

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

Tobias Anker Stripp^{1,2}, Dorte Toudal Viftrup¹, Ricko Damberg Nissen¹, Sonja Wehberg¹, Jens Søndergaard¹, and Niels Christian Hvidt¹

¹University of Southern Denmark, Department of Public Health

²Harvard University, Department of Epidemiology and Biostatistics

In this paper, we present how we used structured, iterative rounds of qualitative cognitive interviews to test the acceptability and comprehensibility of a questionnaire on existential and spiritual constructs. We intended to use the questionnaire in a digital cohort survey in Denmark. We conducted the translation and cultural adaptation according to the World Health Organization guidelines. Fourteen individuals with various demographic backgrounds and disease states participated in cognitive interviews according to an interview guide. Think aloud and probing (improvised and scripted) were used. Interviews were conducted through four iterative rounds with adjustments to the questionnaire in between rounds. We analyzed data through a deductively driven directed content analysis with a predefined theoretical framework. The method successfully provided evidence for improvement of the questionnaire as issues identified during interviews decreased in iterative rounds of testing as hypothesized. Acceptability and comprehensibility were satisfactory. However, some participants had difficulty continuing to think aloud during the interviews. The authors argue that this difficulty, at least in part, was caused by participants being reluctant to verbalize existential and spiritual thoughts as these topics may be sensitive and considered highly personal in the Danish secular culture. Allowing the participant to wane off in thinking aloud and instead increasing improvised probing might be a solution to mitigate this challenge.

Keywords: existential, spiritual, secular, cognitive interviews, survey methodology, directed content analysis, acceptability, comprehensibility

1 Introduction

The purpose of this study was to translate and adapt questionnaire instruments on existential and spiritual constructs, compile them into a questionnaire, and test and improve that questionnaire through qualitative methods. This paper's questionnaire measurement property terminology is congruent with the COSMIN group terminology where applicable [e.g. as reliability (reliability, internal consistency, measurement error), validity (content, construct, and criterion validity), responsiveness (responsiveness), and interpretability] (Mokkink et al., 2018). We wanted to examine how the end-users experienced the questionnaire and digital setup before distributing the survey in a quantitative field test. We hypothesized that we would observe fewer issues with the questionnaire after each consecutive round of cognitive interviews and adjustment, indicating questionnaire maturation and sat-

uration of data. The main goal was an acceptable and comprehensible questionnaire that we intend to utilize to study the relations between existential and spiritual constructs and health in Denmark on a large scale in a registry-coupled cohort setup. The target population is adult Danes (age > 18 years) who are either healthy, have cancer, chronic obstructive pulmonary disease (COPD) or are cardiac arrest survivors. We understand *existential* as containing three aspects of meaning-making: religious, spiritual, and secular (la Cour & Hvidt, 2010). According to la Cour and Hvidt, spirituality is embedded in the *existential*. Still, we use spirituality in connection with existential in this work to align the text with the Danish use of the terms, as these have been central in the conduct of the research (Sundhedsstyrelsen, 1999).¹

¹In Danish the term "spirituality" is translated, not just to "åndelig", but to "eksistentiel og åndelig" (see Sundhedsstyrelsen, 1999). Thus, albeit the fact that spiritual aspects of meaning-making is covered by our definition of the "existential" we still refer to it as "existential and spiritual".

Corresponding author: T. A. Stripp, J.B. Winsløvs Vej 9, 5000 Odense C, (E-mail: tkstripp@health.sdu.dk)

2 The cohort on spirituality and health in Denmark

The compiled questionnaire we report in this paper is intended for use in a cohort setting in Denmark in the Existential health COhort DENmark (EXICODE) (Stripp, Wehberg, et al., 2022). With a target population of more than 500,000 invited adult participants, it will be the most extensive registry-coupled survey study on existential health ever conducted in Denmark and (to the best of our knowledge) in the world. While performing such a survey certainly is daunting, addressing existential and spiritual issues in a highly secular country adds to the complexity (Nissen, Falko, et al., 2021; Nissen & Andersen, 2021). Research has shown various barriers to addressing existential and spiritual topics in Danish healthcare. Hence, there was a concern that Danes would be somewhat reluctant to answer questions on these topics (Assing Hvidt et al., 2016). Some would perhaps consider the issue of religion or spirituality to be too personal or possibly even provocative. Some might not have reflected sufficiently upon these questions and feel uncomfortable answering them (ibid). Potentially even more so for severely ill patients who may have unmet (conscious or unconscious) existential needs. Either that or the questionnaire would not be comprehensible as existential sources of meaning and understandings of the “existential” are diverse in Denmark (Hvidt et al., 2021). Thus, we had two primary considerations for the questionnaire that we wanted to address in the study: *acceptability* and *comprehensibility*. Acceptability was understood as whether the questionnaire was acceptable for participants to answer in terms of content, length, and experience. Comprehensibility was understood as whether the questionnaire and its items were understandable, which is paramount in receiving reliable answers (Mokkink et al., 2018).

2.1 Acceptability

Worldwide, Denmark has one of the highest degrees of paid membership to an organized church (appr. 74% of Danes are members of the national protestant church (Kirkministeriet, 2020)) while at the same time having some of the world’s lowest rates of religious activity (appr. 2% of Danes attend church at a weekly basis (Rasmussen, 2008)). This situation has led some to argue that Denmark is the least religious country in the world (Zuckerman, 2008). This contrast is further nuanced by the fact that religion is considered the second-largest taboo in Denmark after mental illness (Jensen & Mørk, 2016). However, it should be noted that although the majority of Danes do not consider themselves religious, some do. As such, we wanted to assess if it was acceptable for participants in a highly secular culture to be surveyed about existential and spiritual topics. A digital survey solution was preferred over pen and paper, as these methods can be considered equal in terms of measurement properties and quality (Egger et al., 2013). For older par-

ticipants, we wanted to counteract skewed participation by testing if the digital setup seemed feasible and acceptable. This would perhaps allow us to implement design solutions in the survey that could address the digital barrier that some participants may have.

2.2 Comprehensibility

Since the cohort will be inviting randomly selected adult Danes and different diseased populations, it was important to evaluate how participants of different genders, ages, existential and spiritual affiliations, ethnicity, and diagnosis groups understood the survey content, i.e., if the survey was comprehensible to them. This was especially relevant since the wordings used for existential and spiritual needs, practices, and lives of the participants might be different from everyday vernacular. Comprehensibility is always needed, and also is in this setting, as Denmark, like other countries, is a highly multireligious, -ethnic, and -cultural setting (Nissen, Viftrup, et al., 2021).

While we focused on how specific severe illnesses (e.g. cancer) promote existential and spiritual needs and seeking, the survey had to be fulfilling and understandable for non-diseased participants too. We did not expect the questionnaire to differ in comprehensibility among different patient populations. While we only considered validated questionnaire instruments for the compiled questionnaire, this approach still contains challenges for comprehensibility: the selected instruments have been validated and tested in specific (international) populations, then we translated the instruments into Danish, and therefore the understandability of our translations were paramount to test.

3 Cognitive interviews

Cognitive interviewing is a well-used qualitative approach to support, evaluate, and develop questionnaire instruments (Collins, 2014). The technique allows real-time and retrospective investigation of the content, design, and setting of the intended survey (Collins, 2014; G. Willis, 2005). It is recommended that qualitative approaches be implemented in the development of questionnaire items and the investigation of the acceptability, feasibility, and comprehensibility of the survey instrument or questionnaire (Boeije & Willis, 2013; Terwee et al., 2018; G. Willis, 2005). Cognitive interviews with representatives of the target end-users were deemed a fitting method for our study since we wanted to examine 1. the acceptability—i.e. whether Danes (both healthy and patients) were willing to answer questions on their existential and spiritual convictions (or lack thereof) in a digital survey setup, and 2. the comprehensibility of the questionnaire—i.e. if the questionnaire on existential and spiritual convictions, needs, and practices was understandable to the Danes in our target population. Inspired by the work of Levin et al. (2009), we intended to use cognitive interviews in iterative

rounds to get a thorough understanding of the working of our questionnaire and how it was received.

4 Objectives

In light of the above, we wanted to use cognitive interviews to test and consequently improve a questionnaire on existential and spiritual constructs in a Danish sample of healthy and diseased participants. Primarily, we wanted to:

1. Examine the acceptability and comprehensibility of the questionnaire.

Further, we wanted to use directed content analysis of iterative rounds of cognitive interviews to:

2. Make recommendations for questionnaire improvement and use these recommendations to amend the questionnaire over subsequent testing rounds.

3. Assess how the questionnaire performed over subsequent testing rounds by quantifying the issues identified in each testing round through a predefined theoretical framework.

5 Material and methods

5.1 Instrument selection and questionnaire

Together with collaborators and through the author group's expert knowledge of faith and health research, we identified relevant questionnaire instruments designed to examine existential and spiritual health constructs (Damberg Nissen et al., 2020), see table 1. These instruments were then evaluated based on face validity assessed by the authors and collaborators and the quality of prior psychometric validation works published in scientific journals on the instruments. In summary, instruments covering various relevant constructs were included; well-being, health status, life and support satisfaction, spiritual needs, engagement in religious and spiritual practices, gratitude and awe, adaptive coping, meaning in life and crisis of meaning, near-death experience content, human flourishing, interpretation of illness, and satisfaction with spiritual care (Bussing & Fischer, 2009; Bussing et al., 2009; Bussing et al., 2005; Bussing et al., 2010; Büssing, Recchia, & Baumann, 2018; Büssing, Recchia, Koenig, et al., 2018; Hanson et al., 2008; Herdman et al., 2011; Martial et al., 2020; Stripp, Büssing, et al., 2022; Stripp, Cowden, et al., 2022; Topp et al., 2015; VanderWeele, 2017; Weziak-Bialowolska et al., 2019). The instruments were then compiled into a combined questionnaire.

5.2 Translation and cultural adaptation

The translation was done according to the WHO guidelines (World Health Organization). Various other translation protocols were considered e.g. the one proposed by Beaton et al. (2000). The WHO guideline was chosen as this was widely recognized, deemed the most feasible approach in terms of quality, time, and funding, and because

the last author had experience with this approach from previous research. This guideline included forward-backwards-translation and evaluation by an expert panel (figure 1).

The forward translations were made by two professional translators who were native in the target language (Danish), and backward translations were made by different (minimum two) professional translators who were native in the source languages of the respective instruments (i.e. English or French). After translation, an expert panel consisting of one of the forward translators, an experienced survey researcher, and two field experts reviewed the original instruments, the forward and backward translations, and revised wordings and phrases to improve the translation and cultural adaptation. The expert panel identified specific items to be tested by probing. A group of external field expert colleagues from the Knowledge Center for Rehabilitation and Palliation, Nyborg, Denmark (REHPA) and the Research Unit for General Practice, University of Southern Denmark, Odense (FEA) were informally invited to test the questionnaire digitally by themselves and give comments on content or design to the authors by email. This feedback was included in the overall optimization of the questionnaire. 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.

5.3 Participants

As the cohort will contain both healthy and diseased participants, representatives from both groups had to be present in the interviewed sample to test the questionnaire properly. 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 by collaborators at university hospital clinical departments who knew the participant from either the in-hospital ward or out-of-hospital clinic. Healthy participants (indicated by not being included based on a diagnosis and having a high level of self-perceived health) and near-death experiencers (NDErs)(persons who self-indicated to have had a near-death experience) were recruited for interviews through relevant networks. No participants with prior knowledge of the field of existential and spiritual health research were consciously selected for interviews.

A total of 14 participants of various gender, ages, religious affiliation, ethnicity, and diagnosis group participated in cognitive interviews. Of these, seven were males. Participants were aged between 32 and 71 years (mean: 53). Atheist, agnostic, "holistic" spiritual (believers with universal or no specific theology), Christian, and Muslim participants were in the sample, as were both ethnic and non-ethnic Danes. Participants were either cancer patients, severe COPD patients, cardiac arrest survivors, NDErs, or healthy. Participants were

Table 1

The content of the questionnaire

Instruments in the Existential Health Cohort Questionnaire	Abbr.	Country of development	Construct	# of items	Item example
WHO Well-being Index (Topp et al., 2015)	WHO-5	Global initiative	Well-being	5	During the past two weeks ... I have felt active and energetic.
EuroQoL Health states (5 levels) (Herdman et al., 2011)	EQ5D	UK and Spain	Health status	5	Today ... have you felt pain/discomfort?
Brief Multidimensional Life Satisfaction Scale (Bussing et al., 2009)	BMLSS	Germany	Life and support satisfaction	18	How satisfied are you with ... your family life?
Spiritual Needs Questionnaire (Büssing, Recchia, Koenig, et al., 2018; Stripp, Büssing, et al., 2022)	SpNQ	Germany	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	Germany	Engagement in existential 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	Germany	Adaptive coping	8	My faith is my foundation, even in difficult times.
Meaning in life	-	Austria/Germany	Meaning in life and crisis of meaning	6	My life is meaningful.
Near-death experience content scale (Marital et al., 2020)	NDE-C	Belgium	Near-death experience	20	You met a presence and/or an entity (i.e. a deceased person).
Flourish and Secure Flourish Index (Stripp, Cowden, et al., 2022; VanderWeele, 2017; Weziak-Bialowolska et al., 2019)	FI and SFI	USA	Human flourishing	12	How happy or unhappy do you usually feel?
Interpretation of Illness Questionnaire ^a (Bussing & Fischer, 2009)	IIQ	Germany	Interpretation of Illness	8	I regard my disease as ... a call for help.
Satisfaction With Spiritual support ^a (Hanson et al., 2008)	SWS	USA	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]

^a These instruments were omitted as a result of adjustment recommendations during iterative rounds of cognitive interviews since they were not either acceptable or comprehensible.

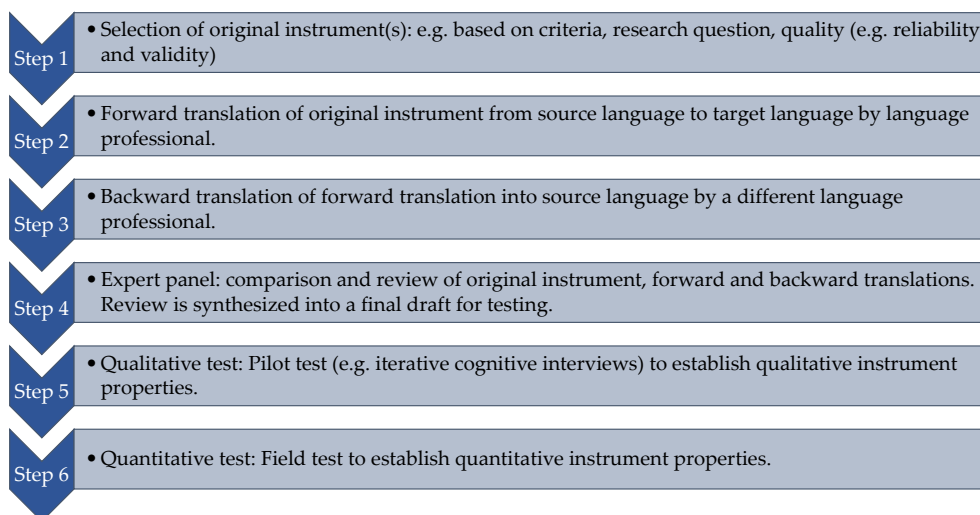


Figure 1

Translation, cultural adaptation, and testing process.

assigned to interview rounds in the sequence they were recruited. Recruiting was somewhat limited due to the covid-19 pandemic, as some potential participants were either too sick or too afraid to want to increase their risk of infection by participating in an interview. Round I had four participants (cancer patients), round II had three participants (cardiac arrest survivors), round III had four participants (NDEs and/or healthy), and round IV had three participants (COPD patients or healthy). Some participants (<3) were not comfortable with a face-to-face interview due to the covid-19 pandemic, in which case the interview was conducted via Zoom (a digital video-conference software package (Zoom Video Communications)). 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 2). Interviews lasted between 15-51 minutes (mean: 32 min.) for the part with filling out the questionnaire and between 26-113 minutes (mean: 65) for the entire interview, including retrospective probing.

5.4 Pilot testing

Pilot testing of the questionnaire was performed qualitatively through iterative rounds of cognitive interviews, see figure 2. Both the techniques ‘think aloud’ and ‘probing’ were used (Collins, 2015). Specifically, three items had been identified by the expert panel for testing by real-time scripted probing (items: KB5, ED2, NDE-filter question). 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.

After each round of interviews, adjustments and recom-

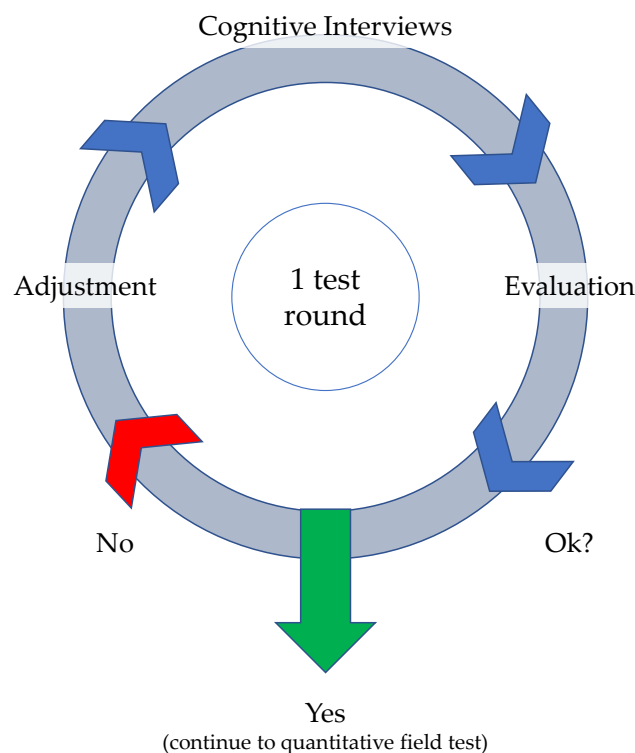


Figure 2

The concept of iterative cognitive testing. Adaptation inspired from de Vet et al. (2011)

Table 2*Demographics of participants included in analysis (n=13)*

Participants	
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)

recommendations to the questionnaire were prepared based on qualitative content analysis of interview summaries from each round of testing (see 2.6.2) (de Vet et al., 2011; Hsieh & Shannon, 2005). The first and last author reviewed the adjustment recommendations and made amendments to the questionnaire accordingly. The amended version was then prepared for the next round of testing. In this way, the questionnaire was tested and improved iteratively through cognitive interviews and adjustment recommendations based on findings from directed content analysis (de Vet et al., 2011; Hsieh & Shannon, 2005). The compiled questionnaire (126 items) was too large for cognitive testing of each item in one interview. However, cognitive interviews focusing on generally testing the questionnaire together with probing for specific items were deemed feasible: (1) because the main goals were to examine the acceptability and comprehensibility, and improve the questionnaire overall, and (2) since the vast majority of questions were from already validated instruments that had been tested in similar participants internationally, most items had to be retained for comparison and copyright purposes anyway. This latter limitation will be discussed later. We needed to test if the translation of the instruments had been successful by examining if the questions were readily understood by participants.

5.5 Procedure of cognitive interviews

The first interview was conducted by both the first and last author to enhance procedural agreement. Subsequent

interviews were conducted by one interviewer (the first author did 10 interviews; the last author did three interviews). The below procedural description is also true for the interviews conducted via the video application named Zoom (<3). All interviews were conducted based on an interview guide (see "Supplementary material"), with one participant at a time. All participants were interviewed only once. The interviews began with the participant being shortly introduced to the study and aim, the interview setting, data management and confidentiality. If consenting to participate, the participant was instructed to think aloud while answering a test question (the method was demonstrated by the windows example (Collins, 2014)). The participant was then told to keep thinking aloud while answering the survey. The participant was then handed a laptop with the digital questionnaire. The reason that the participant should not fill out the survey on their own digital device was due to a need to keep the setup stable between interviews and securing that the interviewer, to a greater extent, could control the technical aspects of the testing. The interviewer would be located so that he/she was able to observe the laptop screen. This enabled the interviewer to notice flaws or issues in the digital design (e.g. by watching the cursor movements on the screen), while also being able to observe participant answering processes (figure 3). The interviewer was passively observing the participant. If issues with the survey arose or direct questions were asked to the interviewer, the interviewer would first try to fence off the contact to see if the participants could elaborate or solve the issue by themselves. If a problem persisted, the

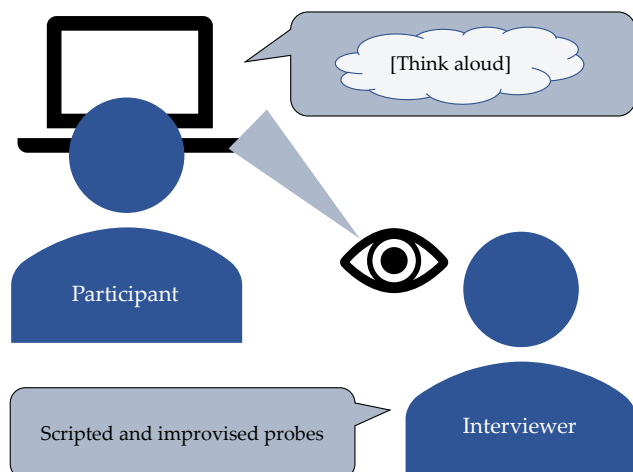


Figure 3

Iconographic representation of interview setting

interviewer would actively intervene and help the participant further e.g. in the digital survey system or by clarifying a concept. While the questionnaire was filled out, both improvised and scripted probes were administered. The improvised probes were used when the interviewer deemed it necessary to make the participant clarify a thought or a specific issue that arose. The scripted probes were used to test specific questions. An example of an improvised probe used was: “That question seemed particularly difficult to answer, why was that?”. A scripted probe used was: “What experience did you think of while answering [NDE-filter question]?”. Then, after completion, 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).

5.6 Analysis

Material

All interviews were recorded using an “Olympus WS-750M Digital Voice Recorder”. 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 content of these interview summaries represented detailed statements or observations related to issues of specific items, instruments, or experiences from the

interview. These summaries were used as the primary data material.

Content analysis and coding

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). Zoom interviews (<3) were analyzed similarly and together with face-to-face interviews, as the interview procedures had been reproduced to the best of capabilities in both settings. This was also deemed feasible since others have found that psychometric properties of face-to-face and remote (online/telephone) interviews were highly correlated (da Silva et al., 2014; Steffen et al., 2014). Several theoretical approaches to conceptualize the issues identified through cognitive interviewing in different settings, enabling interpretation and analysis, have been proposed (Boeije & Willis, 2013; Levin et al., 2009; G. Willis, 2005). Across multiple studies, Willis and colleagues tested questionnaire translations with cognitive interviews (ibid.). They identified three categories of questionnaire issues, which served as the theoretical framework for analysis in the present study: 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; G. Willis et al., 2005). Statements and observations were coded using this framework with the codes: “translational issue”, “cultural issue”, or “general design issue”. Coding was done twice by TKS to enhance coding accuracy and verify the grounding in the data (Gildberg et al., 2015). The intra-rater reliability was calculated as two times the number of shared issues identified divided by the sum of issues identified in both coding rounds². The code “translational issue” was used to specify problems with wrong wordings or flaws in the instrument translation from the source language into Danish. The code ‘cultural issue’ was used to indicate issues with phrases that related to the cultural differences between the country or region where the instrument was developed and the Danish setting. This could relate to e.g. understanding and wording of existential, spiritual, or religious terms and concepts. The code “general design issue” was used to mark problems of a general nature and issues not relating to either translation or culture. These could be e.g. related to the concepts, setup, or digital layout of the questionnaire. Statements or observations that indicated well-functioning aspects were not coded, as these were not considered issues.

²Intrarater reliability = $\frac{2M}{(N_1+N_2)}$

Presentation of results

Observations and participant statements related to acceptability, comprehensibility, or comprehensiveness were reported from interviewer notes, interview summaries and the overall impression of the interviewers. After coding, the frequency of codes was summarized as “nodes” in NVivo, and together with the interview summaries, these analyses resulted in adjustment recommendations to the questionnaire. The process of analysis was repeated after each round of testing. Finally, the frequency of all issues in all rounds was presented descriptively.

5.7 Ethics

The project was registered for legal and GDPR concerns at the SDU RIO with journal number: 10.367, and approved by the SDU institutional review board, the SDU REC, journal number: 20/39546. Data will not be shared openly to protect the confidentiality of participants and to observe the legal requirements of our institution.

6 Results

6.1 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. Some participants had problems with adjusting to the not-familiar hardware used in testing. As one of the older participants explained, when experiencing issues with the mousepad on the handed-out laptop: “I am more used to my own computer and mouse.” Software-wise, the validation system of the digital survey software proved to exhibit some difficulties for some participants. This was related to the feature that once an answer had been ticked off, you could only move the value of the answer and not remove the answer entirely. Similarly, validation rules had been set up for almost all questions, meaning that you had to answer all questions in an instrument to be able to move to the next page. The software’s way of telling respondents which item needed to be filled out was also confusing for some participants. However, both these digital issues were due to the software chosen. The authors did inquire with the software company, and these design issues were non-amendable as they were embedded in their software code.

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” (participant from round I who had been repelled and upset by the IIQ-instrument). A few participants questioned whether their responses would have any value since they were not religious: “I think the questions were a lot about, you know, faith and the like. I am completely fine with other people believing and I respect that, but I don’t really believe in anything myself. So, I don’t know if you can use my answers for anything.” On the other side, 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. A few words were difficult to understand, e.g. “wondrous awe” (da: underfuld ærefrygt) and “devout” (da: andægtig). The implications of these findings are discussed further below.

The interviewers’ overall impression was that the questionnaire was increasingly well-received over testing rounds, as issues were resolved, indicating acceptability. Similarly, the digital setup also performed better throughout testing rounds. It seemed ethically feasible to examine the existential and spiritual needs through survey design in a secular culture as no severe discomfort was observed during interviews. In summary, the interviews supported the acceptability and comprehensibility of the questionnaire, which did not seem to differ across participant characteristics.

It should here be mentioned that a retrospective probe was used to ask whether the questionnaire had been comprehensive in examining the existential, spiritual, and religious needs, practices, and affiliations of the participant. Here, participants generally could not come up with anything that they missed in the questionnaire: “No. I guess there really isn’t any need related to my spiritual life that you didn’t ask. I spend more time in nature since I got my diagnosis. But that question was there as well I think.” The most apparent finding related to the comprehensiveness was related to which terms and examples were given of the divine: “So this question asks if I have had a need to turn towards God/a higher power, but I don’t believe in any of the examples given. I mean, they are all very religious—God, Allah, and so on. And I don’t believe in all that. But I do believe that there is a higher power, or you know, the Universe perhaps.” This led to an expansion in the examples given to various questions (see 3.3).

6.2 Issues identified through iterative cognitive interviews

Frequencies of issues identified through coding can be seen in table 3. A total of 81 issues were identified across the four rounds of testing. Intrarater reliability was 0.987, which indicates a very high degree of coding reliability. Issue frequency was declining in concurrent testing rounds, with 31 issues identified in round I and 14 issues identified in round IV. The average number of issues per participant was also declining across testing rounds, from 10.33 in round I to 4.66 in round IV.

Overall, most issues were related to general design issues. These were related e.g. to errors in the digital setup of instrument categories, incomprehensible question wordings, etc. For instance, some participants were retired, and they complained that a question on satisfaction with school/working conditions was irrelevant to them—and the digital software still required an answer before they could move on with the rest of the questionnaire. Some issues were simply related to spelling or formatting errors. An instrument was completely impossible for the participants to fill out because they didn't understand the answer categories used i.e. it was incomprehensible (Satisfaction with Spiritual Care (SWS)). In rounds I and II, many new issues were found, but the issues found in rounds III and IV were in most cases repetitious. See below for amendments made to issues found.

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 implications of this finding were discussed thoroughly between the first and last author on multiple occasions. Multiple paraphrases were considered, but it was not possible to come up with alternative wordings in Danish in which the conceptual meaning was intact. Deletion of the instrument altogether was not deemed feasible either. Consequently, the items were retained albeit the issues found with them. This is discussed in greater detail below. These two items are the main contributors to the cultural adaptation issues frequency count as they were the primary cultural issues identified in all testing rounds (I, II, III, and IV). Thus, the stable and non-declining issue frequency in cultural adaptation issues can to a large extent be attributed to the decision not to change these two items. A questionnaire was found to cause strong emotional reactions i.e. it was not acceptable for some participants (Interpretation of Illness Questionnaire (IIQ)) and ended up being omitted for this reason.

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 with reference to 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.

6.3 Adjustments based on interview findings

Multiple adjustments were made to the questionnaire based on the adjustment recommendations prepared after testing rounds, see table 4. 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. The questionnaire initially had some items on Covid-19 status, coping, and how the pandemic had affected the participant. However, it became apparent that these questions were conceptually utterly different from all the other items. Specifically, an observer note from an interview conducted by TKS reads: “The atmosphere completely changes when the questions on Covid come up, and this seems disturbing to the participant. It also seems like the flow of “digging down” into own existential/spiritual/religious orientation is disrupted in a bad way due to this conceptual break. Consider omitting the Covid items.” During the study period, the perceived public importance of the pandemic seemed to change as restrictions were lifted etc. and together with the above, this enabled the omission of these items. For cultural issues, and adjustment was made as to when examples of the divine were provided in items, these lists were expanded to include spiritual and holistic transcendent observations e.g. “the Universe” (conceptually equal to God) or “common spiritual practice with others” (conceptually equal to congregation). Some notable improvements were made to the digital setup: “Not relevant” questions were added to most items so that participants were not forced to answer questions that they couldn't identify with. Some questionnaire pages were split up to yield fewer items per page, making it easier for the participant to take in the task.

7 Discussion

7.1 Summary

In summary, we translated, tested, and improved a questionnaire on existential and spiritual constructs through cog-

Table 3*Frequency of issues in each iterative round and issues per participant (n= 13)*

Round	N	Translational issue		Cultural issue		General design issue		Total issues		Issues per participant (rounded)
		n	%	n	%	n	%	n	%	
I	3	2	6	5	16	24	78	31	100	10.33
II	3	1	5	8	38	12	57	21	100	7.00
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

nitive interviews. As hypothesized, a decrease in the frequency of issues identified through directed qualitative content analysis was observed through iterative rounds of testing and adjustment of the questionnaire. The findings indicated that the final questionnaire was both acceptable and comprehensible. Further, the comprehensiveness of the questionnaire in addressing the existential, spiritual, or religious needs, practices, or affiliations seemed satisfactory.

7.2 Interpretation of findings

Can quantifying issues help in improving a questionnaire?

Without going deeply into an ontological discussion on the assumptions inherent in the cognitive interview, a few remarks should be made as context for the subsequent discussion on how “counting issues” might represent a feasible method to examine the quality of a questionnaire. Cognitive interviews are traditionally underpinned by the positivist conception that language, thought processes, and behaviour reflect the objective reality (of a participant) (Boeije & Willis, 2013). Inherent to this understanding, knowledge is something that might be picked up empirically with the right methods or techniques, and it is this understanding that merits e.g. that counting issues identified in a questionnaire may be used to improve such a questionnaire. However, as we shall see, there are also issues with this conception. On the other hand, cognitive interviews and the data they generate are also closely linked to interpretative ontologies in which language is thought to construct reality—rather than merely reflecting it. As such, the subjectivity of the interviewer becomes integral to the process of understanding a phenomenon. According to this ontology, data are co-constructed between the researcher and the participant and not something that already exists “out there” to be collected. Further, this in-depth interpretative understanding of the constructs that the questionnaire addresses is pertinent to establishing content validity. We believe clarity and transparency in ontological standpoints are crucial to research processes (Stripp, 2021). However, we would argue that there is both

a conceptual and pragmatic aspect to address when improving a questionnaire. In terms of concept, it is obvious that comprehensiveness and content validity is key for a survey to be successful, and expert knowledge together with an interpretative approach to assess this is warranted. On the other hand, if a questionnaire exhibits inherent logical flaws in wording or answer categories, it seems reasonable to believe that these issues will substantially affect the response rate and the quality of the data collected. Such issues may not be sufficiently addressed by an in-depth understanding of the participants’ views on the construct measured on a phenomenological level, and thus, a practical solution may be to count issues that participants report to see if problems with the questionnaire become apparent. However, this may also be a faulty approach as there may be no link between the actual issues and the number of participants who report an issue (Beatty & Willis, 2007). In addition to this, as we also experienced, issues that could have had a substantial impact on data quality might first be identified after several rounds of interviews (e.g. it was first in round III that it became apparent that the prefix for the Spiritual Needs Questionnaire had been incorrectly translated) (Blair & Conrad, 2011). Albeit the shortcomings of frequency-counting mentioned above, we considered this, inspired by the previous work of Levin et al. (2009), to be the most practical and feasible approach available in this study.

Saturation of data and interpretation of issues identified

While the reported results provide evidence for the acceptability and comprehensibility of the questionnaire, a few comments should be made. The decrease and stabilization of issue frequency indicated some questionnaire maturation; however, a fifth round of testing might have been warranted in demonstrating data saturation. Although we found a clear decreasing tendency in identified issues over testing rounds this could be “noise”. However, we do believe that there is evidence in the data of a degree of saturation since the main issues that persisted in the last rounds (III and IV) were quite identical and had proved challenging to amend for various

Table 4

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

Issue type	Example	Adjustment recommendation	Adjustment
Translational	C: “Turn to nature (vender mig mod naturen) – do you mean turn against nature?” [Spiritual Engagement (SpREUK-P) – P9] O: [SpNQ] prefix question is rendered wrongly.	None, since this misinterpretation was only present in one participant. Change “[...] have you had any of the following needs?”	None. Changed to: “[...] have you had the need to...”
Cultural	C: “What does ‘wonderous awe’ (underful ærefrygt) mean?” [Gratitude and Awe Scale (GrAw-7) – ED2] 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)] C: “What is meant by ‘support from God’? I believe but I don’t ask/pray for his support.” [BMLSS Support – T6] 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] 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)] C: “How do I fill this out?” [Satisfaction With Support (SWS)] O: the atmosphere abruptly changes when covid-19 items come up.	Omit GrAw-7 OR culturally adapt the wording of “wonderous awe”. Omit the IIQ as participants are experiencing discomfort with item wording. None. Item interpretation is for the participant. Add examples of more holistic or spiritual concepts to the list of examples of transcendent orientations. Add “not relevant”/“don’t know” categories for items that may be irrelevant for some. Omit the SWS as it is incomprehensible for participants. Omit covid-19 items.	None. None: Translation is correct, and no synonymous expression in Danish conveys the conceptual meaning. IIQ omitted. None. “The Universe” added to “[...]” (e.g. God, Allah, angels, saint, the Universe). “Not relevant” / “Don’t know” categories added to questions that may be irrelevant for some. SWS omitted. Covid-19 items omitted.

reasons. Thus, there is a relatively significant contribution of issues from items for which we could not find better alternative wordings. It could still be questioned whether the incomprehensibility of the ED2 and ED6 should have led to the instrument being omitted. However, the construct was of great interest for subsequent research questions— and in preliminary findings from a quantitative test of the questionnaire, the GrAw-7 exhibited excellent internal consistency. This finding from the preliminary psychometric test could indicate that the incomprehensibility of the ED2 and ED6 was perhaps overestimated in this sample.

The sample

A wide variety of demographic representations were present among relatively few participants as it was a biased convenience sample. Thus, the sample size may be a limitation to how the findings from these 13 interviews may be generalized and used as an argument for the feasibility of distributing a digital questionnaire on existential and spiritual health successfully to 500,000 randomly selected Danes. Be that as it may, we are content with the obtained sample and believe that our sample is sufficient to support the findings that we have reported.

Existential and spiritual vernacular

The importance of existential and spiritual vernacular, or lack thereof, seems to have implications as the constructs investigated seemed alien to some individuals. Thus, it proves challenging, still, to balance the nuance and content of existential and spiritual research in a secular context. There is a high risk, it seems, of losing information either due to the lack of existential and spiritual reflection on behalf of the participant, making the concepts presented incomprehensible to them, or conversely by simplifying the abstract nature of existential and spiritual concepts to very broad, shallow, and indistinguishable phenomena. The implications of these conflicts should be further elaborated in future research on faith and health in secular cultures. Interestingly, we noticed that for some participants, filling out the questionnaire was almost a positive health intervention in itself. Many participants indicated that having had the opportunity to expand their view on their own existential and spiritual position, guided by the conceptualizations the questionnaire provided, had been very rewarding. More research is needed to test how items of the questionnaire may be used in communication guides or as a tool for self-reflection. The method presented here may serve as inspiration when conducting qualitative questionnaire research.

7.3 Methodological considerations

Some comments on the cognitive interview method that we have utilized should be made for future practice.

Think aloud and probing

Regarding think aloud data, there are 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.

Why test it if you can't change it?

Also, 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 score (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.

Analysis

Another methodological contemplation is whether the analytical approach was feasible. Very few translational issues were identified, and some items had to be retained for vari-

ous 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).

7.4 Comparison to other studies

The approach applied is similar to the one used in the studies of Levin et. al and others (Forsyth et al., 2007; Levin et al., 2009). We had comparable success with the method. The acceptability and comprehensibility of the instruments tested qualitatively in this report were in line with what had been reported in the validation studies on the instruments in their original contexts.

7.5 Conclusion and perspectives

Overall, the compiled questionnaire was acceptable and comprehensible to cancer patients, COPD patients, cardiac arrest survivors, and healthy participants. Further, it seems comprehensive in addressing their existential, spiritual, and religious practices, needs, and orientations. Additionally, the results indicated that cognitive interviews might be used to decrease especially general design issues of a questionnaire on existential and spiritual constructs in a Danish sample. Conflicts may arise concerning items that need to be retained for comparison or copyright reasons. Researchers need to bear this in mind when testing translations of validated questionnaires. A wide range of participant characteristics was represented in the test. A quantitative evaluation of the Danish instruments' measurement properties is currently underway. We found that qualitative testing is an invaluable tool to improve a questionnaire intended for quantitative purposes.

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