Competencies needed by professional caregivers in order to provide spiritual care to people with a severe or profound intellectual disability – a qualitative study

ABSTRACT

Background: People with severe (IQ<35) or profound (IQ<20) intellectual disabilities (SPID) face several health risks with a possible negative impact on their quality of life. Because findings from other areas of care show that spiritual care can improve quality of life, it is relevant to know if this is the case for people with SPID too. However, professional caregivers working with people with SPID face specific difficulties. Self-reporting of needs and feelings is most of the time not possible due to limitations of verbal communication. Hence, the competencies professional caregivers need to provide spiritual care, reported in studies of other areas of care, may not translate directly to spiritual care for people with SPID.

Research question: Which competencies do professional caregivers in disability care say they need in order to provide spiritual care to people with a severe or profound intellectual disability?

Method: an explorative generic qualitative study using individual semi-structured interviews was conducted with professional caregivers. The purposive sample was based on maximum variation in age and work experience. Caregivers had to work with at least one person with SPID for at least one year to be included in this study.

Results: thematic analysis found four main themes: awareness of importance of spiritual care for people with SPID, being truly attentive, the ability to identify needs of spiritual care through seeing, hearing, and discussing, and the ability to turn signals into actions tailored to people with SPID.

Implications and conclusion: these competencies require specific knowledge, skills and attitudes, in addition to what is known from literature. These findings can be used to complement course content in the education of future professional caregivers. More research is needed to study the spiritual needs of people with SPID.

Keywords: intellectual disability, spiritual care, professional competence, qualitative study

Benodigde competenties voor professionele zorgverleners om aandacht te kunnen hebben voor zingeving bij mensen met een (zeer) ernstige verstandelijke beperking – een kwalitatieve studie

SAMENVATTING

Achtergrond: mensen met een ernstige (IQ<35) of zeer ernstige (IQ<20) verstandelijke beperking ((Z)EVB) hebben te maken met verschillende gezondheidsrisico's. Dit kan een negatieve invloed hebben op kwaliteit van leven. Uit andere zorgdomeinen is bekend dat aandacht voor zingeving, kwaliteit van leven kan verbeteren. Daarom is het aannemelijk dat dit ook het geval zou kunnen zijn voor mensen met een (Z)EVB. Zorgverleners die werken met deze doelgroep hebben echter te maken met specifieke moeilijkheden. Mensen met (Z)EVB kunnen namelijk vaak niet praten en dus ook niet vertellen wat hun leven zin geeft. Vandaar dat al bekende competenties die zorgverleners nodig hebben om aandacht te kunnen hebben voor zingeving, wellicht niet automatisch vertaald kunnen worden naar mensen met (Z)EVB.
Onderzoeksvraag: welke competenties zeggen zorgverleners in de gehandicaptenzorg nodig te hebben om aandacht voor zingeving te kunnen hebben bij mensen met een (zeer) ernstige verstandelijke beperking?
Methode: een kwalitatieve studie werd uitgevoerd, door zorgverleners individueel te interviewen. Een doelgerichte sample werd samengesteld op basis van maximale variatie in leeftijd en werkervaring. Zorgverleners moesten minimaal één jaar werken met minstens één persoon met (Z)EVB om mee te mogen doen in de studie.
Resultaten: met behulp van thematische analyse zijn vier competenties gevonden: bewust zijn van belang van aandacht voor zingeving bij mensen met (Z)EVB, oprechte aandacht geven, signaleren van behoeften op zingevingsgebied door zien, horen en bespreken, en signalen omzetten in acties afgestemd op mensen met (Z)EVB.
Aanbevelingen en conclusie: voor deze competenties zijn specifieke kennis, vaardigheden en houding nodig, welke nog niet allemaal beschreven staan in de huidige literatuur. Deze bevindingen kunnen gebruikt worden als aanvulling op de cursusinhoud in de opleiding van toekomstige zorgverleners. Meer onderzoek is nodig naar specifieke zingevingsvragen bij mensen met (Z)EVB.

Trefwoorden: verstandelijke beperking, zingeving, professionele competentie, kwalitatief onderzoek

INTRODUCTION

Around the world, intellectual disability affects approximately 1% of the population(1). According to the World Health Organization intellectual disability can be divided into four categories: mild, moderate, severe or profound mental retardation(2). Intellectual disability is the current preferred term for mental retardation. Diagnosis is based on IQ score and deficits in adaptive behavior(3). People with a severe (IQ<35) or profound (IQ<20) intellectual disability (SPID) face several health risks associated with higher mortality rates such as poor motor skills, inability to feed themselves, poor communication, and self-help limitations. Furthermore, health problems like dysphagia, epilepsy, spasticity, reflux disease, hearing- and visual impairment are common(4). These factors have a negative impact on the quality of life of people with SPID(5).

Because of its role in prevention of illness and enhancement of recovery, spiritual care could improve quality of life in people with SPID(6–10). This study used the definition of spirituality of the European Association of Palliative Care: “spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience 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(11).” The purpose of spiritual care is to help someone with existential issues of life, in order to improve one’s overall health and well-being(10,12).

Spiritual care is an important part of nursing care, and nurses are willing to pay attention to spiritual and existential needs, even if they experience difficulty how to provide such care(13,14). In 2019 an EPICC (Enhancing Nurses’ and Midwives’ Competence in Providing Spiritual Care through Innovative Education and Compassionate Care) Spiritual Care Education Standard was developed defining four spiritual care competencies: 1) intrapersonal spirituality, 2) interpersonal spirituality, 3) spiritual care: assessment and planning, and 4) spiritual care: intervention and evaluation. For every competence, learning outcomes were described in knowledge, skills and attitudes(15).

However, professional caregivers providing care for people with SPID face specific difficulties. Self-reporting of needs and feelings by people with SPID is often not possible due to limitations of verbal communication(16). Moreover, there is little scientific evidence of competencies professional caregivers need for spiritual care in people with SPID. Experiences of other domains of care with patients experiencing cognitive problems, dementia or other communication issues, have also led to the conclusion that there is a need for research into spiritual care(17). The competencies known from other areas of care may, however, not translate directly to spiritual care for people with SPID(18). In that case, it is important to know what specific competencies professional caregivers need in order to provide spiritual care for people with SPID. The first step is to explore the views of professional caregivers themselves.

RESEARCH QUESTION

Which competencies do professional caregivers in disability care say they need in order to provide spiritual care to people with a severe or profound intellectual disability?

METHOD

Design

An explorative generic qualitative study using individual semi-structured interviews with professional caregivers has been conducted from January 2022 until July 2022. The Consolidated Criteria for Reporting Qualitative studies (COREQ) was used as a guidance for reporting(19).

Population

This study was conducted on four residential locations within one organization that offers 24-hour care for people with an intellectual disability in the Netherlands. The sample was a purposive sample that aimed at maximum variation in age and work experience. The population of this study comprises professional caregivers who work with people with SPID. Within the Netherlands two different kind of professional caregivers provide the same daily care in people with SPID, supervisors A and supervisors B(20). Besides providing care, supervisors B are responsible for writing care plans, communicating with family, paramedics, and doctors, and managing supervisors A in working according the care plans(20). Supervisors A and B are usually people with a nursing degree, nursing assistant degree (in Dutch: verzorgende-IG), or an agogic degree. The main inclusion criterion for supervisors was that they had to work with at least one person with SPID for at least one year.

Data collection

Data was collected using individual semi-structured interviews. The main study parameter was the perception of professional caregivers about competencies they need to provide spiritual care to people with SPID. An interview guide was developed with topics from the EPICC Spiritual Care Education Standard: intrapersonal spirituality, interpersonal spirituality, assessment and planning, and intervention and evaluation(15). The interview guide was pilot tested once, but because rich data was obtained and the interview guide proved to be clear, complete and relevant after analysis, this interview was included in the results.

Data analysis

Data analysis started directly after the first interview. Transcribed interviews were analyzed using the framework of Braun and Clarke, a widely-accepted framework for conducting thematic analysis(21). The software ATLAS.ti was used to uncover and systematically analyze

complex beliefs in the hidden unstructured data. The first author (AS) familiarized herself with the data by reading and re-reading the transcripts thoroughly. Initial codes were generated by marking sections of data and assigning labels line-by-line. After no new codes emerged in the last 2 interviews, it was concluded that data saturation had been achieved. Overarching themes were formulated, by grouping together the codes with similar meanings. The second author and principal investigator (BC) analysed two random interviews. The two authors compared and discussed their findings until consensus was reached, resulting in reviewed themes. The themes were then defined and named. The entire process of the analysis was reviewed for plausibility by the second author, in order to ensure the quality of the analysis. This form of researcher triangulation was applied in order to foster a higher level of conceptual thinking, raising the analysis to a higher level of abstraction, and avoid bias(22). Lastly, the report was produced with quotes from the interviews.

Procedures

The first author approached the manager of the residential locations, to ask for permission to recruit participants. When permission was granted, the first author recruited potential participants by email including the information letter. When someone was willing to participate and met the inclusion criteria an interview was scheduled physically or virtually, chosen by the participant. Prior to the start of the interview, the participant's understanding of the information letter was checked and informed consent was requested. It was explicitly reiterated that the interview would be audio recorded. After finishing the interview, participants were asked to fill in the demographic characteristics on a form.

In order to assure transparency of the data collection and analysis, all steps including executing and reasoning were accurately documented by keeping an audit trail (22). The first author gave the participants a summary of the interview after analyzing the interview, to assess the authors' understanding and interpretation of the data and to ensure trustworthiness(23). In order to keep the research as objective as possible, the first author critically reflected and wrote down her own preconceptions, relationships with the participants and her own reactions to participants' accounts and actions. This method was ongoing through data collection, analysis, interpretation and writing up(23). Throughout the research process, all steps were reviewed for plausibility by the second author.

Ethical issues

The study was conducted according to the ethical principles of the declaration of Helsinki(24) and in accordance with the European General Data Protection Regulation(25). The study was accepted as non-WMO (medical Research Involving Human Subjects Act) by the accredited

Medical Research Ethics Committee of Isala Zwolle (METC-number: 220304) The organization where this study was conducted granted permission to do so. Participation to this study was voluntary and all personal data was processed and stored anonymously using password protected software.

RESULTS

74 professional caregivers were invited to participate in the study. Twelve female professional caregivers with an average age of 38, from four different sites at one village, participated in this study. Participants had an average of about 17 years of work experience (Table 1). The interviews had an average length of 27 minutes (18-36). Five interviews took place through MS teams; the other interviews were conducted in the participant's work environment.

Table 1: demographic characteristics

Gender	Female n (%)	12 (100%)
Age (in years)	Mean (min-max)	38 (20-59)
Education	Nurse n (%)	6 (50%)
	Nursing assistant n (%)	5 (42%)
	Agogic degree n (%)	1 (8%)
Work experience (in years)	1-10 n (%)	5 (42%)
	11-20 n (%)	3 (25%)
	21-30 n (%)	2 (17%)
	31-40 n (%)	2 (17%)
Profession	Supervisor A n (%)	7 (58%)
	Supervisor B n (%)	5 (42%)
Number of people with SPID on site	2-3 n (%)	7 (58%)
	4-5 n (%)	1 (8%)
	6-7 n (%)	4 (33%)

Thematic analysis identified 4 main themes: 1) awareness of the importance of spiritual care for people with SPID, 2) being truly attentive to people with SPID 3) the ability to identify needs of spiritual care through seeing, hearing, and discussing, and 4) the ability to turn signals into actions tailored to people with SPID. The themes are addressed in turn and supported with verbatim quotations from participants identified by code to protect their anonymity. Each theme, can be considered as a competency and is divided into knowledge, skills and attitudes. The competencies listed are considered necessary to the provision of spiritual care, with the

subheadings of knowledge, skills, and attitudes describing what is required to be competent (Table 2).

Awareness of the importance of spiritual care for people with SPID

Participants indicated that attention to spiritual care is important when providing care to people with SPID: "*It is perhaps even more important there is spiritual care(..) than a pill or the physical care itself"*(P10). Why this is so important is explained by two other participants: *"I think if you don't have that* [spiritual care] *at all, then you see a lot more aggression, even at this level"*(P9). "*If you don't have something to strive for(..) in the long run you will become depressed"*(P7).

Knowledge of spiritual care

Participants mentioned the importance to know what spiritual care is: "*I think you have to be able to know what spiritual care is, because otherwise you won't get very far*"(P8). Another participant further specifies this: "*some theory why it* [providing spiritual care] *is important*"(P1).

Interprofessional reflection

A skill mentioned is the ability to reflect on the theme spiritual care and talk about it with each other, because "*everyone thinks differently, so(..) it's very good to hear from each other how you think about it"*(P2). Another reason why it is important for caregivers to engage in conversation together is that not everyone is aware of the importance of spiritual care: *"for a lot of caregivers the value of care lies in providing healthy food and making sure the client is fresh and well prepared to go to daycare. Focus lies on basic, physical care, much less so on spiritual care"*(P8). By not only reflecting on the topic of spiritual care yourself, but also sharing it with others, you help each other become more aware of the importance of meaning in people with SPID according to participants: *"I really believe that every employee wants(..) clients to have a valuable life, but some are more focused on that than others(..). That's why you need those colleagues and that cooperation"*(P10).

Open attitude

A professional caregiver should have an open mind toward all forms of spirituality according to participants: *"for example, if someone has been taught from home that Buddha is the one, I think you have to accept that. And then you shouldn't express too much of your opinion, because you have to go along with what is important to the client"*(P8).

Being truly attentive to people with SPID

Participants mentioned the importance of being truly attentive to people with SPID in order to provide spiritual care. A participant expressed the link between true attention and spiritual care

by giving a concrete example of how she connects with a specific client: *"that I am really with him, almost nose to nose contact, in a bubble together. Then I think: now you are really happy, now you feel contact too(..). Then I think he is aware of who he is and that he is aware that he is alive"*(P1).

Knowledge about SPID

Participants mentioned to have knowledge about SPID: *"what is SPID and how should you interact with people with SPID"*(P4). Participants indicated that it would be good to have knowledge of the LACCS-program (Box 1(26)). One participant told: "*we just had the LACCS training sessions(..). Now you are more 1 on 1 outside of the physical care situations, giving extra attention to her, so she feels loved"*(P5).

Box 1: LACCS-program

The LACCS-program was developed in the Netherlands by Munsterman and de Geeter. This program focuses mainly on the support of people with SPID. According to the LACCS, to live a good life, all five areas must be in order: physical well-being (in Dutch: Lichamelijk), Alertness, Contact, Communication, and Stimulating use of time. A number of values have been formulated for each LACCS area. The values define the basic needs for a persons´ wellbeing.

Contact skills, connect to the client's level with empathy

Participants referred to the skill 'making contact' with people with SPID: *"sometimes it is a real conversation, and sometimes it is a touch or something else. The important thing is to connect in a way fitting the client. I think that's when you really get to something, that's when clients show more of what they actually need from you"*(P10). Another skill that was mentioned is the ability to match the client's level of understanding: "*We live too much on our own level and we need to live more in their world"*(P1). Participants indicated that this is a challenging skill: *"You can learn and expand it, but it's also something that you have to have in you"*(P5). It is mentioned that showing empathy could be helpful. According to participants empathy means: *"that you should always be very conscious of the actions you take"*(P11)*, "what actions am I doing and is that pleasant for her?"*(P5). Another participant explained: "*suppose I am working with a client(..) and I see that she visibly relaxes, that you then also name it: how relaxed you are and how beautiful you smile"*(P8).

Respectful attitude

Participants mentioned to see the client as a unique person and approach them with a respectful attitude: "*to look not only at the syndromes and all the disabilities they have, but especially at who is the client, who is behind it"*(P10)? Another participant said: *"in fact, it should be that you are there for them unconditionally and they feel loved"*(P5). One participant gave a practical example of a respectful attitude: *"when you help them starting the day, do their hair, put on some perfume(..), so she looks really neat. She's worthy(...). She's a beautiful woman too, or a beautiful man"*(P6).

The ability to identify needs of spiritual care through seeing, hearing and discussing

People with SPID cannot put their spiritual needs into words so you need to pay attention to other means of communication to pick up questions or needs they have: "*they basically give so much, but you have to see it"*(P2). So it starts with the previously mentioned competence, being truly attentive. But in addition to that, you need this competence of seeing, hearing and discussing to identify needs.

Knowledge of the individual with SPID

Participants indicated that it is especially important to get to know the client well in order to identify questions of spiritual care in people with SPID. For this, a caregiver needs medical knowledge, knowledge of behavior, input from family, background and input from paramedics. One participant summarized it as follows: *"because you have an overall picture of the history, the family, the life story of someone, you know what the clinical picture is and where certain behaviors come from, you also know what that person likes"*(P7). In particular, knowing the client's history, came up frequently: *"what has already happened in a client's life"*(P12).

Observing, noticing and discussing

The most frequently mentioned skills are observing and noticing. Participants made this clear in various terms: "*observing the body attitude(..), the sounds they make"*(P3), and *"looking purely at body language, facial expressions and alertness"*(P7).

Participants indicated that, despite good observation, it is difficult to always find out what the client wants: "*he looks around, but you can't see if he likes it or not"*(P6). Moreover, as a caregiver you also make a lot of assumptions about what you think the client means: "*It's a lot of assumptions you make based on what you see"*(P8). Therefore, it is important to communicate with colleagues to see situations from different angles. "*I can say: he doesn't like that, but another colleague says: why not,(..) then you have to come to an agreement together"*(P4).

Calm and curious attitude

A caregiver needs a calm attitude according to participants: *"you do have to be able to keep calm(..) to really get to spiritual care, to find out* [which questions] *with calmness"*(P9). Another participant mentioned the concept of time: "*I think that is what is lacking sometimes. That you don't really see what someone needs, but just think: she has to get out of bed, in the wheelchair, ready, to the daycare center. You need to make time for going beyond daily routine care"*(P8). In everything you see and hear from the client, a curious attitude is needed: "*why does he do that? Why is this client always with his fingers in his mouth? Why doesn't he like it when I touch his face?"*(P5) Another participant agrees: *"the why question is also quite important(..).They can't say anything, so you always have to ask yourself"*(P2).

The ability to turn signals into actions tailored to people with SPID

To answer clients' needs regarding spiritual care, participants didn't mention other kind of knowledge than for the previous competencies. However, it still requires specific skills and attitudes from professional caregivers. According to participants the role of the professional caregiver is especially important in turning signals into actions, because the caregiver "*performs actions(..). Maybe the client wants to pray before eating, but she's not going to do that herself, so you have to do that for her"*(P8).

Exploring methodological and engaging appropriate experts

The skill mentioned most by the participants is 'exploring': "*then you try to get it so that he feels comfortable. Maybe he likes to lie stretched out on the bed or on his side. That's what you're going to try"*(P3). Another participant gave the following example: *"when has her spiritual need been affected by something that makes her show this now? So in that you have to explore(..). It could be that it's too quiet(..) or just that there are a lot of stimuli around her and she finds that difficult"*(P5). An important skill that ties into this is creativity: "*I think you have to be creative(..) out of the box"*(P10), "*inspiration to do things with them"*(P.6). To make this methodical, it is important "*to set goals"*(P3), "*step by step to get everything clear"*(P10). Finally, it was indicated that you need to engage the right expertise: *"don't say I'll see or I'll let it slide, but take action. I see this(..) who should I go to?"*(P12).

Patient and learning attitude

A caregiver needs a patience attitude according to participants: "*you shouldn't want to go too fast. For example, if you set a goal, and it doesn't work, don't say it won't work anyway. It takes time"*(P.4). Another participant said: *"people with SPID often have to get used to something for a very long time, so you'll have to apply something for a while"*(P9). To improve creativity it is important to learn from others: "*watching what other colleagues are doing,*

copying things from them, and adding your own touch on it"(P6). Because again, it is important for professional caregivers to be aware of their own assumptions: "*I automatically assume that they like that I'm going to do that with them"*(P7) and: "*what I think is good for them, I project onto them"*(P9).

Table 2: competencies of professional caregivers to provide spiritual care

Competence	Knowledge	Skills	Attitude
Awareness of the importance of spiritual care for people with SPID	Spiritual care	Interprofessional reflection	Open mind
Being truly attentive to people with SPID	SPID LACCS-program	Making contact Ability to match the client's level of understanding Empathy	Respectfully See the client as unique
The ability to identify needs of spiritual care through seeing, hearing and discussing	Individual with SPID Multidisciplinary input Medical knowledge Knowledge of behavior	Observing/ noticing Discussing	Calm Curious
The ability to turn signals into actions tailored to people with SPID	Individual with SPID Multidisciplinary input Medical knowledge Knowledge of behavior	Exploring Creativity Working methodically Engaging experts	Patient Learning attitude

DISCUSSION

Results show that participants believe that four competencies are necessary to provide spiritual care to people with SPID. These competencies are: awareness of importance of spiritual care, being truly attentive, the ability to identify needs of spiritual care through seeing, hearing, and discussing, and the ability to tailor actions to people with SPID. These competencies require specific knowledge, skills, and attitudes.

Participants emphasized many of the knowledge, skills, and attitudes from the EPICC Spiritual Care Education Standard and other research on spiritual care competencies in palliative care, oncology, and mental health care(15,27).

The main new aspect that emerged in the current study is that providing spiritual care to people with SPID requires specific knowledge of the individual with SPID. The reason why this specific knowledge emerged in the current study could be explained by the fact that little is still known about how people with SPID express spiritual needs. The importance of having knowledge of a specific individual before providing spiritual care is consistent with research to people with dementia(28,29). Knowing the client's history is mentioned as an important aspect to consider(30).

Another new aspect that emerged in the current study is that providing spiritual care to people with SPID requires specific skills to compensate for communication problems. Skills that do not emerge or emerge to a different degree in previous research are: observing, exploring, creativity, and discussing potential spiritual needs. The reason that these skills didn’t emerge before can be explained by the fact that previous research has focused primarily on people who can express themselves verbally. Research on people with dementia who lost the ability to verbally express their spiritual needs also mentions the importance of nursing discussing spiritual care together to increase their awareness and knowledge of the subject, determine concepts, and find a rationale for their shared practices(31).

A strength of the current study is that maximum variation in age and work experience was achieved as planned before. As a result, rich information was obtained. Another strength is that all steps of the study were reviewed by the second author to ensure methodological rigor. In addition, participants confirmed through member check that the first author interpreted the answers correctly. Another strength is that the interviewer knew all participants to a greater or lesser extent through her work. This strengthened the trust between interviewer and participant. A limitation is that the interviewer is so well acquainted with care for people with SPID that certain answers were already self-evident to her, which meant that all topics were not always asked in depth. By writing a critical reflection after each interview, efforts have been made to minimize this limitation. Another limitation is that the first author, who conducted the interviews, had novice experience with interviewing. Attending training and studying theory related to interviewing ensured quality as far as possible.

This study does not indicate whether and to what extent spiritual needs of people with SPID differ from those of others, as this was beyond the scope of this study. Future research should focus on what the spiritual needs are of people with SPID and how people who cannot express themselves verbally, express spiritual needs. Findings can be used to complement course content in the education of (future) professional caregivers. This is important in order to optimize the effect of the care given on their wellbeing.

CONCLUSION

Understanding the spiritual needs of people with SPID is challenging. Providing spiritual care to people with SPID requires additional knowledge, skills and attitude than known from previous research. Competencies needed to provide spiritual care for people with SPID are awareness of the importance of spiritual care for people with SPID, being truly attentive to people with SPID, the ability to identify needs of spiritual care through seeing, hearing, and discussing, and the ability to turn signals into actions tailored to people with SPID.

RERERENCE LIST

1. Maulik PK, Mascarenhas MN, Mathers CD, Dua T, Saxena S. Prevalence of intellectual disability: A meta-analysis of population-based studies. Res Dev Disabil. 2011;32(2):419–36.
2. World Health Organization (WHO). The ICD-10 Classification of Mental and Behavioural Disorders [Internet]. [cited 2021 Sep 18]. Available from: https://www.who.int/classifications/icd/en/bluebook.pdf
3. Schalock RL, Luckasson RA, Shogren KA, Borthwick-Duffy S, Bradley V, Buntinx WHE, et al. The renaming of mental retardation: Understanding the change to the term intellectual disability. Intellect Dev Disabil. 2007;45(2):116–24.
4. van Timmeren EA, van der Putten AAJ, van Schrojenstein Lantman-de Valk HMJ, van der Schans CP, Waninge A. Prevalence of reported physical health problems in people with severe or profound intellectual and motor disabilities: a cross-sectional study of medical records and care plans. J Intellect Disabil Res. 2016;60(11):1109–18.
5. Petry K, Maes B, Vlaskamp C. Measuring the quality of life of people with profound multiple disabilities using the QOL-PMD: First results. Res Dev Disabil. 2009;30(6):1394–405.
6. Chen J, Lin Y, Yan J, Wu Y, Hu R. The effects of spiritual care on quality of life and spiritual well-being among patients with terminal illness: A systematic review. Palliat Med. 2018;32(7):1167–79.
7. Visser A, Garssen B, Vingerhoets A. Spirituality and well-being in cancer patients: A review. Psychooncology. 2010;19(6):565–72.
8. Ramezani M, Ahmadi F, Mohammadi E, Kazemnejad A. Spiritual care in nursing: A concept analysis. Int Nurs Rev. 2014;61(2):211–9.
9. Harrad R, Cosentino C, Keasley R, Sulla F. Spiritual care in nursing: An overview of the measures used to assess spiritual care provision and related factors amongst nurses. Acta Biomed. 2019;90(6):44–55.
10. Ghorbani M, Mohammadi E, Aghabozorgi R, Ramezani M. Spiritual care interventions in nursing: an integrative literature review. Support Care Cancer. 2021;29(3):1165–81.
11. EAPC. EAPC Reference Group on Spiritual Care [Internet]. [cited 2022 Apr 30]. Available from: http://www.eapcnet.eu/eapc-groups/reference/spiritual-care/
12. Bulduk S, Usta E, Dinçer Y. The Influence of Skill Development Training Program for Spiritual Care of Elderly Individual on Elderly Care Technician Students' Perception of Spiritual Support. J Relig Health. 2017;56(3):852–60.
13. Strang S, Strang P, Ternestedt BM. Spiritual needs as defined by Swedish nursing staff. J Clin Nurs. 2002;11(1):48–57.
14. Green A, Kim-Godwin YS, Jones CW. Perceptions of Spiritual Care Education,

Competence, and Barriers in Providing Spiritual Care Among Registered Nurses. J Holist Nurs. 2020;38(1):41–51.
15. van Leeuwen R, Attard J, Ross L, Boughey A, Giske T, Kleiven T, et al. The development of a consensus-based spiritual care education standard for undergraduate nursing and midwifery students: An educational mixed methods study. J Adv Nurs. 2021;77(2):973–86.
16. Cooper SA, Melville CA, Einfeld SL. Psychiatric diagnosis, intellectual disabilities and diagnostic criteria for psychiatric disorders for use with adults with learning Disabilities/Mental Retardation (DC-LD). J Intellect Disabil Res Suppl. 2003;47(1):3–15.
17. Lunder U, Furlan M, Simonič A. Spiritual needs assessments and measurements. Curr Opin Support Palliat Care. 2011;5(3):273–8.
18. Van Leeuwen R, Cusveller B. Nursing competencies for spiritual care. J Adv Nurs. 2004;48(3):234–46.
19. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. Int J Qual Heal Care. 2007;19(6):349–57.
20. VGN. Competentieprofiel ABC [Internet]. 2005 [cited 2021 Oct 9]. Available from: https://www.vgn.nl/system/files/2019-12/Beroepscompetentieprofiel ABC DEF.pdf
21. Kiger ME, Varpio L. Thematic analysis of qualitative data: AMEE Guide No. 131. Med Teach [Internet]. 2020;42(8):846–54. Available from: https://doi.org/10.1080/0142159X.2020.1755030
22. Boeije H. Analysis in Qualitative Research. First edit. Los Angeles: Sage; 2010.
23. Holloway I, Galvin K. Qualitative research in nursing and healthcare. fourth edi. United Kingdom: Wiley-Blackwell; 2017.
24. WMA declaration of Helsinki - ethical principles for medical research involving human subjects [Internet]. [cited 2021 Nov 1]. Available from: https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/
25. Blackmer WS. EU general data protection regulation. Am Fuel Petrochemical Manuf AFPM - Labor Relations/Human Resour Conf 2018. 2018;2014(March 2014):45–62.
26. de Geeter K, Munsterman K. LACCS-programma: een goed leven voor iedereen met EVMB [Internet]. 2017 [cited 2022 May 18]. Available from: https://www.laccsprogramma.nl/
27. Attard DJ, Ross DL, Weeks K. Developing a spiritual care competency frameworkfor pre-registration nurses and midwives. Nurse Educ Pract [Internet]. 2019;40(April):102604. Available from: https://doi.org/10.1016/j.nepr.2019.07.010

28. Carr TJ, Hicks-Moore S, Montgomery P. What's so big about the "little things": A phenomenological inquiry into the meaning of spiritual care in dementia. Dementia. 2011;10(3):399–414.
29. Ødbehr LS, Hauge S, Danbolt LJ, Kvigne K. Residents' and caregivers' views on spiritual care and their understanding of spiritual needs in persons with dementia: A meta-synthesis. Dementia. 2017;16(7):911–29.
30. Toivonen K, Charalambous A, Suhonen R. Supporting spirituality in the care of older people living with dementia: a hermeneutic phenomenological inquiry into nurses' experiences. Scand J Caring Sci. 2018;32(2):880–8.
31. Ødbehr LS, Kvigne K, Hauge S, Danbolt LJ. Spiritual care to persons with dementia in nursing homes; a qualitative study of nurses and care workers experiences. BMC Nurs. 2015;14(1):1–9.