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Existential issues in later-life care, a Swedish case study

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> "Once you learn how to die, you learn how to live" (Morrie, in Albom 1997: 82)

Introduction

The need to address existential issues in care contexts has recently received some attention in Swedish studies on aging and later life (for example Whitaker 2004, Jeppsson-Grassman and Whitaker 2006, Forssell 1999, DeMarinis 1998, Anbäcken 2006[1]). However, in day-to-day care it is perhaps not such a hot topic. Perhaps it could even be labeled as taboo, in the sense that there is no place to seriously address and talk about it. I would say that palliative care is the main channel for issues regarding care at the end of life, regardless of age. And within palliative care, existential issues (or spirituality), though clearly within the definitional domains of palliative care, seem to be found in the margins. Hospice care and existential care are two concepts that go together well, while the more ordinary arenas of the common nursing homes for older people in Sweden — and in Japan — are not generally characterized by the awareness of these sometimes intangible aspects of life-and-death issues. Nonetheless, palliative care has entered the scene in the practice of eldercare, as terminal care is now carried out as part of total care that is given at nursing homes and residential care homes for elderly in Sweden. Many municipalities (as well as private providers of care) offer care staff training (in various degrees) in terminal care and palliative care (for example in Linköping). The focus, however, is more on the physical and psychological aspects and, again, the spiritual aspects are dealt with cursorily.

Thus, while palliative care, by definition, explicitly includes the spiritual needs of humans as to be met in a triad of physical, psychological and spiritual (Forssell

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1) The National Board of Health and Welfare found in 2007 that around ten studies had been done in Sweden with focus on the last phase of life for older people.

1999), many studies bear witness to spirituality being either excluded or not as clearly handled as the other two. Why is this so?

This article will address this question through an empirical case study performed in a small to middle-sized town in the south of Sweden, mainly during the year 2006. It will also include a selected literature review. The focus is later life (elder-care) but with regard to definitions it also borrows from studies on spirituality in palliative care. The empirical study is thus central, and some questions that have emerged from it are dealt with in relation to a limited amount of literature.

When is the last stage of life?

This is a question that pops up in the whole context of palliative care issues. As this article focuses on later life, or old age, it is still not sufficiently defined. Do we think of the very last days at a care home for "elderly" or could the move to such a setting be seen as the last stage of life, i.e. being the last home? Can we go back one step and define short stay or respite/recurrent care as the threshold to the end of life? Perhaps these need to be described. Short Stay is usually a unit within a nursing home for elder people, a unit where no one stays permanently, usually up to three months, while being either assessed or waiting for a permanent residential care home. Here it is common to share rooms, two-bed rooms, while in permanent residential units the most common model is a one-room flat cantered around a common dining room cum kitchen, usually for ten residents. Respite or recurrent care is usually used by spouses, when one spouse needs increasing care and the other needs some rest. It can of course also be used by single elderly when children cannot cover up in between home-help services. The pattern can be two weeks at home and two weeks at the short recurrent care unit (which in the case of my study was a part of the short-stay unit).

Thus it is more of an intermediate step and not necessarily the final move. It is still a distinct step marking that the aging ahead most probably will take a different turn than aging in place. However, the paradox might be that perhaps the aged resident, after the move to the care home, feels that present time, daily life here is central and that thoughts concerning death and dying and the very last days to come here do not take over but could even be in the margin (although this may fluctuate). Another perspective could be that, although the new resident would like to talk about these issues, he or she feels that it is not a common subject. A third factor can be next of kin, diverting conversations away from such topics by focusing very much on the move, on how nice the room or the setting is, the meals or the staff, etc.

LITERATURE REVIEW

Spirituality and existential issues

In this article the focus is on care at the end of life, in old age. Thus, the vast field of palliative care research, which concerns end-of-life care, mainly in the case of cancer or terminally ill persons, is not included, apart from two articles that deal with definitions of spirituality and one (Sand 2008) which points out aspects that I have also noticed in later-life literature. I am aware that a joint analysis of general palliative care and palliative care in eldercare might have added new perspectives and dimensions, as is often the case when crossing borders and fields. The aim of this article, however, is to discuss existential issues in later-life care, hence the limitation. I also address the concepts of spirituality in relation to existential issues. In this I am aware that there might be some discussion going on regarding any differences between these two. Here I simply address the issue as I find myself more comfortable using the concept "existential issues", not the least in this piece of work, as the term spirituality was not used either in the task I was given or in the interviews. Another reason is that spirituality cannot be referred solely to the WHO definition (which most studies in palliative care seem to be based on), as within theology there are other dimensions of spirituality than the broader definition of spirituality that WHO has founded. Existential issues I define broadly as pertaining to man's quest to find meaning in and of life, for oneself and for mankind.

Chochinov and Cann (2005) provide both an overview and an analysis of the state of the art of spiritual aspects of dying. They take their point of departure in history and the Cartesian dualism of separating body and mind, the body belonging to medicine and the spiritual realm to the clergy. Suffering thus was to be understood as mainly physical. Today, however, studies on death and dying take spiritual pain seriously. Chochinov and Cann describe the changes in medical schools in the US, how spiritual aspects have entered the curriculum markedly in the last ten years. They also look at spirituality from patient as well as care-provider perspectives. However, death in old age is not specifically focused on. Various studies show that patients expressed spiritual or existential needs, to be treated as whole persons. While many would like doctors to talk to them about spiritual or religious beliefs, busy professionals make many hesitate. Respect for patients, their need to be met as whole persons in combination with a partnership model in which respect for patients' values and beliefs is fundamental, paves the way for a more integrated spirituality within the medical field, it was concluded. The authors go on to examine what spirituality is. They found 92 (!) definitions of spirituality but managed to boil these down into seven categories of "definitional themes" (ibid., p. 106):

1) Relationship to God, a spiritual being, a Higher Power, or a reality greater than

the self
2) Not of the self
3) Transcendence or connectedness unrelated to a belief in a higher being
4) Existential, not of the material world
5) Meaning and purpose in life
6) Life force of the person, integrating aspect of the person
7) Summarizing definitions that combined multiple themes

Puchalski (2008) further discusses the concept of spirituality, tracing it back to its roots. In Latin *spiritus* means breath or breathing (ibid., p. 36) and in Hebrew *ruah* means the breath of God, and in the story of creation in the Old Testament it says that "God formed man . . . and breathed into his nostrils the breath of life; and man became a living being" (Genesis 2: 7). Further, she models a theoretical framework of spirituality which I find interesting and easy to follow as it sorts the concept into themes that make it possible for a definition of spirituality from many perspectives without trying to make compromises to fit everything in.

I therefore use it and quote her model in the table below (Puchalski 2008, p. 37)

Table 1 Definition of Spirituality (Puchalski 2008, p. 37)

Essence	The core of one's being, the source of one's humanity, a way of being and experiencing life that comes through a transcendent dimension.
Meaning	Ultimate meaning — that which defines in relation to a transcendence, sacred or divine. Meaning in life, gives purpose.
Transcendence	An awareness of something greater than oneself; sacred, divine, God, higher power, energy, force.
Relationship	Connection to self, others, God, sacred, nature
Values	Beliefs, morals, standards that guide one in life; experiential appreciation of beauty, love, nature.

Literature addressing later-life care and existential issues

My first work with the direct purpose of focusing on existential needs in later life (2006) set me on a journey where I retrospectively picked up existential issues from some of my previous studies. One such was on the meaning of "culture" in the daily life of eldercare, another on how life was experienced and viewed when one's spouse was placed in an institution, a third on elderly care home residents' narratives of aging and life; all this seemed to fall into place in a framework within which I could use the overarching concept of existential issues. Man's drive for answers to existential questions became the searchlight. Some conclusions from the work were that:

1) Existential needs are sparsely encountered in Swedish residential care settings,

while palliative care is increasingly common as terminal care takes place here.

2) Such needs are acknowledged by those staff, including heads of staff, who are concerned about the issue.
3) American studies show that the topic seems to be addressed more in the US than in Sweden, but whether it is hospital settings and hospices that are the main target or if it can be said to the same extent about residential homes for the aged remains a question to be answered. Still, religious issues, church attendance etc. are generally more "mainstream" in USA than in Swedish society, although churches are allotted certain residential care facilities to visit with short church services and devotions in which singing hymns together is a part that is highly appreciated by many (though perhaps not all).
4) Staff need training to be able to provide this kind of space where residents feel safe and that it is all right to talk about existential thoughts, not only joys but also sorrows.

From the literature in the article mentioned above (2006) I will summarize parts that are relevant for the present study and which fit with definitions of spirituality in aging contexts. Some new comments are also added to this.

Simmons defines spirituality as "the quality of a lived life, seen from the inside" (Simmons 1998, p. 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". Simmons sketches two spiritual perspectives as pertaining to religion. He 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 then explains spirituality as a relationship of the human person to 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., p. 78); perhaps this could be paraphrased as how humans develop wisdom gained from life. 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., p. 79). How are these people handled by the care staff in residential care facilities? This question was asked both in the article (Anbäcken 2006) and in the project which is in focus here.

Simmons continued the discussion of how nursing homes as communities can develop, offering a view of human beings as developing, growing throughout the whole course of life — including the last stage, lived at a nursing home. 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 for meaning (instead of just encouraging the residents to be cheerful) is needed (ibid., p. 87).

A contrast to Simmons' description can be found in Whitaker's (2004) ethnographic study of "life's last abode", in which she found that a substantial part of the days was guided by the chronological order of each day, characterized by a constant state of waiting, for the next meal, for a bath, for bed, for the end (ibid., p. 85). A question that arises when relating these two studies to each other is: How can practical daily needs and existential needs be met in the everyday life of the nursing home? Are these practicalities of daily life to be theorized as "existential conditions" of "time, space (place) body and dignity" (ibid., p 238)

Angrosino concluded from his review of Thomas and Eisenhandler 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, p. 374). Spirituality is thus interpreted as the fundamental component in personal growth and maturity during the life-course.

Fletcher concluded from the narratives on the religious beliefs 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, pp. 182–184). Those 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. Fletcher (as I interpret her) concludes from her qualitative study that, while religion informs life's meaning in old age, there are differences as regards the ways this is due to faith as such or faith as a social experience (ibid.).

Another perspective is taken by Langer (2004), viewing the strength of resiliency and the spirituality in counseling older people, proposing "strength-perspectives counseling". Here again the definition of old age as a period in life in which the individual uses her/his accumulated and internalized life wisdom to handle the challenges of later life, is in focus. Langer contrasts the traditional negative views of life in old age, with losses of all kinds, from functions to friends, and the fact 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 also common in Swedish care facilities. All residents are interviewed (briefly or at some length) about their life history so that staff are given a broader and deeper picture of each person, his or her dislikes and likes. These could indeed be useful tools to channel spiritual needs in a way that care staff can handle.

Of the five themes Langer brings up to describe a successful adjustment to aging, I pick up three: first, the ability to balance joy and sorrow throughout life; secondly, to accept that there is an existential solitude; and thirdly, to find meaningfulness — that life has a purpose (Langer, 2004, p. 612). Here it is fitting to add Frankl's (1986) emphasis, 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 in line with what Öberg concludes in his PhD thesis on "Life as a Narrative" (1997), based on numerous life-history interviews. He sided with many gerontologists who view older people in the context of their lived lives, the historical setting with shared events (such as a world war, certain politicians, authors, music, etc.) and also the values and goals that have guided them in life.

With this summary concluded, we move on to some other studies. Hagberg (2002) outlines the meaning of the memories of the life lived as he analyses and discusses how reflections on the life course may add positively or negatively to well-being in old age, with regard to existential issues. He outlines a model for life-course studies and makes clear connections between childhood/youth and how old age is experienced, concluding that our aging is both a product of the life we have lived and the person this life has molded. In this he also notes that cohort effects should not be disregarded, thus aging at a certain time in history. Coping is also related to this, since the rapid changes we live with mean that well-being is very much about how well we cope with these changes, to what extent we can sense coherence, referring to Antonovsky's SOC model (1993). Hagberg concludes that "a successful life course would then mean that during the different stages of life we acquire trust, autonomy, ability to take initiative, creativity, strong identity, ability to intimacy, generativity and integration" (ibid., p. 73, my translation). In later life, then, if we have a sense of coherence when looking back on life, especially regarding the factors trust, autonomy and intimacy which are important for the totality of SOC, later life can be experienced as meaningful and manageable (ibid., p. 75).[2] Hagberg ties this discussion to existential issues. If meaningfulness is understood in relation to experiences of trustful relations to persons that have been important to them, and if they dare to have a reflecting attitude, this can lead to a deeper understanding and will to encounter existential issues (ibid., p. 76). Life-history studies give evidence that people quite often relate to earlier experiences and that these past experiences in this way are present here and now in our lives. While Hagberg includes negative as well as positive aspects of looking back, in old age, instead of

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2) Hagberg claims that this is well in line with both Antonovsky and Erikson.

the "anti-Butlerian" view that nostalgic dreams alienate from reality, he uses Butler's argument that through this, former problems and conflicts can be re-regarded and integrated into the understanding of our selves. Another aspect which I would like to link spirituality is that this recasting of life experiences has a moral/ethical dimension. The individual values his/her life, finding perhaps not only that it was "good" but encounters mistakes which can involve feelings of sorrow, guilt, shame. To be given the chance to reconcile, to be able to find peace in the existential issue of one's own life in relation to others and also to life universally, this is part of what spirituality is. This state of mind when one is willing to encounter the deep questions of life's meaning is crucial for well-being. Finally, for the practice of eldercare this kind of life-course reflection can mean continuing to interpret one's life and to reach new understandings of the past (ibid., p. 80).

Okamoto (2006) has carried out a study of spiritual needs of elderly people in nursing homes in Japan, and focuses on the quest for meaning of life. The question he asks is how we can encounter the spiritual pain felt by those nursing home residents that feel they have lost their purpose in life. While a great many other areas of care are secured, as long as spiritual pain is not being confronted there may be an existential vacuum. He refers to a PIL test (2006, p. 100) which is based on logotherapy (from Frankl 1991), the *will* to meaning as a driving force. This Okamoto finds to be revealed at nursing homes if the residents in their late life are given the chance to fulfill their need to search for meaning (ibid.). He goes on to say that this process may include reconciliation, coming to terms with life.

The "slow death" was a definition that caught my attention in the review of the National Board of Health and Welfare of studies on terminal care for older people in Sweden (2007: 37). This "slow" death as one distinctive determinant of life and death in old age can be linked to one of the conclusions in the review, that the philosophy of palliative care needs to be adjusted to and realized at care homes for elderly. It entails other aspects than palliative care in other life stages. Summing up the review, the following was found to be important here: conversations and fellowship, to be able to participate in the ordinary "trot" of life as far as possible, to be given the opportunities of self determination in the midst of dependency. Moreover, dignity and "ordinariness" of daily life seem to be interwoven. The role of philosophy of life matters, so that those who have a positive view on the future and a deeply rooted faith (regardless of which faith) more often felt secure. The importance of telling ones' life story was underlined in many studies and contrasted to findings showing that older people often are left alone with their thoughts (2002, p 49–51). The review concludes that there is a need to talk about existential issues and about ones' life, both past, present and future with the elderly, and that the content of the care and of the everyday life should support meaningfulness and dignity (ibid, 2007).

I close this part with a very recent study, which, while not focusing on elderly, brings up some aspects of existential issues that are useful in the discussion of my study. A recent PhD thesis on existential challenges in palliative care, by Lisa Sand (2008), arrives at a conclusion that supports the view that the body is important, that it in fact is an "existential aspect". Indeed the body harbors the existential existence (Sand 2008). Here she sides with Simmons (1998), mentioned earlier, who talks about embodied spirituality (see also Hudson 2006, below). Sand further emphasizes the physical loneliness, the need to be touched, something which studies on aging and especially dementia also underline and use in introducing, for example, tactile massage as a way of communicating and comforting beyond words. Another finding in Sand's study, which to me is very much an existential matter, is the loneliness she perceived as present at the end of life. Without empirical findings of my own, I dared to bring up this aspect (2006) with reference to Moustakas (1961), who speaks of an existential loneliness which is intrinsically interwoven with our existence as human beings.

Aging, spirituality and palliative care

In this section I have chosen an anthology which has its specific focus on aging while looking at spirituality and palliative care. This volume was co-published simultaneously with the *Journal of Religion, Spirituality and Ageing*, Vol. 18, no. 2/3, and 4, 2006. However, I do not go through all the chapters, I have picked up a few of the contributions, and some in more depth, inasmuch as I will relate my case study to these.

I am attracted by the title of *Rosalie Hudson*'s chapter "Disembodied Souls or Soul-Less Bodies: Spirituality as Fragmentation" (2006, pp. 45–57, which offers readers a vast existential issue to ponder. The author discusses this from a Judeo-Christian biblical understanding (while not denouncing other religions) and asks questions such as "Has the new spirituality pushed religion to the margins?" and What happens to our humanity when we separate soul from body?" (Hudson 2006, p. 49). She is concerned about the way spirituality in eldercare may be reduced to assessment forms which are used by professionals who do not always have the sensitivity and maturity to use them in a wise way, and states that "Spirituality is not a diagnostic category based on facts to be processed; spirituality involves the story of the persons' life. . ." (ibid.). In my search hitherto for literature on spirituality and care in later life, Hudson's article is the first one I encounter that includes a Christian theological analysis which, while being clear on this (and critical of religious reductionism), also states that it has "application for people of all faiths and no faith" (ibid., p. 53) as Christianity's task is to answer existential questions as "Who am I?" and "Who will accompany me on life's journey and to whom may I be a companion?" (ibid., pp. 53–54). She goes to the very roots of Christian theology and writes that "The resurrection claim is that we will be known, not in some vague floating spiritual essence, but in our full-bodied humanity. While the mystery of cross and resurrection remains the subject of faith rather than sight it is evident from Christian theology that the soul is not a separate entity, superior to the body" (ibid., p. 54). Thus Hudson's terminology of "embodied souls and ensouled bodies" (ibid., p. 54). At the end of the article Hudson ties all this into the practice of care where, when entering another person's stories, we encounter "the heart and soul and body of human care" (ibid., p. 56).

In "Spiritual Care: Recognizing Spiritual Needs of Older People" (2006, pp. 59–71) *Elizabeth MacKinlay* addresses this issue in relation to a friend, Bryden, whom she follows on her journey into dementia with a diagnosis at 47 years of age. As dementia is often characterized as loss of oneself, the words of this friend show that it can also be an inspirational journey: "At the centre of our being lies the true self, what identifies us to be truly human, truly unique, and truly the person we were born to be. This is our spiritual heart, the centre from which we draw meaning in this rush from birth to death, whenever we pause long enough to look beyond our cognition, through our clouded emotions into what lies within" (Bryden 2005, p. 163, in MacKinlay 2006). Bryden also expresses worries, realizing her condition will worsen and she may become bedbound and no longer able to communicate with her daughters, and the anxiety accompanying these thoughts. "There is a need to understand death in the context of life" (2006, p. 61). MacKinlay further elaborates on the concept of spirituality as "core meaning, deepest life meaning, and relationship; for many people this is worked out in relationship with God and others; for many others, there is no relationship with God and others, but relationship with others become primary" (ibid.). She goes on to state that religion is part of spirituality for a number of people, but spirituality is more than religion, it is a part of all human beings (regardless of religion), just as it is acknowledged that we all have a body and a mind (ibid., p. 63). The problem is that it is far from equally regarded in the care sector. She goes on to refute three common assumptions that care staff may have, based on their own understanding (or sometimes lack of it, I would add). Greatly simplified, these are that if a resident is an active church member, then spiritual needs are met, while a resident who is not a churchgoer is seen as having no spiritual needs, and thirdly that if a person has dementia it means that she/he does not have any spiritual needs (ibid., p. 66).[3]

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3) In an American context it might be easier to categorize like this, while in Sweden church attendance can no longer be used as a comparable yardstick, although of course it is still applicable to a large number of people in later life.

This leads on to reflections on how care staff talk to residents, what questions they are asked. A Swedish PhD study addresses this issue in a similar way (Wadensten 2003) borrowing Tornstam's theory of gerotranscendence (2005). Here, spirituality as a concept is not common, the focus is on transcendence, wisdom of life and it is clearly situated as part of aging and later life. What I found uniting these two concepts, gerotranscendence and spirituality, is the consequences these ought to have in the daily settings of care in later life: are these elderly persons regarded as having existential needs? Or do care staff mainly address physical and material needs, of the body and of the environment (meals, hygiene, medicines, cleaning and laundry)? How often do staff sit down with a crying resident and take time to listen to griefs, sorrows, frustrations? Wadensten studied the process when nurses tried to use the theory of gerotranscendence in their practical care work, as she had found that very little of theories on aging seemed to be used at all in eldercare (ibid.).

Ann Harrington (2006: 169) carried out an ethnographic study of nurses' encounters with patients and their families with the aim of seeing whether a previous model of "spiritual care" was useful and whether a better one could be developed. As with Wadensten (2003), this is thus an example of intervention studies in which models/theories are tested in practice. These result in a pronounced need for education of care staff working with older people. Harrington finds, for example, that spiritual care includes communication with patients about "issues of life's meaning, strength or hope in illness (ibid., p. 182).

MacKinlay offers a model in which aging spirituality in later life is seen as a continuing process. "Meaning is at the centre of what it is to be human" (2006, p. 67). She goes on to describe how in old age and near death some find God at the centre of their being while others find other relationships to be the core. Finding "final life meaning" that transcends loss and in which one achieves new intimacy with God/and or others cannot merely be captured in whether someone actively goes to church or not (ibid., p. 67).[4] I find it useful to relate my own empirical findings to her conclusion that really has practical implications for eldercare: "if we neglect these [needs] especially for people at critical points of their lives and for those who are facing their frailty, dying and death, then we neglect something equally important as failing to provide food and cleanliness to aged care residents" (ibid., p. 69).

Using my Swedish-Japanese "cross-cultural comparative research glasses", my interest was caught by one of the chapters in the volume, from a theological point of view. *Ruwan Palapathwala* analyses and discusses "Aging and Death, a Buddhist-Christian Conceptual Framework for Spirituality in Later Life" (2006, pp. 153 ff.). While going into quite some depth on basic notions, especially *anatta* (no soul or

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4) See the previous footnote.

no-self in Buddhism) and *pneuma* (spirit in Christianity),[5] he argues that the spiritual quest "comes from the More in us which is the dimension of true self-*anatta* or *pneuma* — the Seat of the Divine" (ibid., p. 155). Moreover, this quest forms the basis of spirituality. Palapathwala's definition of spirituality is "our transcendental awareness about the "more" in us which seeks progression in and through our quest for "where from" and "where to" (ibid., p. 155). The scope of my review here does not allow space either to follow his theological analysis of spirituality and the Buddhist-Christian view of human life or his further analysis of the self, soul and spirit. My point here is his suggestion as to practical outcomes of his proposed framework for spirituality in later life, based on his conclusion that the concepts of *anatta* and *pneuma* are important "to understand the conditions of human existence — aging, suffering, and death — and the place of spirituality in life generally and in later life specifically" (ibid., p. 165). Three areas in later-life care are addressed: In an increasingly materialistic and consumer-oriented society, pastoral care needs to take a broader perspective of human life and the aim of human life. The need to accept "suffering as an ingredient of human existence", in both Buddhist and Christian views of what human life entails, aging, suffering and death are real aspects of the conditions of life. This gives the strength to accept — not deny — these as elements in life. Thirdly, spirituality in later life should not be seen as a consumer "product" (ibid., p. 166). He describes in terms that to me are very close to those used in life-course perspectives , such as Öberg (2002), of the kind of understanding "in the light of one's total experience of life" (Palapathwala 2006, p 166) but in this with emphasis on the acceptance and participation in the experience of aging. Another line of thought which is similar to that intrinsic in the life-course perspective is that the spirituality which should guide you in later life is a mature spirituality that has continuously sustained you from young years onwards. Thus, it becomes crucial that care staff can encounter the aging person in his or her spirituality, to accept life in all stages until the last breath (ibid., p. 166).

Reaching the last part (3) of the collection of articles, I have chosen to review one that is very close to my own study. *Linda Kristjanson* (2006: 189) shows that in residential homes for older people, a palliative approach to care is indeed relevant, specifically that aspect which deals with spiritual needs. She goes on to define palliative care in terms of WHO's definition, that palliative care is based on a positive (life-affirming) attitude to death and dying and that physical, psychological and spiritual needs should be equally met. Kristjanson takes Australia as a case and observes that there is a clear increase of dying and death taking place at residential aged care facilities (ibid., p. 191)[6].

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5) Both *anatta* and *pneuma* in Palapathwala's text were written with a macron on the last a.

What further caught my interest is her view, which I share, that there are some broad challenges unique to this group, persons at the end of life, who more often than not experience the final stage of life as a normal part of the aging experience (though for some aging and terminal illness amalgamate). They often experience cognitive changes, a potential loss of dignity and worries about separation from beloved ones. For care staff this may be felt as a challenge with uncertainties, how to encounter the persons with individual needs pertaining to spirituality in the midst of these three areas of "worry". Kristjanson goes on to emphasis dignity as central in spirituality and palliative care contexts, as dignity is very closely interwoven with the sense of meaning and quality of life (ibid., p. 195). Moreover, since dignity can mean different things the only way is for care staff to talk about what it means with each resident. She discusses dignity both in terms of how persons look at themselves and a variety of feelings connected to that (among others she mentions their way of making sense of things, maintenance of pride, self-esteem, hopefulness, acceptance and resilience) and as regards needs of practices such as prayer, meditation and taking one day at a time (ibid., p. 196). Social dignity, such as privacy but also worries about perhaps leaving things unfinished for one's family to take care of, were seen as important to address. Another area is bereavement support, for residents who experience the death of neighbors in the residential community, for residents with dementia, and also bereavement support for family members (ibid., pp. 198–199).

Finally, the specifics of spiritual support were discussed, resulting in practical advice on how to implement this in residential care facilities for older people. Silent support, liaison and active listening were brought up as important channels. Silent support means being there in a non-judgmental way, liaison means facilitating for services requested by residents, such as chaplains or other counseling care workers, or families and friends but also that worship ceremonies can be held, that certain music or other multimedia material is available and not interrupting during spiritual activities. Ultimately, active listening means listening to both body language and actual words, and perhaps providing confirmation (ibid., pp. 201–202). The need for multiprofessional teams so that residents and families are in a real sense able to express their individual spiritual needs is mentioned in the guidelines which conclude her study. Her closing words on "our capacity to remain engaged" (ibid., p. 203) are words we will come back to in the discussion of my findings in a similar empirical setting in Sweden7).

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6) This is very much the case in Sweden as well, while in Japan the resident is more often brought to the hospital for the very last stage of terminal care. Thus the eagerness and haste to work for more palliative care in these settings may vary.

With this we will enter into the case studied by this article.

How it started, the task and research question

The idea of the research and development project "Quality and meaningfulness in eldercare — on giving room for 'life questions' in care, from the perspectives of care receivers, families and care staff" was processed in early 2006, from the municipality X and the higher education centre in X and myself (as sole researcher). As the municipality wanted to develop quality in short-term care facilities, the main empirical setting was two short-term care (including recurrent care) centers, but also the long-term residential unit which was located in the same facilities.

The whole study, from planning to the final educational workshop for the staff, took less than two years. The empirical study was carried out from September 2006 until March 2007 and the report was published in January 2008.

The overarching research question that the whole study was based on is as follows: Do existential issues have any space in the everyday life of care, and if so, how, in what ways? What are the needs? What can be developed?

The setting

The "field" was the short-term unit (in Swedish *korttidsboende*, "short-stay accommodation") of this municipality, organized in two localities. At one of these two (the bigger one) there was also a permanent residential unit. As systems vary internationally I will briefly describe what "short stay" (as I will hereafter call it) means in Sweden. In most cases it is a waiting unit, often located at nursing homes) where older people, either after a hospital stay or with a deteriorating physical or cognitive function, can stay while being assessed for, or waiting for, a move to residential care home. Often there are special rooms within the short-stay unit which are designated for respite or recurrent care. This means that a person stays there usually for two weeks, returns home, which in most cases means home to the spouse, and stays at home for two weeks, thus "recurrent" care.

The first step to entering the empirical setting was the letters of information to those who volunteered to be interviewed. A letter with similar content was distributed, by myself, to the guests/residents as I spent a couple of days visiting. A letter to their next of kin was also left visible in the room. As for the staff, the information was given through the head of staff, and their interviews happened last after the others were done (a deliberate choice so as to minimize risk of influence). Categories and the interview persons are as follows:

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7) The literature reviewed in this article should first and foremost be seen as a sounding board to the empirical findings.

1) Guest at short-stay or respite/recurrent care units and residents at the unit for permanent accommodation, totally eight, whereof three women and five men, aged 75 to 89 and one below pension age. One lives permanently here, one is here on recurrent care and the other six are on short stay, which means that their future placement is being processed. In most cases it means moving to a residential care facility. Fictive names that appear in the text begin with B (for *Boende* = resident in Swedish)
2) Next of kin: two spouses and two adult children, fictive names beginning with A (for *Anhörig* = next of kin in Swedish).
3) Staff: eight staff members, all female, were interviewed in the following combinations: five in two group interviews and three in single interviews. All work on day schedules.[8] The fictive names of all staff begin with P (for *Personnel*).

Though all names do not appear in quotes, in the process of analysis I have attempted to cover the sorted themes from the content of all the interviews whether they are explicitly quoted or not. In many cases when I refer to the interviewees I mention them with fictive names but depending on the flow of the text, or to depersonalize it if something is sensitive, they are sometimes simply referred to as "one of the" and the like. When I refer to the "users" of care, in this study, I mostly write guests/residents, since those on short stay are guests and those in a permanent residential unit are residents.

A critical self-reflection concerns whether I made the theme too broad, as the starting point in the information letters to all categories of interviewees was the question: How was the experience of coming her? On the other hand, this broad "door opener" helped me as well as the interviewees to have a relaxed attitude. Had I focused more strictly I might have come further on specific existential issues, on the other hand it could also have meant that doors were closed. The broad perspective combined to approach the whole topic in an inclusive way, perhaps much in line with the broad definitions of spirituality that I found as I launched the journey of the project further.

Main findings

If there is such a thing as qualitative content analysis it is perhaps the best methodological description of the way I sorted the material into overarching categories. But perhaps I am even closer to ethnographic analysis (cf Wilkinson, 2006) since

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[8] It is common in Sweden to have separate night staff. For this study it could have added value if I had interviewed people from this category too, as perhaps night time facilitates some space for existential needs, something which was hinted in one of the interviews.

each interview was unique and the interview guide used mostly as a tool to guide the conversation, the time and scope spent on each category differed and meant also that not every interview touched every issue equally. In some cases the interviews were carried out at two occasions. It also differed between the three groups of people that were interviewed: guests/residents in later life, next of kin (spouse or adult child). I went about sorting and analyzing all interviews (all but one were tape-recorded transcribed) and rather early in this process the main categories below emerged. At the end of this process (which included many rounds) new subcategories emerged, or rather issues that were related to the main questions but of subordinate importance to the focus of this study. These I do not include here, though they were part of the original report. The seventh categorization came out of an analysis of the future (5) and death (6). With this stated, the categorization below can (still) be said to cover most of the content.

1. Everyday life here-and-now or memories
2. Being well received — from the first arrival to the daily encounter
3. Care of the body and the room (the abode of the body)
4. Care of the soul (mind, heart, spirit)
5. The future
6. Death
7. Existential issues

1. Everyday life here-and-now or memories

The guest/residents encounter daily life in a variety of ways, very much depending on the life stage and the situation right now. Britta, for example, represents the contented person, who is happy about the lived she has life when she looks back, missing her spouse, but not overwhelmed by grief. Her faith in God bears through it all, the past, present and the future. The short-stay unit as such, however, means a degree of insecurity: "*I'm to be placed out later and then maybe it will become a little worse.*"

Bo, who is here on recurrent care, is aware of the commuting between home and here (two weeks each), it is not "fun" but it works all right: "*. . .one has to get along. . .*"

Both express a feeling of security, with a touch of ambiguity. Safety, yes, but also living in a kind of vacuum, a "transit hall". The two spouses who were interviewed struggle with making a new pattern of daily, weekly, monthly life, enjoying the rest they get but at the same time in the process of reorienting themselves, from togetherness to otherness. The ability to enjoy daily life is dependent on whether one's spouse is being well cared for or not, one case showing this in a positive and another in a negative sense.

The way staff communicate with the residents/guests makes a difference. Some staff said that while their caregiving tasks were much about making everyday life function in routines from morning to evening, the talks with the guest/residents often concerned the past, sometimes the near future. But if anything becomes too sensitive, nice memories are always safe to return to.

2. Being well received — from the first arrival to the daily encounter

In small nuances with shades from plus to minus, the matter of being well treated, being met with a kind and listening attitude, is communicated by the residents/guests. I cannot but interpret many of these elderly as feeling that they have to be happy about whatever attention they get, they cannot expect a vast amount of time, and many say that they understand how busy the staff must be. While Bertil cannot express enough gratitude for the staff who do not shun him now that he is mourning the death of his wife, Beata feels that she is seen as being in the way. To staff it is a matter of course that they should treat everyone well, from routines to comforting, but they do not express much self-criticism or reflections on how their actual behavior may be interpreted.

3. Care of the body and the room (the abode of the body)

Not very much was being expressed by residents and their next of kin as regards care of the body and the room, but one daughter captured the momentary emotion she was filled with on the day her father came here, "*I remember the room was nice . . . there were advent candles . . . it was so nice, I was close to tears when I entered here . . . and you know, this feeling you get when you come in here. . .*" To her the room — at this very special time of the year, advent, was a kind of guarantee that everything was fine here, that her father had come to a safe haven. It is "carefree" (without worries) is the expression or feeling that is transmitted by residents, or as Beata puts it "*Food is fine, it is no one's fault that I am here*", patiently trying to get used to her permanent residence. For staff daily routines are given importance, especially that everyone gets up in the morning; it is as if the personal integrity of each individual depends on this, being healthy, not ill, being a resident or a guest, not a patient.[9] Or as Paula puts it "*Many are very happy about, and in love with, their beds*". Another said something similar to the above, that it is important for personal integrity to get up and get going, get washed and get dressed, but of course it should be possible to have some flexibility when it comes to the exact

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9) At one unit, however, where staff had a stronger identification of themselves as acting within the nursing paradigm, patient was not a negative word.

time to get up in the morning. To make the common dining-living rooms look nice and cozy is obviously important, and as it was coming up to Christmas quite a lot of energy was devoted to decorating. While the above comment from the next of kin underlines the importance of this, the residents' view of this was not clearly voiced.

4. Care of the soul (mind, heart, spirit)

One of the short-stay elderly expressed very clearly that he missed the care of the soul, that existential needs were sadly absent; this was the thing he was very anxious to verbalize in the totality of the interview, where most words were spoken more passively. Others expressed themselves more moderately, some would welcome chapel or singing hymns. Someone (who expressed a Christian faith) said that "*there is not much talk about faith and such here at xxx*" or "*I don't come close to it and don't want to intrude*". A third comment was "*faith means everything to me*". From families' point of view it seems as if there are no expectations on staff being there to help with existential needs. They, as next of kin, may provide it if it is important. In the course of our conversation it nonetheless became clear that chapel times would be appreciated by some; the person who mentioned this was herself active in a church visiting group who visits homes for the aged for this very purpose. But again, the more "hands-on care" is what next of kin expect from staff.

Existential issues from care staff's point of view showed a variety of views. Some seemed to like this being part of their professional work while others had not given it much thought. Pernilla does not think that conversations about the meaning of life pop up, "*no, it's more about how it was in old times . . . that we talk about*" and "*One's got to have time to talk with them, which one perhaps does not have*". When asked what to do if someone starts crying, Petra answers that "*then I try to comfort*". It does not happen often but if it does she tries to make the person think of something else. Like, "*what would you like to have with the coffee?*" From one of the units especially it was clear that the staff had good communication with each other, so if someone needed to stay longer with one resident, the other staff covered for the work of the missing staff. Here they also said that they had time to visit families and talked to them: "*Oh yes, it can be about anything, we can have deep talks.*" In another of the interviews I asked if a professional (chaplain or a counselor) would be needed for some residents, and while affirming that some would need it Petra also says that being here is limited in time (short stay): "*I don't think that they see this as the last place, since they can be home sometimes. I think it's a gentle transition.*" To summarize, it seems that while many voiced the importance of having time to "care", to take a little extra time for someone, it comes as it happens; at afternoon coffee or after the evening meal can be a good time, with less stress, it was explicitly mentioned.

5. The future

"I'm to be placed out later and then maybe it will become a little worse," said one person who hoped there would be no move "*. . . if I was able to stay here . . . but that is not allowed. . .*". To another one it is good to be here while waiting for a permanent residential home, the only thing dreaded is being sent back home again. For a third person, already at the permanent unit, it is waiting for the son to visit that remains. And waiting for the end of life to come – something that the son does not want to listen to. For Britta waiting can be rather undramatic, whether it is waiting for Christmas or for death, showing an attitude of trust that everything will be fine: "*someone will come and see to it that I am taken out to the others who are here*" *(at Christmas) and about death "I have prepared everything . . . what they have to do . . . so that there won't be too much fuss about it. I have my faith,"* thus expressing that it is good to have a hope. One of the spouses felt that this Christmas would probably be the last for the partner: "the will to live is not there anymore", and is now considering permanent residential care. Another spouse admits that sometimes thoughts on how life afterwards, if surviving the other, will be. "*But [I] think that one's got to have lived through half the process already.*" A daughter focuses more on the near future and think that's what her parent does too, being so much better now and hoping for a nice permanent care home. Most of the staff seem to think that future means the very near one for the elderly here. "*If they talk of the future they want to go home*" and "*when I get better I will go and visit my children*", and in line with this short perspective on the future also expressing the consciousness that there is no faraway future for them: "*next year this and that will happen, then I won't be alive anymore.*"

6. Death

With this we are into the matter of death and dying. "*I am waiting for an end to come*" says Bror, in a conversation in which he brightened up when we entered the subject of the end. Beata does not fear death in an existential way either, but worries about pain as she says "*I pray God every evening*" not to have a painful death. Bertil's focus is on his beloved wife who died very recently, about reunion. A son visiting his parent has "*a feeling that xxx lives only for my visits*", himself wanting to keep the focus on the present, keeping his parent going and keeping death away. "*There will come a day and I don't want it to come soon, that it will come as late as possible . . . I don't know if I'm prepared or not, how I will take it. . .*" He always jokes away any talk about death that his parent tries to bring up. To Anneli death is part of life, it is "*as natural as anything . . . nature, life must have its* *way*".

Staff show a variety of views; one refers to families of the old parent, that children do not accept that their parents are so old that they are about to die. It is easier to talk "around" instead of directly, recalling a case when both the resident and the visiting family talked about not being able to come home anymore, "*what will happen to my belongings*". The same staff cannot recall anyone having asked for counseling or anything specific, but maybe about not wanting to be alone. One interview states clearly that the end is nothing to talk actively about: "*There is no reason . . . it is nothing to make a big fuss about*". Perhaps this quotation needs to be linked to the fact that no death has happened yet at this unit. It is striking that to those among the staff who have experienced death or have thought through it or have a faith, it makes a difference in the way they talk about death: "*I feel I can remain there, it's nothing that scares me off, this thing with death*". Another staff member mentions that many have been worried before death and the help given is painkillers, so a counselor would be welcome. Yet another comment is that they have to be something of a counselor themselves but "*there's a difference between that and someone who's not coloured by the environment here*". The "after-care", after death, is not uncomfortable says Pernilla, as "*they often have been ill for a while and what a relief their pain is over*"10). In cases where the dying process is long it is a time of readjustment for both families and staff. Feelings of both sorrow and relief can appear at the same time. A wish for supervision was expressed by this person. There seem to be routines for how to handle "expected" death; these include taking time to be with that person, a bedside vigil during the night, making the person nice and orderly after death, "*just as one would like it to be oneself*", bringing some flowers, a hymnbook or a bible, but according to individual wishes, including the families'. In one of the interviews the subject of multiculturalism was brought up, the need to keep up the knowledge of traditions in other cultures.

Paula brought up the issue of residents' thoughts of death and explained that "*I feel I can be there, it's nothing that scares me . . . so it's something I feel I have dealt with so it's not wearing me out*". To her it helps that she has a faith herself. "*I have come to terms with it, I don't fear death. I think it can make a difference for whether one wants to talk about it or not, but as for me it's nothing I feel that oh, no, so unpleasant.*"

Another said that "*There are those who have a faith in God and if you know that, I myself believe in God, then you can sing sacred songs*". Our talk went on and when asked what to do if it was a person with another religion the answer was that

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10) In the staff interviews, some talked of earlier experiences of care, thus not only about this specific setting.

"*you try to investigate a bit about it*" and perhaps it can mean simply sitting there, caressing the hand. Yes, "*the most important thing is that one is there . . . some don't want to be alone and then it's important to be there, hold their hand or something*," says Patricia. Petra tells of an experience underlining her view that one has to be open to the wishes of the other. A family member asked, after the death of a resident, if they could sing a hymn, and they did: "*They were happy about it and it was such a small thing we could offer, if I may say so*."

The following agrees well with a couple of the interviews and, I would add, the way many wished it could be, as Paula tells of her feelings when someone had passed away: "*sometimes it can feel very peaceful . . . this pain that many feel simply leaves. I don't know how to express myself, but there is a total peace really . . . these expressions of pain are gone, really. I think one can feel it that way, one can perhaps feel sad; I have no answer to why. Both peace and sadness*."

7. Existential issues

In some of the interviews with staff we touched the matter of the need for education and training with regard to death and dying (which will be dealt with under "Workshops"). Here, I will move on to existential issues, as these are so intertwined with some of the previous categories. Clearly questions about the meaning of life varied depending on life experiences, views of life, faith, what is considered as "meaningfulness" and also family relations. Health in a holistic sense was mentioned as important, for example one person who suffered from dementia-like symptoms after a stroke expressed himself as follows: "*to be well and like that and to be able to use things*". Others mentioned relations, both family and friends. One spouse described their marital relation thus: "*yes when I think of xxx I think yes, it is ours this, it is we, it has always been so, it is us . . . Yes the togetherness is there. But the closeness is a bit distanced*". Fellowship with a "neighbor" at the short-stay unit, caring for somebody, adds positive feelings of "existing", being part of the community. Faith was something that quite a few expressed. One felt unsure about whether it was OK to talk about it, as maybe others found it "private". One spouse misses this explicit part of their shared life. Another spouse believes that the spouse at short stay is safe, thanks to faith, and as for herself life issues mean that "*there is someone who is holding the reins . . . we don't have the 'total' but there is one with higher power that has it. And afterward we can see the meaning, but not when we are in it*." She tells of a faith that has deepened with the years. A person who does not express a personal faith (but a more general one) emphasizes that the family is stability. Death is natural. Life now is about the parent having it as good as possible to the end. Her "existential language" involves actively engaging with her parent. It is about safeguarding that the parent has a dignified existence.

What do existential issues mean for staff? It is nothing one speaks of at work, says Petra. Why? Perhaps because "*death has been a bit and still is a bit taboo*". Existential questions, older people don't understand what that is, Paula muses. Petra states that she cannot tell either. But if we boil it down to what is most important for you in life, well "*then they would say to come home again because this is not home*," Pernilla imagines. "*The most important thing is what they have done in their lives, because they are keen to talk about that . . . and then they feel when we listen, that 'Oh what fun it was when we did that, oh my'*," Petra reflects. To my explicit question whether they talked more about fun subjects, one answer was yes, but "*'that other' needs to be brought up too, because many are sad and low when they come here and that surely has its reason.*" "*And when someone starts crying it's easy to say, 'no you shouldn't cry, today we are happy'.*" Sometimes it seems the right way but the need to be sensitive to listen to them must not be forgotten, as another reflection that was heard. A comment from staff interviews related to this was that "*You don't have the strength to bear the atmosphere that comes* [i.e. when someone is sad], *you have others to tend to and then you have to be happy.*" The whole context with time pressure is thus an underlying factor, in which routines of the day fragment the care.

Obviously the subject of existential issues provoked some staff and there were variations showing that among them there were those who did not seem at ease with these issues, or at least had not given them much thought before, and those who through years of experience had a kind of "natural" way of dealing with a variety of feelings that residents and guests may show. Some had thought it over more, and in this case the connection to a personal (Christian) faith was clear. However, no one among the staff signaled that they would take the initiative, but were to different degrees ready to encounter these needs. Those who showed an awareness of existential matters dared to talk about death and dying, while to others (with experience) it was the practical care and after-care that was easy to talk about, and yet others with no experience of death and dying and who had some difficulties in starting to talk (the workshop days showed however, a clear change here) but expressed that they could have deep talks with next of kin and take time to sit down and linger on, when guests at their short-stay unit showed they needed a listening presence. The need for professional help from a counselor (social worker) or a priest/pastor was mentioned, and one answer was: "*absolutely, I think many would need that because there are a lot of depressions and instead they get medicine . . . and it's surely good that we have that but I think the other part is needed too even though one doesn't have so many years or months left one needs a person who is professional to talk to.*" From others I gathered that if a resident/guest or next of kin person actively asked for it such help would be provided, though not actively offered. Another factor is that whether or not "the end of life" is present in everyday life here concerns the fact that this is short-stay or respite care, thus not permanent residence (except for one small unit of residential permanent care). Thus death and dying is not so present at short-stay. But of course sudden deaths may happen and then it becomes traumatic for the staff — "*Why wasn't I there?*" — and it immediately "*starts to rush around in your head*" and it is important to talk to the others who were working at the moment of death and with the nurse, "*but not so big, just talk just like that*" (she seems to mean that not too formalized talks are preferred). Since church services are common events at Swedish residential care homes, the topic was brought up and staff expressed varied opinions regarding their role. Apparently it is seen as something outside their professional boundaries, although some could see the possibilities, that for some people a visiting church could add quality, but perhaps not mainly through traditional services; maybe they could come to the dayroom and sing some songs or the like. Meeting the older people where they are, it takes time for staff to help them visit the meeting room on a specific floor where church services used to take place (now cancelled).

The welcome talk was a matter we talked about, and it seems to be a bit unclear, as if it works more as practical information than as a chance to get to know the person and his or her wishes and thoughts about the stay here. And yet, even if it is not a final placement, coming here means that something more or less drastic has happened that makes living at home difficult; it can either be a relief to be able to leave the hospital or a difficult transition with many feelings involved. For some it means that one has given up the fight, realizing one cannot move back home anymore, and this place becomes the waiting room or the transit hall. For others this transit hall is a nice experience on the journey. As the workshops later would show, the idea of making a better and welcoming start which would give room for more personal issues including existential needs began to be formulated in some of the interviews. Perhaps it would be good to include some brief version of a life history in this. In one of the interviews with an adult child the needs of next of kin became clear, as he expressed "an emptiness", maybe close to a feeling of having betrayed the parent, even though it was a clearly expressed wish on the parent's part to stay here.

Beata, who is here permanently, now says with tears choking her voice that "*it was tough*" to come here, although she is fully aware of her needs after the stroke. For Bengt, on the other hand, it is a great relief, finally here! For couples there are other aspects than those between parents and adult children to deal with. And perhaps these are not dealt with in depth; feelings of not being able to manage on their own anymore are often the main focus of both decisions and feelings. The deeper existential layers of a long life shared together are not dealt with openly but are perhaps manifested in other ways. For example, one of the interviewees said that the attitude of the staff made it difficult to visit, feelings of being in the way, while perhaps staff felt that this was a "bothersome" next of kin. To what extent care staff can and should also include the visiting next of kin in their care work is a relevant question to ask.

Loss and coping are thus two other analytical concepts that emerge. Most of the older persons and their next of kin are involved in the process of coping at some stage in a process. Loss was expressed (though in other words) by several, while some seemed to have already come to terms with it into their course of life. One of the younger "short stayers" talked about the loss of family life. In case of the couples the formerly close relation was in another stage now and it seemed as if the husband and wife did not talk to each other about it. Both focus on the other's needs, being either a "care watcher" or the "manager" balancing home and short stay into a new routine of life, while the spouses at short stay (in these two cases) either heroically want it this way for the spouse's sake, or accept it but perhaps not as fully as the spouse thinks. One spouse really has made this a reason to speak publicly about the experience: "*what has happened has given me so much . . . negative happenings do not have to mean destruction. It can mean the door to something very positive . . . and it is the small things in daily life, not journeys to the moon, but small things like getting up in the morning, being able to do what is necessary during the day . . . feel good about it. . .*" This person has had some years to adapt to the situation and after a lonesome start now plans to see friends and even travel during the short-stay periods, while during the weeks together their social and spiritual life in church is continued. The shared faith means a lot to both of them, as is evident from the two separate interviews. In either case it is a reorientation of daily life and of a couple's shared life that takes place over time. Perhaps the spouse in recurrent care, out of compassion for the spouse who would have to bear the burden of caregiving, holds back his or her own feelings of longing to be at home.

Before moving further into analysis and discussion I will summarize needs for changes that have emerged from the findings (including the workshops), those needs that can be linked to the overarching theme of the study and of this article: existential issues.

1. Clearer routines was something that all three parties would appreciate, with counseling or "talk" support as an option.
2. More education, if possible on how to be better equipped to encounter a variety of existential issues, and a variety of individuals.
3. Time to reflect, for staff, to have the time to think through what they are doing and why, the needs of their guests/residents/next of kin, and thus to think a bit

further than the practicalities of each day.

4. Distributing the responsibilities within a staff group so that in each group, one of the staff, who really wishes it, is given well-defined main responsibility for the "soft" issues, the existential issues. With it should go the opportunity to take part in specific training (such as taking a class in some subjects, such as palliative care, counseling social work, diaconal work=church social work) within the area.
5. A dialogue with the community such as: the church, different clubs and associations including ethnic associations, depending on how the community is structured both socially and physically (perhaps even the social networks of staff, residents and next of kin could add to this).

Findings that will be further analyzed and discussed

What then are existential issues in the care context(s) for older people in this Swedish case study? The approach was quite wide — the experience of coming to short stay (or moving in here permanently) and the questions regarding the future that this might evoke. In the rear-view mirror it can be seen as consistent with the variety of ways in which spirituality is defined. However, I did not use the concept of spirituality in this study, I used "existential issues", or perhaps even a lighter phrasing, in Swedish: "issues regarding life" *(livsfrågor)*.

Nonetheless, in the literature I introduce I have referred a great deal to spirituality as I have found that it includes existential issues. It is also placed in the context of palliative care, i.e. that palliative care which occurs in later life, at the end of life as part of aging. Here life course is also central as I draw from the idea that we interpret our lives in the perspective of the lived life and that we reinterpret it in the course of life, in an active process which continues, often until the very end of life (for example Hagberg 2002, Tornstam 2005, Öberg 1997). Since among the interviewees in my study there were those who expressed a Christian faith and the meaning it had to them in relation to the issues that the interviews dealt with, I find it meaningful to relate to Hudson (2006), who raises questions of Christian theology in relation to spirituality. Other interviews dealt more with human relationships than the relationship to a divine other or to God, and thus the definition of spirituality can be applied to the whole scale of definitions of spirituality that are brought up in the literature review.

I do not claim to make a theoretical analysis of "existential issues", rather it is the empirical findings that are in focus here and guide the aspects that are brought up from others' studies.

“Live for, Live off, Live with”

What is important in life — in daily life — at the end of life?

On one of the walls on one of the floors was a small work of art with three sayings, as if to remind care staff of something important: Live for, Live off, Live with. Somehow these words summarize what existential issues meant to many in this study, in all three categories: guests/residents, next of kin and staff. In the section to follow, the results of the study will be discussed under headings that capture core meanings.

To be seen as a whole person

To residents/guests it means having someone who listens both to the words said and to what is sometimes hidden behind (cf. Kristjanson 2006, Hudson 2006), someone who is not shy of tears but who provides a secure environment where both tears and laughter are welcome.

For next of kin this may mean knowing that the loved one is cared for by staff who care in a total sense, both doing the practical bodywork of care and doing it with kindness and dignity. But also that they as “next of kin”, as persons who care for their loved one, need to be seen by the staff, something which Anbäcken and Nitta also emphasize (forthcoming 2008). The critique they may voice is grounded in concern for their loved one — and perhaps feelings of not being able to do enough themselves.

Many, among both guests/residents and next of kin, actually expressed very little expectations, they know or perceive that staff are busy. This is a risk factor, since obviously there are uncertainties as to what exactly it is that makes staff so busy. To guests/residents who are the targets of the work, feelings of being a burden to the busy staff are a risk, as such feelings are effective to shut out existential needs requiring trust and time (at least the feeling that there is time) to appear.

Staff also need to be seen, for who they are, and from there gain insights about the holistic care they can provide, where their limits are and where they can ask for help.

Inclusive support

Support in a way that makes both the old person and the next of kin feel included would make a lot of difference and spare frustrations for all involved. Especially for spouses it is a matter of letting go of the expertise one has had, which can be frustrating, and staff need to understand the agony going with it. After all, the promise one gave in marriage was to love in “sickness and in health . . . till death do us part” (cf. Anbäcken & Nitta, 2008). The two cases of couples in my study showed that the time process mattered as well as whether there was a feeling of being in control. While Anna felt that she now had found a rhythm of living partly as single (during respite care), partly as co-habiting wife, she could enjoy this combination, while at the same time grieving for the way life turned out. Her (Christian) faith and her activities, such as actually speaking publicly about her experience, have meant an existential process of (re)interpreting her life and faith. In the loss of a husband who is not fully the person he used to be, she has not lost herself, her faith has matured. As for him, he also emphasizes that faith means everything to him. However, his process is more "floating", not being fully aware of how life is now organized. It is obvious that others are in control, but his feeling is still that he can choose. He would in such case (of real choice) live at home. Life at respite care is acceptable — not more.

Spiritual undernourishment

The person who clearly expressed that being here meant spiritual undernourishment obviously was in need of spiritual guidance, a chaplain who shared his faith and could listen and give reassurance on certain issues. Hudson's (2006) call for a spiritual care that really sees to the individual's life story comes in handy here, but also MacKinlay (2006) as she ranks the neglect of spiritual needs in the same category as the neglect of physical needs. Although, in this case, the visiting spouse provided some support, bringing devotionals, even a portable electrical organ, it perhaps make them feel tired to have to provide everything on their own. And with staff that seemed uncertain about how to deal with these kinds of existential needs, the visiting spouses' activities may be felt as a reminder that they do not do enough.

A neighbor at the same unit seemed easier to encounter for staff. His existential grief, having lost his beloved wife just a few days back, was something they could handle, it was perceivable. They did not run away, they stayed with him, and he felt their support (cf. Kristjanson, 2006).

Routines — fragmenting the care?

If we take a look from staff's perspectives, it seems that their daily work takes place within certain day-to-day routines. Morning: help the guests/residents out of bed, hygiene, getting dressed, eating breakfast, and in between the meals the chores to perform, keeping the common rooms and the individual rooms nice and tidy. In the course of the day: communicating with the elderly they meet, while giving individual care or in the common dining-living room. As distinct breaks during the day, staff meet for coffee, shutting themselves away from the life going on around them. This is a pattern in Swedish society at most workplaces, and thus nothing bad in itself. However, as I watched this (and participated myself in some coffee breaks) I sensed that this time could also have been a time to be with the elderly in a relaxed way, have coffee with them, listen to music together, just sharing some time without chores. Routines thus set quite a lot of boundaries, which mostly happens in an unreflective manner; daily routines fragment the care.

Those among the staff who were ready to face existential issues can probably find time and place for this in the flow of the day. Those who had long experience showed the ability to communicate in a light but pleasant way, though perhaps not enough on tearful or deeply existential matters. This was spoken of in terms of being able to joke and so with them at afternoon coffee or after dinner when there is time.

Listening to the life stories (Hagberg, 2002) seemed to be at least partially done, as photographs were a means to talk about the past. This seemed to be a safe area for most of the staff: to follow their elderly back in time or to children and grandchildren now, to talk about nice events in the past. But it could also mean changing the subject if it became too tearful: "What shall we take with the coffee?" or "Today we are happy." Thus reminiscence was more a means of "safe" communication than a tool to draw near to existential issues.

Those one or two who clearly expressed that they were ready to encounter death and residents'/guests' talk of death, and their lives in relation to that, would need such space in their work schedule. If not, it is easy to be drawn into the webs of routine which does not allow time-consuming and also irregular schedules. Their own readiness needs space and flexibility, as life-and-death talks can neither be planned as regards the start or the finish.

Palliative care

Palliative care has its "pros", when it comes to openness for the subject of death, since it is clear that it is care given at the end of life. A certain level of training has been given, staff members know what it is about, though my findings support earlier studies (Forssell 1999, Whitaker 2003, Anbäcken 2008) that two of the three key components in palliative care are known and practiced: physical and psychological care, thus physical pain is alleviated with the help of medicine, emotional care is given, but spiritual needs, or even spiritual pain, is left aside — it seems. From my empirical material I cannot say how often staff have experienced end-of-life care; this is, after all, mainly a short-term stay, which makes a difference when it comes to the final stage of terminal care. But it was clear from the interviews that a limited few would like to provide this care. After the workshops even more had a more positive view of death and dying (cf. Albom) expressing more readiness to encounter it.

Dignity

Dignity was the most appropriate word for many of my encounters with the guests/residents, especially Beata. With her ethnic background differing from the majority here, I noted a similarity to narratives of Japanese elders at residential homes (part of a comparative study, forthcoming in 2008). The similarity was that war was part of their life experience. As I compare the two analyses it strikes me that gerotranscendence came to the forefront of my mind in both studies. Wisdom of life, cherishing life even with all the difficulties both past and present, talking clearly about death — these were uniting features for these interviews. Beata spoke very distinctly of her world-view and her faith, one of the most verbal persons, though excusing herself for her "bad" language, probably thinking that her accent was hard for me. Beata was also the only one who answered very precisely when I asked if she knew what the interview was going to be all about. Her immediate answer was: "I know. I've read the letter." Dignity was also the word that spoke to me in the "sounds of silence" of Bror, who solemnly gave up and came to live here, so that the dear wife would have some rest. This reminded me of dignity, as Simmons put it, that awoke a response in myself in the interview setting (1998). The findings thus point in the direction of Kristjanson's (2006) emphasis on dignity as central as it is closely interwoven with the sense of meaning and quality of life.

Life-course perspective

Many of the interviews took on a pattern of viewing back. X mourning his wife, their love story, from youth until now, he is living as if in a vacuum for the time being, and perhaps an appropriate question would be: after this initial phase, when staff apparently have done very well, what happens? Is there knowledge enough to follow up his needs, after one or two months?

What do I *care* about, what do I want to talk about as I perhaps tell of the course of my life? This study shows variations of one's great love: from spouse to God. If staff take some time to really listen, useful keys to understanding each person will appear, sooner or later. For some people, talking does not come just like that; perhaps a walk, or baking a cake for afternoon coffee is the way to establish a good steadfast relationship. What are the limits (and possibilities) in the environment for this: the care setting in terms of housing (individual and common space), staff, routines, next of kin?

The literature brought up has underlined the need to take existential (spiritual) needs seriously in later-life care. Care professionals need to study both these concepts and aging theories in relation to their care practice. The need to understand spirituality that transcends cultures and faiths, as well as to have an understanding of the faiths and cultures they actually meet in their work, are both important.

Moreover, the need to personally have encountered these issues was also found to make a difference which influenced their care work. Most of the definitions of existential issues in relation to the findings could be linked to a life-course perspective, and also to aspects of reminiscing (cf. Hagberg 2002, Langer 2004, Tornstam 2005).

Concluding discussion on the three categories and existential needs

Residents were those with the most varied knowledge, i.e. knowledge from their experience of life. It was clear that this knowledge had been molded throughout the course of each person's life, as the parts of their life stories that were told gave evidence of this. They could all in one way ore the other be related to Öberg's typologies (1997)

The immigrant with the experience of war, how cohort, generation and transitions in life have impacted her life and been agents in molding her into the person she is, as she now lives everyday with composure and dignity in the consciousness of impending death. She expresses wishes, both for her present life and for the end.

The pastor who had dedicated his life, together with his companion through life, to the parishes that had become his life work, is not afraid of dying in an existential meaning, but would like to talk about the last moments of life on earth. His intellectual capacity seems unreduced, though hidden under the existential turmoil now being experienced, in the transition process the couple are going through. This turmoil also reflects what for example Moustakas (1961) and Sand (2008), define as existential loneliness. With a supportive environment he could add much to the "neighboring" community inside the unit, for example with music.

The widower's present was so colored by this new status that any other characteristic of life at the time being of the interview and empirical study was difficult to discern. But the friendship with one of the "neighbors" here could perhaps help him to come back to a life after the trauma.

The lady beaming with a tranquil contentedness told a life story that confirms Hagberg's (2002) statement that childhood and youth make the deepest imprints on the rest of the life in comparison with middle-age life. Her happy memories of those periods of life shone through up to the present time. Spiritual needs were described as being "met" in her own personal experience of faith.

The "fighter" whose authority from his prime still shows forth, and whose fight for the right can be seen as a leitmotif, also comes in here. Now, one major goal has been reached and he is ready to enjoy the last part of his life without worries about living alone at home. He and his next of kin have fought as a team for this, the existential foundation for them being to have a good life, based on doing things right, fearing no one (but God in a traditional faith of church as part of life's frame).

Then there is the person who is content but still harbors feelings of sorrow because of not being able to run the course of life uninterrupted by illness. Living at home is no longer possible, and this is a loss. Still the faith that has borne all through life is still there, sustaining. To this person faith appears to be the existential reality that governs life – and gives comfort.

As regards next of kin, apart from the differences between each case, there are profound differences between whether the next of kin is a spouse or an adult child (cf. Anbäcken & Nitta 2008). For the spouses this situation of recurrent care/short stay means a time of profound changes that affect themselves. The shared life is now being fragmented. While rest and refreshing time helps them in this, it may also add to a bad conscience. Depending on how far this process has gone, feelings vary. If coping goes well, a sense of meaningfulness may color off on feelings and thoughts. Faith has guided throughout life and does so still, but the timing in this process shows a clear impact, as in the early stage trust and worries are mixed, while in a later stage trust and a transcendent view of life has emerged. Ways of communication with staff also have an impact on this, the worries of the "early stage" person seem difficult for staff to handle, while the "late stage" people have an autonomous relation to staff. What unites the feelings expressed by visiting children is the correlation between a good relation to staff and their worries for the loved one? Existential issues are expressed differently among the children, one showing that these issues follow her path of life and continued in a consistent way, guiding her in the actions taken for her parent. The other one feels more guilt, not wanting to talk about death and the separation, wanting to affirm life and fight for the parent to receive more rehabilitation for well-being in daily life. Here critical views about the staff are also expressed, as the feeling is that they do not see the parent as an "active" person. Here "active" needs to be interpreted broadly and thus I borrow the UN standards for active aging, which describe active in a wide range of meanings, physically, mentally and socially (in Kalache, Barreto and Keller, 2005).

I found both compliance and lack of compliance between staff's views of existential issues in my study, and what literature shows in discussing and defining spiritual needs in aged care. Compliance is found in the need to be seen as a whole person, with the history of life each one has. Less compliance is evident when it comes to comprehending that perhaps being in the present care context means that time has come to put one's life together. Understanding of this was voiced, but perhaps not so as to give it enough attention in the daily work. There are a variety of reasons for this, which can be challenged and changed: the routines being a hindrance, the feeling of always being busy, the lack of time to reflect together on these issues in the staff group. Other, more personal reasons, can only be left to each individual to handle.

Among the staff there were some that I found to be somehow "shy" about this (perhaps among those a bit more advanced in age) but they radiated a sense of self-assurance and a positive attitude about working with older people, transmitting that they have a good relationship. Among the younger one I found great variation between two categories, those who hardly knew what existential issues meant, expressing stereotyped views on elderly and religion when the interview touched on the subject specifically regarding existential needs, but when describing their care work elsewhere in the interview they showed capacity to maintain a listening attitude, being ready for flexible solutions if some of the elderly, for example, sat longer on the bedside. The other category of "younger" staff showed a composure, a readiness to take care of the whole person, not shunning religiosity or the subject of death, but being available for the other person, showing readiness until the very moment of death. This category had treated these issues themselves, through personal experience and/or through faith.

Life's last abode or transit hall — what difference does it make?

Is the dream of moving home again alive or are those doors closed? This is perhaps an issue at stake at short stay in particular but also in recurrent care. Is the focus different from when moving to a permanent residential care unit? And is there any correlation to existential needs and how they are encountered in these two settings?

There is no single answer, in either setting, though we can assume that the final move, to "life's last abode" (Whitaker 2004), may entail a more profound existential challenge. It seems appropriate to state that it should be part of the basic knowledge for staff to include existential needs as a "normal" aspect also at residential care homes. But here too, at short stay, if the move has been a positive one it can infuse new energy to live fully here and now. This can also be related to whether the person has come to peace with life and has hope (cf. Anbäcken 2006). This study, however, is specifically interested in short-term care, or short-stay and recurrent care. Bearing in mind that this is not a final move, that it either means waiting for a permanent residential care unit, or a continuation of "commuting" between home and the recurrent care unit, the question is whether it is now, the present, that counts more than the future. Thanks to coming here, the condition of some people turns to the better and it may mean that present time rather than future and death that is in the forefront. Certainly, this can apply to the guests/residents to varying degrees in this study. The relief of finally being here was very much clear for one of the guests who with the help of his next of kin had experienced a long procedure, a fight, to be allowed to come here. To others, in most cases the daily life here is important, it is the context in which they live and from where they look backward and forward in life. I would say that, even when "here and now" is the tangible issue, it is important how this "here and now" is organized, to facilitate a secure environment where one's joys and sorrows can be seen as equally important and can be encountered, not neglected. For the person who suffered spiritually from the lack of such care, I do not think much is needed from staff to make a change. It is about being seen and listened to, and being taken seriously.

So is short stay a transit hall to the last journey in life? Today, and perhaps the near future — that is how far the plans go, even for those three who clearly had their minds set on heaven. Also at this time of life, everyday life is what is at hand. Sand similarly describes the endeavour of terminally ill persons to keep death at some distance while cherishing life (2008). It is here and now that life can be reviewed, making this period of one's life a rich one, developmentally and indeed existentially.

Education

I have deliberately chosen to close this article with the two workshop days that ended the project, or meant a new start to it, in these particular empirical settings. Before that let me just say a few words about education. Several studies brought up the need for education to enhance spirituality and encounter existential needs at the end of life, spiritual care models (Kristjanson 2006, Harrington 2006), dignity therapy as proposed by Chochinov and Cann (2005), and aging theories (Wadensten 2003).

More or less clearly outspoken spiritual needs are seen in my study. Of course my way of being and asking questions, guiding the interview forward, may have had an influence; this is part of the qualitative interview method: the researcher counts, she/he is not a fly on the wall (cf. Hammerslay & Atkinson 2003). But even if I lower my voice, the other voices were clear enough on this. There is a need to give space to existential issues in later-life care, and education for staff is one way to tackle this. The remaining overarching question for this study is therefore how to facilitate this in the routines of the care settings.

The workshop days

During two days in November 2007, the results of the study were presented to staff from the units where the study had taken place. This was initially planned as an important part of the project, as one aim of it was that it should be a development project, not a "desk product". Thus the report as such was also written for this group. A third step is also planned (but not as yet carried out): to produce teaching material for study circles at the workplace.

Standing in front of staff and see how they would respond to the results was like being on trial. Had I really managed to catch the essence in our talks, had I perhaps lost something important that they wanted to say? At the end of the two sessions I asked those present to write down some lines about what the session had meant to them. Their comments revealed that they had benefited from the feedback session. The opportunity to reflect further on the situation of the guests/residents was valued. The reminder that each one of the guests/residents is unique, that their needs are unique and that everyone thus should be met individually, was heeded, as some of the quotations underline:

> "Routines cannot make us forget the person."
> "The pensioner should be able to decide more about how the day should be."
> "Time for reflection within the staff group."
> "Individuality in fellowship."
> "Important to be reminded of the importance of talking about death, it is after all natural."
> "That we as staff are so important that we sit down and talk with the residents, that we take that time."

There was also a comment about learning from that which does not work so well: "it gives an eye-opener".

Thus, these two opportunities to report back to staff about the project were a positive kind of "education in place"; it came from their own settings, they could recognize it as "their own world".[11] Feedback with a balanced blend of good and negative aspects seemed to be appreciated. Of course, only the daily life at this short-stay and residential unit will really tell to what extent any impact will last. Also, there were staff who did not want to participate in either the study or the workshop sessions. Hopefully there will be after-effects from those who felt enriched by the project and who acquired some tools to continue working for change. Also, the fact that the head of staff supported the project and was present at the workshop sessions emphasized that this was a top-priority issue. Moreover, the commissioner from the municipality in charge of eldercare affairs was also present and took part in the discussion with the staff.

The "welcome" of new guest/resident attracted a lot of interest and was addressed in some detail. If the first reception is warm and welcoming and if the guest/resident

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[11] All those who participated (all categories) received a copy of the report. The risk of speaking from one's own context is also tangential to research ethics. I expended quite some effort on "packaging", keeping the ethical rules of anonymity without distancing the text from their world (s).

feels that the staff there "care about me as the person I am", this ought to have a positive impact on the stay and also on the day-to-day life. Also, it should pave the way for existential issues, give space for them, if these are elicited as part of the checklist in the welcome protocol. This could, for example, have questions such as: What means the most to you? Are you worried about anything specific? Would you like to talk to a social worker, a counselor, a chaplain, or a special coordinator among the staff? Any wish to participate in church or other religious or other events? Music? Literature? Thoughts about the end, how do you wish it to be? Family? Thoughts and worries about now?

The final words I borrow from two persons, one is the same person who opened this text, the other is a staff member I met in a study five years ago, whose words still echo.

"But if Professor Morris Swartz taught me anything at all, it was this: there is no such thing as 'too late' in life. He was changing until the day he said goodbye" (Albom 1997).

"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 you think only of *what* to do, not *who* to help" (in Anbäcken 2002, p. 40).

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