

# On The Need to Address Spirituality and Well-being in Later Life Care:

## Some Reflections

Els-Marie Anbäcken\*

### Abstract

This article is a combined theoretical and empirical study, with emphasis on the former. However, it aims at relating theoretical findings to the everyday context of care for older people. The two contexts addressed are later life, referring to people primarily aged around 80 and above living in care homes, and the last stage of later life. The questions addressed are: Does spirituality matter in the care, and if it does, how is care viewed and how is it performed? Literature on the theme of dignity and old age, spirituality and terminal care, including palliative care, quality-of-life and well-being, religion and faith are reviewed briefly and in a reflexive manner. Among aging theories, gerotranscendence is mentioned. This is also linked to a research and development project on culture and meaningful everyday life in old age care, carried out by the author and a project group in 2000–2001. This project brought to the fore the importance of encountering the person first and the care task to be performed second. Also the need for staff to view cultural (existential) matters as a part of care was highlighted and discussed. Education needs to include these matters. To garner fresh input from the field, three informal interviews were carried out in April 2006 with persons working in the care sector or a related field; the results of these are also used as tools for reflection. The role of ordinary care workers and the role of volunteers, exemplified by the deaconess (a Swedish church social worker), is briefly outlined particularly regarding terminal care and needs. An important point is that, regardless of their stage in life, humans have a quest to come to terms with issues regarding meaningfulness of life. Using one's course of life as a tool to address life questions is elaborated on and linked to the practice of care. Upon a move to a nursing home, a life history document is written for the new tenant. This, it is suggested, can be used much more vividly as a tool to approach matters pertaining to spirituality and well-being. The article concludes with the importance of facilitating for people in later life care to live fully to the end. Finally it suggests a community research study to test some of the issues of this study.

**Key words:** dignity, eldercare, existential questions, meaningfulness, life-course

\*Linköping University

## Introductory Vignette

*Early afternoon at Flower Manor nursing home. Three ladies and one gentleman meet in the living room part of Mrs Svensson's little flat. Her son is visiting and now the peak of the fellowship is at hand. He leads the little group in a hymn which they know well, and then there is a short Bible reading followed by prayers. Oh, how they pray! Hearts overflowing with thanks to a loving and kind God almighty, who holds the whole world in His hands-including these four individuals. They have walked with God through life and the move to the nursing home does not change this life course. One lady prays for the situation in a country far away. Her world is not limited to the daily routines here at Flower Manor or to the limits that her frail body sets. Her spirit is as alert as ever. While she knows where she is heading, she is looking forward to the wedding of her grandchild-and shows me eagerly the new dress bought for this occasion.*

This article is exploratory. It is not built on a specific empirical study; it is based on the accumulated empirical and theoretical knowledge from the field of old age care that I have as a researcher in gerontological social work. I also draw on my experience as a daughter and daughter-in-law to a mother and mother-in-law who both live at care homes. For the specific purpose of this article, a limited literature search was carried out, and, in addition to that, I met with three care professionals for talks related to the theme of this study. The intention is therefore not to give any full account but to uncover and reflect on just a few glimpses found. The point of departure I referred to, the Swedish context and the literature, is international, but mainly western. This is a limitation, but I welcome the reader to reflect on the content with cultural glasses other than those of the author.

What then are the issues addressed here?

First, it is a matter of a basic view of humans in general that informs the care of older people. How are older people viewed in society in general and in care settings in particular<sup>1)</sup>? How care is defined is an underlying question which is not analysed here<sup>2)</sup>. Does it matter if care is seen as physical or spiritual - or inclusive of both? Can these two perspectives, making up a holistic view of humans, be combined in everyday life in care settings? Is care staff educated to see both aspects of care - and does their work situation allow the time needed to give holistic care? These are the questions underlying the reflections that the reader is invited to take part in. The disposition of the article is as follows.

After a background taking its point of departure in personal experience and some further reflections evolving from these, the article takes its theoretical point of departure in the concepts of welfare, well-being and quality of life, particularly in relation to spirituality. After that the reader is introduced to a research and development project that took place in cooperation between Linköping University and a number of municipalities addressing a broad spectrum on the theme “culture in care”, in which spirituality evolved as a theme - even though we at that time did not label it spirituality. The category of people the present article addresses in late life could include any person aged 65 and above who utilizes some kind of public social care, but in practice it targets those with quite large care needs and, more often than not, those above 80 years of age [Aktuellt om Äldreomsorgen, 2004]. Moreover, we limit this category to only those who live in care (or nursing) homes which in Sweden are usually referred to as special housing<sup>3)</sup>. From this phase of later life and those who need relatively more care the article then moves to the vantage point of the very last stage of life, or terminal care. The role of the deaconess, a church social worker, is also mentioned, since she plays a special role in the Swedish setting of volunteers. Finally some examples from educational texts are elucidated before a concluding discussion on the theme of needing to address spirituality and well-being in later life care.

## Background

Somehow there is silence with regard to spirituality in the main context of care for the elderly in Sweden. This is true at least in the everyday care that is observable from a visitor or family perspective. There is a call for research on better care for those who are frail and have multiple diagnoses, for more continuity in the home help services and for more social and dignified care (see, for example, Ministry of Health and Social Affairs [2006]) but seldom is the latter specified in terms of spirituality and well-being in this first decade of the 21<sup>st</sup> century. When multicultural care is focused it is common to address the needs that arise from different social and cultural backgrounds, religion included (see, for example, DeMarinis [1998]). But in more general terms there is a distinct silence. The church volunteer visitors or the church volunteer devotions and song times are part of weekly or monthly activities, at Flower Manor as at most special housing in Sweden. However, to what extent it is seen as an integrated part of the totality of activities offered, which of course are (and should be) free to choose from, is not studied much. This could also be said about other volunteers and their contributions to activities<sup>4</sup>).

In terms of terminal care I would say more affirmatively that the consciousness of spirituality has entered the practice of old age care. Does the end of one's life and the transition to death allow room for existential questions, or at least to prepare such room for them, perhaps through rituals (often practical ones) rather than words? The fact that an increasing number of people die in special housing, in fact half among those aged 85 and above [Jeppson-Grassman & Whitaker, 2006], has made terminal care a part of the care staff's scope of work. Palliative care has in the same way become part of terminal care and it might be expected, perhaps, that this would have led to an awareness of the spiritual and religious needs that, according to various studies, exist. Especially when we look at definitions of palliative care which could be summarized: Palliative care is the total care of patients

at a time when the disease from which they suffer no longer responds to curative treatment. It has three pillars: physical, psychological and spiritual [Forsell, 1999: 12]. The opposite could also be said, according to Grassman and Whitaker; namely that these spiritual aspects are rather absent in palliative care [Jeppson-Grassman & Whitaker, 2006].

From my own experience, during my father's death at a care home four years ago, I recall the matter-of-fact communication from his staff, treating me as his daughter. They were kind, considerate and calm, radiating a sense of professionalism: they knew the taught procedures for terminal care and they communicated with us and welcomed our presence without demands<sup>5</sup>). Looking back I would say today, however, that what they did was to provide us space for a peaceful farewell, assuring us they performed physical care in a professional way, including a kind and respectful attitude, but avoiding the spiritual aspects - perhaps leaving them to us as they knew we had a Christian faith.

From other experiences in the care home sector, I have seen and heard that the staff seems to know how to handle these terminal phase situations in practical ways. I have been told - perhaps selectively so - at several study visits with Japanese students and professionals to Swedish special housing (but very seldom have I heard about similar situations in Japanese nursing homes) that when family members cannot be at bedside at the end, a staff person sits there. For these occasions it is a matter of fact that additional staff are called in, so that a staff person well-known to the dying person is present. However, I have never spoken with staff in-depth about existential aspects until very recently. For the purpose of this article I asked three persons if I could have some time to talk with them on spirituality and elder care from their viewpoints respectively: that of the care worker, the home chief and a person from outside the care institution, a deaconess. Questions like the following were brought up: Have you experienced terminal care here? How did you experience it emotionally and cognitively? Did/do you talk about this in the staff group informally and/or formally? Do you usually get any

supervision and if so, could you please tell me about it? In your daily care, how is there room for existential/spiritual questions? We will come back to these conversations further on in this article. First, however, let us briefly ponder the concept of spirituality before taking a closer look at the concepts of well-being, welfare and quality of life, and then later tie these thoughts again to spirituality.

The careful reader may have noticed that “spirituality” has not been defined specifically so far in this article. In fact, I hesitate to introduce a single definition, since in my view it would take a separate work to discuss a variety of its aspects, including a more thorough ontological and epistemological discussion regarding spirituality<sup>6</sup>). In the literature I refer to for the purpose of this study, spirituality is mentioned directly or indirectly in combination with concepts such as religion, faith, the meaningfulness of life, dignity, identity, existential questions, and in my own project on care and culture it could even be seen as a part of what constitutes culture. I also referred to the WHO survey instrument WHOQOL-SRPB [2002] which covers questions of life aspects related to spirituality, religious and personal beliefs (SPPB)<sup>7</sup>).

### **Well-being, Welfare and Quality of Life**

In the broad spectrum of studies on aging and care, quality of life has often been part of research foci. Numerous surveys have been performed internationally with this as a main focus or as an underlying issue that nevertheless informs these studies. Without giving specific references I am quite sure that much of this can be found in Japanese studies. Here, only a few aspects of quality of life will be brought up and only in relation to a holistic view of well-being to which, as I see it, spirituality can be linked. The WHO defines it as “individuals’ perspective of their position in life in the context of the culture and value system(s) in which they live and in relation to their goals, expectations, standards and concerns” [WHOQOL, 1999, 3]. According to Nordenfelt [1991]<sup>8</sup>) the concept of quality of life came about in the 1960’s [1991]. It entered the health care sector, with a ho-

listic view that health care must enhance the quality of life of the whole person. It is in this sense that I see a parallel to well-being. Nordenfelt discusses the concept from (among other perspectives) a philosophical point of view and points out how difficult it is to define it. How can we possibly assess what is quality in someone's life? It can be measured with different standards, such as moral, aesthetic, religious, etc. He further analyses different aspects of scales to measure this kind of quality and concludes (at least partially) that only certain conditions for well-being or quality of life can be studied. Another term is suggested for a related dimension, namely, an experience of meaningfulness. Two intrinsic meanings of the concept are elaborated by Nordenfelt. Meaningfulness of life is thus, according to him, experienced when a person can see and value a sense of coherence in her life. The second is to strive for an ideology, a good cause. From this vantage point Nordenfelt further elaborates that there are related aspects to meaningfulness, such as self-respect (*cf* dignity further on in this article) that can add further weight to a sense of meaningfulness. He also refers to *Eudaemonism*, the philosophy of happiness rooted in Aristotle (384–322 BC) that can be seen as a sounding-board for quality of care definitions. This article cannot give full credit to Nordenfelt's deep analysis, rich in nuances, but, the point I wish to make, and which I borrow from him, is that "quality of life is a multi-dimensional umbrella concept with many meanings" [*ibid.*: 96, my translation]. This includes Nordenfelt's view on the individual as a supreme authority when it comes to judging his/her own happiness [Nordenfelt, 1991].

Allardt is another Nordic researcher who has dealt much with welfare analysis. In his classic book on welfare in the Nordic countries<sup>9</sup>, "Having, Loving, Being" [1975], he (similarly with Nordenfelt) describes the multi-dimensionality of welfare. People have basically three kinds of needs: material (to have), relationships (to love) and (to be) treated as persons and not as objects within society. The point to make for this paper is, drawing especially on Nordenfelt and Allardt, that when we think of well-being and quality of life for people in later life in general

and for those among them who need extensive care in particular, we need to address these issues with much respect for each individual's experience and perception of what well-being, quality and meaningfulness of life entails.

Life history is a genre often used in recent gerontology. Hagberg [2002] has, among others like Öberg [1997], claimed that reminiscence and the evaluation of certain periods in life history are important for satisfaction with life for older people in general. In studies that Hagberg has performed it has been found that *how* one's life history is viewed has an impact on the well-being experienced at present, and also which periods during the life course<sup>10)</sup> which have the greatest meaning for the different aspects of well-being defined as "the feeling of coherence" (SOC), in an Antonovskyan as well as Eriksonian sense [in Hagberg, 2002: 75]. Antonovsky's [1987] classical definition of SOC, the sense of coherence, is composed of three components: "comprehensibility", "manageability" and "meaningfulness". If a person can make sense out of her circumstances and feels she can manage with resources available and can feel that life is worthwhile, then she has (to varying degrees) a sense of coherence (for example, Antonovsky [1987: 147]).

Borglin, in her PhD thesis on quality of life among older people, calls for studies which ask older people about the meaning they attribute to quality of life [2005: 22]. She also ties this concept to SOC, a sense of coherence [Antonovsky, 1987], as these enforce each other: a person with a high sense of coherence is likely to indicate a high quality of life [Borglin, 2005: 31], since their definitions suit each other well. So again the message we need to hear is that of the person's own accounts and definitions.

Following these lines of thought, the Swedish theory of gerotranscendence will be introduced briefly [Tornstam, 2005]. Tornstam, in my interpretation, has scrutinized all traditional aging theories and found them "too superficial" or at least not fully covering the experience of aging. The title of his most recent work clarifies that it is the developmental aspect he is focusing on: old age means development (perhaps not in the same sense as Erikson)<sup>11)</sup>, in that we as human beings tie our

life threads together in a search for meaningfulness, wholeness. What I find interesting for its usefulness both in theory and practice is that Tornstam discusses that all existing aging theories can give different interpretations to common scenarios in old age care [ibid., 2005: 8–9]. If Mrs Andersson does not want to participate in the activity group today, it may mean that she is not feeling well; she feels tired and does not want to meet the others as it simply seems tiring. Or it may mean that she would rather sit on her veranda, letting the summer breeze surround her and letting her thoughts wander freely [ibid.]. Or, I would like to add, it may also mean that if the care staff has the time to motivate her to go, or help her dress, she would in fact like to participate. Similar events can thus be interpreted in quite opposite ways. What demands then, does this view place on care staff?

Tornstam's study emphasises the need for care staff to be educated not only for hands-on care but also in gerontological theories that can help them both meet the needs of the care home residents and also make their own work more meaningful and less stressful.

Understanding the theory of gerotranscendence can result in practical consequences which are rather easy to carry out, as Tornstam shows. He lists many practical guidelines for care staff to consider in their daily care work, such as letting the elderly decide for themselves whether to participate in activities, respecting their wishes to be alone, encouraging them should they start talking about death, and encouraging them also to talk about childhood and how they have developed throughout life [Tornstam, 2005: 182]. The examples are many, and from them I chose the following, which held many associations, at least for those who have experienced working in nursing home settings:

Do ask in the morning what the older person dreamed about instead of asking how they feel. If they did dream, ask then about the dream and what it might mean. [ibid.: 182]

As a matter of fact, I have often imagined the difference in the conversation that would follow.

Moreover, this could be interpreted at least in part as synonymous with the term spirituality. Addressing older people in care as persons with the ability to reflect and formulate in words thoughts on life and the meanings thereof is to treat them with dignity. The next part will focus on exactly this, the concepts of dignity and spirituality.

### **Dignity and Spirituality**

Dignity and Old Age [Disch, Dobrof and Moody, 1998] is the title of an anthology<sup>12)</sup> which contains a series of articles related to the overall theme. We leave aside a deep analysis on what dignity means, and instead make use of dictionary definition<sup>13)</sup>. Moody picks one of three definitions from Webster's dictionary [Moody, 1998: 41] which is relevant to the purpose of this (and his) study: dignity is "the quality or state of being worthy, honoured, or esteemed". He discusses the links between dignity and quality of life, the latter having a longer history, and the former not as studied yet, yet the way he talks about dignity bears clear connotations to how spirituality and quality of life are spoken of. Objective and subjective factors (which are often at stake in these discussions) make it difficult to formulate definite standards but Moody's later findings show that despite negative objective factors people can state that they have a good subjective quality of life. And this is why he now focuses on the conditions under which quality of life is felt as high in spite of negative objective factors. Another focus is on which social and psychological processes seem to be more important than the objective conditions for the perceived quality of life [Moody, 1998: 42].

Without going further into the chapter on "Dignity over the Life Course" [Coles, 1998: 1], the title inspires us to think in terms of dignity as a human quality regardless of age. The emphasis on a life-course perspective when dealing with matters on aging and care is in this way is tied also to existential matters, which

makes sense to me. Dignity in care in late life should not be seen as separate from dignity at other stages in life. It should, however, also be analysed in relation to the specifics of this phase, of *late* life.

We take a leap to the chapter titled “Spirituality and Community in the Last Stage of Life” [Simmons,1998: 73]. Simmons starts out with a conviction: “the last years of life cannot be adequately described without attention to a struggle to keep the human spirit from being overwhelmed by frailty” [ibid.]. He describes this struggle also in terms of the quest for the meaningfulness of life [ibid.]. What especially attracted my attention in his contribution is that he turns to those who work with frail older adults. He did some “unscientific” interviews - as I also did as part of this paper - with care staff and noted two common trends among them. The first was a treatment with the same dignity as that with which anyone else would be treated and the second to do so because of a personal experience, often related to faith, of the staff that was decisive for this attitude [ibid.: 74]. There was yet another level he encountered in some interviews: The dignity that was reflected from people in the last stage of life called for a similar response [ibid.: 75].

Simmons defines spirituality as “the quality of a lived life, seen from the inside” [Simmons, 1998: 77]. He further refers to spirituality as “*embodied... realities that touch the depth of the human person...*” but also states that “it is through the fragile language of the body that we apprehend the mystery of the world, of others, of the Other” [ibid.]. Simmons sketches two spiritual perspectives as pertaining to religion. He both explains it in terms of identified religion, the example taken from the Judeo-Christian faith, thus defining spirituality as intrinsically and intimately related to a personal God and that spirituality then is explained as a relationship of the human person with God. The other, non-religious, spirituality he describes is that of the inner being of man that, in reflecting on life, is not defeated by temptations and despair [ibid.: 78]; perhaps this could be paraphrased as how humans develop life’s wisdom. To Simmons these two perspectives are

united in people who “embrace a reality that touches the depths of the human person in this last stage of life” [ibid.: 79]. How are these people met by the care staff in special housing?

Next, Simmons somewhat answers this question by drawing attention to “intentional communities” where spirituality is taken seriously as a part of the community life within the nursing home. The examples he gives show the importance of residents in nursing homes continuing to be a part of the community, experiencing joy and sorrow that can be part of rituals/festivities in which all take part. This is set in contrast to being guided by the chronological order of each day, characterized by a constant state of waiting, for the next meal, for a bath, for bed and so on [ibid.: 85]. How could this insight be a tool to bring about some change in the every day life of the nursing home?

The remaining part of Simmons’ chapter/article is a continued discussion on how nursing homes as communities can develop, offering a view on human beings as developing, growing throughout the whole course of life - including the last stage - lived at a nursing home. This leads on to the next point, supporting a quest for meaning. It is truly human to reflect on what is important in one’s life and on what the meaning is of *our own* lives. A community - the nursing home - that supports this quest (instead of just encouraging the residents to be cheerful) is needed [ibid.: 87]. While quality of life was not mentioned as a specific concept in Simmons’ article, when reaching the final paragraphs therein, I found it between the lines: quality of life is to live fully to the end, allowing all feelings on a scale from sorrow to joy to exist<sup>14</sup>). This brings us to a closer look at spirituality and religion.

### **Spirituality, Religion and Faith in Later Life**

In my search of databases and journals I have come across a number of articles on the themes of spirituality, for example, in *the Journal of Cross-Cultural Gerontology*, but also in the field of social psychology. Time was too limited to make a

through literature search or to even find some of the original works. I venture to mention two book reviews which summarized some points in an eloquent way. The first one is authored by Michael Angrosino [2004] who reviews *Religion, Belief and Spirituality in Later Life* by Thomas & Eisenhandler. The way spirituality is described creates a coherence with other research that is brought up in this paper. In short, spirituality is interpreted as the fundamental component in personal growth and maturity during the life-course. Angrosino finds the different authors reaching the conclusion that “later-life spirituality is essentially a matter of the ability to link daily tasks and states of physical and mental health with a stance of transcendence from which it becomes possible to reconsider and re-evaluate everyday life” [2004: 374]. Another point made by social gerontologists, especially when distinguishing cohorts and generations, is to view the older people referred to in studies in the context of their lived lives, the historical setting with not only shared events (like a world war, certain politicians, authors, music, etc., etc.) but also the values and goals that have been the shining stars they have followed [ibid.: 375].

Another book review, authored by Belzer [2004], is on Eisenhandler’s social gerontological work *Keeping the Faith in Later Life*, which looks at spirituality, religious belief and behaviour in later life. A typical research question of hers is “What role does faith play in coming to terms with the many changes posed in later life” [ibid.: 162]? She conducted interviews with 36 adults at ages between 60 and 93, living in the community, and also 15 adults at ages from 73 to 96, residing in long-term care settings. Many noteworthy results could be mentioned from the findings, such as prayer being the most common religious practice mentioned by her interviewees. Many kept the pattern of faith from their childhood, but some exposed doubts and reflected on how their “faith life” had changed during their experiences along the course of their lives [ibid.: 162]<sup>15</sup>.

In *the Journal of Aging Studies*, Susan Fletcher concluded from the narratives on the religious beliefs<sup>16</sup> of 12 women living in three assisted-living facilities that

a relationship with a divine other in whom they trusted added to the maintaining of life's meaning in late life [2004: 182–184]. Those too who expressed doubts and/or were open to personal and relativistic interpretations of faith also found meaning, however, in the social interactions that were part of the religious community. This study goes to quite some depths to analyse the differences between those to whom God and belief, the tenets of their faith, are important, and those to whom the next level (as I interpret Fletcher) is more important; the religious community with its social interactions and also the deeds towards others with which one pleases God [ibid.]. Fletcher thus concludes from her qualitative study, that while religion informs life's meaning in old age there are differences as to the ways this is due to faith as such or faith as a social experience [ibid.].

Another perspective is taken in *the Journal of Educational Gerontology* in an article which aims at viewing the strength of resiliency and the spirituality in counselling older people [Langer, 2004]. We find again the definition of old age as a period in life in which the individual uses her/his accumulated and internalised life wisdom to handle the challenges of later life. Langer contrasts the traditional negative views on life in old age, with losses of all kinds, from functions to friends, and that the focus in research is very much on care-giving and support. The important contribution Langer adds, I find, is that he brings together the aspects of care-giving and the individual's life history to reach a deeper layer than is commonly found in the practice of "life history checklists" that are common also in Swedish care facilities. All residents are interviewed (briefly or in some length) about their life history so that staff are given a broader and deeper picture of each person, her/his dislikes and likes. The intention of these could be perhaps a bit more ideologically clad in the following, which I borrow from Langer:

*Human beings, who happen to be old, often get lost in the process of assessment, diagnosis, and service brokering. If our concern as care providers is to enable an older person to remain "independent" or "in the community" for*

*as long as possible, we must tap into the personal values and lifelong commitments that guide the way that person uses his or her time, solves problems, and ultimately lives out his or her remaining years.* [Langer, 2004: 612]

Langer then continues to sketch, with reference to Wagnild and Young [1990], five themes describing a successful adjustment to aging: The capability to balance joy and sorrow throughout life, the quality of perseverance that helps individuals persist and constantly (re)build their lives, to believe in themselves, to accept that there is an existential solitude and finally to find meaningfulness - that life has a purpose [Langer, 2004: 612]. Langer draws on other findings to build up a platform for what he calls “strength-perspectives counselling” and the key sources he draws from are Baltes & Baltes [1990] and Francl [1963]. Baltes & Baltes make their point that individuals continue to develop throughout life, drawing on their experiences and finding meaning in them, through which they are helped to cope with stress and adversity in life. Francl emphasises along those lines that the drive for or “will” to meaning is essential and that suffering especially provides challenges for incorporating those experiences into our lives. The attitude with which we encounter these hardships, or the ability to choose an attitude, is crucial for how life is perceived, experienced and interpreted. This is precisely what Öberg concludes in his PhD thesis on “Life as a Narrative” [1997]<sup>17)</sup>, based on numerous life history interviews.

With this in mind we move to the practice of care for older people and ask, initially: Do findings like these inform policies for care and, if so, how?

In searching for new ways of viewing aging and old age in Sweden the parliamentary committee (SENIOR 2005) suggested two guiding goals for the National Development Policy for Older People in Sweden. The first of these two overarching goals was not new; it was on safety and security in care. The second one is very much in line with the above thinking on how to include a life-course per-

spective, encompassing the characteristics of one's humanity in terms of one's capacity to grow - throughout the course of one's life. It reads as follows:

*All people should, regardless of age, be able to grow as individuals, influence and have an impact on the development of society, and be met with respect.* [National Board of Health and Welfare, 2003: 27, my translation]

Five years ago a project was carried out in Linköping and some other municipalities in Östergötland county in Sweden. Before the above policy was announced this project, on which we will now focus, attempted to study it from the perspective of activities and attitudes in care.

### **Culture and Meaningful Daily Life in Elder Care**

In 2000 and 2001 a research and development project with this name, in which I participated as a researcher, was carried out as a joint project initiated by care staff in various positions in the field and two researchers, myself and a colleague, Cedersund. The care staff were all members in a network for "culture workers" and their overall aim was to work for a higher consciousness among all staff, of the meaning of activities that add meaning to the daily lives of older people in care settings.

What does culture and meaningful daily life mean to you? We asked this of a group of "diary-keepers" in the project. They were instructed to write down, in some kind of diary, from daily experiences on this theme. One such diary-keeper presented her contribution in poem-like form - in which she listed a variety of small and big events which tied together the perspectives of daily life and life-course. These brought to the fore much of the essence of the whole project, on what meaningful daily life in care can be, in simple as well as delicate events and how research support these findings. Only the last lines are cited here.

*following an old lady to her house and taking a look at it  
putting up new curtains with advice from the residents  
explaining how to find the toilet for the twentieth time  
turning off the radio because one lady wants silence  
comforting the next of kin and serving them coffee  
sitting and holding the hands of a dying person*

[Anbäcken, 2002: v, my translation]

As the report was going to be published, her poem became the introduction to the publication, as these lines brought the issues of the whole project to the fore.

Although the project embraced many cultural activities, from reading to wheelchair dancing, drawing, and ideas on how to create nice group activities, there was also a workshop on listening and being present in difficult moments. Here spiritual issues were *allowed* to become tangible. “Validation and Reminiscence” was another workshop which touched on matters of identity and care.

Our study showed that activities could be seen in different ways. Social activities that are important for well-being were meeting with others, interacting, doing nice things together, and doing things that one is interested in. The latter view makes the content of the activities important while the former emphasizes the communication, the encounters, perhaps the aspects that come as a consequence of the practical fact that activities are arranged.

As already mentioned one group of staff had the task of writing a kind of diary, which resulted in either diaries or reflections on how culture, activities, communication and encounters were part of their care work - from the perspective of the themes that had been highlighted during the seminar day.

These staff had all chosen to work with activities in one or another sense, and from their perspectives, they felt that priorities were more often on medically-related care or practicalities such as toilet, shower, meals, medication. “If there is time left we can do activities” was the attitude they often felt they encountered

from other staff. Another was that even though they were charged to see to it that activities were part of the care, the limited budget prevented any extras. Among the totality of their reflections and our discussions as we met in the group, the following examples are extracted: How can more of the older people in the community, living with home help services, attend social activities arranged at the service house? A new idea was tested, so that on a specific national holiday - when each person received an invitation card - a larger number of persons than usual attended the arranged program. This was interpreted as the importance in being seen (much in line with Allard's: to be [1975]). The role of volunteer organisations as a needed complement was mentioned, exemplified by two deacons who are "walk-mates" for those who might wish to take a walk. To give individual care can mean to take someone out in the sun to listen to birds singing, or to plant spring flowers. The importance of music, and of colour, was also mentioned. The good encounter is also an "activity", someone pondered; it is about how you talk, with dignity, to a fellow human being. One care staff said that which summarizes much of this project and much of what this article is about as well:

Take a deep breath before you open the door to the next person and think of who it is who lives there. When time is scarce it easily happens that one thinks only of *what* to do, not *who* to help. [Anbäcken, 2002: 40]

Yet, one of the impressions that lingered on after this study was the collision between those who wanted, symbolically speaking, to give room for spirituality in the everyday life within care settings and those who would rather keep themselves in what DeMarinis defines as a Swedish cultural characteristics: an emphasis on the importance of planning, punctuality and orderliness. According to DeMarinis, Sweden is seen as a *low culture* in the sense that emotional expressions are kept at a low level [1998: 76–78]. Perhaps I draw too much from DeMarinis if I apply her analysis to our findings, given that the *cultural* aspects are viewed within the

field of emotions whereas the practical work belongs to the mainstream as it is in line with other cultural characteristics. But it is tempting enough to apply it.

I think that cultural codes are nevertheless important to be aware of when approaching existential questions. How we in society approach these generally has an impact on how too they are addressed within care settings.

From this broader perspective of care settings for older people as arenas of daily life, we now focus more specifically on the very last stage of life (though the beginning and end of which are not clearly defined).

### **Terminal Care**

The work of Kübler-Ross [1968] was the ice-breaker for questions on providing care with dignity for those dying at institutions. Dying with dignity means to view the person as a whole being, and thus treat both physical symptoms, alleviate pain, and meet emotional and spiritual needs. Moreover it also means to behave in a culturally respectful manner. Levy likened the process with that of a “midwife” to the dying process [Levy, 1989: 391]. She also touches on matters this paper addresses specific to spirituality and quality of life, as she states that the hospice provides patients and families with a context that helps them ponder the meaning of life, in the light of the inevitable death [ibid.: 392]<sup>18</sup>). Similarly, but from a different perspective, the deaconess I spoke with on these matters<sup>19</sup>) told of her role. Furthermore, Grassman and Whitaker give an example of how relieved a dying person was when the deacon confirmed that “yes, you are dying” [2006]. Representing a special professional agency, that of the church, the deaconess is expected to communicate professionally about these things.

The *Gerontologist* featured “End of Life” as one of the themes in Vol 45, no 5, Oct 2005. Under the heading End-of-Life Care, Wetle et al. [2005: 642] focus on terminal care in nursing homes, from the perspectives of 54 family members interviewed in a qualitative study. The results show the lack of support from health care professionals. They criticize regulations which prioritize “taskfocused” rather

than “person-centred” care [2005: 642] and address the need for education regarding palliative care [ibid.: 649]. They also emphasise that the experiences of family members make up an important source of knowledge which ought to be used to enhance terminal care at nursing homes, which increasingly are becoming one’s last abode in life [ibid.: 650].

In *the Journal of Aging Studies*, Nakashima and Canda examine, through qualitative interviews with 16 elderly hospice patients, how resiliency has had an impact on their experience of a positive death. These patients all expressed, in varying degrees, that spiritual beliefs and activities, such as prayer, gave them strength [2005: 115]. But this does not mean that negative feelings were absent. Loss was, for example, expressed, as well as pain, of course. What other factors were found to support resiliency - apart from spiritual ones? Relationships with caring family members within a stable social care setting, and confronting death leading to an awareness of life’s limitations. All interviewees in their study made preparations for their own funerals. A majority of them were comforted through their spiritual beliefs. Two processes that were seen were how the creating of life narratives helped to integrate the past into the present. Telling one’s life to another person (the researcher) is encouraging in the sense that the subject analyses life - the good things, the difficulties - and how she/he overcame these. The interviewee felt strengthened by in telling of his/her life, making an account of it, seeing oneself as having managed some important tasks - in short, positive constructs of life strengthens resiliency during this last phase of life [ibid.: 119]. The other process was the ambivalence expressed: while one is aware that one is dying, at the same time a feeling also exists that one has to do something, to keep moving. Many showed a will to fight, to do what they could to live. There was thus a dual process: to surrender, “let God handle it”, and to strive on; the authors conclude that this was a dynamic process “that supported well-being in the midst of dying” [ibid.: 118].

In Forssell’s report on the death of older persons [1999], a nuanced scenario is

sketched. In the Swedish context, which has already been mentioned here, an increasing number of people die at care homes for older people. Her study is based on interviews with next-of-kin and with staff and focuses on their respective views on how the last phase of life was experienced and what they thought and felt about it. It reiterates what I mentioned earlier as uncertainty, perhaps numbness, that often appears when these issues are confronted. Forssell exemplifies with many citations both the good stories and the less good ones of death among the old. A great degree of tacit knowledge of the staff, combined with an articulated wish from family members to be more involved in the care was noted. The interviews showed the uncertainty many felt about spiritual matters and that many even avoided talking about death or existential questions [Forssell, 1999: 107–109]. For the aim of this contribution I will only select one of her findings, related to spirituality as part of the holistic view it encompasses: “*Palliative care affirms life and regards dying as a normal process. Palliative care emphasizes relief from pain and other distressing symptoms, integrates the physical, psychological and spiritual (emphasis mine) aspects of patient care...*” [Forssell, 1999: 12]. Forssell addresses an often *hidden* aspect which could be more addressed in palliative care: the right to feel a kind of pain, in the sense that it may lead to being open to talks on life and death, about the fact that the person is dying. The right to be in control and share thoughts with loved ones need also be included [ibid: 107–109]. From another perspective, Lars Andersson [2002] addresses loneliness and social relations referring to Moustakas [1961], who speaks in terms of an existential loneliness which is intrinsically interwoven with our existence as human beings. He brings up two seemingly contradictory aspects in this: agony as a defence mechanism against having to encounter loneliness, but also that this existential loneliness brings about conditions for us to mature or to develop creativity.

Whitaker has gone further into this topic in her PhD thesis entitled “Life’s Last Abode” [2004], in which she followed, through participant observations but also interviews with elderly residents, their families and staff, experiencing life at a

nursing home. Whitaker's well-informed study has much to say not only about terminal care but about how life at the institution, both for the elderly and their families, is coloured by what she labels as "existential conditions" of "time, space (place), body and dignity" [Whitaker, 2004: 238]<sup>20</sup>.

We will now meet the three persons I introduced on the first page of this article, who may help to give some more context, or flesh out concepts which perhaps have tended to be theoretical.

### **Three Short Stories**

#### **1 "Maria" - deaconess**

The deaconess, Maria (not her real name), whom I met for a discussion of spirituality and old age care, confirmed some of Grassman's and Whitaker's findings [2006], such as the importance of having a relationship over time with older people in the parish. A relationship of trust was emphasized as crucial. But she also exemplifies those cases where the relationship between church social work and formal municipal social work cooperates well. She started her career in this parish and community by contacting the staff at the service house and letting them know what the church could do. And with her background in case assessment for old age care, she was already familiar with the environment. Here at the service house they offer devotionals and have a monthly meeting. The most recent example was taken from one of the special homes in the community, which had been converted from permanent stays to short stays. It is now a home for older persons after a hospital stay, where residents receive further assessment or rehabilitation, determining if they can return home or else require special housing. Maria said that in her experience many were told that they have an incurable disease.

The reorganisation (as a short stay home) took the staff by surprise and they are in the process of reorienting themselves within their care work. Maria and one of the priests were asked to give them some education on ethical matters, which resulted in two discussion groups where staff could bring up their problems and

questions. “Precisely when one has got to know a person he or she dies or moves to another housing.” Or: “How can we react when their children believe that the parents will live on forever?” Maria gives credit to the staff, “they really are good at these encounters - but there is not enough time and they can sometimes panic; there I can give support. It is important for staff to have someone to turn to”<sup>21</sup>). Grassman and Whitaker brought up a similar example in their article [2006] about the importance of acknowledging that a person is dying in able to really communicate in the last phase of life.

## **2 “Elsa” - director of a care home**

The talk with the chief of staff at a special home made it clear that there is a growing awareness of the need to handle terminal care issues. All her staff will be able to participate this coming fall in a basic course on palliative care, an education program that the municipality offers thanks to state support (“The Competency Cycle”, *Kompetensstegen*). But already in this care home, one of the staff is a palliative care representative and gives an introduction on these matters to all new staff. As our talk moved into the home as “life’s last abode” (referring to Whitaker’s PhD thesis 2004), Elsa added that even though the home is such, it does not mean that a sense of the present is not important. In fact, some feel healthier after having moved here and receive adequate care (including regular meals) and their focus is not on “life’s last journey”. In this sense, Elsa’s view is in line with both Nakashima and Canda’s and Whitaker’s findings, the former showing clearly the dynamics of being ready to ‘give in’ and to ‘live on’ and the latter, Whitaker’s findings, that the nursing home setting (in her study) installed a feeling of waiting - for dying and death [2004] - although this was also part of the contradictory themes that Whitaker found.

## **3 “Anna” - care worker**

Anna has worked for 22 years in elder care, as a home helper and on staff at nurs-

ing homes. She has encountered death many times in her profession. "It can be so beautiful", she says, "a dignified end". This last time of life is often a refined time, but may be difficult for the family members. Anna talks about the importance of debriefing among the staff: "It is good to bring it up within the staff group, and have the possibility to cry". From her long experience she summarizes that how this after care is done depends on the staff group. Not everyone can handle these matters or talk about them. Seen in the light of Forssell's study [1999] it appears that Anna does not fit in with those who felt insecure about these matters; she confirms that it differs from person to person. In her education there was only a little on palliative care in 1986, but "repetition is needed" because "no death is like another". Anna also brings up the importance of respecting each individual, their different faiths/religions, and takes examples from her experience. It is important for the family that the end be a good time because they carry it with them for the rest of their lives. Anna recalls special moments related to the end of life and relates this to something that adds meaning to her work. "These moments that I carry with me make work mean something more - not only now - as there is something more, but *after*..."

We ended by talking about church volunteer groups; Anna finds them good but adds that small circles would be fine, where they could bring out their questions, talk about life. The final comment I will share from my talk with Anna is, "There is a crying need to take hold of these questions, for family members, staff, residents, for all involved!"

The last area on which this study was focused is educational matters, although it will be dealt with very cursorily. The point is to include education and on the job training when thinking about and facing these matters. Why? Because the problems addressed here are how these issues can be interwoven in the care workers' knowledge base. A review of courses in which staff are enrolled (depending on the generosity of the director), including university and municipal special training courses, would be a base for an empirical study on this theme. Since that

falls outside the scope of this article it is simply stated as a need and with that we move on to a special education center.

### **Education and Training**

One Swedish resource of knowledge with regard to education and research in this area is Ersta University College's Sköndal Institutet. Ersta Diakoni, part of Ersta University College in Sweden, encompasses, for example, a hospital, therapy home, elder care, of which the latter is well known for their work with reminiscence and validation. They are certified to educate in validation methods, which strengthens the self-esteem of older people suffering from dementia through a confirming attitude in encounters during the care of these persons. Reminiscing also aims at strengthening self-esteem and identity [www.esta.se/Page 83.aspx, 2006–04–21]. These two methods used especially in dementia care in Sweden (and internationally), coexist well with spirituality as they relate to a holistic view on the person, looking beyond those physical/emotional expressions which mainly are seen as negative consequences of dementia behaviour, targeting, or perhaps rather interpreting, the innermost identity of these persons.

“Diakoni”, diaconia, is in Sweden a well-known concept in the Lutheran church, now called the Church of Sweden, and refers to a deacon or deaconess, a church social worker, which is a profession with roots reaching back to 1848 [Nationalencyklopedin, 1995: 282]. The main education for this profession in Sweden is found at Ersta. In other Christian churches the equivalent title is usually “church sister”; in their case the most common field of work is among older people, making individual home visits at ordinary homes as well as at retirement homes. They commonly offer devotionals as an “activity” at care homes, which are free for anyone to take part in.

Often they have an organized volunteer group for this work. It can also be the priest or pastor instead of or together with the deaconess. Other areas of specialization include counselling during terminal care, providing help specific to the fu-

neral and often the leading of *grief groups* following the funeral (see for example Grassman's & Whitaker's analysis of these two settings, 2006).

Taking both terminal care and the whole stage of later life into account, it is clear that this is a very complex subject to study, both in research and in practice. Similarly it is a unique time in each person's life. In what ways does the education for care workers meet these challenges? Let me just mention a project that has been related to Linköping University, as Nordenfelt (referred to frequently) was a member of that project group.

### **Educating for Dignity**

Educating for Dignity, A Multi-disciplinary Workbook, is the result of an EU project (QLG 6-CT-2001-00888) under the Fifth Framework (Quality of Life) Programme named Dignity and Older Europeans in which six European countries participated: France, Spain, Sweden, Slovakia; Ireland and the UK. The workbook is practical, aimed at care workers, and expresses the hope that it will "contribute to improving the quality of care and quality of life of older people across Europe". In its practical approach it nonetheless uses a theoretical approach to learning by reflecting on other cases. Through critical reflections on practical cases learned from contexts other than one's own, we gain new knowledge (page 3). The concept of *dignity* is a basic one that recurs throughout the whole material, and it "emphasizes the importance of the person's autonomy or integrity". This includes being empowered to live according to one's own moral principles. Members in the project, professionals in care work, talked about their frustrations when resources (time, money) hindered them from providing care that truly respected their clients' autonomy (page 5). The concept that was drawn on was *Menschenwürde* [cf Moody, 1998: 33], which is first and foremost based on *humanity*, with the necessary ingredients of *dignity of identity*, *dignity of moral status*, and *dignity of merit* together with respect for both self and others. The aim of this workbook is to of-

fer knowledge on what it may mean to be an older person in society and in care settings and how care professionals can become better able to do their work with dignity<sup>22</sup>).

### Concluding Thoughts

This article has attempted to reflect on spirituality and well-being in relation to a dignified care for people in later life (and life's end). The arena has been care settings and the actors have been on the one hand the elderly themselves, on the other hand the care workers who are there to offer the needed care in a way that should enhance the quality of life for those receiving that care.

One important point of departure is Nordenfelt's conclusion that we cannot set definite standards as to how quality of life, or well-being, should be defined. This is individually interpreted and care workers need therefore to always see each individual, as was noted by one of the participants in a Swedish culture and care study, emphasizing the importance of thinking about *who* to meet instead of focusing on *what* to do for this person.

The project highlighted the need for staff to acquire knowledge - through education, on-the-job training, and the time to incorporate this into daily work practices - very much in line with what the EU workbook for practitioners brings forth (see above). Moreover, the theoretical frame, as Simmons, among others, mentions earlier, emphasizes fulfilling the quest for meaningfulness. As human beings we search for meaning in life - this common notion is supported by research on end-of-life issues.

Spirituality, we have seen, is a broad concept, as it is closely related to existential questions on the meaning of life, which perhaps awaken more insecurity in others who are not in an end-of-life phase, as was seen in, for example, Nakashima and Canda [2005], and Fletcher [2004]. Apart from the importance of faith, trust in the Other, the Divine or God, one more aspect of spirituality has been dealt with, "the quality of a lived life, seen from the inside" [Simmons, 1998, 77].

This has been reflected on together with the meaning of the course of one's life, in research commonly labelled as "the life-course perspective", and models such as the sense of coherence (SOC) or life histories that help people interpret their lives and come to terms (or not) with the life that was theirs [cf Öberg, 1997].

The small interviews carried out to garner some fresh glimpses from the field showed that the role of the manager (director) of a special home is important to how the staff handle terminal care situations. Are there routines, is there education and knowledge available and is there someone to turn to? But perhaps, in many instances, it suffices with commonly held ethical values expressed in behaviors: listening attitudes, respect and empathy. The interviews with both Maria and Anna support that.

The dignity expressed by people in the last stage of life called for a similar response [Simmons, 1998: 75]. This citation could as well have been said by Anna in perhaps other words. To her it is a privilege to be entrusted to share the last steps of a long life. Sometimes this can be difficult for family members. Staff that has at least some distance, in comparison with families, can serve as a buffer.

Another aspect seems to be more difficult to tackle: facilitating activities that stimulate feelings and thoughts as well as physical well-being. There is much tacit knowledge of staff with regard to these matters, as was shown in the culture and care study [Anbäcken, 2002], but they expressed difficulty in bringing about a change of attitudes, saying it was too time-consuming, for example. Perhaps also the culturally embedded notion that "soft" matters like spirituality should be left to privacy (and experts perhaps). Life histories have been suggested by Anbäcken and Dahlgaard [2005] to be used more "spiritually", though we did not explicitly use this word as we saw it as a tool to enhance quality in elder care. If these personal life stories are really used and followed up on, quality in the care ought to improve in general, as we stated, but they could also give rise to talks on life and what is meaningful to the person in question.

Old age care is one of the themes that gerontologists study, although gerontol-

ogy, as different from geriatrics, mainly focuses on normal aging. Still, both in Japan and Sweden, as soon as the term elderly<sup>23)</sup> is mentioned it seems to be synonymous with care. The focus is instantly on care needs. The majority of these “elderly” are healthy - we tend to forget that. Moreover, those elderly in need of care are fully human with needs that transcend those of care! Questions on life are not limited to any specific age. Nevertheless, perhaps questions on how life developed is a more pressing issue the older one becomes.

In academic writing an important characteristic is critical reflection. It would take another empirical study to put to test some of the literature findings I have referred to and reflected on here. While there are some studies on this theme the everyday practice of care seems not to be thoroughly informed by these, at least not in Sweden. It would therefore be challenging to study some of the issues brought up here, in a community research and development project from the point of view of the elderly, their families and the care staff.

### **“Desire to Live - Courage to Die”<sup>24)</sup>**

One of the headings on a web site on Elder care caught my attention: “Lust att leva-Mod att dö”, “Desire to live - courage to die” ([www.erstadiakoni.se](http://www.erstadiakoni.se)); my translation). This could, in a nutshell, describe the essence of what this study has found as a result of the empirical findings of others as well as from my own experience. It encompasses an everyday life perspective of here and now precisely because it recognizes the spiritual dimensions of life. The latter guarantee that the quest for the meaningfulness of life, that in one way or the other, has followed the individual throughout the course of his or her life should not be avoided in later life but instead is allowed to inform it; in care as well.

#### **NOTES**

- 1 ) Care is here limited to that which is outside medical care at hospitals. Care at homes for the aged and at home is targeted, see below.
- 2 ) In cross-cultural comparative studies Anbäcken has found that it is of crucial impor-

tance to carefully analyse concepts such as care and needs, as they may connote differing meanings [cf 2004, 2005].

- 3 ) “Special housing” is a translation of the Swedish term “Särskilt boende” which includes all care institutions that municipalities are in charge of, both those directly run by them or those contracted to private providers of care. None of these institutions are in the medical sector and there are no geriatric hospitals, only geriatric wards. Special housing encompasses nursing homes, homes for the aged, service housing and group homes for elderly persons suffering from dementia.
- 4 ) Since comparisons with Japan in this respect automatically comes to the fore of my mind, it could partly be interpreted as being due to the fact that volunteer activities are not integrated in care work in the way it is in Japan. Perhaps the case in Sweden could rather be interpreted as the way to treat any volunteer activity; it is not integrated in the staff’s world but is seen as a parallel and supplement of a different kind?
- 5 ) My father’s Christian faith was well known to the staff and I think they felt safe and relieved: they could leave spiritual issues to his family. The way they let us know that there was no urgency, I think, helped us to spontaneously arrange an informal memorial service we had with the family only. It took a couple of hours to gather us all, but we felt no stress and it was an unforgettable moment when Mother, the children and grandchildren had gathered around his bed, in their care home apartment, later that day, thanking God for my father’s life, thanking God for my father’s being at “home” now.
- 6 ) From my personal viewpoint, which is spirituality from a Christian perspective, much more could be told and discussed since not only the identity of man but also the identity of God and the relation between God and man need to be considered in such a discussion. I thus agree with one of Simmons’ descriptions of spirituality, mentioned earlier in this article, as intrinsically and intimately related to a personal God and that spirituality then is explained as a relationship of the human person with God [Simmons, 1998: 77].
- 7 ) Perhaps the explanation offered to one of the questions reflects what is commonly referred to as spirituality in the post-modern society: “While some of the questions will use words such as spirituality please answer them in terms of your own personal belief systems, whether it be religious, spiritual or personal [WHOQOL-SRPB, 2002: 20].
- 8 ) Nordenfelt is an international authority in the philosophy of health and illness. It would be interesting to go into greater depth with reference to his philosophical reflections on what health is and is not, what happiness is and is not in relation to the loss of functions in late life (see, for example, Nordenfelt [2001]).
- 9 ) “Att Ha Att Älska Att Vara” [1975] is the Swedish original title which I translated to Having, Loving, Being. Allard further discusses the Nordic model of welfare which dis-

- tinguishes between a figure in which he treats “life-level” and “life quality” as separate elements in relation to the concepts of welfare and happiness [1975].
- 10) In this article the term life-course often appears. Sometimes it is written of as the course of one’s life, her/his life, depending on the context. In research on aging and care the term life-course is commonly used as a concept addressing aging as a continuous process in life and in which persons construct their life stories (for example, Öberg [1997]).
  - 11) Erikson’s developmental theory of eight stages are not referred to directly here, but referred to in Tornstam.
  - 12) It was co-published simultaneously as *Journal of Gerontological Social Work*, Volume 29, Numbers 2/3 1998.
  - 13) For a full analysis and discussion on this rich topic, I recommend the whole chapter [1998: 13–72].
  - 14) Moreover, another author’s work came to mind, a book with the expressive title “Soul Pain; The Meaning of Suffering in Late Life” [Black, 2006]. Susan Black takes another view of this subject by listening to older adults’ narratives of suffering and she concludes that, for them, suffering is a part of the course of their lives. On the other hand, this does not make them uncritical, they can at the same time analyse, in terms of political language, inequalities they have experienced. I must confess that I have not yet fully read this book, but what little I have read so far inspires continued reading.
  - 15) Belzer [2004: 163] hints that Eisenhandler’s chapter on faith in long-term care settings contrasts the experience of faith between those in and outside institutional care settings, and mentions specifically that a “sacred space” is developed in care facilities.
  - 16) They were fundamental Christians, Catholics, liberal Protestants and Jewish believers [Fletcher, 2004: 171].
  - 17) “Livet som berättelse” [1997] is the original title, which I translated into: “Life as a narrative”.
  - 18) Hospice as a specific institutionalised form of terminal care, will only be mentioned here, as the inspiration or even idea behind the terminal care concepts that have been developed. What is interesting here is that in 1989, when demographic aging and the problems commonly ascribed to that, was not yet headline level, Levy’s article on “The Hospice in the Context of an Aging Society” foresaw the future problems with more elderly and less economic resources for the care. There is also research which voices some criticism to the hospice ideology on the ideal death risking to hide the fact that “each person has to die in her own way”, as Rinell-Hermansson expressed it [1990: 49 in Forssell, 1999].
  - 19) The interview was free and conversational [cf Patton, 1987] and it was explained as

an opportunity to talk about these matters, for this article and for a possible future study.

20) Whitaker's study [2004] is written in Swedish but with rich summaries of each chapter in English providing both an informative and a well-analysed piece of research that is clearly limited to a Swedish context. Here nursing home life is spoken of from the perspectives of both elderly residents and their families, facing or perhaps in most cases experiencing the dying process. The striving for dignity was one of the landmarks characterising the efforts of the families in the midst of the physical decline of their loved ones. The triangle drama in which three parties are involved, the elderly residents, their families and the care staff further adds to questions regarding meaningfulness of life, until its end.

21) Quotations are not verbatim, as I did not record our interviews.

22) Hopefully this is being translated into Swedish and the other native languages in the project; I otherwise doubt that it would be used in the education or practice of care.

23) The careful reader may have noticed that I have used different terminology for "the elderly", avoiding this term, in fact, as it is seen as ageist when it is used to classify a group of people. Depending on the context the words used are elders, older people - and elderly.

24) Needless to say there is much literature that I have not had the chance to read yet, nor even glance at. What I can say from the limited search I have done is that while there is a certain area which focuses explicitly on spiritual aspects on aging, there are many connections to make between, for example, more traditional (Q & L) studies on how elderly experience Home Help Services or how everyday life at homes for the elderly can harbour each individual with her or his life histories, from joys to sorrows, and include religion and/or philosophy of life.

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Spirituality is something that's talked about a lot but is often misunderstood. Many people think that spirituality and religion are the same thing, and so they bring their beliefs and prejudices about religion to discussions about spirituality. Though all religions emphasise spiritualism as being part of faith, you can be "spiritual" without being religious or a member of an organised religion. What's the difference between religion and spirituality? Spirituality recognises that your role in life has a greater value than what you do every day. It can relieve you from dependence on material things and help you to understand your life's greater purpose. Spirituality can also be used as a way of coping with change or uncertainty. What can I do now? What is spirituality? And are you spiritual but not religious? Spirituality involves connecting to the Divine through your own personal experience ... You need to be able to really feel what spirituality is in your bones in order to find a genuine spiritual path that truly helps you. For me, spirituality is a direct experience: it's not a belief, it's not a compartmentalized practice, it's something that I strive to actively live and experience in everyday life. To me, spirituality is about growing up and waking up. It's a uniting, present-moment force. It's about finding out who I am and moving beyond all labels. Spirituality is a broad concept with room for many perspectives. In general, it includes a sense of connection to something bigger than ourselves, and it typically involves a search for meaning in life. As such, it is a universal human experience—something that touches us all. People may describe a spiritual experience as sacred or transcendent or simply a deep sense of aliveness and interconnectedness. How can I live my life in the best way possible? Experts' definitions of spirituality. Religion and spirituality are not the same thing, nor are they entirely distinct from one another. The best way to understand this is to think of two overlapping circles like this: In spirituality, the questions are: where do I personally find meaning, connection, and value?