and not first providers of care as they used to be), and 3) thinking about our mortality can and should be avoided (Balboni & Balboni, 2019, p. 89). While these arguments are well articulated and highly relevant for understanding the present state of the healthcare system, for now, it is enough to state that these three discourses or plausibility structures reinforce a healthcare system focused on the body-as-machine-paradigm rather than a holistic approach to care taking all dimensions of health into account (physical, mental, social, and spiritual). The interested reader may explore further in "*Hostility to Hospitality"* (Balboni & Balboni, 2019).

[1] Plausibility structures influence how individuals perceive and interpret the world, what they consider to be true or believable, and what is considered acceptable or credible within their cultural or social context (Berger, 1967).

05.02 A common human phenomenon?

While we in medical research are usually keen on identifying physical properties of the human condition, less so psychological or social ones, the spiritual dimension of health is, although often overlooked, arguably similarly present and essential to the universal human experience (Hvidt et al., 2021; Sallnow et al., 2022; Schnell, 2010). We humans have sought to understand the meaning of our existence since prehistoric times and continue to do so today (Schnell, 2011). History, whether theological or (secular) philosophical, is full of such contemplation. But is the spiritual dimension so widespread and important to humans to warrant inquiry in (health) research?

A simple but intriguing argument that the spiritual (including religious) experience is indeed a universal human phenomenon is that of the late Harvard University psychologist William James. He states the following in his seminal work *The Varieties of Religious Experience:*

"[…] in a world in which no religious feeling had ever existed, I doubt whether any philosophic theology could ever have been framed" (James, 1902).

Since it is evident that philosophic theology at some level has emerged virtually everywhere on our planet, it should be possible to conclude that spiritual experience is universal to the human condition, and not contingent first upon its theological or philosophical institutions (i.e. the religious societies). Indeed, spirituality (as measured by religious affiliation) is thriving and increasing worldwide – not diminishing. It is estimated that people affiliated with a belief will increase by 2.3 billion by 2060 (an increase of 3.5 percent points relative to the total population) (Pew Research Center, 2017). That a spiritual dimension of health can be viewed as important (and distinct from just the physical, psychological, and social dimensions) might also be justified in the fact that roughly 5.5 billion of the world's population affiliates with Christianity, Judaism, Hinduism, or Islam (Pew Research Center, 2017). In addition, these are all religions with concepts that resemble the soul or another form of transcendent identity that cannot be completely explained as supervenient on material reality, indicating that most of the world's population actually, to some extent at least, believe in some form of transcendent reality – making an ontologically distinct spiritual dimension of health arguably justified. In Denmark, the number of individuals considering themselves as a "believer" is diminishing, however, at the same time we see an increase in people believing in a "divine, spiritual lifeforce

[…] with or without God", while the prevalence of individuals going to service at least once per month is stable (P. Andersen et al., 2019).

But how is this relevant in our societies today? It is essential at many levels. Nissen and Andersen recently argued that in Denmark due to secularization trends, spiritual affiliation, practice, and belief are tabooed and individualized (Nissen & Andersen, 2021). A survey by Gallup from 2016 found that Danes consider "faith and religion" the largest taboo second only to "mental illness" (Jensen & Mørk, 2016). Despite being a taboo, in light of the above, spirituality might be seen as a common human condition – something that has always been, still is, and probably will continue to be part of the human experience. Acknowledging this, numerous (Danish and international) influential health care stakeholders, institutions, and societies recommend that health care includes caring for a physical, psychological, social, *and* spiritual dimension (see 03.03 Terminology and Definitions on "Dimensions of health"). This is in accord with the 'total pain model' developed by Dame Cicely Saunders – in which pain can relate to both physical, psychological, social, and spiritual aspects (Richmond, 2005; Stripp & Joshi, 2023). The institutions supporting such holistic definition of health include among others the World Health Organization, the World Organizations of Family Doctors, the Danish Health Authority, the Danish Society for General Practice (DSAM) and other professional groups (Allen et al., 2011; Saxtrup et al., 2022; Sundhedsstyrelsen, 2017; World Health Organization, 1993). The Lancet Commission on Palliative Care similarly considered spiritual suffering and pain on the same level of importance as physical and psychosocial pain (Knaul et al., 2018). The official recommendations from all of these institutions support care for the spiritual dimension of health by recognizing the innate need of humans to "*experience, express and/or seek meaning, purpose and transcendence" (Nolan et al., 2011).* It thus seems reasonable to conclude that spirituality, although not "necessary", important, or relevant for some individuals, is still a salient and important dimension of the life of many humans. In order to secure an inclusive approach to health, one could well argue that a spiritual dimension would need to be included albeit some might consider it irrelevant. But does it relate to health, and if so, in which way?

05.03 Spirituality and health

When it comes to the health effects of spirituality, a growing body of studies, with considerably small risk of bias and utilization of modern advanced statistical causal inference models with strict confounding control, provides high-quality evidence that: believing in a higher power, regularly practicing your faith

(especially through religious service attendance), and experiencing a high degree of meaning and purpose is strongly protective for physical, mental, and social health (Ahrenfeldt et al., 2017; Ahrenfeldt et al., 2023; Balboni et al., 2022; Chen et al., 2021; Czekierda et al., 2017; Herold et al., 2020; Li et al., 2016; Sokol et al., 2021). Previously there has oftentimes been numerous issues with the robustness of studies reported on spirituality and health, the main issues being poor measurement tools and predominantly cross-sectional studies without the design needed to draw causal inferences (Koenig, 2008). This has led to numerous studies reporting that spirituality leads to e.g. wellbeing (sometimes achieved by having spirituality measures contaminated with e.g. mental well-being items) – a form of tautological reasoning that cannot be used to draw any causal inferences regarding the effect of spirituality on health. However, the above cited studies from both Denmark and other countries utilize well-validated measures, prospective designs, and strict confounding control, providing a new level of evidence. Readers wishing to read more intensively on the evidence underlying these assumptions are referred to the Handbook of Religion and Health, which is the most comprehensive collection of research in this field (the newly edited 3rd edition has more than 10.000 references) (Koeing et al., 2023). While much of the research cited is from more religious cultures such as the U.S., findings in other cultures as well as in Denmark, have replicated the results. As an example of this, I and colleagues recently published a study in the European Journal of Epidemiology, with longitudinal data from Denmark (SHARE, 2021), showing a 30% reduced hazard ratio for all-cause mortality (44% for women), and a 33% reduced incidence rate ratio for hospitalizations among men, in people who had participated in a religious service in the past 30 day (Ahrenfeldt et al., 2023).

When it comes to the effect of spirituality on the individual, especially participation in religious activity has been studied. This is partly due to the ease of measuring a construct such as “number of visits to church” rather than “faith” or “spiritual well-being” which are more complex, although multiple prominent researchers have made substantial efforts in measuring such outcomes as well. Numerous health benefits have been found as the effect from believing in a higher power, regularly practicing one’s faith (especially through religious service attendance), and experiencing a high degree of meaning and purpose (Ahrenfeldt et al., 2017; Ahrenfeldt et al., 2023; Balboni et al., 2022; Chen et al., 2021; Czekierda et al., 2017; Herold et al., 2020; Li et al., 2016; Sokol et al., 2021). According to the works of Schnell, believing in a higher power (vertical self-transcendence) is a strong predictor of meaningfulness and purpose in life (Schnell, 2009). Furthermore, when a patient is diagnosed with severe illness, they may often

respond with a crisis of meaning or fear of death, etc. (spiritual needs) – such feelings and concerns are related to the existential dimension (e.g. spiritual needs), and call for spiritual care (A. H. Andersen et al., 2019; Büssing et al., 2010; Hanson et al., 2008; Larimore et al., 2002; Momennasab et al., 2012; Stripp & Joshi, 2023; Sulmasy, 2002; Taylor et al., 2013).

While it for some may be considered out of scope for health care professionals (as it is often considered solely the responsibility of the hospital chaplain) to provide spiritual care, some studies have shown that providing spiritual care may contribute to job satisfaction, reduced burnout, and greater well-being among health care professionals (Turan & Yavuz Karamanoglu, 2013; van de Geer et al., 2018; van Leeuwen et al., 2008; Vlasblom et al., 2011; Wasner et al., 2005; Weaver et al., 2008). While the reason for this is less clear (Doolittle et al., 2013), it is known that meaningfulness and purpose is connected to reduced burnout and higher work life satisfaction (Doolittle et al., 2013; Shanafelt, 2009). It has been suggested that the effect of providing spiritual care on burnout is a result of increased experience of meaning and purpose on behalf of the care provider (Yong et al., 2011). Future research would have to explore this further.

Since a range of studies point to decreased mortality, reduced risk behaviors e.g. smoking/drinking/drug abuse and even lower risk of certain diseases among other things, as an effect of spirituality, it has been suggested to be an important public health matter (Chen et al., 2018; Ennis & Kazer, 2013; Jafari et al., 2013; Kennedy et al., 2002; Kristeller et al., 2005; McClain et al., 2003; Tajbakhsh et al., 2018; Thygesen et al., 2012; van de Geer et al., 2017; Williams et al., 2011). Some studies have found a substantially reduced cost of care in patients receiving sufficient spiritual care (Balboni et al., 2013; Balboni et al., 2010). This latter study showed that the cost of care in the final week of life for patients who felt their spiritual needs were met was more than 50% reduced compared to patients who were not satisfied with their spiritual care, a figure that were even larger for minority group patients.

05.03.01 Potential mechanisms of action

But how does spirituality affect health? Can we conceive of any plausible mechanisms of action? Figure 2 provides a theoretical model for the causal pathways between spirituality and health outcomes. As is shown there are numerous potential mechanisms of action, some which have been exemplified in the figure. Some have been studied and some are difficult to measure. To illustrate: since it is well-know that lifestyle factors affect health (e.g. smoking

increases risk of lung cancer), and it is also known that religious people smoke less (Herold et al., 2020), the effect of spirituality on health could possibly (in part) be ascribed to reduced smoking. The challenge and objective then is to as accurately as possible measure all the potential outcomes on the pathways from spirituality to health to be able to control for these in analyses. Having done so, mediation analysis techniques could then be utilized to examine which of the factors contribute to the total protective effect of spirituality on health (Hernan & Robinson, 2023; VanderWeele, 2015). In fact, this has been tried in a few studies (Kim & VanderWeele, 2019; Li et al., 2016). In the study by Kim and VanderWeele, the authors sought to identify how various mediators contributed to the reduced mortality-rate seen in people attending religious service. Albeit using a broad range of potential and feasible mediators such as social factors (e.g. seeing friends), lifestyle factors (e.g. smoking), and mental factors (e.g. life satisfaction or positive affect), only part of the total effect of religious service attendance on health was explained (Kim & VanderWeele, 2019).

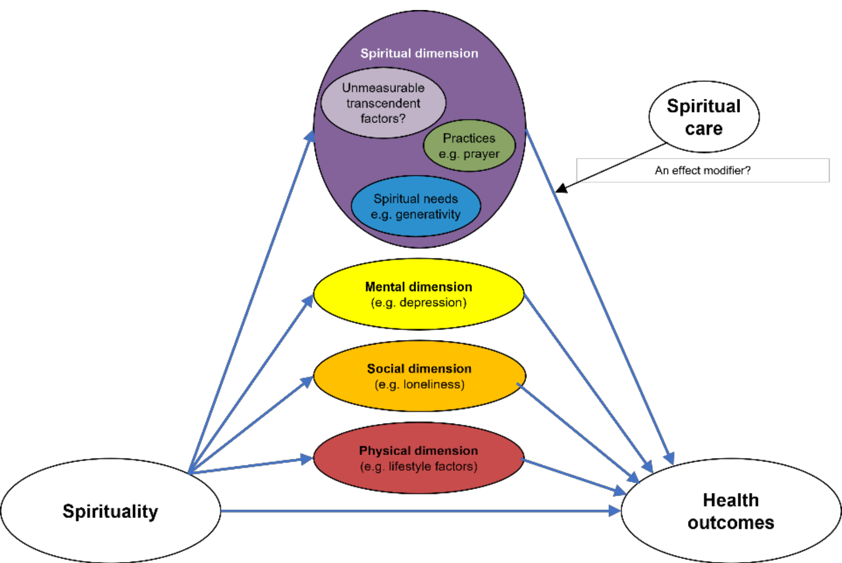

Figure 2 - A theoretical model of how spirituality affects health outcomes through e.g. spiritual needs.

Then what is the role of spiritual care? It could be speculated, based on current evidence, that spiritual care somehow modifies the effect spirituality has on health. Drawing on the literature from spiritual and religious coping as expanded by e.g. Pargament, it could be thought that care for spiritual matters enhances

the chance of using positive religious coping rather than negative religious coping – a difference that is described to have important implications for health (Pargament et al., 1998; Pedersen et al., 2013; Rosmarin et al., 2013).

To more clearly be able to understand the mechanisms of how spirituality affects health, large longitudinal studies with rich confounder and mediator data with numerous waves of data enabling control for baseline exposure and outcome will be needed. Still, as researchers we should be humbly aware, considering Popper's theory of falsification (Popper, 1959), that there might be other factors that mediate the effect e.g. transcendent factors, which are currently at the time of writing unmeasurable but which in theory could play a role in the mechanism of action. Many people believe that e.g. divine entities may directly influence the physical world and thus it could be speculated that such a potential could also play a role when explaining the mechanisms of action between spirituality and health. Such a metaphysical discussion, however, reaches well beyond the aims and scope of this thesis.

05.04 Spiritual needs and spiritual care

Having laid out the background rationale for my thesis I shall now dive deeper into the nature of spiritual needs. Above, it has been described how attention to the spiritual dimension of health is recommended by various stakeholders. But is this what we see in practice today? To do so, one would first have to look at what spiritual needs are. While spiritual needs have already been mentioned, their nature will be further explained here.

Spiritual needs are by the above definitions considered *needs* or *concerns* related to "*the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred*" (Nolan et al., 2011). As such, spiritual needs are experienced by the patient as needs related to the spiritual dimension of life and distinguish themselves by not being related to the physical body (e.g. pain from a broken leg), the psychological state (e.g. anxiety), or the social context (e.g. loneliness). Examples can be the need for practices or conversations that address fear of death, loss of meaning, hope, or communion with the divine (Bussing et al., 2013; Hocker et al., 2014; Koenig, 1994). Spiritual needs may emerge during aging, illness, or life crises (Kimble, 1995). Importantly spiritual needs are not necessarily related to a transcendent reality e.g. God, as it may also be related to classic secular meaning making

systems – such as the need for being in nature or helping loved ones. Unmet spiritual needs may lead to spiritual pain cf. the total pain model.

A recent review of spiritual needs instruments demonstrates that many questionnaire instruments are available internationally (but less so in Danish) which address the spiritual dimension of health (Damberg Nissen et al., 2020). However, most of the identified instruments are not readily implementable in Danish culture due to a predominant religious focus. Due to the cultural barriers mentioned above, such a focus would not be feasible as a measure of 'spiritual needs' in Denmark. A more comprehensive understanding of spiritual needs is needed: an instrument devoid of strict religious vernacular, while not denying or leaving out the possibility for religious affiliation, and at the same time providing a pluralistic and heterogenic framework for spiritual needs, acknowledging that the spiritual dimension may be both related to transcendent non-secular understandings, but also to non-transcendent secular beliefs and orientations.

Further analysis of the spiritual care catalogue by Nissen et al. (2020) proposed a reduced number of instruments potentially relevant in the Danish culture (Nissen et al., 2021). An instrument that seems to achieve the necessary flexibility is the "Spiritual Needs Questionnaire" (SpNQ) by Arndt Büssing (Büssing, 2021; Büssing et al., 2010; Büssing, Recchia, Koenig, et al., 2018; T. K. Stripp, A. Büssing, et al., 2022). The SpNQ measures spiritual needs in four main dimensions (1) 'religious needs,' which cover needs related to the transcendent, e.g., God, Allah, the Universe, or other higher power, as well as needs related to religious communities and practices; (2) 'existential needs,' which cover those related to reflections on life and death, meaning in life etc.; (3) 'generativity needs,' which relates to the need to give something to others and help other people; and lastly, (4) 'inner peace needs,' which covers needs related to a sense of inner peace or rest in nature (T. K. Stripp, A. Büssing, et al., 2022). Büssing states on the homepage of the SpNQ[2] that the "factors are in line with the definition of spirituality as described by the European Association for Palliative Care (EAPC)" relevantly matching and aligning with the definitions used in this thesis.

Research on spiritual needs in Denmark is sparse and difficult. There are at least two reasons for this. First, few instruments have been developed or translated into Danish. As such, the translation and development of the SpNQ (DA-SpNQ-

[2] www.spiritualneeds.net

20) reported in this thesis is, to the best of my knowledge, the first attempt to make available a tool to measure spiritual needs available in Danish (T. K. Stripp, A. Büssing, et al., 2022). Currently, the SpNQ is available in 13 languages. Büssing himself argues that the SpNQ is both a research and a clinical tool (Büssing, 2021). Clinically, it may stimulate conversation and help clinicians prepare a spiritual care plan, supporting spiritual care initiatives. Other related works by Danish scholars have been undertaken to support and measure aspects of the spiritual dimension of health in Denmark which require mention here. The Sources of Meaning and Meaning in Life (SoMe) questionnaire by Schnell has been translated into Danish (la Cour, Frølund, et al., 2012). The FICA instrument by Puchalski has been preliminarily translated into Danish, although to the best of my knowledge it has not yet been validated or properly tested. Other important validation works has have been undertaken in Danish with questionnaires worth mentioning, e.g. the work on EORTC QLQ-C15-PAL by Groenvold (2006) – however, although this scale is sensitive to many aspects relevant to the palliative patient, it is completely devoid of content addressing the spiritual dimension. The FICA is a clinical spiritual history tool and the SoMe is measuring meaning in life and sources of meaning; both tools are related to, but do not measure, spiritual needs.

Second, many Danes have a hard time defining words such as “existential” or “spiritual” (la Cour et al., 2016; la Cour, Ausker, et al., 2012). One reason for this, is arguably the lack of spiritual vernacular in the lived Danish language. Due to the above discussed secularization processes, many Danes have lost the nuances and understandings of important words and constructs related to these topics, e.g. ‘ærefrygt’ (en: awe), ‘andægtig’ (en: devout), ‘tro’ (en: faith) (T. A. Stripp, D. T. Viftrup, et al., 2022). Thus, the situation is often that either patients are unable to express spiritual needs due to lack of words or people avoid sharing their specific needs even if they are themselves aware of such needs, due to risk of stigma and taboo. This is aggravated when both public and academic definitions of e.g. spirituality are unclear. When spirituality is considered exclusively a religious construct, the non-religious feel left out; and when it is considered esoteric, the religious people might reject the term (Stifoss-Hanssen, 2009). Thus, many are lost for words when confronted with spiritual issues or concerns – both in research and in the clinical setting. This is another reason why studies on spiritual needs are essential in post-secular cultures: if spiritual matters are indeed central to the human experience, they become especially so during illness and other crises, despite the patient or the healthcare professional’s inability to address or even express such ideas and needs. Research on spiritual needs has the potential to help recover some of our spiritual vernacular.

The conceptual content of the SpNQ is shown in Box 1. Building on the EAPC definition of spirituality all of the statements in Box 1 can arguably relate to "*the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred*" (Nolan et al., 2011), making them, at least for the sake of this thesis, "spiritual needs". Some items can clearly be related to the transcendent and readily be construed as a "spiritual/religious need" e.g. "pray for yourself" or "turn to a higher presence". However, critique has rightfully been raised whether all the 20 items can be classified as "spiritual needs" or if this definition is too broad to be meaningful. Some argue that a number of the inquiries and topics denoted as "spiritual needs" in the SpNQ could instead be considered to belong to the psychological or social dimension rather than the spiritual. This is a relevant objection.

BOX 1. CONCEPTUAL CONTENT OF THE SPIRITUAL NEEDS QUESTIONNAIRE.

Did you have a need to…

Religious needs:
- Pray for yourself
- Pray with someone
- Someone prays for you
- Turn to a higher presence e.g. God, Allah, the Universe
- Participate in a religious ceremony (e.g. service)
- Read religious/spiritual books

Existential needs:
- Be forgiven
- Forgive someone
- Dissolve open aspects of your life
- Talk about the question of meaning in life
- Talk about the possibility of life after death
- Find meaning in illness and/or suffering

Inner peace needs:
- Dwell at a place of quietness and peace
- Plunge into beauty of nature
- Find inner peace
- Talk with someone about fears and worries

Generativity needs:
- Pass own life experience to others
- Be assured that your life was meaningful and of value
- Give solace to someone
- Give away something from yourself

To exemplify, it has been questioned whether e.g. "find inner peace" or "give away something from yourself" can be called a spiritual need as these could easily be construed as solely psychological or social needs. However, the need of e.g. giving something from yourself to other generations (i.e. generativity) is a self-transcendent act through space and time (you do something good that extends beyond your immediate physical body and time) and may thus be understood as different from a psychological need which is mainly self-oriented/relates to mental states in the present moment, or the immediate past or future. Further, it qualifies as something "spiritual" following our EAPC consensus definition as "*the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred*". Inner peace might be more difficult to classify as a spiritual need rather than a psychological one, and as I have already mentioned in 03.03 some phenomena are difficult to classify as either/or as they are rather on the border and will be understood differently by different people. Still, inner peace may arguably be considered as spiritual in the sense that it relates to the EAPC definition of spirituality as the way persons "*connect to the moment, to self"* and *"to nature*" (Nolan et al., 2011). Furthermore, questions of "inner peace" are continuously found as essential for the construct of spirituality in studies examining spiritual life, spiritual well-being, and spiritual needs. As a result items addressing "inner peace" have made their way into almost all of the internationally commonly used questionnaires on spirituality and spiritual needs, such as the SpNQ by Büssing (2010), the Spiritual Health And Life-Orientation Measure (SHALOM) by Fisher (2010), the Spiritual Needs Assessment for Patients (SNAP) tool by Sharma et al. (2012), and also the widely used Spiritual Wellbeing Scale by Paloutzian and Ellison (1982). It could obviously be argued that despite all these scholars including questions of inner peace in their questionnaires on spirituality, they simply all got it wrong – inner peace was a psychological question all along. However, sometimes in research lines will have to be drawn through shades of grey and the issue of whether inner peace belongs in the psychological or spiritual domain might be one that will not be resolved anytime soon. For the sake of this thesis, I find the above arguments sufficiently compelling to accept Büssing's classification of "inner peace" as a spiritual need.

The care provided for spiritual needs is termed 'spiritual care' (Hvidt et al., 2020). Spiritual care both addresses the suffering, but also engages with the patient's resources and own practices related to the spiritual dimension. Health professionals generally think that existential and spiritual matters may positively impact health and coping (Hvidt et al., 2016; Kørup et al., 2017). In alignment with

this, most agree that spiritual care should be administered (Kristeller et al., 1999; Monroe et al., 2003). In contrast, evidence show that patients largely do not receive such spiritual care (A. H. Andersen et al., 2019; Assing Hvidt et al., 2017; Ehman et al., 1999; Flannelly et al., 2003; Kristeller et al., 1999; McCord et al., 2004; Monroe et al., 2003; Voltmer et al., 2014). There have been substantial objections towards the inclusion of spiritual care in standard care. Influential voices have argued that spiritual care should not be part of health care initiatives (Sloan et al., 1999). Sloan argues that such a dimension of health should be cared for in other arenas of society. While this argument has merit, a contrary position is clarified by viewing the situation similarly to the 1960's taboo around sexuality where the clinical PLISSIT tool was developed to help clinicians address sexual matter with patients because it became evident that the sexual life of patients was important to them during times of illness (Annon, 1976). The thought then was that if it is to the patients' benefit to discuss sexuality, the health care provider should do so, even if they do not share the interest in the topic or the sexuality of the patient. And so, perhaps, it is with spiritual care.

A different objection towards spiritual care is brought forward by Bishop in the seminal work "The Anticipatory Corpse" (2011). Bishop is ultimately suggesting that the historical objective of the medical community has been, and still is, to conquer death by installing and using increasingly sophisticated technological (and cruel and inhumane such as needles, operations etc.) methods that alter the body through a body-as-machine paradigm (Bishop, 2011). While I shall not in deep recap the book, it suffices to say that Bishop argues, convincingly, that spiritual care and research in spirituality and health, albeit often proclaimed as an effort to promote holistic and patient-centred care, is just an expansion of positivist biomedical practice that ultimately considers humans as machines thus making compassionate care acknowledging the fellow human being and their suffering impossible.

05.05 Developing a measurement tool

The above describes what spiritual needs are, and, I believe, sufficiently, how they are different from e.g. physical or psychological needs. But how can we measure spiritual needs? Spiritual needs (like most other phenomena) may in simplification be examined through qualitative and quantitative measures. The qualitative methods in this regard aim at delineating the experience of spiritual needs of the informant through e.g. interviews or observations. Such data may then be analysed in a variety of ways based on purpose and scholarly discipline (Brinkmann & Tanggaard, 2020). A psychometrically valid questionnaire

instrument is needed for quantitative measurement of spiritual needs (Frick et al., 2006; Nissen et al., 2021; Sharma et al., 2012). By 'psychometrically valid', what is meant is a questionnaire that has been quantitatively tested and validated by use of specific statistical analyses and criteria for the specific population in which it is used. Importantly (and often understated and frequently left out), qualitative testing of the questionnaire is also needed to provide evidence that a questionnaire is indeed validly measuring what it purports to (Collins, 2014; de Vet et al., 2011). The terminology and theoretical framework used in this thesis for the psychometric validation of questionnaire instruments is the COSMIN guidelines and taxonomy (see 03.03 for the COSMIN taxonomy) (Mokkink et al., 2018). In summary, the recommended approach to the development of a tool to measure e.g. spiritual needs is to perform both qualitative and quantitative testing, which is what I shall do my best to undertake in this thesis.

In summary, I have tried to argue that spirituality is relevant for the human experience and that since there is growing evidence for its effect on health outcomes, it is now relevant to examine how, if, and which spiritual needs are experienced in the population and among patients (analyses of spiritual needs in patient groups are outside the scope of this thesis). Such investigation will potentially open the doors for adequate spiritual care when people become patients, care which may have important public health potentials.

06 AIMS AND OBJECTIVES

To ask the right question is already half the solution of a problem. — Carl Jung

This thesis aims to examine spiritual needs in Danes, the importance of which has been clarified above. Following the COSMIN guidelines for best practice regarding questionnaire methodology, I start by translating and testing the DA-SpNQ-20 qualitatively. Subsequently the DA-SpNQ-20 is quantitatively tested to assess the psychometric properties. Then, the DA-SpNQ-20 is deployed in a large random sample of adult Danes to examine spiritual needs in Danes.

In order of appearance the specific objectives are inserted from their respective published papers:

1. To translate into Danish and qualitatively test through cognitive interviews the EXICODE questionnaire – a compiled questionnaire on existential and spiritual constructs. Specifically, the objectives were to (T. A. Stripp, D. T. Viftrup, et al., 2022):
   1.1. Examine the acceptability and comprehensibility of the questionnaire.
   1.2. Make recommendations for questionnaire improvement through directed qualitative content analysis and use these recommendations to amend the questionnaire over subsequent testing rounds.
   1.3. Assess how the questionnaire performed over subsequent testing rounds by quantifying the issues identified in each testing round through a predefined theoretical framework.

2. To quantitatively test the psychometric properties of the Spiritual Needs Questionnaire in a field test among adult Danes. Specifically, the objectives were to test (T. K. Stripp, A. Büssing, et al., 2022):
   2.1. The structural validity of the DA-SpNQ-20 with EFA.
   2.2. The reliability of the translated instrument through measuring the internal consistency coefficient 'Cronbach's alpha' with original structure retained.
   2.3. How the originally proposed factor model of the SpNQ fits the DA-SpNQ-20 by confirmatory factor analysis through structural equation modelling.
   2.4. The repeatability of the DA-SpNQ-20 by use of intra-class-correlation and a Bland-Altman plot.
   2.5. Test discriminant validity by examining correlations between spiritual needs and well-being through use of a correlation matrix.

3. To investigate the spiritual needs of randomly selected adult Danes and associations to demographic and person characteristics. Specifically, the objectives were to (T. A. Stripp, S. Wehberg, et al., 2023):
    3.1. Estimate the prevalence of spiritual needs in a random sample of adult Danes.
    3.2. Examine associations between individual characteristics and spiritual needs using multivariable logistic regression.

07 METHODS

What we observe is not nature itself, but nature exposed to our method of questioning. — Werner Heisenberg

The methodology of this thesis draws on various disciplines, i.e. medicine, theology, psychology, public health, and statistics. The approach is partly qualitative, partly quantitative. In the following I shall give an overview of the methods used, to put the reader in a position to be able to evaluate the scientific quality of the thesis, as well as comfortably read the results section. For a highly detailed methodological account pertaining to specific parts of the thesis I refer the reader to seek out the relevant methods sections in the published manuscripts (appendices A, B, and C).

I shall start with describing how the EXICODE questionnaire was prepared and translated into Danish. I shall then give a description of the approach taken to qualitatively test the questionnaire and improve the acceptability and comprehensibility. Then the psychometric evaluation of the DA-SpNQ-20 will be described, and ultimately, the way in which I deployed the DA-SpNQ-20 to investigate spiritual needs in a randomly selected sample of adult Danes.

For accuracy purposes, parts of the following methods section are quotations from published papers: section 07.01 from (T. K. Stripp, S. Wehberg, et al., 2022), 07.02 from (T. A. Stripp, D. T. Viftrup, et al., 2022), 07.03 from (T. K. Stripp, A. Büssing, et al., 2022), and 07.04 from (T. A. Stripp, S. Wehberg, et al., 2023).

07.01 Preparation of the questionnaire

The EXICODE questionnaire was developed as a compiled questionnaire consisting of various validated instruments on existential and spiritual constructs (T. K. Stripp, S. Wehberg, et al., 2022). We, the author of this thesis together with collaborators and colleagues, identified relevant instruments based on 1) research objectives, 2) prior experience in the project group, and 3) “The catalogue of spiritual care instruments” (Damberg Nissen et al., 2020). Identified instruments were then evaluated by three criteria: 1) they had to have high face validity – i.e. by initial evaluation they should indeed seem to be measuring the constructs it purported to, 2) there had to have been conducted high quality validation works on the instrument (i.e. reports of development, qualitative testing, psychometric analyses etc.) published in scientific journals, and 3) the instrument would have to fit the Danish population i.e. it should be “devoid of strict religious vernacular, while not denying or leaving out the possibility for religious affiliation, and at the same time providing a pluralistic and heterogenic framework for spiritual needs, acknowledging that the spiritual dimension may be both related to transcendent non-secular understandings, but also to non-transcendent

secular beliefs and orientations” (see 05.04 above). These criteria made it more probable that the instruments chosen would yield high quality data.

In summary, instruments covering various relevant constructs were included; well-being (WHO-5) (Topp et al., 2015), health status (EQ-5D) (Herdman et al., 2011), life and support satisfaction (BMLSS)(Bussing et al., 2009), spiritual needs (SpNQ) (Büssing, Recchia, Koenig, et al., 2018), engagement in religious and spiritual practices (SpREUK-P) (Bussing et al., 2005), gratitude and awe (GrAw-7) (Büssing, Recchia, & Baumann, 2018), adaptive coping (AKU) (Bussing et al., 2010), meaning in life and crisis of meaning (adopted from (Schnell, 2009)), near-death experience content (NDE-C) (Martial et al., 2020), human flourishing ((S)FI) (Weziak-Bialowolska et al., 2019), interpretation of illness (IIQ) (Bussing & Fischer, 2009), and satisfaction with spiritual care (SWS) (adopted from (Hanson et al., 2008)). The instruments were compiled into a combined questionnaire and prepared for qualitative testing (Table 2).

Table 2 - Content of the EXICODE Questionnaire: Instruments on existential and spiritual constructs.

Instruments in the Existential Health Cohort Questionnaire	Abbr.	Construct	# of items	Item example
WHO Well-being Index (Topp et al., 2015)	WHO-5	Well-being	5	During the past two weeks… I have felt active and energetic.
EuroQol Health states (5 levels) (Herdman et al., 2011)	EQ5D	Health status	5	Today… have you felt pain/discomfort?
Brief Multidimensional Life Satisfaction Scale (Bussing et al., 2009)	BMLSS	Life and support satisfaction	18	How satisfied are you with… your family life?
Spiritual Needs Questionnaire (Büssing, Recchia, Koenig, et al., 2018)	SpNQ	Spiritual needs	20	During the last month did you have the need… to be forgiven?
SpREUK-P (Bussing et al., 2005) + GrAw-7 (Büssing, Recchia, & Baumann, 2018)	SpREUK-P + GrAw-7	Engagement in existential and spiritual practices + gratitude/awe	25	How often do you engage in the following: I meditate.
Adaptive coping (RGH and escape subscales) (Bussing et al., 2010)	AKU	Adaptive coping	8	My faith is my foundation, even in difficult times.
Meaning in life (adopted from SoME (Schnell, 2009))	-	Meaning in life and	6	My life is meaningful.

		crisis of meaning		
Near-death experience content scale (Martial et al., 2020)	NDE-C	Near-death experience	20	You met a presence and/or an entity (i.e. a deceased person).
Flourish and Secure Flourish Index (Weziak-Bialowolska et al., 2019)	FI and SFI	Human flourishing	12	How happy or unhappy do you usually feel?
†Interpretation of Illness Questionnaire (Bussing & Fischer, 2009)	IIQ	Interpretation of Illness	8	I regard my disease as… a call for help.
†Satisfaction With Spiritual support (Hanson et al., 2008)	SWS	Satisfaction with spiritual care	5	I have spoken with [which type of professional?] about … meaning in life. [If YES, then rate your satisfaction with that encounter]

† These instruments were omitted as a result of adjustment recommendations during iterative rounds of cognitive interviews since they were not either acceptable or comprehensible. From (T. A. Stripp, D. T. Viftrup, et al., 2022)

07.01.1 Translation and cultural adaptation

The translations of instruments (BMLSS, SpNQ, SpREUK-P, GrAw-7, AKU, MAPS, NDE-C, (S)FI) were done according to the WHO guidelines (World Health Organization). The WHO guideline was chosen as this is a widely recognized protocol, and it was deemed the most feasible approach in terms of quality, time, and funding, and because the main supervisor had experience with this approach from previous research. This guideline included forward-backward-translation by language experts and evaluation by an expert panel (Figure 3).

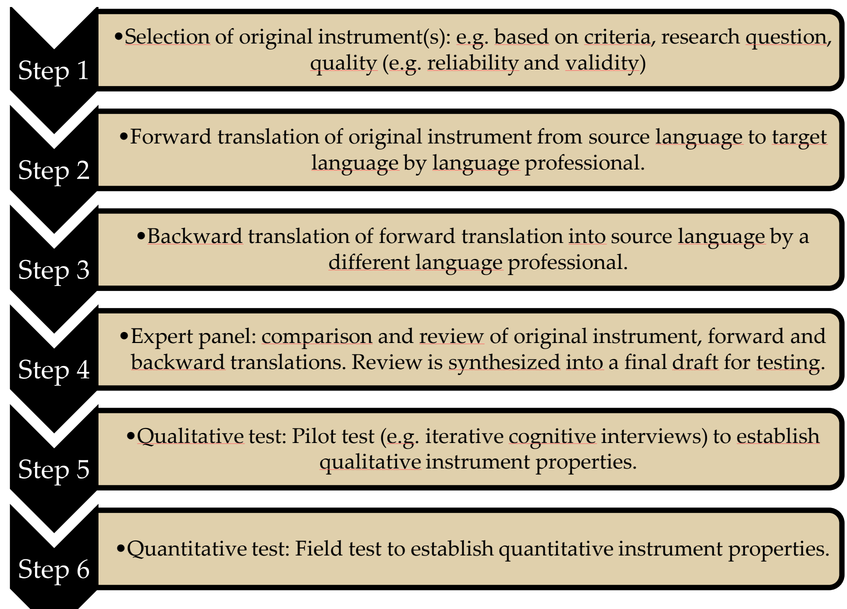

Figure 3 - The process of translation, cultural adaptation, and testing of a questionnaire.

From (T. A. Stripp, D. T. Viftrup, et al., 2022)

The questionnaire was then digitally set up in Ramboll's SurveyXact (RMC, 2022) and prepared for testing with cognitive interviews. SurveyXact is an online survey software that may collect, store, and analyze survey data.

07.02 Qualitative testing

Pilot testing of the questionnaire was performed qualitatively through iterative rounds of cognitive interviews with one interviewee at a time, using an interview guide (appendix D) – see Figure 4. Purposive sampling was used to ensure as diverse representation as possible with regards to gender, age, religious affiliation, ethnicity, and diagnosis group. Patients were recruited for interview through relevant networks or by collaborators at university hospital clinical departments who knew the participant from either the in-hospital ward or out-of-hospital clinic.

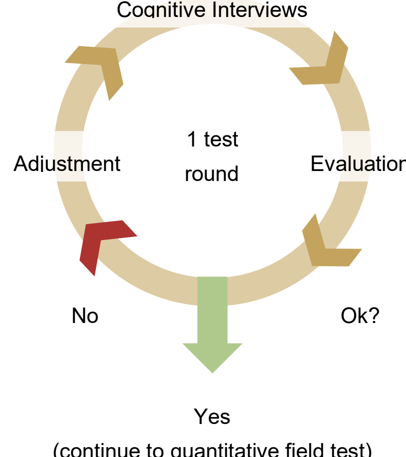

Figure 4 - The concept of iterative cognitive testing.
Adaptation inspired from de Vet et al.(2011).
Reproduced from (T. A. Stripp, D. T. Viftrup, et al., 2022)

The goal was to examine whether the questionnaire was acceptable and comprehensible to different individuals. The classic techniques of cognitive interviewing were used, namely 'think aloud' and 'probing' (Collins, 2015). Improvised probing was allowed if deemed necessary by the interviewer. Retrospective scripted probes were administered after the participant had completed the items in the questionnaire.

First the participant was asked to fill out the survey while thinking out loud and while the interviewer (the author) administered improvised and scripted probes – see Figure 5 for an iconographic representation of the interview setting. Then, after completion of the survey, open-ended retrospective scripted probes were administered to assess (1) the overall experience with the questionnaire (e.g. length, discomfort, interest) while filling out the questionnaire – indicating acceptability and (2) whether the questionnaire was comprehensive in covering aspects of existential and spiritual practices and needs of the participant (in case of diseased participants, then in relation to their disease, and in case of healthy participants, in relation to their life in general).

After each round of interviews, adjustments and recommendations to the questionnaire were prepared based on qualitative content analysis of interview summaries from each round of testing (de Vet et al., 2011; Hsieh & Shannon,

2005). The theoretical framework for the content analysis is described below (07.02.1). The objective of the content analysis was to identify issues or concerns with the questionnaire, the digital setup, or the experience of the participant. The criteria used was that an issue should either be related to the general design of the questionnaire, to cultural discrepancies in understanding or perceiving the items, or issues with translation. The aim was to improve the acceptability (i.e. that it was acceptable for the respondent to answer the questionnaire), the comprehensibility (i.e. that it was readily understandable and easy to read), and the comprehensiveness (i.e. that it fully covered inquiries and experiences that the participant may have had which related to the spiritual dimension of health). The adjustment recommendations were reviewed and gave rise to amendments to the questionnaire accordingly. The amended version of the questionnaire was then prepared for the next round of testing.

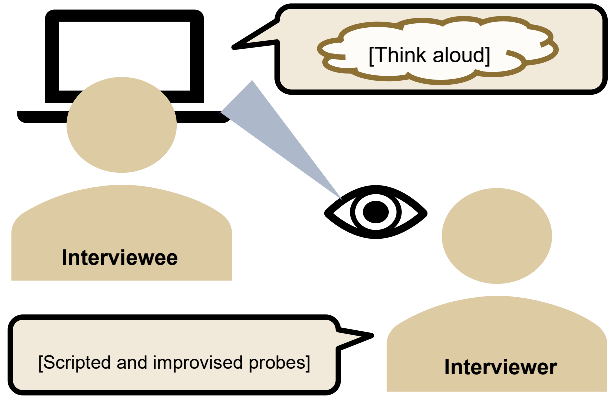

Figure 5 - Iconographic representation of interview setting.
From (T. A. Stripp, D. T. Viftrup, et al., 2022)

07.02.1 Analysis

All interviews were recorded and the software package 'NVivo 12' was used to transcribe, listen to, and summarize interviews. Detailed handwritten interviewer notes were transferred to NVivo by hand. Detailed interview summaries were prepared using audio records, transcripts and/or interviewer notes. The interview summaries underwent a directed content analysis, which is a deductively driven qualitative analysis method initiated from a theoretical framework of codes that are applied to the data (Hsieh & Shannon, 2005; Miles & Huberman, 1994).

A predefined framework was taken from the works by Willis et al. which contain three categories of questionnaire issues (Boeije & Willis, 2013; Levin et al., 2009; Willis, 2005): 1. translation issues, occurring due to source language not properly processed, 2. culture-specific issues, where cultural differences between source language culture or setting and target culture required adaptation of questions, and 3. general issues, that appeared universal and related to comprehension (Forsyth et al., 2007; Levin et al., 2009; Willis et al., 2005). Statements and observations were coded using this framework with the codes: 'translational issue', 'cultural issue', or 'general issue'. Coding was done twice by TAS to enhance coding accuracy and verify the grounding in the data (Gildberg et al., 2015).

07.03 Psychometric validation

The psychometric validation of the DA-SpNQ-20 used purposive and convenience sampling in a cross-sectional survey with a retest. Participants were invited to participate through a link on social media (i.e. Facebook and LinkedIn) or the learning platform 'Itslearning' used by the medical students at the University of Southern Denmark. The purpose was to get as large a sample as possible with a large age range. Mainly, random peers in the authors networks and medical students were invited to participate. Sampling was conducted between 4th – 18th of June 2021. Participants who had indicated that we could send the survey to them again were invited through self-reported e-mail addresses to a retest two weeks after the test was ended. The survey was administered digitally, and responses were collected through 'SurveyXact' (RMC, 2022), an online digital survey system. Participation was voluntary and no financial or monetary renumeration was offered. Respondents who had not filled out the entire Da-SpNQ-20 or not filled out all the demographic questions regarding age, gender, and religious affiliation and denomination were excluded.

Data on sex, age, and religious affiliation and denominations were collected with single items. Questionnaire outcome measures were the DA-SpNQ-20 and the WHO-5 (see 07.05 for thick descriptions of outcomes).

07.03.1 Analysis

The sample was randomly split in two equally large groups with sex and age as conditions for randomization. The first half of the sample (sample A) was used for

the exploratory factor analysis (EFA) with principal-component factor method (Rencher & Christensen, 2012). A Kaiser-Meyer-Olkin (KMO) test of sampling adequacy was calculated, and a scree plot was used initially to assess number of factors. Then rotation was performed with varimax and Kaiser normalization.

The second half of the sample (sample B) was used for confirmatory factor analysis (CFA) within the structured equation modelling (SEM) framework to confirm the originally proposed structure. A linear model with Sattora-Bentler adjustments was used. The goodness of fit of the model was evaluated by the Root Mean Square Error of Approximation (RMSEA), the Standardized Root Mean Square Residual (SRMR), the Comparative Fit Index (CFI) and the Tucker-Lewis Index (TLI). The levels for a good fit were considered RMSEA <0.08, SRMR <0.08, CFI ≥0.90 and TLI ≥ 0.95 (Hooper et al., 2007; Kline, 2005).

Internal consistency was measured by *Cronbach's alpha*, of which values between 0.70 and 0.80 were considered satisfactory with higher values indicating good internal consistency (Bland & Altman, 1997).

To establish repeatability we used a two-way mixed-effect model for the absolute agreement between DA-SpNQ-20 overall sum scores for time 1 (test at baseline) and time 2 (retest two weeks after data collection was ended for test) to determine intra-class-correlation (ICC(2,1)) (Qin et al., 2019). To examine the systematic error a Bland-Altman plot with levels of agreement was used (Altman & Bland, 1983).

The total sample was used for a correlation matrix to examine divergent validity between the DA-SpNQ-20 and the WHO-5.

07.04 Measuring spiritual needs

To examine the spiritual needs of Danes I used the survey data collected in EXICODE Wave1 (cross-sectional) (T. K. Stripp, S. Wehberg, et al., 2022). EXICODE is based on a Danish national digital survey linked to individual-level data from comprehensive Danish nationwide health registers (T. K. Stripp, S. Wehberg, et al., 2022; Thygesen et al., 2011).

In total, 104,137 randomly selected adult Danes were successfully invited to participate in Wave I of the EXICODE digital survey.

Demographic variables on age, sex, education, income, socioeconomic status (SES), cohabitation, work status, civil status, and chronic diseases were derived from Danish National Health register data. Single survey items probed for specific existential and spiritual denominations and practices. Questionnaire outcomes included were spiritual needs (DA-SpNQ-20), well-being (WHO-5), human flourishing ((S)FI), Meaning in life (MAPS items), and life satisfaction (BMLSS).

07.04.1 Analysis

Multiple univariable and multivariable logistic regression models were fitted to estimate the odds ratio (OR) for having spiritual needs by demographic characteristics (age, sex, SES, habitation, civil status, and chronic diseases) and health, and existential characteristics (self-perceived physical health, well-being, satisfaction with life, meaning in life, crisis of meaning, and various religious orientations and practices). In this way, potential confounders were controlled for in the multivariable models. A few "classic" potential confounders (i.e. smoking, alcohol consumption, BMI) were deliberately not measured since the measures were considered less important. Model 1: Demographic variables were fitted in multivariable models on SpNQ dimensions. Model 2: Both demographic and surveyed variables on existential and spiritual denominations and practices were fitted in large multivariable models to examine associations with spiritual needs dimensions. Linear regression models for continuous outcomes were also examined.

Observations that had missing data for the primary outcome (SpNQ) were excluded. Missing values for categorical variables (2%) were assigned to the majority category which only alters the interpretation. For two continuous variables (satisfaction with life, and meaning/crisis of meaning), missing values (0-2%) were set to the overall mean level (simple imputation).

07.05 Description of variables

07.05.1 The Spiritual Needs Questionnaire

For a complete overview of the DA-SpNQ-20 and its items see appendix E. The DA-SpNQ-20 measures the intensity of spiritual needs. The SpNQ been tested and validated in patients with chronic diseases, elderly, and healthy but stressed persons (Büssing et al., 2010; Büssing, Recchia, Koenig, et al., 2018). The originally proposed factor model was established by principal component analysis

showing four dimensions in the SpNQ and later confirmed by SEM (Büssing, Recchia, Koenig, et al., 2018): *religious needs* composing of the six items N18, N19, N20, N21, N22, N23 (cronbach's alpha (α) = .87-.92), *existential needs* composing of the six items N5, N10, N11, N12, N16, N17 (α = .74-.82), *inner peace needs* composing of the four items N2, N6, N7, N8 (α = .73-.82) and *giving/generativity needs* composing of the four items N14, N15, N26, N27 (α = .71-.74). Items are scored on a 4-point scale from no need to a very strong need (0 – no, 1 – yes, 2 – strong, 3 – very strong). The scale is considered ordinal and transferred to a linear score by computing mean sum scores for each dimension. A mean score of all items in the 20-item DA-SpNQ-20 can also be calculated (SpNQ Sum Score).

07.05.2 Well-being

The WHO-5 is a 5-item generic scale measuring subjective well-being. It has high construct validity and responsiveness (Bonsignore et al., 2001; Topp et al., 2015). It is a unidimensional instrument (α = .82) (de Wit et al., 2007) that has been validated and tested in multiple populations worldwide. Each item is scored on a 6-point scale from "0 – never" to "5 – all the time". The raw sum score is transferred to a score from 0 to 100 by multiplying with 4. Scores < 50 would indicate low wellbeing and risk of depression.

07.05.3 Human Flourishing

Self-perceived physical health was derived from the D2.1 item of the Flourish Index (T. A. Stripp, R. G. Cowden, et al., 2022; Weziak-Bialowolska et al., 2019) as "In general, how would you rate your physical health?" and scored on an 11-point VAS-scale from 0=poor to 10=excellent. Cronbach's α for the FI and SFI were good in five different cultural populations in which estimates of alphas were α_{FI} = 0.822-0.902 and α_{SFI} = 0.763-0.875 (ibid.).

07.05.4 Meaning in life and crisis of meaning

Meaning in life and crisis of meaning was measured by the following items: "I see a meaning in my life"; "My life is meaningful"; "I experience that my life is absolutely worth living"; "I suffer from not being able to see a meaning in my life"; "I lack a meaning in my life"; and "My life seems empty". Some of these items are from Tatjana Schnell's Sources of Meaning Questionnaire (Schnell, 2009). Items are scored on a 6-point Likert scale from '0—don't agree' to '5—totally agree',

and the score for meaning and crisis of meaning is the mean score of the three first and last items, respectively.

07.05.5 Life satisfaction

The Brief Multidimensional Life Satisfaction Scale (BMLSS-10) is a 10-item instrument that quantifies satisfaction with five main aspects of life, i.e., intrinsic, social, external, perspective, and health (Bussing et al., 2009). It has been tested in healthy elderly and in patients with chronic diseases. It has a single-factor structure (Cronbach´s $\alpha = 0.92$). The BMLSS is scored on a 7-point Likert scale from ‘0—very unsatisfied’ to ‘7—very satisfied’. The score is transformed into a scale ranging from 0-100.

07.06 Data management

A thorough data management plan (DMP) was prepared including a codebook on all outcomes. The DMP is available upon request but left out of the thesis for brevity. Although data will be FAIR (Deutz et al., 2020), data from EXICODE will not be freely available in a repository due to legal and ethical limitations. The invitation letter sent to participants can be seen in Appendix F.

07.07 Ethical and juridical matters

The ethics statement is similar to the one reported in the EXICODE protocol paper (T. K. Stripp, S. Wehberg, et al., 2022). Two institutions declared that the project did not require ethical approval by Danish law: the *Danish Regional Scientific Ethical Committee* (journal number: 20202000-116) and the *Danish Authority for Patient Security* (STPS). However, due to institutional best practices, the project was evaluated and approved by the institutional ethics review board *University of Southern Denmark Research Ethics Committee* (SDU REC) (journal number: 20/39546). The project follows *The Danish Code of Conduct for Research Integrity (UFM, 2014)* and is carried out following the *Helsinki Declaration* (WMA, 2013). The project was registered for legal and General Data Protection Regulation (GDPR) concerns at the *University of Southern Denmark Legal Services* (SDU RIO) (journal number: 10.367).

07.08 Software and significance level

Data was analyzed in the software package STATA 16.1 or newer, with a significance level of alpha=0.05. The STATA package ‘concord’ was used (Cox & Steichen, 2000).

08 RESULTS

The truth is like a lion; you don't have to defend it. Let it loose; it will defend itself. — Saint Augustine

In the following results section I shall in sequence present the most central results from each of the three papers that make up this thesis. The interested reader, once again, is referred to the appendices A, B, and C, for more detailed results sections pertaining each manuscript.

For accuracy purposes, parts of the following section are relevant direct quotations from the published papers: section 08.01 from (T. A. Stripp, D. T. Viftrup, et al., 2022), 08.02 from (T. K. Stripp, A. Büssing, et al., 2022), and 08.03 from (T. A. Stripp, S. Wehberg, et al., 2023).

08.01 Qualitative testing of the SpNQ

A total of 14 participants of various gender, ages, religious affiliation, ethnicity, and diagnosis group participated in cognitive interviews to test the EXICODE questionnaire.

Table 3 - Demographics of participants included in analysis (n=13).

Variables	Total
N included in the analysis	13
Female, male	6, 7
Age	32-71 (mean 53)
Diagnoses / health inclusion criteria of participants	Active cancer
	Cardiac arrest survivor
	Severe Chronic Obstructive Pulmonary Disease (COPD)
	Near-death experiencer
	Healthy
Existential/religious/spiritual nominations of participants	Atheist
	Agnostic
	'Holistic' spiritual (believers with universal belief or no specific theology)
	Christian
	Muslim
Ethnicity	Danish
	Another ethnicity than Danish
Interview length with the test of the survey	15-51 minutes (mean: 32 min.)
Total interview-length incl. scripted probes	26-113 minutes (mean: 65)

From (T. A. Stripp, D. T. Viftrup, et al., 2022)

One interview was aborted halfway through due to fatigue on the part of the interviewee and was not considered for analysis. Thus, a total of 13 interviews were included in the analysis (Table 3).

08.01.1 Acceptability and comprehensibility

Notably, for most participants, it was difficult to maintain the think aloud process. Prompting participants to keep thinking aloud often disrupted the flow of the interview. To counteract this decrease in think aloud activity, the administration of improvised probes was increased to ensure that thoughts on items and constructs became apparent.

The digital setup resulted in a range of findings related to acceptability. These findings were not associated with the question quality but rather with technical aspects of hardware or software used that decreased acceptability and access to the questionnaire.

Related to whether it was acceptable to be surveyed about existential and spiritual aspects, some participants felt that the questionnaire was too religious: *“I think this was way too religious for my taste. If I had known that I wouldn’t have participated”*. Many participants also declared that it had been enlightening and interesting to get the chance to reflect on their own existential and spiritual life: *“For me, it has been really interesting to answer all these questions. I mean, it is not something that I think about often or talk with my family about, but I can feel that they are important to me. And you know, some of these questions – I have never even thought about them before.”*

Albeit different ages, diagnoses, ethnicity, and religious affiliation, participants experienced that the questionnaire was comprehensible. The terms used to express different needs and views on existential and spiritual constructs were readily understandable.

08.01.2 Issues identified through iterative cognitive interviews

Frequencies of issues identified through coding can be seen in Table 4.

Table 4 - Frequency of issues in each iterative round and issues per participant (n= 13).

Round	N	Translational issue: n (%)	Cultural issue: n (%)	General design issue: n (%)	Total issues: n (%)	Issues per participant (rounded)
I	3	2 (6%)	5 (16%)	24 (78%)	**31 (100%)**	10.33
II	3	1 (5%)	8 (38%)	12 (57%)	**21 (100%)**	7
III	4	1 (7%)	6 (40%)	8 (53%)	**15 (100%)**	3.75
IV	3	1 (7%)	8 (57%)	5 (36%)	**14 (100%)**	4.66
Total:	13	5 (6%)	27 (33 %)	49 (61%)	**81 (100%)**	6.43

From (T. A. Stripp, D. T. Viftrup, et al., 2022)

Overall, most issues were related to general design issues. These were related e.g. to errors in the digital setup of instrument categories or incomprehensible question wordings.

The second-most frequent issues were cultural issues. Misinterpretation and misunderstanding of existential and spiritual content were considered cultural issues. Two distinct items in the GrAw-7 (ED2 and ED6) had a substantial impact on analysis results and were early in testing identified as yielding cultural adaptation issues. Some participants had difficulties understanding the central conceptual words in the items, i.e. ED2: '[…] wonderous awe' (da: underfuld ærefrygt) and ED6: '[…] devout' (da: andægtig).

The least frequent issue category was translational issues. It seemed most of the translational flaws had been identified in the expert panel review, although few persisted in the testing. The importance of these issues seemed negligible.
After the four iterative rounds had been performed, data suggested that some saturation had been achieved since the issues identified in rounds III and IV were quite similar (also conaidering the above description of the cultural adaptation issues). Further, the remaining issues were mostly related to problems that could

not be fixed either due to limitations in the digital software used, copyright, or reasons of comparison.

08.01.3 Adjustments based on interview findings

Multiple adjustments were made to the questionnaire based on the adjustment recommendations prepared after testing rounds, see Table 5. Issues were thus solved iteratively between testing rounds and as the development of the digital survey came along. In addition, various minor spelling and formatting errors were corrected when noticed. The major revisions were mainly related to the omission of selected instruments (IIQ and SWS) that participants had either felt uncomfortable answering or experienced as incomprehensible.

Table 5 - Examples of issues identified, amendment recommendations, and amendments made (O=observation, C=citation).

Issue type	Example	Adjustment recommendation	Adjustment
Translational	1. C: “Turn to nature (vender mig mod naturen) – do you mean turn against nature?” [Spiritual Engagement (SpREUK-P) – P9]	1. None, since this misinterpretation was only present in one participant.	1. None.
	2. O: [SpNQ] prefix question is rendered wrongly.	2. Change “[…] have you had any of the following needs?”	2. Changed to: “[…] have you had the need to…”
Cultural	1. C: “What does ‘wonderous awe’ (underful ærefrygt) mean?” [Gratitude and Awe Scale (GrAw-7) – ED2]	1. Omit GrAw-7 OR culturally adapt the wording of “wonderous awe”.	1. None: Translation is correct, and no synonymous expression in Danish conveys the conceptual meaning.
	2. C: “It just keeps getting worse. If I had known that these questions were so sectarian, I would have never signed up for the interview!” [Interpretation of Illness Questionnaire (IIQ]	2. Omit the IIQ as participants are experiencing discomfort with item wording.	2. IIQ omitted.
	4. C: “I feel that the examples given here are very religious. I consider myself spiritual, but not religious, so I cannot really identify.” [Spiritual Needs Questionnaire (SpNQ)– N23]	4. Add examples of more holistic or spiritual concepts to the list of examples of transcendent orientations.	4. “The Universe” added to ‘[…] (e.g. God, Allah, angels, saint, the Universe).’

General design	1. O: Some items are irrelevant for some, e.g. work satisfaction when retired – but the digital design still forces an answer. [Brief Multidimensional Life Satisfaction Scale (BMLSS)]	1. Add "not relevant"/"don't know" categories for items that may be irrelevant for some.	1. "Not relevant" / "Don't know" categories added to questions that may be irrelevant for some.
	3. O: the atmosphere abruptly changes when covid-19 items come up.	3. Omit covid-19 items.	3. Covid-19 items omitted.

From (T. A. Stripp, D. T. Viftrup, et al., 2022)

08.02 Psychometric properties of the SpNQ

Respondent flowchart is found in Figure 6 (Stripp, 2021).

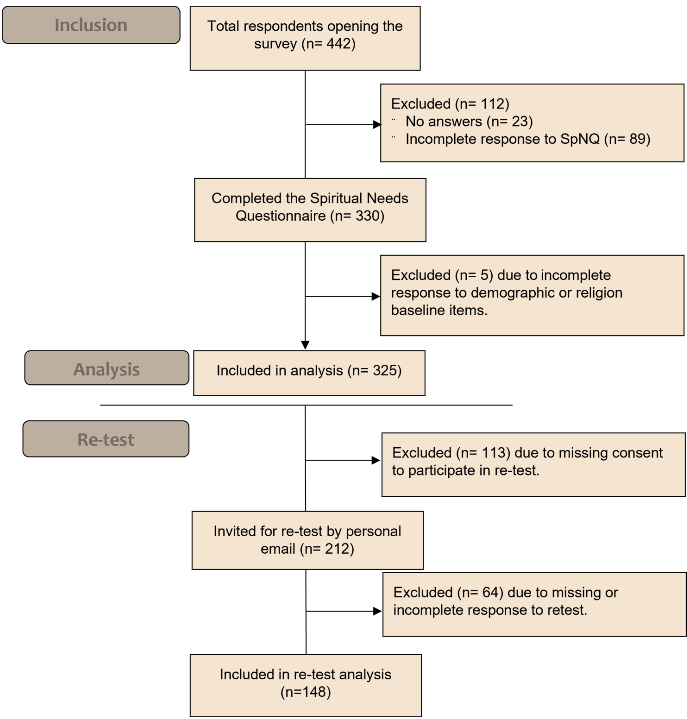

Figure 6 - Flowchart of respondents (n=325).
From (T. K. Stripp, A. Büssing, et al., 2022)

A total of 325 respondents were included in the main analysis and 148 in the retest. Their demographics and existential affiliations are shown in Table 6.

Table 6 - Participant Demographic Characteristics (n= 325).

	Total: n nonmissing (%)	Sample A - EFA: n(%)	Sample B - CFA: n(%)	Chi-squared (p-value)
Overall	325 (100.0)	165 (100.0)	160 (100.0)	.
Sex	323 (99.4)	163 (98.8)	160 (100.0)	.377
Man	87 (26.8)	44 (26.7)	43 (26.9)	.
Woman	236 (72.6)	119 (72.1)	117 (73.1)	.
Age	324 (99.7)	164 (99.4)	160 (100.0)	.986
Mean (sd)	43.9 (16.3)	44.0 (16.3)	43.8 (16.3)	.
18-44	159 (48.9)	80 (48.5)	79 (49.4)	.
45-64	133 (40.9)	68 (41.2)	65 (40.6)	.
65+	33 (10.2)	17 (10.3)	16 (10.0)	.
Religious/Spiritual	325 (100.0)	165 (100.0)	160 (100.0)	.198
Religious	96 (29.5)	44 (26.7)	52 (32.5)	.
Spiritual	59 (18.2)	34 (20.6)	25 (15.6)	.
Religious and Spiritual	60 (18.5)	28 (17.0)	32 (20.0)	.
None	77 (23.7)	37 (22.4)	40 (25.0)	.
Don’t know	33 (10.2)	22 (13.3)	11 (6.9)	.
Self-percieved believer	325 (100.0)	165 (100.0)	160 (100.0)	.299
Believer	196 (60.3)	94 (57.0)	102 (63.8)	.
Non-believer	68 (20.9)	35 (21.2)	33 (20.6)	.
Convinced atheist	31 (9.5)	16 (9.7)	15 (9.4)	.
Don’t know	30 (9.2)	20 (12.1)	10 (6.3)	.
Faith	232 (71.4)	113 (68.5)	119 (74.4)	.646
Agnosticism	9 (2.8)	4 (2.4)	5 (3.1)	.
Christianity: protestantism	142 (43.7)	72 (43.6)	70 (43.8)	.
Christianity: catholicism	22 (6.8)	7 (4.2)	15 (9.4)	.
Universal faith, w/o specific theology	30 (9.2)	15 (9.1)	15 (9.4)	.
Other	19 (5.8)	9 (5.5)	10 (6.3)	.
Don’t know	10 (3.1)	6 (3.6)	4 (2.5)	.
Believe in afterlife	325 (100.0)	165 (100.0)	160 (100.0)	.731
Yes	167 (51.4)	85 (51.5)	82 (51.3)	.
No	82 (25.2)	44 (26.7)	38(23.8)	.
Don’t know	76 (23.4)	36 (21.8)	40 (25.0)	.

From (T. K. Stripp, A. Büssing, et al., 2022)

The distribution across answer categories, the mean score per item, standard deviations, discrimination index, skewness, and kurtosis estimates are presented in Table 7. The skewness varies across items with both negatively and positively skewed items (range: -0.52;1.65), however, most items are right-skewed. Similarly, the kurtosis across items is both platykurtic and leptokurtic with most items being platykurtic (fewer extreme values than a normal distribution). Thus, while a perfect normal distribution was not expected from this ordinal scale, skewness and kurtosis go in both directions across the scale.

Table 7 - Distribution of answers pr. item and response category (n= 325).

Item	Answer category				Mean score	SD	DI	SW	KT
	0: n (%)	1: n (%)	2: n (%)	3: n (%)					
N2	63 (19.4)	125 (38.5)	94 (28.9)	43 (13.2)	1.36	0.94	0.6	0.20	2.16
N5	98 (30.2)	104 (32.0)	94 (28.9)	29 (8.9)	1.17	0.96	1.0	0.28	2.02
N6	59 (18.2)	71 (21.8)	107 (32.9)	88 (27.1)	1.69	1.06	1.3	-0.30	1.88
N7	39 (12.0)	61 (18.8)	127 (39.1)	98 (30.2)	1.87	0.98	1.3	-0.52	2.28
N8	54 (16.6)	69 (21.2)	117 (36.0)	85 (26.2)	1.72	1.03	1.3	-0.32	1.97
N10	178 (54.8)	74 (22.8)	48 (14.8)	25 (7.7)	0.75	0.97	1.1	1.02	2.82
N11	142 (43.7)	91 (28.0)	61 (18.8)	31 (9.5)	0.94	1.00	1.4	0.69	2.27
N12	221 (68.0)	60 (18.5)	27 (8.3)	17 (5.2)	0.51	0.86	1.2	1.65	4.74
N14	41 (12.6)	82 (25.2)	129 (39.7)	73 (22.5)	1.72	0.95	1.2	-0.29	2.19
N15	57 (17.5)	88 (27.1)	109 (33.5)	71 (21.8)	1.60	1.02	1.2	-0.14	1.93
N16	187 (57.5)	78 (24.0)	38 (11.7)	22 (6.8)	0.68	0.93	1.2	1.20	3.34
N17	141 (43.4)	110 (33.8)	52 (16.0)	22 (6.8)	0.86	0.92	1.4	0.80	2.70
N18	214 (65.8)	51 (15.7)	32 (9.8)	28 (8.6)	0.61	0.98	1.4	1.40	3.63
N19	198 (60.9)	50 (15.4)	42 (12.9)	35 (10.8)	0.74	1.05	1.5	1.12	2.79
N20	145 (44.6)	62 (19.1)	63 (19.4)	55 (16.9)	1.09	1.15	1.7	0.51	1.76
N21	169 (52.0)	56 (17.2)	46 (14.2)	54 (16.6)	0.95	1.15	1.5	0.75	2.01
N22	170 (52.3)	62 (19.1)	55 (16.9)	38 (11.7)	0.88	1.07	1.6	0.82	2.25
N23	139 (42.8)	42 (12.9)	67 (20.6)	77 (23.7)	1.25	1.23	1.8	0.29	1.45
N26	57 (17.5)	113 (34.8)	100 (30.8)	55 (16.9)	1.47	0.97	1.4	0.07	2.05
N27	134 (41.2)	101 (31.1)	59 (18.2)	31 (9.5)	0.96	0.99	1.3	0.68	2.34

SD=standard deviation, DI = discrimination index, SW=skewness, KT=kurtosis.

08.02.1 Structural validity of the DA-SpNQ-20 with exploratory factor analysis

The first half of the randomly selected sample (n=165) was included for the EFA. First, we did the KMO test of sampling adequacy to assess whether the data was suitable for EFA. The KMO measure overall was very good with 0.88. A screeplot was made indicating that three to four factors explained most of the variance. The EFA identified four factors with an eigenvalue >1.0. The EFA was conducted with the principal-component factor method used in Stata with Kaiser normalization and Varimax rotation. The factor loadings (Table 8) supported on the whole the same four-factor structure as the development validation (Büssing et al., 2010; Büssing, Recchia, Koenig, et al., 2018).

Table 8 - Exploratory factor analysis measure (n=165).

Dimension	KMO	Item-rest corr.	α	Factor I	Factor II	Factor III	Factor IV
Religious Needs			0.93				
N18	0.89	0.67	0.92	**0.84**	-0.00	0.13	0.14
N19	0.92	0.76	0.92	**0.79**	0.10	0.28	0.18
N20	0.88	0.74	0.91	**0.84**	0.22	0.06	0.13
N21	0.87	0.66	0.92	**0.82**	0.06	0.00	0.19
N22	0.92	0.71	0.92	**0.74**	0.30	0.08	0.12
N23	0.85	0.76	0.90	**0.87**	0.23	0.00	0.16
Existential Needs			0.77				
N5	0.79	0.41	0.77	0.00	0.23	**0.78**	-0.07
N10	0.90	0.58	0.73	0.20	0.36	**0.54**	0.12
N11	0.87	0.63	0.71	0.30	*0.45†*	**0.41**	0.13
N12	0.89	0.62	0.75	*0.42†*	0.27	**0.23**	0.31
N16	0.90	0.57	0.73	0.30	0.00	**0.58**	0.34
N17	0.88	0.61	0.74	0.39	0.09	**0.45**	0.31
Inner Peace Needs			0.75				
N2	0.71	0.39	0.80	-0.05	**0.14**	*0.80†*	0.06
N6	0.89	0.59	0.70	0.17	**0.70**	0.01	0.34
N7	0.86	0.62	0.59	0.11	**0.79**	0.19	0.23
N8	0.89	0.61	0.62	0.12	**0.74**	0.35	0.08
Generativity Needs			0.73				
N14	0.84	0.54	0.63	0.13	0.16	0.09	**0.82**
N15	0.87	0.61	0.65	0.19	0.14	0.24	**0.77**
N26	0.86	0.60	0.60	0.35	0.34	-0.11	**0.64**
N27	0.91	0.64	0.78	0.45	*0.52†*	0.26	**-0.03**
Overall	0.88	.	0.91	.	.	.	.

Original factor structure in **bold**. † Highest loadings marked by italics for items where highest loading is different from the original structure. From (T. K. Stripp, A. Büssing, et al., 2022).

08.02.2 Reliability of the DA-SpNQ-20 measured by ‘Cronbach’s alpha’

All dimensions in this multidimensional instrument were considered to have acceptable or very good internal consistency: *Religious Needs* alpha=0.93, *Existential Needs* alpha=0.77, *Inner Peace Needs* alpha=0.73, and *Generativity Needs* alpha=0.75. *Inner peace needs* and *generativity needs* would yield higher domain alphas if N2 and N27 were either re-assigned to other dimensions or deleted. The instrument´s overall alpha was very good at 0.91, although this should be seen in light of the instrument being multidimensional.

08.02.3 Structural validity of the DA-SpNQ-20 with confirmatory factor analysis

SEM analysis was performed with the second half of the sample (n=160), see Figure 7. The model was established with item-factor relations from the original factor model. The goodness of fit estimates for the data were RMSEA = 0.095, CFI = 0.836, TLI = 0.810 and SRMR = 0.092. The fit estimates did not reach the predefined levels to be considered a good fit. The results from the CFA did however show some evidence to support the model with the original factorial structure retained.

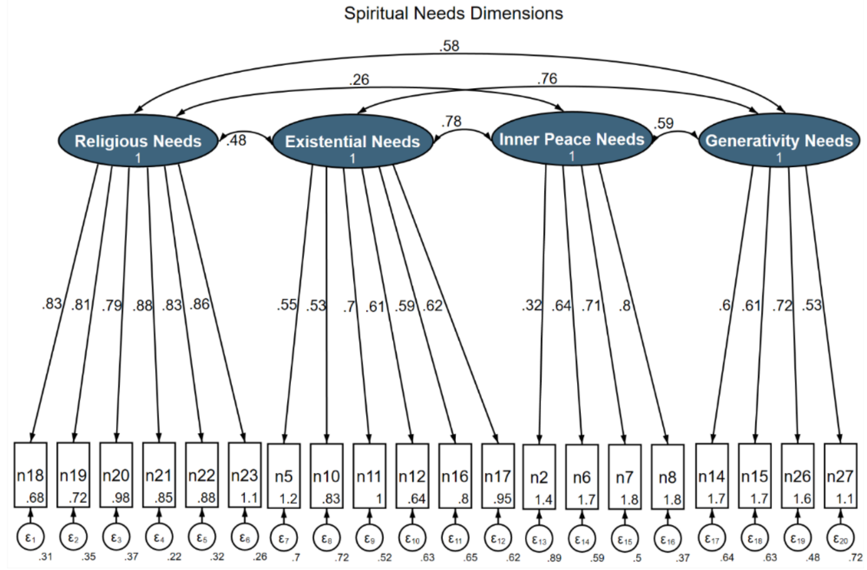

Figure 7 - Structural Equation Model for the DA-SpNQ-20 (n=160).

From (T. K. Stripp, A. Büssing, et al., 2022)

08.02.4 Test-retest reliability of the DA-SpNQ-20

The ICC(agreement) for the DA-SpNQ-20 sum scores was 0.86 [0.81; 0.89] (std. error: 0.02). The Bland-Altman plot showed no apparent bias and rather homogenous variation across the measurement range (Figure 8). The systematic difference was 0.052 [0.0004; 0.103] (sd: 0.316) with 95% Limits of Agreements of [-0.57; 0.67].

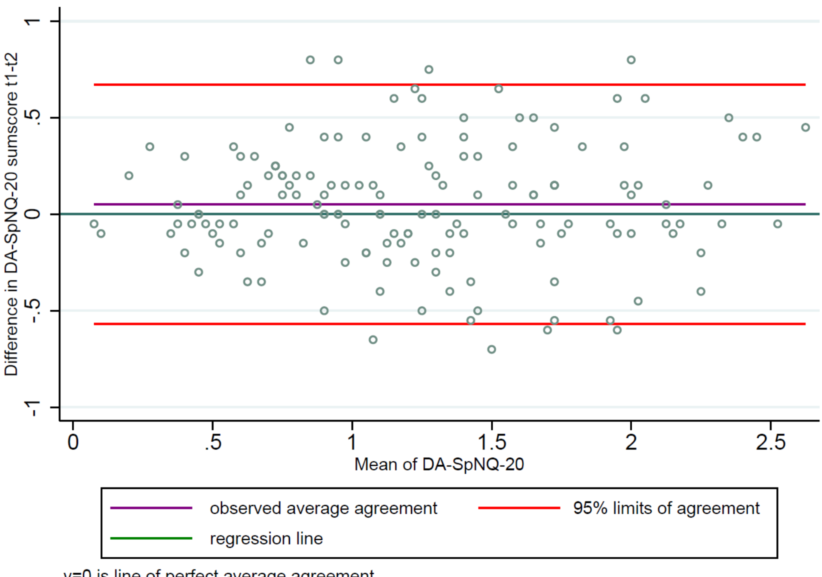

Figure 8 - Bland Altman plot of difference in SpNQ overall score in test and retest with limits of agreement (n=148).

From (T. K. Stripp, A. Büssing, et al., 2022)

08.02.5 Discriminant validity

Marginal only correlations were seen between the DA-SpNQ-20, its factors, and wellbeing (as measured by the WHO-5) (Figure 9). Internally the SpNQ dimensions intercorrelated, as would be expected. However, the religious needs dimension correlates the least among dimensions and least with inner peace needs. This is congruent with the finding from the SEM analysis which yielded a low correlation between these two dimensions of 0.26.

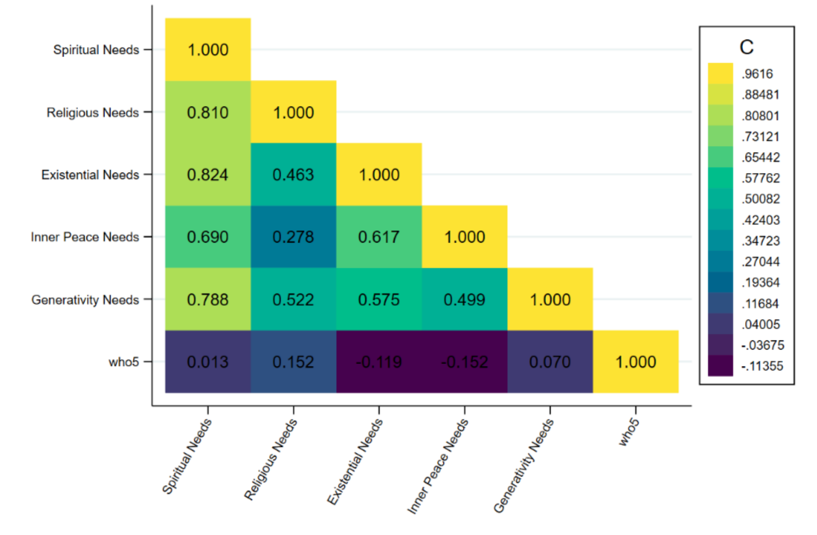

Figure 9 - Correlation matrix showing discriminant validity of the SpNQ with the WHO-5 (n=325).

From (T. K. Stripp, A. Büssing, et al., 2022)

08.03 Spiritual needs of adult Danes

In total, 26,678 of the selected Danes responded yielding a response rate of 25.6% (Figure 10).

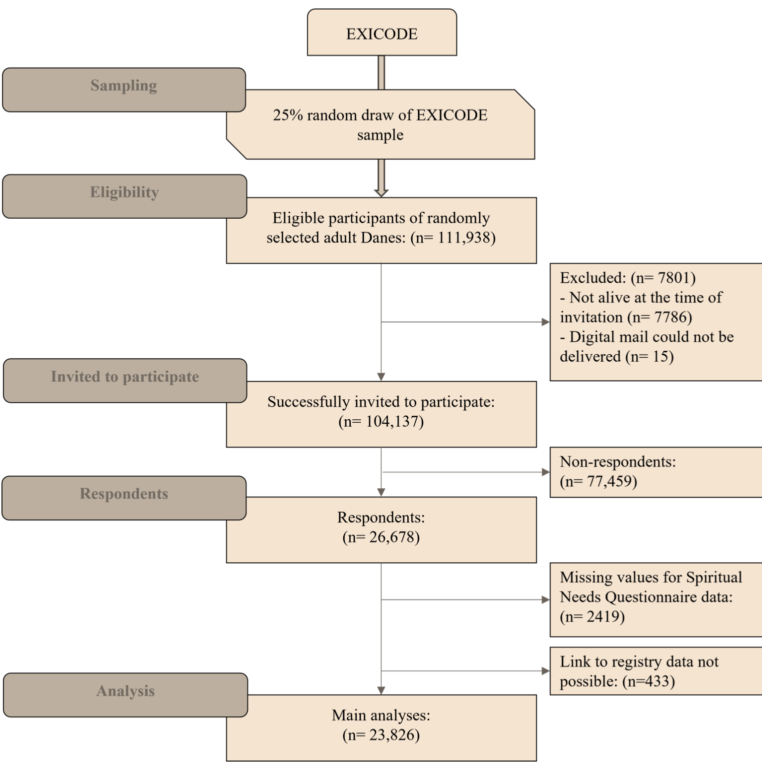

Figure 10 - Flowchart of study sampling and participants.

From (T. A. Stripp, S. Wehberg, et al., 2023)

Respondents differed statistically significantly from non-respondents on all measured demographic variables (Table 9).

Table 9 - Demographic variables of participants invited to the survey by respondents and non-respondents (n = 104,137).

		All	Respondents	Non-respondents
Total		104137 (100.0)	26678 (25.6)	77459 (74.4)
Sex	*Male*	51980 (49.92)	11827 (44.33)	40153 (51.84)
	Female	52157 (50.08)	14851 (55.67)	37306 (48.16)
Age, years	*18-25*	14703 (14.12)	1710 (6.41)	12993 (16.77)
	26-35	18007 (17.29)	2446 (9.17)	15561 (20.09)
	36-45	16450 (15.8)	3042 (11.4)	13408 (17.31)
	46-55	18708 (17.96)	5072 (19.01)	13636 (17.6)
	56-65	16484 (15.83)	6088 (22.82)	10396 (13.42)
	66-75	13009 (12.49)	5826 (21.84)	7183 (9.27)
	75+	6776 (6.51)	2494 (9.35)	4282 (5.53)
Education, years	*7-*	24433 (23.46)	4698 (17.61)	19735 (25.48)
	12-	42472 (40.78)	10998 (41.22)	31474 (40.63)
	15-	33096 (31.78)	10473 (39.26)	22623 (29.21)
	Missing/Unknown	4136 (3.97)	509 (1.91)	3627 (4.68)
Income, relative to age	*Lower*	31201 (29.96)	6336 (23.75)	24865 (32.1)
	Middle	34871 (33.49)	9277 (34.77)	25594 (33.04)
	Upper	36128 (34.69)	10866 (40.73)	25262 (32.61)
	Unknown/missing	1937 (1.86)	199 (0.75)	1738 (2.24)
Living status	*Living alone*	34349 (32.98)	7725 (28.96)	26624 (34.37)
	Living with someone	67851 (65.16)	18754 (70.3)	49097 (63.38)
	Missing/unknown	1937 (1.86)	199 (0.75)	1738 (2.24)
	Unknown/missing	1937 (1.86)	199 (0.75)	1738 (2.24)
Working status	*Working*	50927 (48.9)	12179 (45.65)	38748 (50.02)
	Student benefit	6998 (6.72)	1000 (3.75)	5998 (7.74)
	Other public benefit	25700 (24.68)	5644 (21.16)	20056 (25.89)
	Public and private pension(s)	19549 (18.77)	7773 (29.14)	11776 (15.2)
	Unknown/missing	963 (0.92)	8 (0.03)	881 (1.14)
Civil status	*Married*	48085 (46.17)	15256 (57.19)	32829 (42.38)
	Widow/er	3975 (3.82)	1437 (5.39)	2538 (3.28)
	Divorced	10979 (10.54)	3297 (12.36)	7682 (9.92)

	Unmarried	39161 (37.61)	6489 (24.32)	32672 (42.18)
	Missing/Unknown	1937 (1.86)	199 (0.75)	1738 (2.24)
Chronic disease	*No*	84242 (80.9)	20801 (77.97)	63441 (81.9)
	Yes, one	17819 (17.11)	5210 (19.53)	12609 (16.28)
	More than one	2076 (1.99)	667 (2.5)	1409 (1.82)

All groups were statistically significantly different at p<0.001, based on Chi-squared tests excluding missing values. From Stripp et al. 2023.

Respondents were slightly more likely to be female, somewhat older, better educated, had higher income, and were more inclined to live with someone, be married, and be retired/living on a pension than non-respondents. Among respondents, 23,826 participants had complete SpNQ and register datasets (

Table 10), of which 55.7% were female, and the mean age was 55.66 years (SD = 16.27; range = 18-98).

Table 10 - Demographic variables of the sample of randomly selected adult Danes included in analyses by sex (n = 23,826).

		All	Female	Male
Total		23826 (100.0)	13277 (100.0)	10549 (100.0)
Age, years	*18-25*	1360 (5.7)	838 (6.3)	522 (4.9)
	26-35	2042 (8.6)	1295 (9.8)	747 (7.1)
	36-45	2643 (11.1)	1648 (12.4)	995 (9.4)
	46-55	4610 (19.3)	2679 (20.2)	1931 (18.3)
	56-65	5598 (23.5)	3057 (23.0)	2541 (24.1)
	66-75	5390 (22.6)	2733 (20.6)	2657 (25.2)
	75+	2183 (9.2)	1027 (7.7)	1156 (11.0)
Education, years	*7-*	4051 (17.0)	2246 (16.9)	1805 (17.1)
	12-	10031 (42.1)	5359 (40.4)	4672 (44.3)
	15-	9744 (40.9)	5672 (42.7)	4072 (38.6)
Income tertiles, relative to age	*Lower*	5485 (23.0)	3343 (25.2)	2142 (20.3)
	Middle	8347 (35.0)	4700 (35.4)	3647 (34.6)
	Upper	9994 (41.9)	5234 (39.4)	4760 (45.1)
Living status	*Living alone*	6846 (28.7)	4162 (31.3)	2684 (25.4)
	Living with someone	16980 (71.3)	9115 (68.7)	7865 (74.6)
Working status	*Working*	11087 (46.5)	5974 (45.0)	5113 (48.5)
	Student benefit	863 (3.6)	586 (4.4)	277 (2.6)
	Other public benefit	4898 (20.6)	3254 (24.5)	1644 (15.6)
	Public and private pension(s)	6978 (29.3)	3463 (26.1)	3515 (33.3)
Civil status	*Married*	13960 (58.6)	7372 (55.5)	6588 (62.5)
	Widow/er	1293 (5.4)	917 (6.9)	376 (3.6)
	Divorced	2969 (12.5)	1817 (13.7)	1152 (10.9)
	Unmarried	5604 (23.5)	3171 (23.9)	2433 (23.1)
Chronic disease	*No*	18557 (77.9)	10134 (76.3)	8423 (79.8)
	Yes, one	4684 (19.7)	2736 (20.6)	1948 (18.5)
	More than one	585 (2.5)	407 (3.1)	178 (1.7)

From (T. A. Stripp, S. Wehberg, et al., 2023)

All groups were statistically significantly different at $p<0.01$, based on Chi-squared tests. More female respondents were believers and/or religious, spiritual, religious and spiritual compared to male respondents who more frequently considered themselves non-believers or convinced atheists and neither religious nor spiritual or none of them (

Table 11). Women were more inclined to indicate that God was important to them (both today and when a child/young). The same was true for existential and spiritual practices: women were more inclined than men to indicate that they prayed (34% vs. 16%), meditated (27% vs. 13%), or visited church (17% vs. 11%).

Table 11 - Spiritual characteristics of sample included in analyses, by sex (n = 23,826).

Variables	All	Female	Male
	23826 (100.0)	13277 (100.0)	10549 (100.0)
Do you consider yourself as ...			
Believer	9869 (41.4)	6007 (45.2)	3862 (36.6)
Non-believer	6415 (26.9)	3095 (23.3)	3320 (31.5)
Convinced atheist	2161 (9.1)	855 (6.4)	1306 (12.4)
Don't know	5381 (22.6)	3320 (25.0)	2061 (19.5)
If believer, then what faith?			
Agnosticism	414 (1.7)	173 (1.3)	241 (2.3)
Buddhism	229 (1.0)	146 (1.1)	83 (0.8)
Hinduism	29 (0.1)	15 (0.1)	14 (0.1)
Islam	179 (0.8)	110 (0.8)	69 (0.7)
Judaism	16 (0.1)	7 (0.1)	9 (0.1)
Christianity: catholicism	534 (2.2)	310 (2.3)	224 (2.1)
Christianity: protestantism	8059 (33.8)	4752 (35.8)	3307 (31.3)
Aesir faith*	94 (0.4)	26 (0.2)	68 (0.6)
Universal faith w/o specific theology	911 (3.8)	646 (4.9)	265 (2.5)
Other	384 (1.6)	229 (1.7)	155 (1.5)
Don't know	752 (3.2)	444 (3.3)	308 (2.9)
Not answered/missing	12225 (51.3)	6419 (48.3)	5806 (55.0)
What denomination suits you best?			
None/don't know/missing	16272 (68.3)	8372 (63.1)	7900 (74.9)
Religious	4095 (17.2)	2380 (17.9)	1715 (16.3)
Spiritual	1959 (8.2)	1417 (10.7)	542 (5.1)
Religious and spiritual	1500 (6.3)	1108 (8.3)	392 (3.7)
Do you believe in an afterlife?			
No/missing	11381 (47.8)	5033 (37.9)	6348 (60.2)
Yes	5320 (22.3)	3699 (27.9)	1621 (15.4)
Don't know	7125 (29.9)	4545 (34.2)	2580 (24.5)
How important is god in your life today?			
Not important/missing	19158 (80.4)	10326 (77.8)	8832 (83.7)
Important	4668 (19.6)	2951 (22.2)	1717 (16.3)
How important was god in your life as a child?			
Not important/missing	18172 (76.3)	9839 (74.1)	8333 (79.0)

Important	5654 (23.7)	3438 (25.9)	2216 (21.0)
Do you pray?			
No: rarely, never, missing	18983 (79.7)	9908 (74.6)	9075 (86.0)
Yes: regularly, often	4843 (20.3)	3369 (25.4)	1474 (14.0)
Do you meditate (any form)?			
No: rarely, never, missing	19740 (82.9)	10431 (78.6)	9309 (88.2)
Yes: regularly, often	4086 (17.1)	2846 (21.4)	1240 (11.8)
Do you go to church?			
No: rarely, never, missing	20887 (87.7)	11350 (85.5)	9537 (90.4)
Yes: regularly, often	2939 (12.3)	1927 (14.5)	1012 (9.6)

All groups were statistically significantly different at p<0.001, based on Chi-squared tests. From (T. A. Stripp, S. Wehberg, et al., 2023)

08.03.1 Spiritual Needs of adult Danes

For the full 20-item scale, 95.4% (score of at least 1 on at least 1 item) or 81.9% reported at least one strong or very strong spiritual need (score of 2 or 3 on at least 1 item) within the past month. Within specific SpNQ domains, 34.8% or 17.9% reported any religious needs, 72.1% or 41.5% any existential needs, 89.3% or 63.3% any generativity needs, and 88.6% or 68.7% any inner peace needs.

Danes in this sample were overall more likely to report having spiritual needs in the past 30 days than not (overall SpNQ mean score for the entire sample=0.71, SD=0.51). The prevalence of spiritual needs per dimension in ranked order were (1) Inner Peace needs (mean=1.21), (2) Generativity needs (mean=1.08), (3) Existential needs (mean=0.54), and (4) Religious needs (mean=0.29). Females generally reported a higher level of spiritual needs across all four domains. Respondents with ≥15 years of education likewise reported higher levels of spiritual needs across all domains (except for Existential needs). People in the lowest income tertile reported the highest levels of spiritual needs overall and across all dimensions compared to people in the middle or highest income tertile. Similarly, people who lived alone reported higher spiritual needs overall and across all dimensions compared to people who lived with someone.

08.03.2 Correlates of Spiritual Needs to individual characteristics

Estimation results from the multivariable logistic regression models are presented in Figure 11.

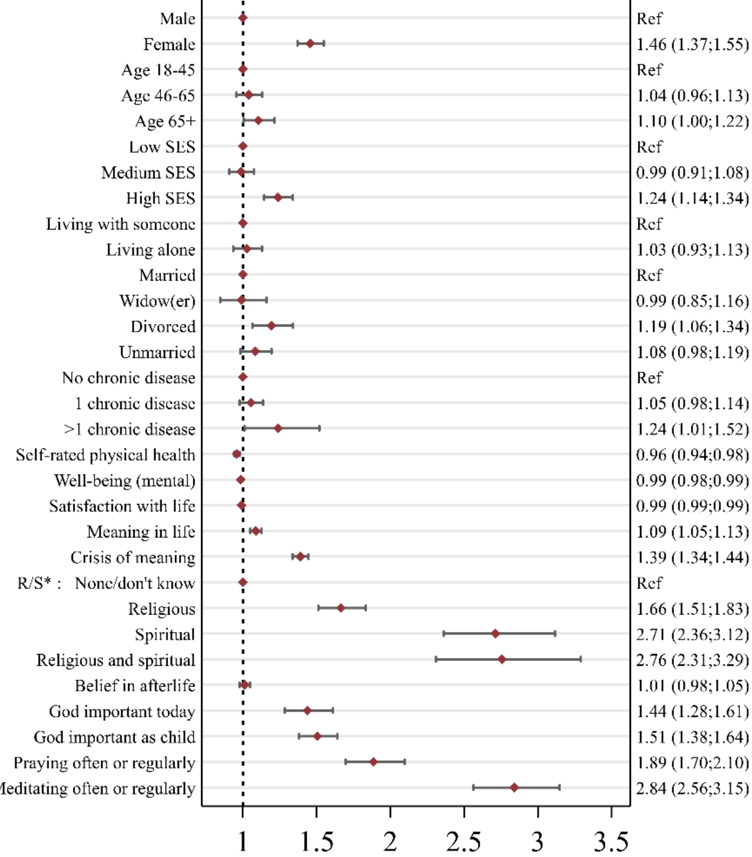

Figure 11 - Forest plot of odds ratio (OR) of spiritual needs (overall) and corresponding 95% confidence intervals (CI) by demographic variables and existential and spiritual denominations and practices (n=23,826).
From (T. A. Stripp, S. Wehberg, et al., 2023)

Overall, being female, having high SES, being divorced, having meaning in life or a crisis of meaning (crisis three-fold association size), being religious, spiritual or both, considering God important today and as child, as well as meditating or

praying often all had positive ORs for having spiritual needs within the last 30 days. Self-rated health, well-being, and satisfaction with life was negatively associated with spiritual needs. The OR was strongest for regularly meditating.

The below per dimension results are found in the online version (including supplementary material) of (T. A. Stripp, S. Wehberg, et al., 2023):

The OR of having religious needs was negative in females (compared to males), and for demographic variables, only the oldest age group was more likely to have religious needs. Crisis of meaning, considering oneself religious or spiritual or both (R+S+), believing in an afterlife, considering God as important (both now and when child), praying, and meditating were all strongly related to having religious needs, although some associations were reduced in multivariable analyses compared to the univariable ones.

Female sex, age 65+, being divorced or unmarried, having greater than one chronic disease, having a crisis of meaning, considering oneself religious, spiritual, or both (R+S+), believing in an afterlife, finding God important now and during childhood, praying, and meditating, all predicted a greater likelihood of having existential needs. In contrast, a lower likelihood of having existential needs was associated with medium SES, better self-rated physical health, greater well-being, and more satisfaction with life.

After adjusting for covariates, a greater likelihood of having generativity needs was associated with female sex, higher SES, being divorced, having meaning in life and a crisis of meaning, considering oneself religious or spiritual or both (R+S+), finding God important during childhood, praying, and meditating. Better self-rated physical health and higher well-being was associated with fewer generativity needs.

In the fully adjusted model, female sex, high SES, meaning in life, having a crisis of meaning, considering oneself religious or spiritual or both (R+S+), finding God important during childhood, praying, and meditating, were all positively associated with having inner peace needs. In contrast, older age, greater well-being, and higher satisfaction were associated with fewer inner peace needs.

09 DISCUSSION

Nothing in life is to be feared, it is only to be understood. Now is the time to understand more, so that we may fear less. — Marie Curie

09.01 Summary

In this thesis, I have examined spiritual needs in a random sample of adult Danes, in which it was found among respondents that 81.9% reported at least one strong or very strong spiritual need within the last month. Needs related to finding inner peace and giving something to others (generativity) were most frequently reported. I found that considering yourself as religious, spiritual or both or having a practice related to such affiliation e.g. praying or meditating, were strongly associated with increased odds ratio for having spiritual needs. Reporting lower well-being, lower satisfaction with life, and lower self-reported physical health also yielded increased odds ratio for having spiritual needs – which is congruent with the theoretical and empirical expectation. While these findings might not be surprising in themselves, they are an important step in delineating in which way spiritual needs are salient in the Danish population. While the study population was not representative due to differences between respondent and non-respondents, arguments for and against the representativeness of the findings will be discussed below. This study represents to the best of my and my colleagues' knowledge, the largest study to date on spiritual needs in a population sample.

I showed how the Danish version of the Spiritual Needs Questionnaire (DA-SpNQ-20) was tested qualitatively. Although issues were found, it ended out being both acceptable and comprehensible to interviewees. Retrospective probes also hinted at the satisfying comprehensiveness of the measure. I further analyzed the psychometric properties of the DA-SpNQ-20 measured by internal consistency, structural validity, retest reliability, and divergent validity and provided some evidence that the DA-SpNQ-20 is a valid measure, although issues were raised. Future research will have to test the DA-SpNQ-20 in other populations to further establish the validity of the measure.

In the following sections, I shall start by discussing the potential interpretations of the results of the thesis. Then, I shall discuss and scrutinize the validity of my findings by presenting and evaluating methodological strengths and limitations of the thesis. Subsequently, I shall compare my findings to the academic literature and other scholars' works on related subject matters. Finally, I shall put my insights into perspective and suggest how this initial evaluation of spiritual needs in Denmark might stimulate other research on spirituality and health and clinical spiritual care.

09.02 Interpretation

First, I shall discuss the interpretation of the initial work with the DA-SpNQ-20, both the Danish translation and the interviews conducted to test it. Then, the quantitative evidence provided for the psychometrics measures of the DA-SpNQ-20 will be discussed. Finally, the interpretation of my empirical study of spiritual needs in a random sample of adult Danes will be discussed.

09.02.1 Qualitative interviews with the DA-SpNQ-20

It was reassuring of the efficacy of the process that the quantitative count of issues identified across the interview rounds diminished, both overall and as issues/interviewee. Although some saturation was reached it is always questionable whether new information could have been gathered from more interview rounds. What became clear as well was that two items of one of the questionnaire instruments were difficult for respondents to understand. This is not optimal as all questions should be readily understood. There is good reason to have differing degrees of “difficulty” in items (e.g. can you walk 100m, 500m, 2km, or 10km / what is the solution to 2+2, 10-14, or 7*21.5) – but all questions should be comprehensible. The two items recurringly making translation issues in the testing rounds, and which we through many discussions among co-authors ended up not altering for comparison reasons and due to the inability to come up with suitable alternative wordings, belonged to the Gratitude and Awe scale (Büssing, Recchia, & Baumann, 2018). Thus, since the DA-SpNQ-20 had a high degree of comprehensibility and comprehensiveness in testing rounds, I found no evidence that the SpNQ translation had been poor. This together with the fact that no further items or aspects of spiritual needs were suggested by interviewees in the retrospective probing indicate good content validity of the DA-SpNQ-20. The GrAw scale should perhaps be used with caution, however, psychometric analyses not yet published on the scale showed good metrics despite this issue. The translation of the SpNQ into the DA-SpNQ-20, the main outcome of this thesis, showed good comprehensiveness and acceptability.

The interviewees included in the qualitative interviews were open to discussing and being surveyed about their existential, spiritual, or religious life. Almost all interviewees indicated that being asked these questions was a positive experience and that they had an excellent experience pondering such questions that they would rarely consider during everyday life. At the same time, the reflection was stimulated through specific questions that expanded their own

vocabulary related to existential and spiritual vernacular. This might be an essential insight for clinical healthcare professionals who talk with patients daily: based on the interviews reported in this thesis (as well as other works), patients are not likely to be offended by such inquiries but react positively to such. In addition, by leaning into the questions of e.g. the DA-SpNQ-20, the clinician might get helpful and specific examples of questions to ask when evaluating the need for spiritual care. Finally, future studies could examine how particular types of interviews may be interventions in and of themselves. This would be important in planning interview studies and for ethical evaluations.

It should be mentioned here that a single interviewee reacted quite strongly on an instrument with intense religious vernacular revolving around e.g. shame, guilt, and responsibility of disease (the Interpretation of Illness Questionnaire (IIQ)). In my view, this reaction from a single interviewee, although relevant, does not really affect the other conclusions drawn regarding how interviewees reacted to the questionnaire and the SpNQ in particular. The reason for this is that the reaction was solely directed at the IIQ and no other questionnaire in the compiled survey. The consequence of this reaction was that the IIQ was removed from the compiled questionnaire in future testing rounds. Thus, the reaction of this single interviewee, although relevant to mention here, is not deemed important for the other conclusions drawn in this thesis.

Based on the conducted interviews it is not possible to say whether the "positive experience" reported would also have been described after an interview regarding e.g. symptoms of a urinary tract infections. The point being that it is impossible at this stage to say with certainty whether the positive reaction was based on simply having been in an interview setting with someone genuinely listening to your experiences as an interviewee or if it was due to the topic of spirituality. While it could likely be both it is nonetheless relevant that it was regarded as a positive experience to be inquired about spiritual aspects – no matter the reason.

A final point that I will raise is the regarding the methodology of the cognitive interviews conducted. Interestingly, the interviews conducted to test the questionnaire qualitatively had a stricter cognitive process during questionnaire testing and a more open process following the questionnaire testing during retrospective open-ended probing. This resulted, in hindsight, in a situation where two ontologies of interviews were mixed. The strict cognitive interview may arguably represent a more positivist approach where it is considered possible to attain the "right/true" questionnaire, devoid of flaws and with a specific intended

purpose of measurement. Conversely, the open retrospective probes simulated, to a greater extent, a “classic” hermeneutic qualitative interview in which data was generated with the interviewee and with no specific goal of the interview but to explore the lifeworld of the interviewee. This combination might be quite fruitful, which I have discussed further elsewhere (T. A. Stripp, T. Q. B. van Sas, et al., 2023). However, it also produces inherent tensions between the epistemic goals of the interview.

09.02.2 Validity of the DA-SpNQ-20

The content reported in this thesis and in (T. K. Stripp, A. Büssing, et al., 2022) is the first attempt to provide evidence for the psychometric properties of a Danish translation of the SpNQ: the DA-SpNQ-20. The results from the classic test theory analyses conducted is overall satisfactory and point towards a valid tool. However, there is never a perfect questionnaire, and the DA-SpNQ-20 is no exception. While measures of internal consistency, repeatability as well as convergent validity was good, the structural validity analyses did not reach the predefined level for a good model fit and require mention here.

Generally, both the EFA and the CFA showed acceptable results. However, in the EFA two items did not load as expected. Item N2 “*to talk with others about your fears and worries?”* and item N27 “*to be assured that your life was meaningful and of value?”* loaded strongest on existential and inner peace needs, respectively. Following was what reported in the original validation paper by Büssing, it was expected that item N2 should load strongest on inner peace needs and item N27 on generativity needs. The reason for this might well have been the rather young and healthy sample as we argue in (T. K. Stripp, A. Büssing, et al., 2022). This created a dilemma since it leaved us with two paths to choose between: either we “forced” the items into the factors where we considered them to belong based on e.g. theoretical knowledge or we reassigned the items to different factors e.g. based on the EFA, thus making it difficult to compare data with the DA-SpNQ-20 to other works using the SpNQ. We decided to keep the items in the original factors after discussing the issue among co-authors. The reasons for doing so were mainly that the EFA based on 165 rather young and healthy individuals was not considered sufficient evidence to alter a scale that had shown to be stable across 13 translations and numerous validation studies. Theoretically, both items N2 and N27 could probably belong in either the factor suggested by the EFA or the original factor. Our decision, however, obviously ended up having consequences for the measurement properties of internal validity of the factors themselves, and for the CFA. Since our data found that N2

and N27 related to other items than what the original structure prescribed, keeping them in the original factors both reduced the internal validity of those factors and the SEM model fit estimations. This was also apparent since the SEM model fit estimates failed to reach the level of a good fit. However, the interpretation is that the model fit estimates were acceptable at this point since the levels were not disappointingly low. While more analyses could perhaps have been undertaken to investigate this issue further (Rappaport et al., 2020; Ryu, 2014), we were not able to do so at the time of conducting the study. My interpretation based on this is to repeat the psychometric property analyses in future studies in both healthy and diseased samples of more diverse ages and with better sampling to examine whether the measures reported on the DA-SpNQ-20 in this thesis can be supported or not.

While validation works in specific diseased populations are still to be conducted, given the validation works of the SpNQ conducted internationally in so many patient populations, cultures, and languages, I expect the Danish tool will sustain further scrutiny. It might be expected to find even more robust psychometric properties in diseased populations for which the instrument was initially developed than in the relatively young and healthy sample reported here. Studies testing the DA-SpNQ-20 in clinical settings i.e. at a hospice and general practice, are already set in motion. Such validation works will provide further evidence for or against the theoretical understanding and framework of the DA-SpNQ-20.

The distributions of the DA-SpNQ-20 responses where quite heterogeneous making it difficult to ascertain with certainty whether there is any floor or ceiling effects that makes some interpretations of results limited. Skewness and kurtosis analyses showed both right and left skewness as well as platy- and leptokurtic distributions across items. While descriptive analyses are relevant nonetheless (e.g. x% reported this, x% reported that) a very skewed distribution might hamper some analyses. To account for this, in the empirical study a multivariable logistic analysis was chosen as the main analytic tool.

Based on these initial psychometric analyses, it will be interesting to see the clinical utility of the instrument and perhaps dive deeper into the scoring categories and the changed scores of patients so that the DA-SpNQ-20 might potentially be used as a tool to measure change in spiritual needs as an effect of spiritual care. Future studies in Denmark and abroad should pursue such evaluations. While the score categories in the current DA-SpNQ-20 version is an ordinal scale, it could rightfully be questioned whether a Likert-scale version should perhaps be developed to potentially achieve more normally distributed

responses making valuable analyses available e.g. responsiveness or minimal important change. This also raises the question of whether it could be relevant to develop a completely new instrument in Danish for measuring spiritual needs. However, since it is not the COSMIN recommendation to do so without very good reasons and since quite some evidence supports the validity of the SpNQ (and the DA-SpNQ-20) I will leave this question unanswered for now.

In conclusion, our data provides some evidence for good and acceptable psychometric properties of the DA-SpNQ-20, however, it was not a perfect measure of spiritual needs in this rather healthy and young sample. Currently, it is the only option available, making it the most suitable instrument to examine spiritual needs in a random sample of adult Danes.

09.02.3 Empirical evidence for spiritual needs in Danes

In this thesis I have provided data on spiritual needs in a sample of randomly selected adult Danes. First, I will discuss the (internal and external) validity of the evidence provided and secondly consider the importance of the findings.

One could question whether people answer truthfully (i.e. introducing an information bias) to sensitive questions on faith and spiritual convictions or if the items in the DA-SpNQ-20 were easy to understand. While I have done my utmost to address some of these relevant internal validity questions in the first studies (the qualitative testing and the quantitative psychometric analyses) one can never be completely sure. In that regard, research is a cumulative practice where evidence for or against certain understandings is accumulated over time. While my qualitative and quantitative studies did not show that the SpNQ was a perfect questionnaire, neither did they show that the SpNQ is a faulty questionnaire that is unable to provide reliable and valid answers. Though some floor effects were noticed across several SpNQ items, all answer categories were used across all items including extreme values. In addition, analyses showed good variance across demographics.

While the sample in the study (n=104,347) is vast compared to other studies examining similar outcomes there are some concerns that should be addressed which may interfere with the representativeness or generalizability of interpretations. The first concern is the response rate of 25.6% raising the question of selection bias. There are various reasons to be suggested for the response rate not being higher – that the survey was done during the Covid-19

pandemic, a time when people were receiving a higher-than-normal number of surveys making it perhaps more difficult to get people to answer. Further, it was a population sample and not specifically a patient sample probably resulting in a substantially reduced interest and commitment on behalf of respondents. In the patient populations surveyed specifically, response rates were substantially higher (e.g. +35% for cancer patients). Interested parties can see the invitation letter to the EXICODE1 survey in Appendix F where it is noted that the survey invitation mentions words such as meaning, values, and faith. While the use of such wordings might increase the risk of selection bias, i.e. respondents more interested in such topics are more likely to answer, it is not feasible, neither ethically nor legally, to refrain from informing potential participants about what they will be participating in as this will make an informed consent impossible. Thus, I tried to convey the lowest amount of information about the survey, while still ensuring that enough study information was given to make people able to make an informed decision/consent to participate. While these might be relevant explanations, they do not diminish the risk that a selection bias is likely.

Discussing the missing data and missing mechanisms, since the sample was a random draw from the entire population of adult Danes, made by an independent third party, a sampling bias is unlikely to have occurred. I have conducted the analyses assuming that non-responders were missing at random (MAR), the missingness being explained by some of the variables available in the register. Although the concern regarding the response rate would be ignorable if participants were non-responders completely at random, analyses showed that respondents and non-respondents differed on all measured covariates indicating that there is a skewed participation. However, with so many individuals as I included, there is sufficient power to identify very small differences even if they are in truth unimportant. If the total sample had instead been e.g. 500 individuals it might well have been impossible to detect any differences between respondent and non-respondent characteristics at a 0.05 level with the distribution, we got. While this is true, surveys usually have a skewed self-selection unless the sampling is strictly controlled, raising other questions of validity. To counter this we used selection-relevant covariates in the regression analyses. With very few missing data (at item- and construct-level) (see 07.03.1 for handling of missings) the importance of missing data is considered negligible.

Providing with caution some evidence that spiritual needs are prevalent in the Danish population (81.9% of respondents reporting at least one strong or very strong need within the last month) adds a new perspective to the general discourse on spirituality in Denmark. Up until now, spirituality largely has been

considered less important in Denmark primarily due to the low adherence to religious activity despite the large membership count in the Evangelical-Lutheran Church in Denmark. However, the study legitimizes conversations about spirituality since needs related to this dimension of life seems common. I believe that such conversations are crucial in a society – both in private and public spheres. It was also clear that in respondents, as expected, religious needs were the least prevalent – but other needs related to salience, meaning, purpose, and being in nature were substantially present. This is in some ways similar to a recent depiction in “The People of the Spruce Forest” of the Swedes’ relationship to nature and how nature became the “new religion in Sweden” by Thurfjell (Thurfjell, 2020). Thurfjell argues that although Sweden is considered a highly secular country with low interest in existential or spiritual thoughts, Swedes have unconsciously removed themselves from the church and instead wandered into the spruce forest to contemplate life’s big questions about meaning and purpose. Perhaps a similar movement is happening in Denmark.

Higher age was associated with increased spiritual needs of all types except for inner peace needs. There was a lower degree of young adults among the respondents than in non-respondents. While there are numerous potential interpretations of this, including aspects of spiritual development in young adults, I do not consider having enough evidence to interpret the importance of age sufficiently. The spiritual development of young adults could also have been influential. Young adults often engage in a quest for meaning and purpose in life. Spirituality can be a source of guidance and provide a framework for understanding one's purpose and identity. However, such search for meaning is highly individual, and while some on the teachings of their parents on this journey, others find their own set of values and convictions, making it difficult to speak generally about the importance of age in relation to the results apart from what the regressions point towards. I believe it is fair to say that the increasing OR for having inner peace needs with lower age can be interpreted as a sign of despair or mental distress in young people, in accord with numerous contemporary studies showing that currently there is a well-being crisis among young people (Chen et al., 2022).

It is clear that the topic of having spiritual needs is a complex one. There are no perfect measurement constructs, and spiritual needs measured by the SpNQ are no exception. But it might still be one of the most useful and well-validated instruments currently available to address this topic in a post-secular context. However, any answers reported with the SpNQ, no matter how high the score, are currently not sufficient to guide a clinical intervention in itself. Thus, I believe

that my thesis may primarily stimulate discussions about the potential importance of spirituality in health care – it cannot guide any intervention. The clinical perspectives are discussed below.

09.03 Strengths and limitations

While I have done my utmost to be transparent about my own presuppositions, to reduce bias in the work presented by following rigorous methodology, and to obtain valid and useful results, there are always both strengths and limitations in research.

A general strength of the thesis is the rigorous and stepwise methodological approach following the gold-standard for survey research: first the qualitative testing and adaptation of the questionnaire through interviews, then a psychometric test, and lastly the proper empirical data collection. This process has been tedious but is the best way to increase the chance of getting valid results.

In addition, increasing the internal validity of the thesis, the protocol for what I aspired to study and how was submitted for peer-review to BMJ Open before the survey was conducted (on the 21st of October 2021) (T. K. Stripp, S. Wehberg, et al., 2022).

Each study included in this thesis has its limitations and strengths. The below methodological considerations are expansions of the limitations sections of the respective papers as follows: 09.03.1 from (T. A. Stripp, D. T. Viftrup, et al., 2022), 09.03.2 from (T. K. Stripp, A. Büssing, et al., 2022), and 09.03.3 from T. A. Stripp, S. Wehberg, et al. (2023).

09.03.1 Cognitive interviews

Regarding think aloud data, there were differences in the quality of the data. In the present study, most participants had difficulty thinking aloud. Reminding the participant to think aloud when they stopped doing so was very disruptive to the flow of the survey and building rapport. The reason why it was complicated for many to think aloud could relate to the sensitive nature of existential and spiritual themes – a fact that the authors of this paper had perhaps not considered well enough before commencing the interviews. However, the authors argue that willingness to think aloud is a variation that is expected to be randomly distributed between participants and something that cannot be controlled. When participants

stopped thinking aloud, it was respected, as it was assessed that letting people answer silently and instead increase improvised probing would yield a higher test quality. In extension, the sensitive nature of the questions on spirituality might also lead to a risk of the interviewee not mentioning important aspects of their spirituality when probed. However, I believe this has low importance since the theoretical work behind the SpNQ is very thorough with many interviews conducted to identify the items included, thus reducing the risk that important aspects of spiritual needs have been left out. There is also a concern that I tested too many items in a single cognitive interview. The number of items that one can test in a single interview depends on the objective of the interview. If it is the objective to deeply scrutinize each item, as few as 10-20 items might be feasible in a single (60 min) interview (Collins, 2014). However, since I wanted to test the comprehensiveness and the acceptability, and less so the validity – having evidence for the validity of the instruments from past research conducted with the instruments – I found it feasible to test the entire EXICODE questionnaire in one interview. While it was clear that I could only gain in-depth knowledge of a few select items, I was more concerned about the overall workings of the questionnaire. This might have resulted in too shallow a test of items.

The utility of using interviews to test instruments that allow for very few amendments due to comparison and copyright issues can rightfully be questioned. If you can't change anything, why test it? This dilemma became apparent through this study and highlighted a very important conflict that researchers may encounter: the conflict between the theoretical foundation of their work and the experiential reality of a limited empirical sample. As is evident from a multitude of survey research, item development is (unfortunately) often done solely on theoretical grounds and not based on qualitative interviews, even though the latter is best practice (de Vet et al., 2011). We agree with the recommendations and would also argue that these qualitative approaches are necessary. However, although the researcher's range of motion might seem limited, significant changes might still be possible while also adhering to comparison and copyright issues. In this study, we e.g. omitted an entire instrument (the IIQ) – not due to lack of understanding but simply because it was not acceptable for the participant to answer it. Another instrument was omitted due to incomprehensibility. The order of the questionnaire was amended to improve the flow of the questionnaire. Items on Covid-19 were dropped since they appeared conceptually too far away from the rest of the content. Multiple minor formatting mistakes were also corrected over the course of testing rounds. These changes were based on information we would not have had unless we had done

the tests. The decline in issue frequency likewise points to a fruitful outcome of the tests.

Another methodological contemplation is whether the analytical approach was feasible. Very few translational issues were identified, and some items had to be retained for various reasons, although they produced many cultural adaptive issues in all rounds of analysis. Perhaps, other analytical approaches could have been more fitting e.g. an inductive analytical approach. Also, since some items kept providing comprehension issues, it could be questioned whether the instrument they belonged to should have been omitted altogether.

Albeit a quite heterogeneous sample with regards to participant characteristics, the sample was too small to report the exact distribution of characteristics due to a need to retain the anonymity of participants. Although there did not seem to be differences in acceptability or comprehensibility across different participant characteristics, such as health conditions, this was not always possible to examine. For instance, the IIQ was omitted after the first round of interviews, so we couldn't assess whether it would have been acceptable to participants in subsequent rounds. It is a limitation that there was only one coder (TKS) and that he had also been conducting the interviews. Consequently, the use of the intra-rater-reliability measure was the only possible measure to report. However, the authors acknowledge that multiple interviewers and coders would perhaps have been preferable (making e.g. inter-rater-reliability analyses available).

09.03.2 Psychometric testing

The study provides rigorous classical statistical quantitative examination of the DA-SpNQ-20. This complements the qualitative testing done previously. A limitation to mention was that we did the EFA and then inferred item-factor relations and model structure from the original structure of the SpNQ instead of from the EFA results. This was done since we deemed the gain from preserving the original items and structure higher than the loss of some structural validity. We wanted to retain the possibility of comparing the DA-SpNQ-20 to international research. In doing so we were aware that the CFA would yield a lower fit, than had we used the model result from the EFA. This also became apparent with the CFA model fit statistics failing to reach the levels for a good fit – which is another limitation of the validity of the DA-SpNQ-20. However, it is noteworthy that alphas for all domains were still good or better. Sex and age were slightly skewed in the sample, and a large portion of respondents were students. There is somewhat of a discourse in society that women are generally more existentially and spiritually

oriented and usually have a more reflected orientation towards such concepts – this might have resulted in a selection bias although effort had been put into inviting as diverse a sample as possible. It is a limitation that no valid clinical data was obtainable from respondents making it impossible to determinate their health status or mechanisms of missingness. Since we used convenience sampling no data were available on “non-responders”. There is a substantial risk of selection and sampling bias towards healthy, high digital literacy and existentially and spiritually interested responders, which we did not have the data to mitigate. Although the test-retest results showed evidence of good instrument reliability, the retest was conducted two weeks after the initial data collection was ended, and not two weeks after the individual respondent had answered. Consequently, some respondents would have had a four-week gap between test and retest – thus increasing the risk of a substantial change having occurred.

Another issue with the DA-SpNQ-20 worth mentioning and hinted at earlier is the scoring category. When developed by Büssing, it was conceptualized as a clinical tool in which a patient could mark “yes” or “no” when prompted for a spiritual need. Only if the patient marked “yes” the patient was prompted to score the intensity of the experienced need. This approach was then later transferred to an ordinal scale from 0 – “no”, to “3 – yes, very strong”. A Likert scale would probably have yielded better responsiveness properties if the DA-SpNQ-20 were to be used in longitudinal studies. However, this has never been tested with the SpNQ. Further, although our results point to some degree of a floor effect, the importance of this effect in a research context is unknown. In a clinical setting, it might still be a beneficial scoring category, as it may easily transfer to concrete spiritual care plans as specific needs of specific actions might be evident.

Finally, it is obvious that 20 items, no matter how they were developed, will never be able to fully capture the spiritual needs of all individuals. We are aware of the unavoidable risk of simplifying and reducing the lived experience of spiritual needs when forcing such needs into 20 predefined items with predefined answer categories. All individuals are obviously free to express themselves what spiritual needs are to them – however, free-text answers would not have been feasible for the inquiry of this thesis.

09.03.3 Evidence for spiritual needs in Danes

First, this was a cross-sectional study, and as such, direction of causation for the associations cannot be determined. Second, the response rate was 25.6% with non-responders tending to be younger, less educated, have lower income, and be either students or unmarried showing that the sample was not representative and raises important concerns regarding generalizability. The importance of this limitation has been thoroughly discussed above. Though these are noted limitations, it is not an unexpectedly low response rate as other population-based studies in Denmark have shown similar response rates (Assing Hvidt et al., 2022; Ebert et al., 2018). It could be questioned whether respondents who are more interested in spiritual matters than the general population were overrepresented and more likely to participate, potentially resulting in a selection bias. Surprisingly, and perhaps providing some evidence against this, those with chronic diseases (usually considered less likely to respond) and people who were relatively less religious than the general Danish population (usually considered less interested in participating in EXICODE1) were more prevalent in respondents compared to non-respondents. However, with significant differences between respondents and non-respondents on all covariates a substantial risk of selection bias should be noted. With regard to strengths, our sample was large compared to other studies of spiritual needs, enabling unique insights and power. Use of detailed National Danish Registries further strengthens the study, as it provides detailed administrative data – also on non-survey-responders. The sample was a random selection of adult Danes, and generally results are in line with the theoretical background of the study thus providing some external validity. The measures used in the study all had documented acceptable psychometric properties.

It should be noted that the measure of meaning in life employed in the study was simple, not capturing potential multidimensional aspects of the construct and not taking potential discrepancies individuals can have towards meaning in life into account e.g. having a sense of meaning and still wanting to die. In future versions of EXICODE it could be relevant to include a more comprehensive measure of meaning in life.

A final matter that should be discussed is the chosen cut-point for spiritual needs. There is no (clinical) study with the SpNQ that addresses this issue: what score on the SpNQ is “high enough” to be considered a relevant or clinically important need. I chose a cut-point in the logistic regression of ≥0.5 in overall SpNQ score to depict having had spiritual needs. I chose this level as it represents having

reported “1 – yes” to 10 items and “0 – no” to 10 items; or “2 – yes, strong need“ or “3 – yes, very strong need” to five or three items, respectively – a level which I consider to have a relevant sensitivity. Other cut-points could have been chosen rendering different results in the regression analyses. The descriptive statistics obviously are not affected by the choice of cut-point.

09.04 Comparison to other works

The methodology used in the cognitive interviews are rather similar to a paper by Levin et al. (2009). We had similar success with the method, although we identified different methodological implications as discussed above. Regarding the psychometric properties of the DA-SpNQ-20, we found similar results as have been reported in multiple other samples in different cultures (Abreu et al., 2021; Bussing et al., 2013; Büssing et al., 2010; Büssing et al., 2015; Erichsen & Bussing, 2013; Hocker et al., 2014; Riklikienė, 2021). No studies have investigated spiritual needs in a large randomly selected population before – so we cannot compare to our sample.

However, the SpNQ has been used in various other (primarily diseased) samples (Abreu et al., 2021; Bussing et al., 2018; Büssing et al., 2020; Büssing et al., 2015; Büssing & Riklikiene, 2021; Büssing et al., 2021; Riklikienė, 2021). Our Danish sample has the lowest religious needs, a dimension where the highest level is seen in a sample from Poland, a largely catholic population. Generally, inner peace needs are the highest in reported samples – including our adult Danes. Generativity was relatively high in the Danish sample but also high in healthy mothers of children with Downs syndrome in Lithuania. The Danish pattern of the distribution of spiritual needs, somewhat surprisingly, is most similar to Lithuania, although Danes score substantially lower in all dimensions (T. A. Stripp, S. Wehberg, et al., 2023). These patterns of spiritual needs suggest the intensity and type of spiritual needs depend on cultural and religious factors on the one hand, and personal factors (e.g., personal stressors such as illness) on the other. Furthermore, differences or similarities and potential implications for health care should be interpreted with caution since the religious and spiritual landscape has influenced the development in each country and region very differently (*The Oxford Handbook of Religion and Europe*, 2021).

09.05 Future perspectives

Looking forward, it is relevant to consider which perspectives the thesis provides for future research in the field of spirituality and health and for clinical spiritual

care. First, I shall discuss relevant future research questions, then the potential clinical utility of the results provided in the thesis.

First, providing evidence that spiritual needs could be common in the Danish population, raises interesting research questions that warrants answering: what is the relationship between spiritual needs and the need for spiritual care? Can spiritual needs as measured by the DA-SpNQ-20 serve to monitor spiritual care (e.g. can proper spiritual care reduce experienced spiritual needs over time)? How is spiritual care best administered, to whom, when and where? Will spiritual care improve health outcomes? How do we ensure a health care system that is sensitive to the spiritual dimension of health, given that spiritual needs potentially are common?

An interesting future perspective, that I believe the field of spirituality and health is ready to consider, is randomized controlled trials to investigate the clinical effect of spiritual care interventions. It can be hypothesized, that spiritual care interventions may help a patient's spirituality towards becoming a resource, thus perhaps harnessing some of the health benefits associated with spirituality that was presented in the background section (05.03). Such interventions should, aside from looking at clinical outcomes, also look at the impact spiritual care has on spiritual needs (given the above discussion of the term "spiritual needs"). Can we actually solve these needs, and if we do, how can we measure a change? To solve these challenges, the training of researchers capable of investigation the field of religion, spirituality, and health including spiritual care is warranted (Tobias Anker Stripp et al., 2023). While it is still debated whether a randomized controlled trial is a feasible way of studying spiritual care, such studies would potentially have the validity to provide clinical guidance.

Importantly it should be noted that there is limited evidence of the direct clinical implications of spiritual needs – future studies should address this. Currently, spiritual needs might theoretically be considered on the pathway between existential and spiritual domains of life and positive health outcomes (effect modified perhaps by spiritual care) (see Figure 2). Future longitudinal studies are needed to examine these specific effects.

Second, while clinical implications of the evidence provided in this thesis is purely speculative, there might be potential clinical implications to be suggested from the results. While this thesis does not directly lend itself to clinical advice since patients were not (specifically) asked, and since that would be an entirely different research question that required different methods of inquiry, it should be

discussed if my findings can potentially and reasonably be considered to have any clinical perspective, bringing the thesis into dialogue with the broader research field of spiritual care.

The high prevalence of spiritual needs in the reported sample of randomly selected adult Danes could reasonably hint at the fact that many patients also have prevalent spiritual needs. Why? Firstly, in a random sample, diseased Danes who are patients themselves will also be included – thus patients are also part of the sample indirectly. Secondly, the evidence provided show spiritual needs are present in randomly selected (healthy and diseased) persons. If that is indeed the case, spiritual needs are also expected to be present in patients since illness, ageing, and approaching death only increases concerns and needs related to existential, spiritual, and religious dimensions of life (Levin et al., 2011; Moberg, 2012). So, we may expect spiritual needs to be prevalent in patients – which is not novel or spectacular in any way. But the evidence here provided is quite compelling corroborating numerous small scale and qualitative studies. The importance of spiritual needs for clinical care is much more difficult to ascertain – including the need for spiritual care for spiritual needs.

My results indicate (by amount of variance explained in regression models) that a few questions related to the existential and spiritual life and practices would probably be able to identify whether a person would report spiritual needs. While this could be useful information in clinical practice, reported spiritual needs is not the same as a need for spiritual care.

The theoretical discussion of spiritual needs and their relation to clinical care is also crucial to consider as reported spiritual needs are *not* similar to the need for spiritual care. Spiritual needs taken care of by the individual themselves and/or experienced as egosyntonic might be a source of strength and resilience. Hence, it might be perfectly possible that someone would score high on the DA-SpNQ-20 but does not need any spiritual care from others. In such a case, the DA-SpNQ-20 might stimulate reflection about clarifying the needs or practices already utilized by the individual. A very different situation, which – importantly! - looks similar in the instrument scoring, is the case where the individual scores high on the DA-SpNQ-20, but those needs are either egodystonic or something that the individual cannot fulfill themselves. In this latter case, spiritual care is probably warranted and might have clinical implications and effects. The central task then becomes this: how do we differentiate between spiritual needs that gives rise to spiritual pain and require spiritual care, and spiritual needs that do not require any spiritual care and which may even be a source of strength and

resilience? While there is no question inherent in the DA-SpNQ-20 (or any other SpNQ versions) that clarifies this issue, the clinical utility might become more apparent when used together with other questionnaire instruments or methods. If the DA-SpNQ-20 is administered together with a measure of mental health (e.g. the MDI or PQ-4), this latter instrument might point in the direction of spiritual care if the mental health score is low and the SpNQ score is high. Another approach would be to administer the DA-SpNQ-20 and follow it up with a clinical interview. To exemplify, it might be relevant to collect the DA-SpNQ-20 responses and then afterwards inquire with the patient: "So, I see that you answered that you had a very strong need for X. Could you tell me a bit more about that? […] Is that something you would like us to help you with or would like to talk further about with e.g. a chaplain?"

It could also be discussed whether spiritual care for spiritual needs should only be provided when there is suffering and pain. I guess sometimes it might well be relevant to support or discuss spiritual practices even though there is no spiritual pain present. Such discussion might be thought to potentially inspire hope or reinforce positive coping strategies. Be that as it may, such practices might find little support in a health care system where time is short – even though helping people to cope more positively might be economically feasible in the long run.

In extension, spiritual pain is also just a natural part of life. As influential medical humanity scholars such as Bishop have argued, racing to administer spiritual care for people or patients who have concerns regarding faith or meaning or purpose might be seen as yet another way to instrumentalize/medicalize humans rather than actually providing care from a holistic and patient-centred perspective (Bishop, 2011). While this might be true, Bishop himself does not offer any immediate solutions to this apparent paradox. Further discussion of this issue and potential ways forward in relation to health care practice is outside the scope of this thesis and interested readers are suggested to read on elsewhere e.g. The Anticipatory Corpse by Bishop (2011) or Hostility to Hospitality by Balboni & Balboni (2019). It will go as far, however, as to say that I believe such discussions and insights from the medical humanities will be crucial in developing the health care system of tomorrow.

Personally, I have a dream that obtaining a spiritual history is part of every initial patient assessment – my thesis perhaps lending some support for such a practice. By now, physical, social, mental, and lifestyle factors are included in the patient anamnesis that health care professionals collect. I think a question addressing potential spiritual matters should be included in this primary

assessment. Importantly, this would support a slow but necessary change in discourse towards a more holistic health care system.

A final comment should be about the potential future use of the DA-SpNQ-20 to monitor or screen for spiritual needs in e.g. digital health solutions or similar. Since it has been shown that the DA-SpNQ-20 can be used in a digital version and still yield rather valid results, it might perhaps be implemented in online survey or mobile app solutions. However, future research should continue to establish the psychometric properties of the measure. As mentioned above, the clinical relevancy and specific thresholds for important change scores needs to be investigated further. A project examining how the DA-SpNQ-20 could be used by general practitioners and in hospice settings is currently in planning. It is our hope that the DA-SpNQ-20 can stimulate and support general practitioners and other health care professionals to provide better spiritual care.

10 CONCLUSION

The more you know, the more you know you don't know.
— Aristotle

The EXICODE questionnaire was developed as a compiled questionnaire containing several internationally validated questionnaires covering various existential and spiritual constructs. It was translated into Danish through a forward-backward translation process protocol. The compiled questionnaire was then tested through cognitive interviews. Some questionnaire instruments were omitted as they were not acceptable to interviewees. The final version was found to be both acceptable and comprehensible for respondents with a few items providing issues – although all the content of the main outcome used in this thesis (DA-SpNQ-20) was tested to be good. The compiled questionnaire was improved across iterative rounds of interviews, where it was also noticed that the number of issues found within the questionnaire declined – indicating increasing questionnaire maturation.

The DA-SpNQ-20 (an instrument included in the EXICODE questionnaire) was psychometrically tested in a convenience sample. The instrument showed acceptable – but not good – structural validity through both exploratory and confirmatory factor analysis, the latter within a structural equation model framework where model fit estimations did not reach the level for a good fit. The DA-SpNQ-20 was established with four dimensions: religious needs, existential needs, generativity needs, and inner peace needs. Cronbach's alphas as a measure of internal consistency were acceptable, good, or very good across domains and overall, with values between 0.73-0.93. Skewness and kurtosis analyses indicated some risk of floor effects, as expected with this ordinal scale designed primarily as a clinical tool, although the distribution were heterogenous across items. Repeatability was high with an ICC of 0.86 and low systematic error was shown in a Bland Altman plot. It was different from the WHO-5 Well-being index, underlining discriminant validity. In conclusion, the DA-SpNQ-20 was not acceptably valid and reliable in a sample of healthy and relatively young adult Danes – although issues with the instrument were found. More research is needed to further establish psychometric validity of the DA-SpNQ-20.

Spiritual needs across 20 items in the DA-SpNQ-20 were broadly present among the surveyed 104.137 randomly selected adult Danes. A total of 81.9% of the 26.678 respondents reported at least one strong or very strong spiritual need within the past month. Within specific dimensions of spiritual needs, inner peace needs were most frequently reported, followed by generativity, existential, and religious needs. Women, persons of high socioeconomic status, divorced persons, those who reported meaning in life or a crisis of meaning (crisis much stronger associated), those considering themselves religious, spiritual or both, and those meditating or praying regularly all had higher odds ratios for having

spiritual needs. People with lower self-rated physical health, lower well-being, and lower satisfaction with life similarly had higher odds ratios for having spiritual needs. Within specific dimensions of needs, these characteristics shifted slightly – however, meditating (and praying) continued to yield a strong odds ratio across all dimensions of spiritual needs. While these results may not initially seem surprising, they are novel in providing quantitative evidence for spiritual needs in Danes.

The thesis has numerous strengths and limitations both adding to and questioning the internal validity of the results. The most important factors strengthening the internal validity of the results are: the study protocol was made and published before the study was conducted and it was strictly followed; the main outcome questionnaire was tested to the highest standards (COSMIN) with both qualitative and quantitative tests which showed good and acceptable results, respectively; a large and randomly selected sample was invited to participate; detailed national registers with individual level data collected unaware of the research question or design was used to control confounders and covariates (also among survey-non-responders); and various statistical analyses were employed to examine the sensitivity of the results. The most important factors questioning the internal validity of the results are: many questionnaire items were included in the cognitive testing in each interview; rather few and heterogenous interviewees were included in the cognitive testing; the original structure of the SpNQ was retained in the DA-SpNQ-20 albeit the EFA hinting at a different factor structure, leading to the CFA yielding only acceptable, but not good, model fit estimations; and a substantial risk of selection bias challenging representativeness in the empirical evidence for spiritual needs in Danes, especially due to a response rate of 25.6% and significant differences between respondents and non-respondents on all measured variables. The external validity seems robust as results are in line with theoretical expectations.

This is the most extensive study ever conducted on spiritual needs. Taken the strengths and limitations presented into account this thesis provides some, although not definitive, evidence that Danes have spiritual needs. The data provides some evidence to Denmark indeed being a post-secular country despite having endured strong secularization processes.

This raises interesting perspectives regarding the place of spiritual care in health care and the understanding of spirituality as a dimension of health. Since randomly selected adult Danes reported a high prevalence of spiritual needs, it is expected that such needs will be present and even perhaps elevated in patient

populations indicating the importance of clinical personnel being aware of such needs when people turn patients. This could potentially provide arguments for addressing and engaging spiritual care on a more regular basis, although more research on the link between reported spiritual needs and the actual need for spiritual care is warranted. In extension, health policymakers could use this evidence to sustain the realization of health care practices that support a more holistic and patient-centered approach with a deeper attention and sensitivity to the spiritual dimension of health. I believe, and this is in accord with national and international guidelines, that spiritual care should be a regular and valued practice at all levels of our health care system: in primary (general practice) and secondary care. There is potential for gain at various levels in realizing this: for patients, health care professionals, and the health care system at large.

Future research will have to investigate the effect of specific spiritual care interventions on spiritual needs, health outcomes as well as health economic outcomes. Furthermore, the clinical implications of having spiritual needs require more research with longitudinal designs.

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Read the best books first, or you may not have a chance to read them at all. — Henry David Thoreau

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12 APPENDICES

A bend in the road is not the end of the road. Unless you fail to make the turn. — Helen Keller

Appendix A

Peer-reviewed published paper:

Testing the acceptability and comprehensibility of a questionnaire on existential and spiritual constructs in a secular culture through cognitive interviews

in *Survey Research Methods*.

The following manuscript has been published in the international scientific and rigorously peer-reviewed journal:

Survey Research Methods
(Journal Impact Factor: 5.2, ISSN: 1864-3361)

The author of the manuscript (T. A. Stripp) has permission to reprint it in this thesis. All co-authors (fellow holders of copyrights) have accepted that the paper was reprinted here and acknowledge that T. A. Stripp conducted most of the work (67-100%) related to the study.

The paper can be referenced as:

Stripp TA, Viftrup DT, Nissen RD, Wehberg S, Sondergaard J, Hvidt NC. Testing the acceptability and comprehensibility of a questionnaire on existential and spiritual constructs in a secular culture through cognitive interviews. Survey Research Methods 2022; 17(1): 75-89.

DOI: 10.18148/srm/2023.v17i1.7971

For copyright purposes, the manuscript is omitted from this e-publication and readers are referred to the above reference instead.

Appendix B

Peer-reviewed published paper:

Measuring Spiritual Needs in a Secular Society: Validation and Clinimetric Properties of the Danish 20-Item Spiritual Needs Questionnaire

in *Journal of Religion and Health*.

The following manuscript has been published in the international scientific and peer-reviewed journal:

Journal of Religion and Health
(Journal Impact Factor: 2.7, ISSN: 1573-6571)

The author of the manuscript (T. K. Stripp) has permission to reprint it in this thesis. All co-authors (fellow holders of copyrights) have accepted that the paper was reprinted here and acknowledge that T. K. Stripp / T. A. Stripp conducted most of the work (67-100%) related to the study.

The paper can be referenced as:

Stripp TK, Büssing A, Wehberg S, et al. Measuring Spiritual Needs in a Secular Society: Validation and Clinimetric Properties of the Danish 20-Item Spiritual Needs Questionnaire. *Journal of religion and health* 2022; **61**(4): 3542-65.

DOI: 10.1007/s10943-022-01533-5

For copyright purposes, the manuscript is omitted from this e-publication and readers are referred to the above reference instead.

Appendix C

Peer-reviewed published paper:

Spiritual needs in Denmark: a population-based cross-sectional survey linked to Danish national registers

in *The Lancet Regional Health – Europe.*

The following manuscript has been published in the international scientific and rigorously peer-reviewed journal:

Lancet Regional Health - Europe
(Journal Impact Factor: not yet determined, ISSN: 2666-7762)

The author of the manuscript (T. A. Stripp) has permission to reprint it in this thesis. All co-authors (fellow holders of copyrights) have accepted that the paper was reprinted here and acknowledge that T. A. Stripp conducted most of the work (67-100%) related to the study.

The paper can be referenced as:

Stripp TA, Wehberg S, Büssing A, Balboni TA, VanderWeele TJ, Søndergaard J, Hvidt NC. Spiritual needs in Denmark: a population-based cross-sectional survey linked to Danish national registers. The Lancet Regional Health - Europe 2023; 28:100602.

DOI: 10.1016/j.lanepe.2023.100602

For copyright purposes, the manuscript is omitted from this e-publication and readers are referred to the above reference instead.

Appendix D

Cognitive interview protocol for the EXICODE questionnaire

Introduction

The interview today is part of a research project on various topics related to values, meaning, faith, and thoughts on life. We are conducting the project to understand how such topics are connected to health. Thank you for taking time to participate.

PURPOSE:

The purpose of today is first to test a questionnaire that is to be used in a large survey study, and second to ask you a bit about your experiences with filling out the questionnaire.

FRAME:

I expect the interview to last around 60 minutes.

RECORDING:

The interview will be recorded, and it will only be myself and my close colleagues that will be able to hear the recording.

SHARING OF DATA, ANONYMITY, CONSENT:

Your information will only be shared in an anonymized form. Effectively, this means that it will never be possible to identify you in disseminations from this interview. It is completely voluntary to participate, and you may revoke your consent at any time. By participating, you consent that your data may be used for research and statistical purposes.

Part one – testing of the questionnaire

First, I would like you to state your name and age.

Now I would like to ask you to answer this questionnaire. While doing so, I would like to ask you to say your thoughts out loud as you read the questions and reply. You can do it like this (*GIVE EXAMPLE WITH THE WINDOWS*). That way I can get an insight into what thoughts you have made to get to your answer. It's not because there's a wrong or right answer, but it makes it possible to me to observe how the question works. Along the way, I may ask a few questions, and otherwise, we will talk about your experience with the questionnaire once you have answered it. In the questionnaire, there are some questions that use words such as "existential, spiritual, faith, or religion". You may understand these terms in a way that fits your worldview. Generally, these terms point towards aspects of meaning, hope, faith, values, or inner important feelings and beliefs that most humans have.

Do you have any questions before we begin?

SURVEY ADMINISTERED ON LAPTOP

Are questions comprehensible and acceptable?	*The interviewer may administer improvised probes during the questionnaire testing if he/she finds this relevant.*
Is the IIQ acceptable?	How did you experience answering the question of whether you considered your disease / life condition as a "weakness by myself"? (IIQ item KB5)
How is the word "wonderous awe" understood?	What do you understand by the words "wonderous awe"? (GrAw-7 item ED2)
Does the NDE-filter question work as expected?	What experience did you think of while answering that question [NDE-filter question]?

SURVEY ANSWERED

Part two – retrospective probing on acceptability and comprehensiveness	
Is the questionnaire acceptable to answer for the participants? (acceptability)	Was the length appropriate, too short, or too long? Did you have any particular emotional reactions while filling out the form? Were there any questions that you found particularly difficult or easy to understand/answer? Was the digital setup of the survey easy or difficult to use?
Is the questionnaire actually measuring the existential and spiritual needs and practices participants express? (comprehensiveness / content validity)	The questionnaire taps quite a few needs, practices and other questions related to existential, spiritual, or religious topics. In relation to your condition, are there any existential, spiritual, or religious needs that you have had that the questionnaire did not inquire about? Are there any existential, spiritual, or religious practices that you enjoy or spend time doing that were not mentioned in the questions?

Appendix E

The Danish Spiritual Needs Questionnaire

The Danish Spiritual Needs Questionnaire (DA-SpNQ-20) (*English in italics*).

	Har du i løbet af den seneste måned haft behov for… *During the last month, have you had the need …*	**Nej** *No*	**Lille** *Small*	**Stort** *Large*	**Meget stort** *Very large*
N2	at tale med andre om din frygt og bekymring? *to talk with others about your fears and worries?*	0	1	2	3
N5	at afklare uafklarede aspekter af dit liv? *to resolve unfinished aspects of your life?*	0	1	2	3
N6	at fordybe dig i naturens skønhed? *to plunge into beauty of nature?*	0	1	2	3
N7	at hvile et sted, der giver dig fred og ro? *to dwell at a place of quietness and peace?*	0	1	2	3
N8	at finde indre fred? *to find inner peace?*	0	1	2	3
N10	at finde mening i sygdom og/eller lidelse? *to find meaning in illness and / or suffering?*	0	1	2	3
N11	at tale med nogen om meningen med livet? *to talk with someone about the question of meaning in life?*	0	1	2	3
N12	at tale med nogen om muligheden for et liv efter døden? *to talk with someone about the possibility of life after death?*	0	1	2	3
N14	at give noget af dig selv? *to give something of yourself?*	0	1	2	3
N15	at trøste nogen? *to give solace to someone?*	0	1	2	3

N16	at tilgive nogen fra en bestemt periode af dit liv? *to forgive someone from a distinct period of your life?*	0	1	2	3
N17	at blive tilgivet? *to be forgiven?*	0	1	2	3
N18	at bede sammen med nogen? *to pray with someone?*	0	1	2	3
N19	at nogen beder for dig? *that someone prays for you?*	0	1	2	3
N20	at bede for dig selv? *to pray for yourself?*	0	1	2	3
N21	at deltage i en åndelig / religiøs ceremoni (fx en gudstjeneste eller andet fælles ritual)? *to participate in a spiritual / religious ceremony (e.g. congregation or another ritual with others)?*	0	1	2	3
N22	at læse bøger med et åndeligt / religiøst indhold? *to read books with spiritual / religious content?*	0	1	2	3
N23	at vende dig mod en højere magt (fx Gud, Allah, engle, helgener, Universet)? *to turn to a higher presence (e.g., God, Allah, angels, saints, the Universe)?*	0	1	2	3
N26	at give din livserfaring videre til andre? *to pass on your life experience to others?*	0	1	2	3
N27	at blive forsikret om, at dit liv har været meningsfuldt og værdifuldt? *to be assured that your life was meaningful and of value?*	0	1	2	3

Appendix F

Invitation letter to the EXICODE 1 survey (Danish)

Hvad bringer mening til dit liv?
Hvordan påvirker det din sundhed?

Kære

Forskning viser at tanker om de store spørgsmål i livet spiller en vigtig rolle for helbredet. Det drejer sig fx om hvad der giver én mening, ens værdier og hvad man tror eller ikke tror på.

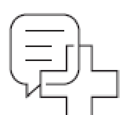
Derfor har vi brug for din hjælp

Gennem et forskningsprojekt ønsker vi at bidrage til at gøre forløb og behandling for patienter og pårørende i Danmark bedre.

Du er sammen med andre voksne danskere blevet tilfældigt udtrukket gennem CPR-registeret til denne spørgeskemaundersøgelse. (brev 1) //

Du er sammen med andre voksne danskere blevet udtrukket til denne spørgeskemaundersøgelse fordi du i et nationalt sundhedsregister er registreret til at have været i kontakt med sundhedsvæsnet i 2020 pga. en diagnose eller undersøgelse relateret til kræft. Registrene kan være behæftede med fejl, og du bedes se bort fra denne meddelelse såfremt du ikke har haft kontakt til sundhedsvæsnet i 2020 i relation til en kræftdiagnose. (brev 2) //

Du er sammen med andre voksne danskere blevet udtrukket til denne spørgeskemaundersøgelse fordi du i et nationalt sundhedsregister er registreret til at have været i kontakt med sundhedsvæsnet i 2020 pga. en Kronisk Obstruktiv Lungesygdoms-diagnose (KOL). Registrene kan være behæftede med fejl, og du bedes se bort fra denne meddelelse såfremt du ikke har haft kontakt til sundhedsvæsnet i 2020 i relation til en KOL-diagnose. (brev 3) //



Du er sammen med andre voksne danskere blevet udtrukket til

SDU

denne spørgeskemaundersøgelse fordi du i et nationalt sundhedsregister er registreret til tidligere at have haft et hjertestop. Registrene kan være behæftede med fejl, og du bedes se bort fra denne meddelelse såfremt du ikke har haft et hjertestop. (brev 4)

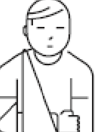
Din besvarelse er meget værdifuld og alle holdninger er lige vigtige!

→ Klik her for at deltage

Åbner spørgeskemaet ikke, når du klikker på linket, kan du gå ind på www.datafabrikken.dk og indtaste følgende kode:

Det tager ca. 10-15 minutter at besvare. Vælger du at deltage, bedes du besvare spørgeskemaet inden d. 13/12-21.

Hvad siger andre der har deltaget?



"Det var en rigtig spændende mulighed for at reflektere over nogle af de lidt store spørgsmål, som jeg ikke altid lige tænker så meget på." – citat fra en tidligere deltager.

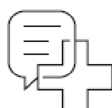
Har du nogen spørgsmål?

Hvis der er noget du er i tvivl om så klik ind på vores hjemmeside: https://www.faith-health.org/exicode eller læs mere på de næste sider.

På forhånd tusind tak.
Vi er taknemmelige for din hjælp.

Med venlig hilsen,

Tobias Kvist Stripp, læge, ph.d.-stud.
Niels Christian Hvidt, professor, dr.theol.
Jens Søndergaard, professor, ph.d., læge
Forskningsenheden for Almen Praksis, SDU
– du kan skrive til os på: exicode@sdu.dk



Hvis du ikke ønsker at deltage og ikke ønsker at modtage flere henvendelser fra os, klik her:

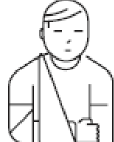
Hvis du kontakter os omkring din besvarelse, bedes du oplyse nedenstående ID-nummer:

Yderligere oplysninger

Det er frivilligt at deltage og dine oplysninger behandles fortroligt. Der kræves ingen forudsætninger for at svare. Du kan holde pause undervejs i din besvarelse, hvis du har brug for det.

Oplysning om behandling af pers[illegible]plysninger

Projektet er juridisk registreret på SDU og er etisk godkendt af SDUs etiske komité. I forskningsprojektet indsamler SDU oplysninger om dig og er ansvarlig for beskyttelsen af dine personoplysninger. Sundhedsvæsnet er ikke involveret i at du er blevet inviteret, og om du deltager eller ej, vil ikke få konsekvens for din ret til evt. behandling. Indsamlingen sker via de nationale sundhedsregistre og spørgeskemaundersøgelse. De personoplysninger der behandles, er spørgeskemabesvarelser samt registeroplysninger om: helbred, socioøkonomi, brug af udvalgte sundhedsydelser samt udvalgte medicinske præparater.

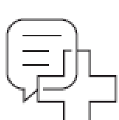


Sådan bruger vi personoplysningerne

SDU behandler personoplysningerne fortroligt - i overensstemmelse med gældende ret. Oplysningerne vil kun blive brugt til forskning mens formidling af forskningsresultater vil ske i anonymiseret form. Vi sørger for at opbevare dem sikkert, så det kun er de relevante forskere på SDU, der har adgang til dem. Oplysningerne bliver slettet eller anonymiseret når der ikke længere er brug for dem, og dette vil ske senest fem år efter afslutning af projektet. Det er d. 1/5-2029.

Samtykke og deltagelse

Når der skal bruges personoplysninger til forskningsprojektet, er der nogle særlige bestemmelser i lovgivningen, som giver



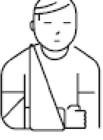
SDU

mulighed for at indsamle og bruge personoplysninger uden samtykke fra deltageren. De findes i databeskyttelseslovens § 10 og databeskyttelsesforordningens art. 6, stk. 1, litra e.

Bestemmelsen giver os lov til at bruge dine personoplysninger til forskning uden dit samtykke, men forbyder også, at bruge oplysningerne til andre formål end forskning og statistik. Du risikerer derfor ikke, at dine oplysninger vil blive brugt til andre formål.

Databeskyttelseslovens § 10 og databeskyttelsesforordningens art. 6, stk. 1, litra e giver også mulighed for, at vi kan videregive oplysningerne til andre forskningsprojekter, men der vil fortsat være tale om sundhedsforskning. Oplysningerne kan genanvendes til forskning.

Ved at indvillige i at deltage, vil vi indsamle de oplysninger, som er nævnt ovenfor, og anvende dem i projektet. Skulle du, på et tidspunkt i forløbet, ikke længere have lyst til at deltage, kan du trække dig fra projektet. Det medfører at vi ikke længere vil indsamle nye oplysninger om dig, men vi har fortsat lov til at bruge de oplysninger, vi allerede har fået.



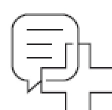
Spørgsmål til databeskyttelse?

Hvis du har spørgsmål omkring databeskyttelse og dine rettigheder kan du kontakte vores Databeskyttelsesrådgiver, Simon Kamber på dpo@sdu.dk.

Ønsker du at klage over behandlingen af personoplysninger, kan du henvende dig til Datatilsynet via www.datatilsynet.dk.

Hvis du har spørgsmål til undersøgelsen som du ikke kunne finde svar på, på https://www.faith-health.org/exicode, kan du stille dem til Tobias Kvist Stripp på email: exicode@sdu.dk

Hvis du efter deltagelse har behov for at tale med nogen omkring tanker, der måtte dukke op i relation til din deltagelse, kan vi anbefale at du kontakter dit netværk, din læge eller en anden, der kan hjælpe dig med dit behov.



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