The content validity of social and spiritual items of the Utrecht Symptom Diary – 4 Dimensional for patients in palliative care: A qualitative study

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Abstract

Background: Palliative care aims to optimise the quality of life of patients with life-threatening illnesses by diminishing multidimensional suffering. The social and spiritual dimensions still seem underrepresented in Dutch palliative care, as caregivers lack words to describe and discuss the patients' associated needs. The ars moriendi model centres on five tension fields that may be pivotal in one's process of dying. They should facilitate communication about needs in the social and spiritual dimension. Recently, these tension fields were integrated into the Utrecht Symptom Diary – 4 Dimensional (USD-4D), a Patient-Reported Outcome Measure (PROM). **Aim:** This study's aim was to assess the content validity of social and spiritual items of the USD-4D, in accordance with the Consensus-Based Standards for Selection of Health Measurement Instruments (COSMIN) methodology. **Method:** A generic qualitative study was conducted using semi-structured interviews from February 2019 to July 2019. Data were analysed independently by two researchers using thematic analysis. **Results:** A total of 12 participants (male N = 7, age range 53–87 years) possessing a life-limiting illness participated. The instructions and response options were clear for almost all participants. The meaning that the participants provided to the items was expressed in themes: maintaining personal identity and autonomy, resilience, letting go, perceived balance in one's life, and death and life after death. This corresponded with the items' intended meaning. Most of the participants found the items relevant and comprehensive. **Conclusion:** The USD-4D constitutes a content-valid PROM from the patient's perspective. The items seem to aid in exploring needs from the social and spiritual dimension and appears supportive in the conversation to further explore these needs. **Recommendations:** Further research is required for the USD-4D's successful integration in Dutch palliative care.

Keywords: Palliative care (MeSH), Multidimensional care, Patient Reported Outcome Measures (MeSH), USD-4D, Validity

Nederlandse samenvatting

Achtergrond: Palliatieve zorg heeft als doel de kwaliteit van leven van mensen met een ongeneeslijke aandoening te verbeteren, door vermindering van multidimensioneel lijden. De sociale en spirituele dimensies blijken in Nederland onder gerepresenteerd. Zorgverleners vinden het lastig om inhoud te geven aan deze dimensies. Het ars moriendi model bevat vijf spanningsvelden welke cruciaal zijn in het stervensproces. De spanningsvelden zijn bedoeld om communicatie over behoeften in de sociale en spirituele dimensie te bevorderen. Recent werden de vijf spanningsvelden geïntegreerd in het Utrecht Symptoom Dagboek – 4 Dimensioneel (USD-4D), een patiënt gerapporteerde uitkomstmaat(PROM). **Doel:** Het doel van dit onderzoek was het vaststellen van de inhoudsvaliditeit van de sociale en spirituele vragen van het USD-4D, volgens de COSMIN methodologie (COnsensus-based Standards for the selection of health status Measurement INstruments). **Methode:** Een generiek kwalitatief onderzoek met semigestructureerde interviews werd uitgevoerd van februari 2019 tot juli 2019. Data werden door twee onderzoekers onafhankelijk geanalyseerd met behulp van thematische analyse. **Resultaten:** In totaal namen 12 participanten (mannen N=7, leeftijd variërend van 53-87 jaar) met een geschatte levensverwachting van minder dan één jaar deel. De instructies en antwoordmogelijkheden waren duidelijk voor de meerderheid van de participanten. De betekenis die patiënten aan de items gaven werd uitgedrukt in thema's: behoud van persoonlijke identiteit en autonomie, veerkracht, loslaten, waargenomen balans in iemands leven en dood en het leven na de dood. Dit komt overeen met de beoogde betekenis van de items. De meeste participanten vonden de items relevant en volledig. **Conclusie:** Dit onderzoek toont dat het USD-4D vanuit het patiëntperspectief inhoudsvalide blijkt te zijn. De items lijkten te ondersteunen bij het verkennen van behoeften in de sociale en spirituele dimensie. **Aanbevelingen:** Meer onderzoek is nodig om het USD-4D succesvol te integreren in de palliatieve zorg in Nederland.

Trefwoorden: Palliatieve zorg, Multidimensionele zorg, USD-4D, Patiënt gerapporteerde uitkomstmaat, Validiteit

Introduction

In 2018, 147.000 people died in the Netherlands, of whom an estimated 75% of these deaths was expected.[1,2] This means that approximately 110.000 patients could have benefitted from palliative care.[3,4] Palliative care describes multidimensional care aiming to optimise the quality of life of patients possessing life-threatening illnesses by diminishing psychical, psychological, social and spiritual suffering.[3]

The National Quality Framework Palliative Care (2017) was elaborated in order to optimise palliative care in the Netherlands. Day-to-day care is guided through standards and criteria on the physical, psychological, social and spiritual dimensions.[5]

Despite the existence of the Quality Framework, the social and spiritual dimensions still appear underrepresented in daily practice.[6,7] Caregivers lack words to describe and discuss the patients' needs within these dimensions.[7,8] However, the social and spiritual dimensions considerably influence the quality of life.[9-11]

A model offering support in discussing the needs in the social and spiritual dimensions is the ars moriendi ('art of dying') model. This model centres on five tension fields which that may be pivotal in one's process of dying: (1) myself – the other, (2) doing – undergoing, (3) holding on – letting go, (4) remembering – forgetting, and (5) knowing – believing. Central in these tension fields is the concept of inner space: a state of mind wherein a person is able to freely and peacefully relate to direct emotions and attitudes caused by a situation.[12] The tension fields are supposed to support the patient in decision making and should facilitate communication between caregivers and patients, which is essential in ensuring that the patients' needs are met.[12,13]

Recently, these tension fields were translated and integrated in the Utrecht Symptom Diary – 4 dimensional (USD-4D), in collaboration with the Dutch Association for Spiritual Carers.[14] The USD-4D comprises a Patient-Reported Outcome Measure (PROM) with five items concerning the social and spiritual dimensions. Depending on the patient's individual needs, the USD-4D provides patients with the ability to reflect based on a practical attitude or on personal values associated with the social or spiritual dimension.[14]

Currently, the USD-4D is utilised in several healthcare institutions in the Netherlands. Although it has proven to be feasible in daily practice, the five items concerning the social and spiritual dimensions have not yet been validated.[15,16] Therefore, it is necessary to assess the validity of these items.[17]

Content validity is often considered the PROMs' most important measurement property. In a large, four-round Delphi study among 156 experts, the current available research concerning PROMs' content validity was thoroughly evaluated and merged into the Consensus-Based Standards for Selection of Health Measurement Instruments (COSMIN) methodology.[18,19] According to this methodology, content validity is defined as the comprehensibility, relevance and comprehensiveness from a patient and caregiver perspective. This provides information regarding the extent to which an instrument's content sufficiently reflects the construct being measured.[18]

Further research regarding the USD-4D's content validity from the patient perspective is required as a first step in the validation process.

Aim

This study's aim was to assess the content validity of the social and spiritual items of the USD-4D for use with patients in palliative care with possessing an estimated life expectancy of less than one year, measured in terms of comprehensibility, relevance and comprehensiveness.

Method

Design

A generic qualitative study was conducted from February 2019 to July 2019. The generic design was considered suitable because this study aimed to explore patients' opinions regarding the USD-4D's content validity for the first time.[20] For this report, the COnsolidatedf criteria for REporting Qualitative studies (COREQ) guidelines have been adhered.[21]

Population and setting

Participants were recruited in one general hospital, one hospice and two home care organisations in the centre of the Netherlands. The study population consisted of adult patients in the palliative phase of their ilness. Eligible patients possessed an estimated life expectancy of less than one year. This was determined using the 'surprise' question,[22,23] in which caregivers were asked, 'Would you be surprised if this patient died in the next year?' Patients were eligible if the answer was 'no'. Furthermore, patients had not used the USD-4D before and were aware of their palliative prognosis. Due to cultural differences in dealing with social and spiritual issues, only Dutch patients were included.[24,25]

A purposeful sampling strategy with maximum variation was employed to ensure a broad and in-depth exploration regarding how patients reflect on the content validity.[26] Maximum variation sampling was utilised to create variation in age, gender, marital status, living situation, illness, time since diagnosis, and religion or ideology.

The USD-4D

The USD-4D complements the Utrecht Symptom Diary (USD).[27] The USD comprises a Dutch-adapted version of the validated Edmonton Symptom Assessment Scale, a self-report symptom intensity scale of the physical and psychological dimension.[28,29]

The USD-4D therefore contains items concerning the physical, psychological, social and spiritual dimension. However, this study focuses on the recently added social and spiritual items.

The USD-4D is intended to for use in daily practice within palliative care. The social and spiritual items of the USD-4D do not measure a construct, but are instead utilised to recognise and monitor needs in the social and spiritual dimension. The USD-4D outcomes are supposed to facilitate communication concerning these needs. All items are assessed using an 11-point numerical scale (0 = yes to 10 = not at all). The recall time is now or at the moment. Patients assess the items biweekly and can also add a symptom by answering the open question, ‘I would also like to let you know that…’ Written instructions are included in the USD-4D.[14]

Data collection

This study’s main outcomes consist of (1) comprehensibility, (2) relevance and (3) comprehensiveness, defined as follows.[19]

1. All USD-4D items, response options and instructions should be understood as intended by patients in palliatieve care.
2. All items should be relevant to the social and spiritual dimension within patients in palliative care.
3. All key concepts are included in the items and the items should comprehensive to identify needs for social support and/or spiritual care

An interview guide based on the COSMIN methodology was employed.[19] The interview guide is added in Appendix A. One pilot interview was conducted to train the interviewer and to test and optimise the interview guide.

The researcher (SdV) conducted one semi-structured interview with each participant between February 2019 and July 2019. No relationship between the interviewer and participants existed prior to the start of this study. Before beginning the interview, participants received the written USD-4D. Given the connection with the USD-4D items, the interviews started with a question concerning the meaning of life. Subsequently, the topics of comprehensibility and relevance were discussed for all five items individually.

Thereafter, the topic of comprehensiveness was discussed for the items together.

All interviews were audio recorded, and field notes were written directly after the interview.

Participants were recruited until matters were completely understood and saturation was reached.[30]

Procedures

Eligible patients were approached by their health care professional before the researcher contacted them. All eligible patients invited to participate received information about the study from the researcher. When patients agreed to participate, an appointment for an interview was made. Before starting the interview, participants were asked to fill in a case report form to collect demographic characteristics. Due to the interview's theme and the potential emotional distress, aftercare was offered to all participants. An experienced hospice nurse was available by telephone.

Data analysis

The data were analysed using thematic analysis by means of an iterative approach, in which data collection and analysis alternated.[31] Interviews were transcribed verbatim. The software NVivo12 (QSR International) was employed to assist the analysis of the interview transcripts.[32] The transcripts were read repeatedly so as to enable familiarity with the data. First thoughts about the data were noted. The initial codes were gathered into overarching themes, which were reviewed in relation to initial codes and the entire dataset. Next, the themes were refined further in order to identify the essence of the themes. When this essence was identified, each theme was named and a clear definition provided. The final analysis included a representation of the information found in the data, as well as how this relates to the aim and literature.[33]

Trustworthiness

Two researchers (SdV and TL) coded all the interviews independently in order to increase credibility.[34] Codes and themes were compared frequently until consensus was reached, a senior researcher (EdG) was available if consensus was not reached. Member checks were applied to correct errors in the researcher's interpretations[35]. Dependability of the interviews was enhanced by the use of an interview guide with standardised questions. The interview guide was checked by a local council of patients' representatives of the palliative care collaborative in the centre of the Netherlands. Small changes were made to the questions to ensure understandability. Furthermore, theoretical memos were used to record methodological issues and to reflect on the researchers' role.[26]

Ethical issues

The study was conducted in accordance with the principles of the Declaration of Helsinki,[36] guidelines for Good Clinical Practice[37] and the General Data Protection Regulation.[38] The Medical Research Ethics Committee of the University Medical Centre Utrecht (UMCU) confirmed that the Dutch Research Involving Human Subjects Act (WMO) did not apply to this study (19-053/C). This study’s quality was checked by an independent quality officer of the UMCU. All participants consented to be approached by the researcher. Written informed consent was obtained before the start of each interview. The data were anonymised and stored on the UMCU data management system and will be safeguarded for 15 years.

Results

Participant characteristics

A total of 31 patients were identified as eligible, of whom an interview appointment was made with 18 participants. Six patients dropped out due to an increased symptom burden or death. In total, seven men and five women were interviewed. The participants’ mean age equalled 69.8 years (range 53–87). The majority of the participants suffered from cancer. Baseline characteristics of the study population are presented in Table 1.

[Insert Table 1]

All interviews were held at the participants’ preferred location, such as at home or in a quiet room in a hospice or hospital. In one of the interviews, a loved one was present. The interviews lasted between 19 and 69 minutes (mean 40).

Comprehensibility

After reading the instructions and the USD-4D items, all patients were able to answer the items. The response options were clear for all participants. However, a few participants indicated that the response options were not logical for them. They suggested reversing the numerical scale to 0 = ‘not at all’ to 10 = ‘yes’ instead of 0 = ‘yes’ to 10 = ‘not at all’, or to reduce the answer options to 0 = ‘not at all’ to 5 = ‘yes’.

One participant stated that he did not understand the first item. None of the other participants indicated that items were unclear. The meaning the participants provided to the items can be identified in five themes: maintaining personal identity and autonomy, resilience, letting go, perceived balance in one’s life, and death and life after death. Table 2 depicts the themes and subthemes for each item. The text incudes Q references, which refer to specific quote to further illustrate results.

[Insert Table 2]

Maintaining personal identity and autonomy

The first item, 'I take time for myself', refers to maintaining one's personal identity and autonomy. Some participants described having to deal with limitations due to their ilness, such as fatigue or pain. These limitations negatively influenced the time people take for themselves and instil them with a feeling of dependence (Q1). A few participants described wanting to maintain control despite such limitations and were focusing on getting through the days in manner comfortable for them. Other participants defined taking time for themselves as making time for relaxation in the form of hobbies or being with relatives and friends. Some participants instead preferred to be alone with their own thoughts and feelings. One participant mentioned her financial independence as concerns taking time for herself and allowing her to do what she wants, such as going on a holiday.

> *Q1: 'I can't say, "Tomorrow, I'm going to the city, and thereafter, I'm going to the cinema". That is not possible. So, taking time for myself, the things I would really like to do, are not possible. So, I can't take time for myself. (R01)*

Resilience

The second item, 'I can bear what happens to me', was associated by the majority of participants with bearing the ilness and physical complaints. Some participants mentioned that it also relates to letting go of life and loved ones in terms of by bearing their own grief and the grief of loved ones (Q2) Due the physical complaints and limitations, some participants also thought about the end of life. A few participants discussed their end-of-life decision making.

> *Q2: 'Look the physical and the pain, I don't care much about that, but that I'm going to die and leave everyone behind. That's unbearable'. (R05)*

Letting go

The third item, 'I can let my loved ones go', was interpreted by all participants as referring to letting their loves ones go. A few participants mentioned feeling a responsibility to prepare their them as well as possible for their death. For example, this included talking about it or enjoying the time they had left.(Q3) Some participants stated that they find it difficult to let go because they are not ready to die yet. For other participants, letting go constituted a slowly growing process.

> *Q3:' I have the greatest difficulty with letting go my loved ones. I try to stay with them for as long as possible and pay as much attention as possible to them'. (R04)*

Perceived balance in one’s life

The fourth item, ‘I feel a sense of balance in my life’, was described in two different ways. First, some participants saw ‘balance in life’ as referring to balance in their daily life. Due to a reduced level of energy and other physical complaints, participants had to make choices in their daily schedule regarding where they wished to feel happy and comfortable. Second, others saw this as having to do with reflection on one’s life (Q04) For example, this involves whether or not participants held any regrets about matters they did not do in their life. Alternatively, this could concern finding balance in dealing with matters that are currently being worked on, but will not be finished before death.

Q4: ‘The way I've lived my life. With all ups and downs. Then I can look back and think, “I would do it like this again”’. (R08)

Death and life after death

In the fifth item, ‘My thoughts about the end of life give me peace of mind’, all participants offered a unique perspective concerning death and life after death. Some participants did not feel a peace of mind when thinking about the end of life because they found it hard to accept that they were suffering from a life-limiting illness. Other participants described that their thoughts about death did not grant them peace because they were afraid of the way they would die, such as because of pain or suffering. Still other participants experienced a peace of mind by preparing for the farewell, including the farewell of their loved ones as well as preparations for after death, such as arranging the burial(Q5). It provided the participants with peace to arrange this farewell so that loved ones know the goodbye went according to the wishes of their loved one. A few participants also felt peace through their spiritual or existential beliefs, such as through their belief in God or once again seeing a daughter who had passed away.

Q5: ‘Well, in that extent, my thoughts about the of life give me rest, but of course I still have to arrange things when I'm not there anymore. Then I have complete rest’. (R03)

Relevance

The themes that were assigned to the items were relevant for the social and spiritual dimension for almost all participants.(Q6) One participant stated that he did not to think about the end of life, but expects to be so tired at some point that life will simply not continue anymore. For him, the fifth item was not relevant.

Participants also indicated that not all items were relevant for them during the interview. (Q7) Some participants described possessing no current needs or symptom burden regarding an item. These items were thus less relevant during the interview. However, for most participants, the item was important earlier in their lives. These participants described that they had already found peace of mind in those items in the past. Participants who found items less relevant did not mind answering them. They experienced a provided space to indicate that the item requires no further attention for them.

Q6: 'Yes, it is important for me to keep doing to the things I like. Due to my physical complaints I'm more at home now. I miss the walking and cycling what I used to do. That's a major loss for me'. (R11)

Q7: 'The item is not relevant for me at the moment, because I have already accepted that I'm incurable ill. I will see how my life goes further'. (R10)

Comprehensiveness

All participants found the social and spiritual dimension to be comprehensively covered by the items. (Q8) They indicated that the items helped them to discuss their needs in the social and spiritual dimension. A few participants lacked words to discuss the spiritual dimension.(Q9)

Q8: 'No, I miss nothing. I think we have discussed everything in this conversation'. (R07)

Q9: 'I am not a spiritual person so I cannot say anything about it'. (R09)

An overview of the comprehensibility, relevance and comprehensiveness is presented in Table 3.

[Insert Table 3]

Discussion

This study aimed to assess the content validity of the social and spiritual items of the USD-4D. Our findings indicate sufficient ratings for the comprehensibility, relevance and comprehensiveness of the USD-4D, since the instructions, items and response options were comprehensible and relevant for almost all participants. The USD-4D was also comprehensive, since no key concepts of the social or spiritual dimension appeared missing.

Strengths and limitations

An important strength of this study is that the data were analysed by two researchers independently. Even though one researcher was unfamiliar with this study's underlying theoretical framework, both analyses led to the same conclusions. Maximum variation sampling generated broad variation concerning age, gender, marital status, living situation and time since diagnosis. This resulted in an in-depth exploration of the content validity. Most participants (92%) were diagnosed with cancer, which seems explainable, since the majority of patients in Dutch palliative care suffer from cancer.[39] However, only two participants (17%) practised a religion. This is not in line with the national figures, though, where 49% of the population was practicing a religion in 2017.[40] Despite this underrepresentation of practising believers, we saw no differences in the results compared to non-believers. Another limitation of this study would be that, although all participants were interviewed at their preferred location, three participants were interviewed in a hospital. It remains uncertain whether this clinical environment and the distraction of incoming caregivers influenced the depth of these interviews.

Ars moriendi model

The meaning that participants provided to the items corresponded with the tension fields from the ars moriendi Model.[14] Certain needs within one or more tension fields could arise when someone's inner space is deprived. When one's inner space is reduced, one becomes less capable of viewing and weighing questions of life. This serves as the basis to open a conversation with caregivers in order to further explore the entire tension field, in which the patients' personal needs could be further discussed.

Starting a conversation

Our findings exhibited differences in the items' relevance depending on symptom burden. However, the participants indicated that they did not mind answering because they experienced a provided space to indicate that the irrelevant item requires no further attention for them. This corresponds with two studies about sexuality and anxiety in patients within palliative care.[41,42] In both studies, patients also indicated that they did not mind being asked about topics that were not relevant for them. However, communication is necessary to find out if a topic is or is not relevant.[42] Caregivers should be aware of their important task of starting the conversation about difficult topics in order to provide patients the ability to talk about their needs, as long as the patient's choice of not starting a conversation is respected.

Multidimensional care

In addition to the social and spiritual dimension, the USD-4D also contains items concerning the physical and psychological dimension.[28,29] Therefore, the USD-4D can be considered a multidimensional PROM. To our knowledge, the USD-4D represents the first PROM that can be used to assess symptom intensity in the physical and psychological dimension and to recognise and monitor needs in the social and spiritual dimension. In clinical practice, the USD-4D contributes to ameliorating multidimensional care, whereby care is tailored to the patients' needs in all four dimensions. This contributes to the improvement of the quality of life of palliative care patients.[3,10]

Future research

The fact that a large number of patients in a vulnerable period in their lives provided consent to be approached for this study itself emphasises the importance of awareness of needs in the social and spiritual dimension. Future research is required for optimal use of the USD-4D in daily practise. First, to assess the content validity in accordance with the COSMIN methodology, caregivers also need to be interviewed regarding the USD-4D's relevance and comprehensiveness. Comprehensibility does not apply for caregivers, because PROMs are assessed by patients.[19] Due to the differences in relevance for each item in this study, it is recommended also to explore how often and at what time patients' should assess the USD-4D. Second, only Dutch patients were included in this study. As such, it remains to be determined whether the USD-4D accurately assesses social and spiritual needs for patients with a multicultural background. Third, previous research has demonstrated that discussing the needs in the social and spiritual dimension is often difficult for caregivers.[7,8] As such, training seems necessary in order to help caregivers effectively perform this critical yet difficult task.[44,45] However, in order to tailor this training to suit the caregivers' needs, these needs must first be explored. A qualitative study utilising interviews or focus groups would be suitable for exploring the needs of the involved caregivers in the future.

Conclusion

As a first step in the validation process, the USD-4D appeared to constitute a content-valid PROM from the patients' perspective. The items seem helpful in exploring needs relating to the social and spiritual dimension and appears supportive in the conversation between patients and caregivers to further explore these needs. This study thus contributes to the amelioration of multidimensional palliative care in the Netherlands.

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Table 1. Baseline characteristics of the study population (N=12)

ID	Age	Sex	Marital status*	Living situation	Level of education**	Illness	Year of diagnosis	Religion or ideology	Practising religion or ideology
R01	71	M	W,P	With others	Low	Lymphoma	2018	Christianity	Yes
R02	62	M	M	With others	Middle	ALS	2018	Christianity	No
R03	67	F	W	Alone	Middle	Lung cancer	2018	None	N/a
R04	74	M	M	With others	Middle	Prostate cancer	2008	None	N/a
R05	67	F	D	Alone	High	NETs	2019	None	N/a
R06	71	M	W,P	With others	High	Pancreatic cancer	2018	Humanism	Yes
R07	53	F	M	With others	Middle	Cervical cancer	2015	Christianity	No
R08	75	M	W	Alone	Middle	Mesothelioma	2018	Christianity	Yes
R09	87	F	W	Alone	High	Gastric cancer	2018	Christianity	No
R10	72	F	S	Alone	Low	Breast cancer	2004	None	N/a
R11	62	M	S	Alone	Low	Anal cancer	2018	None	N/a
R12	76	M	M	With others	Low	Bladder cancer	2011	Christianity	No

Notes: *M: married, W: widowed. D: divorced, P: partner. **Low: primary school, lower secondary general, lower vocational; middle: higher secondary general education, intermediate vocational education; high: higher vocational education, university. Abbreviations: ALS: amyotrophic lateral sclerosis. NETs: Neuroendocrine tumors.

Table 2. Overview of the themes per item

Items	Themes	Subthemes
Item 1	Maintaining personal identity and autonomy	Maintaining autonomy in daily life Maintaining identity in daily life
Item 2	Resilience	Bearing the disease and physical complaints Bearing the grief of having a life limiting disease Bearing the grief of loved ones End of life decisions
Item 3	Letting go	Letting go of loved ones Acceptance/ non-acceptance
Item 4	Perceived balance in one’s life	Balance/ non-balance in daily life Reflection on one’s life
Item 5	Death and life after death	Acceptance/ non-acceptance Preparing for the last goodbye Preparing practical issues Anxiety for the way of dying Existential beliefs

Table 3. Comprehensibility, relevance and comprehensiveness of the USD-4D items

	Comprehensibility Yes	**Comprehensibility No**	
Item 1	11	1	
Item 2	12	0	
Item 3	12	0	
Item 4	12	0	
Item 5	12	0	
	Relevant	**Less relevant at the moment**	**Not relevant**
Item 1	11	1	0
Item 2	8	4	0
Item 3	11	1	0
Item 4	8	4	0
Item 5	11	0	1
	Comprehensiveness Yes	**Comprehensiveness No**	**Comprehensiveness Unknown**
All items	11	0	1

Appendix A. Interview guide

Aspect	Defined as	Questions
Comprehensibility	All USD-4D items, response options and instructions should be understood as intended by patients in palliatieve care.	- What do you think of the items? - How would you translate the item into your own words? - What would you need to answer this item? - What do you think of the response options for the items? Do these options match the items sufficiently? - What do you think of the instructions? - Can you answer the item after reading?
Relevance	All items should be relevant to the social and spiritual dimension within patients in palliative care.	- Do you find the item relevant for your social and spiritual wellbeing? - Do you find the item relevant to identify needs for social support or spiritual care?
Comprehensiveness	All key concepts are included in the items and the items should comprehensive to identify needs for social support and/or spiritual care	- When you look at the items altogether, are they complete to signal a need for social support? Do you miss anything? - When you look at the items altogether, are they complete to signal a need for spiritual care? Do you miss things?