Something wonderful and incomprehensible: Expressions and experiences of spirituality among very old people

Catharina Norberg, Regina Santamäki Fischer, Ulf Isaksson & Kristina Lämås

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Something wonderful and incomprehensible: Expressions and experiences of spirituality among very old people

Catharina Norberg a, Regina Santamäki Fischer a,b, Ulf Isaksson a,c and Kristina Lämås a

aDepartment of Nursing, Umeå University, Umeå, Sweden; bDepartment of Health Sciences, Åbo Akademi University, Vasa, Finland; cArctic Research Centre, Umeå University, Umeå, Sweden

ABSTRACT
This study aimed to illuminate very old people’s experiences and expressions of spirituality and is a part of the Umeå 85+/Gerontological Regional Database (GERDA). The participants (n = 12) had declared an interest in spirituality, were 86–99 years of age, and were interviewed in their own homes. The interviews were analyzed using qualitative content analysis. The findings revealed that spirituality was experienced as being in communion, transcending life’s circumstances, and living in a spiritual reality. Spirituality was expressed as an inner sense of communion with God and with other people, and as a spiritual reality. The participants expressed a desire to talk about spiritual experiences and personal beliefs but regarded spirituality as an uncommon topic. Nurses and other professionals need to be aware of spiritual needs and prepared to give spiritual care.

KEYWORDS
Personal beliefs; spiritual needs; transcendence; Umeå 85+/GERDA; nursing; experiences

Introduction
This paper contributes knowledge about how spirituality was expressed among a sample of very old people who had self-declared an interest in spirituality. There is no consensus regarding a definition of the concept of spirituality within healthcare research (Cohen, Thomas, and Williamson 2008). Among some it is connected to a religion, while for others it has no connection to any specific religion (Sesanna, Finell, and Jezewski 2007). While spirituality has been described as a universal phenomenon, religion can vary depending on culture (McEwen 2005).

The meaning of spirituality in older age has been examined in several studies. Among very old women, spirituality was reported to give strength and the ability to cope with life challenges (Manning 2012). Among older churchgoers, spirituality provided a sense of meaning and a resource for adjusting to the process of aging (Williams 2008). The meaning of spirituality has also been studied among people in old age with conditions such as mild and moderate dementia (Dalby, Sperlinger, and Boddington 2011), while...
undergoing rehabilitation (Schwarz and Fleming Cottrell 2007), and after a diagnosis of breast cancer (Logan, Hackbusch-Pinto, and DeGrasse 2006). Spirituality was found to give comfort, hope, strength and the ability to cope with illness (Dalby, Sperlinger, and Boddington 2011; Schwarz and Fleming Cottrell 2007), as well as a sense of being cared for (Logan, Hackbusch-Pinto, and DeGrasse 2006). In a review about spirituality and diagnosed dementia, the decline in cognitive function did not affect faith or spiritual life; rather, spirituality and religiosity were found to have a positive effect on cognitive function (Agli, Bailly, and Ferrand 2015). Furthermore, spirituality has been described as continuing to develop in older age, and the opportunity to spend more time on spirituality was expressed as a benefit of being old (Shaw, Gullifer, and Wood 2016). All this research suggests that the spiritual dimension has a positive impact on the way older people deal with challenges in life.

In nursing care, the strength that old people may derive from a spiritual identity can be used to improve their coping strategies, helping them to find meaning, and adjust to their current life situation. However, Cohen, Thomas, and Williamson (2008) claim that discussions of spiritual care often focus on preparation for death and dying when the task is rather to live in the here and now. MacKinley (2006) suggest that spiritual needs are as important as bodily needs and should not be an optional extra component of care. Cohen, Thomas, and Williamson (2008) suggest that spiritual care should include active and respectful listening to the words, phrases and terms used to express spiritual beliefs and personal values, and allowing their expression. Caregivers should encourage old people to share stories that are important for them, support their spiritual needs, and recognize cultural and ethnic variations.

Spirituality has been described as connected to religiosity and God or a higher being among older people with dementia (70–94 years) (Dalby, Sperlinger, and Boddington 2011), very old women (82–94 years) (Manning 2012), and older people who defined themselves as Christians (65–87 years) (Shaw, Gullifer, and Wood 2016). In Shaw, Gullifer, and Wood (2016), spirituality was described as something internal to the individual.

To sum up, very old people face challenges associated with aging, and spirituality has been identified as a resource for adapting to and dealing with life challenges. The life-situations and experiences of very old people have been studied from various perspectives; however, less is known about the experience and ways of expressing spirituality among the very old (85 years and older) (see Manning 2012). In order to help older people in their spiritual development, professionals need to recognize and give space for spirituality. To recognize spiritual needs, professionals need to understand how very old people experience and express spirituality. Therefore, this study aims to illuminate very old people’s experiences and expressions of spirituality.

**Study design**

This study has a qualitative design and is a part of the Umeå 85+/Gerontological Regional Database (GERDA), a population-based study that included half of those aged 85, all 90-year olds, and all aged 95 and older in Umeå, Västerbotten, in Northern Sweden, as well as in Ostrobothnia in Western Finland (see Näsman et al. 2017).
Participants and procedure

The participants in this study were a sub-sample drawn from the Umeå 85+/GERDA study in the city of Umeå in 2015 (n = 219). One-third of these participants were randomly selected to participate. The specific inclusion criteria were: being a member of a spiritual or religious society or church, experiencing spiritual or religious activities as significant for their well-being, as well as scoring ≥20 points on the Mini Mental Examination Scale (MMSE) (Folstein, Folstein, and McHugh 1975). In total, 41, 1% had answered ‘Yes’ on a question whether they considered spiritual and religious activities important to them. Of these, 23 persons were consecutively selected to participate in this study. Written information about the study and an invitation to participate were sent to them. Within a week after the written information had been sent, the first author contacted potential participants by telephone to obtain their informed consent to participate and to schedule a convenient time for the interview. Twelve people agreed to participate in the study.

The participants were interviewed in their own homes by the first author [CN]. The participants (n = 12) were 86–99 years of age (mean 89.75 sd. 6.85). Ten were women and two were men. The participants grew up and resided in the north of Sweden. Ten lived alone, two lived with a partner, ten lived in their own home, and two in a residential home. Eight participants were widowed, one was divorced, and three were married or cohabiting. Eleven had children. All participants were ethnic Swedes and had been members of the Church of Sweden since they were born. Two had attended church regularly and ten occasionally. The interviews were conducted from March to May 2017.

The topics for the interview were their interpretation of the concept of spirituality, spiritual development from childhood to old age, and situations of connectedness to a higher power. The interview started with some information about the aim of the study. The opening question was: ‘Please, can you tell me how you perceive spirituality.’ The participants talked freely. After listening to their narratives, the interviewer asked clarifying questions. All interviews were recorded, and the recordings transcribed verbatim. The interviews ranged from 26 to 60 (mean 40) minutes.

Analysis

The interviews were analyzed using qualitative content analysis as described by Graneheim and Lundman (2004) and read several times to obtain a sense of the whole and a preliminary understanding of the text. Meaning units were identified, comprising sentences and paragraphs, and were condensed; these were then labeled with codes. The codes were compared for differences and similarities and transformed into eight sub-themes and three themes. Throughout the analysis process, codes, sub-themes and themes were discussed among the co-authors.

Ethical considerations

Before the interviews started, participants were informed about confidentiality and their right to withdraw from the study or abstain from answering questions without giving any reason. Informed consent was obtained, and participants had an opportunity to ask
questions about the study before the audio-recorder was started. Participants were also assured of confidentiality during the analysis process and in the presentation of the findings.

The interviewer strove to show respect, interest and empathy, which meant giving participants time to express feelings and thoughts, and accepting moments of silence. Furthermore, the interviewer was attentive to the participant’s need to take a break or end the interview.

Very old people are a particularly vulnerable group in research, and sharing thoughts about personal faith/beliefs with somebody may be a sensitive topic and cause a degree of discomfort. However, some expressed appreciation for being asked to share their stories; spirituality is not a common topic of conversation, and some of their experiences had not previously been told. They also expressed a sense of relief that somebody was willing to listen.

Findings

Throughout the interviews, the participants used various expressions to refer to something greater than themselves that guided and supported them through life – expressions such as a Supreme Being, a Power, or God. In this paper, we use ‘God’ to encompass all these different expressions.

The findings revealed that spirituality for these very old people meant being in communion, transcending life’s circumstances, and living in a spiritual reality (Table 1). They expressed a feeling of being in communion with God, with other people in society, and with those no longer alive. However, they found spirituality difficult to talk about and hesitated to share their spiritual thoughts and experiences with others. They expressed a sense of transcending life’s circumstances by narrating a situation that had harmed them and how they had learned to take one day at a time and accept life the way it is. They also talked about mortality as a natural part of life. The participants expressed an awareness of a spiritual reality and described experiences that had strengthened their belief in God, while not always being clear about God’s characteristics.

Being in communion

The participants expressed a sense of communion when describing having a trusting relationship with God. They indicated that they did not usually talk about their experiences of spirituality, and that it was difficult to find words to describe their experiences. They did not want to be seen as religious and therefore spoke of shielding one’s relationship with God. The feeling of communion was also described as feelings of togetherness through memories of and contact with significant others.

Table 1. Overview of themes and sub-themes revealed in the analysis.

<table>
<thead>
<tr>
<th>Theme sub-theme</th>
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<tr>
<td>Being in communion</td>
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<td>Having a trusting relationship with God</td>
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<td>Shielding one’s relationship with God</td>
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<tr>
<td>Feelings of togetherness</td>
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</table>
Having a trusting relationship with God

Communion with God was described as living in a trusting relationship with God. The participants described their relationship to God as a solid foundation that had been laid during early childhood, had carried them throughout life, and supported them into old age. The participants described God as constantly present and reliable, always caring for them and helping them with everyday challenges. The participants described their feelings of deep contact with God as uncomplicated and unquestionable. One woman put it like this:

God is in my mind, and I am in God’s. It’s no more complicated than that. (Helga)

The participants shared memories of previous generations whom they had experienced as living in a trusting relationship with God. Those people were described as having impressed them and been good examples. They had been taught to pray by previous generations and described a constant, ongoing communication with God that had grown more intense with age. Their communication with God was described in a personal and informal way, like talking to a close friend or a buddy. In their prayers, they shared their worries about their children and grandchildren and their thoughts as the day went on. The participants described feelings of relief, security and peace when they were praying:

I had no one else who cared for me; God was the only one I could rely on. (Rut)

Almost every night I pray about help to manage the next day … I don’t know from where I get my strength, but there is something that gives it to me. (Alma)

Shielding one’s relationship with God

Experiences of spirituality were expressed in terms of an intrinsic faith and communion with God, impossible to explain in words. It was considered part of the private area in one’s life. The participants said that spirituality was a very uncommon subject in communication with other people and expressed concerns about sharing their faith even with close relatives and friends. They expressed anxiety about being perceived as pious in a negative sense if they talked about their faith, and they did not want to be defined as religious. They also expressed a risk of being perceived as doubtful about their experiences of God. However, the participants also expressed a desire to talk about their life, their relationship to God, and existential quests. A prerequisite for being able to talk about beliefs and doubts was a trusting relationship with somebody who really wants to listen, since talking about spirituality is considered a sensitive topic:

[Personal beliefs] are not a common topic to talk about with people around you; rather, it is something you will keep to yourself. (Gerda)

Nobody has heard my prayers to my Lord; my relationship with him belongs to my private area of life. (Agnes)

Feelings of togetherness

Experiences of spirituality and feelings of communion among these very old people were associated with feelings of togetherness with other people. Some described
music as a way to achieve connectedness with relatives during periods of illness. The participants narrated situations – from childhood and middle-age to old age – where they had felt a profound intimacy with other people. The participants shared memories from their childhood when they had experienced an affinity with others. They told about their perceptions during church services, sitting together with parents, or their grandparents listening to a service on the radio, and about the serenity that was sometimes tedious but also evoked feelings of closeness and harmony. Some of the participants had attended church regularly throughout their life and described being part of a parish as valuable. Others had attended church occasionally. Going to church was described as an opportunity to meet people and get company and social support. The participants spoke of their experiences of music as a uniting activity throughout their lives. They shared memories of playing music and singing together in their parental home and at church, and said that these memories gave them a sense of joy, happiness, and togetherness:

It is wonderful to sing together in the church, a sense of belonging and community.
(Gerhard)

Helping somebody in a tangible way was described as a way to achieve a sense of affinity to those around them. However, a single meeting with a fellow human being could also lead to feelings of affinity; being able to make somebody else happy could lead to happiness in one’s own life. Close relationships in the family were described as awaking feelings of togetherness:

The last summer, we had coffee in the garden, he [husband] moved the cups away, took my hands and said: ‘We are having a good time together. It is quiet; when it is so quiet that you can hear the silence. That is great, such luck that I found you.’ (Gerda)

Transcending life’s circumstances

The findings show that participants’ experiences of spirituality were also connected to a view of life in which they transcended life’s circumstances. Transcendence embraces reflection on and incorporation of earlier life events (including happy memories and losses), their present life with declining functions, and their future life and approaching death. The narratives showed a basic attitude of reconciliation with life. The participants also talked about death and dead relatives and expressed readiness for death and an awareness of their mortality.

Reconciliation with life

Transcendence was evident in participants’ sharing of memories from their earlier life and reflecting on life’s fragility. They spoke about negative life events such as the loss of a spouse or children, periods of ill health, broken relationships, feelings of loneliness, and a lack of care in their upbringing. Nevertheless, they expressed deep gratitude to God for their life and health. They expressed their belief that life is a gift and that they thus had a responsibility to be grateful and to accept life the way it is. The participants talked about the need for daily adaption to their actual conditions and expressed preparedness for changes in life and health. Their attitude to life was expressed by the maxim: ‘take life as it comes.’ Being grateful was described as a responsibility and a
virtue. Gratefulness, humility, and reconciliation permeated the interviews; participants expressed their awareness of life’s fragility, that life and health cannot be taken for granted, and their gratefulness for every day given to them:

   Every morning when I wake up I feel so happy and thank God for being alive and able to throw my legs over the bed and get up. And then when I’m sitting at the kitchen table and put my hearing aid in my ears and realize that it works, I feel so happy and thank God for hearing. (Helga)

**Living in awareness of mortality**

The participants talked about death and dying in a comfortable way. They claimed not to be afraid of being dead, although they expressed uncertainty about what happens after death. They had grieved for family members and close friends and lived with an awareness of their mortality. Despite their awareness of and acceptance of their own death, they expressed feelings of happiness for still being alive. They expressed their readiness for mortality and reflected on their own dying. They had experiences of their relatives dying: some had been ill for a long time before dying; others had died without any warning, as though they had fallen asleep. However, even if the participants did not express worries about death, they expressed worries about being alone at the moment of dying. Death was described as offering hope and relief; it was something to look forward to, especially in winter and when life was boring. The participants expressed their belief in a reunion with loved ones and a conviction about an immortal soul, although some were uncertain and expressed doubts about living somewhere else after death:

   When I die I am sure I will be fine. I will be buried next to my husband, my parents and my brother. It is all going to be fine that day; I do not worry, because when you grow older, I think you are just falling asleep. It may be different, but I think so. And that day … I will be fine, no problem. (Hillevi)

The participants said that they avoided existential struggles since this might lead to spiritual distress:

   You don’t know how life is on the other side … but I avoid thinking about that a lot because there are those who haven’t felt very well doing that. (Gerda)

**Living in a spiritual reality**

The participants expressed a conviction about a spiritual reality and related how they perceived mysteries in daily living. Their stories included descriptions of being amazed by creation and everything that God has made. However, they also expressed questions about the omnipotent God versus the evil in the world, which was expressed as querying an inconceivable God.

**Perceiving mysteries in daily living**

Participants described experiences of connection to a spiritual reality in terms of supernatural events and their conviction that guardian angels are always close by, watching over them. The situations they described had impinged upon them and made them certain about a spiritual reality. One participant described seeing a vision of light through a
window; she tried to recognize it, but could not see where it came from. Her interpretation was that it came from God. She had kept this memory as a warm feeling in her heart. However, she had avoided telling anyone about the vision because of her fear of being ridiculed:

My conviction is that those who have lived here before us, I do believe that they now are guardian angels. (Randolf)

Participants mentioned messages received from outside the physical world, sometimes as impulses to perform actions that retrospectively had a great impact. For example, one participant who had worked in a hospital said that she got an impulse to check on a patient, even though she had just seen him. She found the patient in respiratory arrest. Her interpretation was that the impulse came from God and that her action had saved the patient’s life. The messages received were also expressed as greetings from dead relatives via signs in nature:

I was sitting in the garden; it was the first summer after [husband’s name] had died. A big butterfly, it was yellow and black; I have never seen such a wonderful butterfly and never experienced a butterfly sitting on my lap. I was watching it and dared not move. I said, is it you [husband’s name] who has come to visit me? (Gerda)

**Being amazed by creation**

Participants expressed their belief in a spiritual reality that becomes visible in the creation. The Creator was spoken of as a higher power who determines everything in the world. They expressed their wonder at seasonal changes, bird songs in springtime, animals’ instincts and beautiful flowers. The ability to walk outdoors and to see everything beautiful was expressed as a spiritual experience and a source of happiness and gratefulness to God. They described being moved and humble about the creation.

Participants also told about mysteries in their own life; about pregnancies and childbirth, and about being healed after a period of ill health. The participants also said that they marveled at their daily life experiences as still being alive and about their ability to manage daily life:

It is amazing that it is possible to have a baby – it is unbelievable, eyes, ears, nose, everything. It must be somebody deciding and caring about everything. Who is the one? It must be a higher power. (Hillevi)

**Querying an inconceivable God**

Participants were certain about a spiritual reality in some ways but expressed puzzlement about God’s characteristics. They had been taught to pray and call for God’s help but were uncertain whether God would really respond to their prayers. They also expressed insecurity about God’s frame of mind and whether this affected God’s willingness to help and protect them. The participants also talked about their doubts and their questions about God’s existence and omnipotence. They spoke of the discrepancy between their view of the Supreme Being and the constant reports of war and evil.

When you see what is happening in the world, you cannot believe there is a God who is in control. Because if God exists, he would not let it happen … but the fact that there is a higher being is something you know since childhood. There is a higher being. (Alma)
Discussion

The aim of the study was to illuminate very old people’s experiences and expressions of spirituality. Spirituality was described as a communion with God and with other people. The participants reflected on their past life and approaching death, thereby transcending their life circumstances. The experience of a spiritual reality seemed to be omnipresent and was described as both wonderful and incomprehensible.

The participants in our study talked about spirituality as an inner sense of communion and an ongoing relationship with God whom they trusted. God was described as always being present and reliable. Our findings are consistent with previous findings; among older people spirituality was understood as an outside force that gave support (Schwarz and Fleming Cottrell 2007). Among very old women, belief in God had helped when life was experienced as miserable (Hedberg, Brulin, and Aléx 2009), and among older people with dementia belief in God gave strength and inspiration and was a resource for dealing with life challenges (Williams 2008). The participants in our study described an ongoing communication with God in a personal and informal way; through prayer they found relief, security, and peace. This finding corresponds to another study among women (39–89 years), which found that praying was a strategy to meet spiritual needs (Logan, Hackbusch-Pinto, and DeGrasse 2006). In a study among older people with dementia, spirituality was a help in accepting life circumstances and maintaining positive emotions despite dementia (Dalby, Sperlinger, and Boddington 2011). In relation to non-Christian religions, a relationship to God has also been found to be an essential part of spirituality. An interview study with three women with advanced breast cancer (39–47 years) revealed that peace and strength come from surrendering to God [Allah]. Their illness had contributed to an awakening about their place in the world and a deeper awareness of Allah as the loving power (Farizah, Muhammad, and Abdullah 2011).

When talking about spirituality, our participants described close relationships with others and being part of a community. This communion embracing both God and other people has also been described in a meta-synthesis about spirituality (Rykkje, Erikson, and Råholm 2011). Rykkje, Erikson, and Råholm (2011) used the concept of connectedness, which was understood as the core of spirituality (Rykkje, Erikson, and Råholm 2011). In a review, Stephenson and Barry (2015) identified connectedness as an important aspect of spirituality that corresponds to all types of relationships with self, God, others, and nature.

Even though the relationship with God was central and obvious for the participants, they usually did not talk about their spiritual experiences. They offered several explanations for this reticence: spiritual experiences were difficult to put into words, and they feared being deemed suspect or labeled as religious. The fact that Sweden is one of the most secularized countries in the world (see Hagevi 2012) may have affected the acceptability of talking about spirituality.

The difficulties of talking about spirituality may also apply to professionals. Even if nurses recognize spirituality as important, their preparedness and knowledge are reported to be limited, and support and guidelines are required (McSherry and Jamieson 2011). In an interview study with physicians (Best, Butow, and Oliver 2016), discussing spirituality was described as a delicate matter, and both the patient and the physician had to feel secure in order to talk about spirituality comfortably. The physicians waited for
indications that the patient was ready to talk about spiritual issues before raising the subject (Best, Butow, and Oliver 2016). Furthermore, MacKinley (2006) claims that a basic prerequisite for being able to give spiritual care is an awareness of one’s own deeper values, concerns, and beliefs. Factors identified as enabling conversation about spirituality were shared spiritual and cultural backgrounds that give insight into a patient’s experience, the patient’s willingness to talk, and the opportunity to be in a quiet place with no disturbance (Best, Butow, and Oliver 2016).

In our study participants expressed a belief in a spiritual reality beside the physical world that was made visible through nature and miracles. Signs, described as intuitions or unexplainable events, were interpreted as messages from God or the spiritual world. This finding corresponds to previous studies. Among older Jewish and Christian people, spirituality includes an openness to miracles (Cohen, Thomas, and Williamson 2008). In a study by Santamäki Fischer et al. (2007) descriptions of spirituality included an ever-present God and a belief about having a personal protector, a guardian angel.

Our understanding of spirituality as a universal element in human nature is in line with MacKinley’s (2006). MacKinley (2002) suggests that spirituality has two components: one generic and the other specific. The generic component lies at the core of each human’s being, and can be understood as an individual’s search for meaning and yearning for relationships. The way participants in our study expressed their understanding of life in light of memories of relationships earlier in life, their present life, and approaching death can be interpreted as the generic component described by MacKinley (2006). The specific components of spirituality are how spirituality is manifested in a person’s life. In our study, the older people described spirituality as relationships; as an inner sense of communion with God, with other people, and with a spiritual reality. Further, they drew on spirituality to interpret signs and miracles in life as traces of God.

According to MacKinley (2006), ultimate meanings are at the center of an individual’s spirituality and may be mediated through relationships (intimacy with other people and with God), through the environment (nature, sea, mountains and gardens), through the arts (music, art and dance), and through religion (worship, prayer, reading of scripture, and meditation). Relationships were prominent in our study, both in relation to God and to other people. Amazement at nature and the significance of music and singing together as a way to feel included in a community correspond to MacKinley’s (2006) environmental and art dimensions. Furthermore, praying was spoken of as an ongoing communication with God. Thus our findings confirm MacKinley’s theory (2006).

One way to interpret the findings is that humans have spiritual needs that seem to be found in relationships, in nature, in art, and in religion. In the care of very old people, nurses need to be aware of spiritual needs since spirituality seems to be of great importance for successful aging (see Flood 2006).

**Methodological considerations**

The procedures used to generate our findings followed the recommendations of Graneheim and Lundman (2004). The findings were discussed in the research group until an agreement was reached. Representative quotations are presented to strengthen the
credibility of the findings. To facilitate transferability, characteristics of the participants and a description of the context have been presented. Since an interview is a co-creation between the interviewer and the interviewee, the interviewers’ pre-understanding may have affected the interview. However, the interviewers’ insight into spiritual and religious experiences and common vocabulary may have contributed to a respectful attitude. In an attempt to reduce the influence of the researchers’ pre-understanding in the analysis, the findings were discussed in the research group and seminars. The participants were a subset of those included in a population-based study, which increased the possibility of obtaining a variety of responses to the research questions. However all of the participants were ethnic Swedes, members of a Christian church and reported spirituality as significant for their well-being; this fact may have influenced the results. Experiences of spirituality among those who are not members in a spiritual or religious society need to be studied further.

Conclusion

Experience of spirituality, in this group of very old people, was described and interpreted as: Being in communion; Transcending life’s circumstances; and Living in a spiritual reality. Since spiritual needs are individual, in caring for very old people, professionals need to take these desires into account. Support for the very old is recommended through: having contact with relatives and friends; making space for conversations; promoting an aesthetic environment; and facilitating outdoor activities. It seems also to be of importance to provide space for meditation and prayer, alone or together with others. Fulfilling spiritual needs may promote successful aging. Thus, meeting spiritual needs puts a demand on education as well as on leadership to support professionals in this. Further research in this area is necessary.

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Disclosure statement

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Notes on contributors

Catharina Norberg RN, PhD is based in the Department of Nursing at Umeå University, Sweden. Her research focusses on spirituality among very old people.

Regina Santamäki Fischer RN, PhD, is an Associate Professor in the Department of Caring Sciences at Åbo Academy University, Finland. Her research concerns spiritual and existential experiences of growing old; and elderly people and health technology.

Ulf Isaksson MHN, PhD is an Associate Professor in the Department of Nursing at Umea University, Sweden. His research has a focus on care of persons with dementia; and eHealth.

Kristina Lämås EN, PhD, is based in the Department of Nursing at Umea University, Sweden. Her research has focused on people in older age and issues of constipation, thriving, and intervention studies including massage and person-centered home care.

ORCID

Catharina Norberg http://orcid.org/0000-0001-7710-4367
Regina Santamäki Fischer http://orcid.org/0000-0002-3902-5008
Ulf Isaksson http://orcid.org/0000-0001-5191-4599
Kristina Lämås http://orcid.org/0000-0002-5877-3458

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