UMEÅ UNIVERSITY

Understanding spirituality and religiosity among very old people

Measurements and experiences

Catharina Norberg

Department of Nursing
Umeå 2018

Responsible publisher under Swedish law: the Dean of the Medical Faculty

Dissertation for PhD
ISBN: 978-91-7601-819-4
ISSN: 0346-6612
New series No: 1942
Cover picture: Catharina Norberg
Electronic version available at: http://umu.diva-portal.org/
Printed by: Print & Media, Umeå University
Umeå, Sweden, 2018

HAN Jag tror på Gud, helt och fullt, men förväntar mig inte att förstå Hans vilja. Gud är där musiken är. Jag tror att de stora kompositörerna berättar för oss om sina upplevelser av Gud. Detta är inget nonsens. Bach är för mig en oföränderlig faktor.

HON Men förut tvivlade du?

HAN Inte på Bach.

HON Nej, men du tvivlade på Gud.

HAN Allt detta struntprat, det är över nu, det har gått sin väg, jag har liksom inga resurser kvar till att babbla om vantro och misstro och såna saker.

HON Hände det något särskilt som gjorde att du slutade tvivla?

HAN Det har kommit stegvis, *peu à peu*, jag kan väl säga att tiden efter Ingrids död har min upplevelse av Guds vilja varit intensiv ... Jag kan stå utanför här, på Hammars, omgiven av havet och molnen och få en upplevelse av ... närvaro.

Ur: Ullman, L. (2016). De oroliga. Dialog mellan den åldrade fadern, Ingmar Bergman och dottern, Linn Ullman.

Table of Contents

Abstract

Background: Spirituality is a multifaceted concept. In this thesis, spirituality is understood as an overarching term and a core of a person´s being. Religiosity is seen as one of many expressions of spirituality. Very old people are a vulnerable population, with an increased risk to be exposed to negative life events. Spirituality is suggested to have an impact on the possibility to adapt to life circumstances and manage age-related challenges

Aim: The overall aim of this thesis was to assess psychometric properties of instruments and to gain understanding about associations and experiences in relation to spirituality and religiosity among very old people.

Method: The thesis has been conducted in the population based Umeå 85+/GERDA study. Half of those aged 85, all 90 year old, and all aged 95 and older in Umeå, Västerbotten, northern Sweden and in Ostrobothnia in Western Finland were invited to participate (cf. Näsman et al, 2017). Questionnaires used to measure religiosity versus spirituality were the Religious Orientations Scale (SROS) and the Self-Transcendence Scale (STS). None of these has previously been validated among very old people in a Swedish context. Factors associated and correlating with STS score are presented. How very old people express and perceive spirituality is also studied.

Result: The participants in study I scored high on both subscales, indicating that they were religious in both an intrinsic and extrinsic manner. The SROS ability to distinguish between intrinsic and extrinsic items was tested. The cluster analysis revealed three clusters interpreted as intrinsic, extrinsic-personal, and extrinsic-social religious orientation, with no cross-loadings.

The revised version of STS, (study II) with 10 items, had satisfactory psychometric properties (α .83). A factor analysis resulted in a two-factor solution (α .78 & .73). Test-retest reliability and concurrent criterion validity were supported.

In study III STS showed a positive association with psychological well-being, self-rated health, having someone to talk with, and being able to go outdoors independently. A negative association was found between STS and diagnosis of depression, dementia disease, osteoporosis, living in a geriatric care institution, and feeling lonely. An accumulation of negative life events was associated with a larger decline of STS score over five years.

Findings in study IV showed that spirituality was perceived as a connectedness to God, and other people. Telling about spiritual experiences was described as uncommon in conversation due to the private nature of the subject area and because of a fear of being considered as dubious. The findings also showed that

experiences of spirituality were connected to a view of life where participants were transcending life's circumstances, and experiencing mysteries.

Conclusion: The results propose that the Swedish version of SROS and STS, aimed to measure religious orientation versus self-transcendence have satisfactory psychometric properties and are feasible to use among very old people. Furthermore, self-transcendence was positively and significantly, associated and correlated, to a number of factors known to enhance well-being. Spirituality was understood as including religiosity, a belief in God, connectedness to other people and conviction about a spiritual reality. The very old expressed a desire to share personal beliefs and experiences of spirituality, but they found it difficult due to a fear of not being taken serious.

Hence spiritual needs can be unnoticed within the health care context, health care professionals need knowledge in order to recognize expressions of spirituality, and skills to support patients in a need of spiritual care.

Keywords: Aged 80 and older, Sweden, spirituality, self-transcendence, Self-transcendence Scale, Religious Orientation Scale, religiosity, psychometrics, experiences, Umeå 85+/GERDA.

Abbreviations

ADL	Activity of daily living
RS	Resilience Scale
SOC	Sense of Coherence
SOM	Society, Opinions & Media survey
SROS	Swedish Religious Orientation Scale
ST	Self-transcendence
STS	Self-transcendence Scale
MMSE	Mini-Mental State Examination
PGCMS	Philadelphia Geriatric Center Morale Scale
PIL	Purpose in Life
QCA	Qualitative Content Analysis

Svensk sammanfattning

Denna avhandling omfattar fyra delstudier. Det övergripande syftet var att testa skattningsskalor med avseende på dess psykometriska egenskaper och få en ökad förståelse för faktorer relaterade till, samt erfarenheter av andlighet och religiositet bland de allra äldsta. Att vara mycket gammal, det vill säga över 85 år och äldre, kan innebära en ökat risk för sårbarhet. Andlighet har i tidigare studier visat sig ha betydelse för välbefinnande, mening och mål i livet, upplevelse av tröst, coping och en hjälp att anpassa sig till de ändrade livsvillkor som åldrandet kan innebära. Det finns ingen enhetlig definition av begreppet andlighet. Andlighet kan förstås som en djup form av religiositet men andlighet kan också förstås som ett övergripande begrepp som kan innefatta religion. En ytterligare förståelse av begreppet är att andlighet innefattar mening och mål i livet vilket kan utryckas på olika sätt genom exempelvis, musik, konst, litteratur, meditation, naturupplevelse, gemenskap och bön. Tidigare studier visar att äldre personer sammankopplar andlighet med religiositet och personlig tro.

Samtliga studier i den här avhandlingen bygger på data insamlat inom Umeå 85+/GERDA. Umeå 85+/GERDA är en populationsbaserad studie där varannan 85-åring, varje 90-åring och samtliga 95 år och äldre inbjudits att delta. Datainsamlingen startade år 2000 och har därefter upprepats vart femte år.

Delstudie I, II och III är tvärsnittsstudier som bygger på självskattningsskalor, mätningar och uppgifter från medicinska journaler. Delstudie IV är en intervjustudie, där deltagarna har ombetts att berätta om hur de uppfattar andlighet.

Delstudie I innefattade 43 personer. Bland dessa var 37 kvinnor och 6 män, medelåldern var 92 år och samtliga bekände sig som kristna. I denna delstudie besvarade samtliga en skala som mäter religiös orientering, det vill säga drivkraften/motivationen för religiositet. Syftet var att undersöka om skalan går att använda bland mycket gamla personer samt om den kan skilja mellan inre och yttre motivation till religiositet. Resultatet visade att skalan är tillförlitlig och att inre och yttre motivation till religiositet går att åtskilja genom att de påståenden som mäter inre respektive yttre motivation till religiositet fördelade sig i olika kluster.

I delstudie II ingick två urvalsgrupper. Grupp 1 innefattade 198 personer. Bland dessa var 126 kvinnor och 72 män, medelåldern var 88, 9 år. Grupp 2 innefattade 60 personer. Bland dessa var 26 kvinnor och 34 män med en medelålder på 39, 2 år. Samtliga besvarade Självtranscendens Skalan (STS). Efter att fem påståenden exkluderats fördelades de återstående påståendena i två faktorer som bedömdes

motsvara intrapersonell självtranscendens och interpersonell självtranscendens. Resultatet visade på god trovärdighet och tillförlitlighet av den svenska versionen.

Delstudie III innefattade 190 personer, 123 kvinnor och 67 män med en medelålder på 88, 8 år. Samtliga besvarade Självtranscendens Skalan (STS). Av dessa besvarade 55 personer skalan vid två tillfällen med 5 års mellanrum. Syftet med studien var att beskriva samband mellan självtranscendens och fysiskt och psykologiskt välbefinnande samt att undersöka samband mellan självtranscendens och negativa livshändelser samt om självtranscendens påverkar livslängd. Resultatet visade ett signifikant positivt samband mellan självtranscendens och välbefinnande, självskattad hälsa, att ha någon att samtala med och att kunna vistas utomhus. Resultatet visade även ett signifikant negativt samband mellan självtranscendens och depression, demenssjukdom, osteoporos, att bo på äldreboende och att uppleva känslor av ensamhet. Vidare visar resultatet att en alltför stor belastning av negativa livshändelser signifikant minskar självtranscendens och därigenom förmåga att transcendera. Självtranscendens påverkade dock inte livslängd/överlevnad.

Delstudie IV innefattade 12 personer, 10 kvinnor och 2 män med en medelålder på 89,7 år. Studien bygger på intervjuer där deltagarna har berättat om sina tankar om andlighet. Resultatet visar att andlighet för dessa personer var nära sammankopplat med religiositet och en personlig tro på något större/Gud som de litade på. Deltagarna beskrev andlighet som en djup kontakt med Gud och viktiga personer som funnits och finns i deras närhet. Deltagarna utryckte en önskan om att få tala om sin tro men samtal om andlighet och tro är inte ett vanligt samtalsämne. Dels för att det är svårt att sätta ord på sin tro men även på grund av en rädsla att inte bli tagen på allvar. Vidare visade resultatet att andlighet handlar om att transcendera livets svårigheter och livsvillkor. Deltagarna berättade om svåra erfarenheter i livet och om den förestående döden på ett naturligt sätt och uttryckte tacksamhet över att få leva. Resultatet visade också att andlighet handlar om att leva i en medvetenhet om att det finns något mera än den synliga världen. Deltagarna uttryckte en stor förundran men uttryckte även frågor om Guds egenskaper.

Sammanfattningsvis visar avhandlingen att skalor som mäter religiös orientering (SROS) och självtranscens (STS) är tillförlitliga och användbara vid forskning bland mycket gamla personer. Avhandlingens resultat visar på ett statistiskt säkerställt samband mellan självtranscendens och hälso- och ohälsorelaterade faktorer. Avhandlingen kan bidra med en ökad kunskap om hur andlighet kan uttryckas. Vårdpersonal behöver både teoretiskt och praktiskt kunnande för att kunna förstå andliga behov och ge andlig omvårdnad.

Original papers

This thesis is based on the following four papers, which will be cited in the text with Roman numerals

I. Norberg, C., Eriksson, S., Lundman, B., Norberg, A. & Santamäki Fischer, R. (2012). Intrinsic and extrinsic religious orientation among the very old. *Journal of Religion, Spirituality & Aging, 24*(4), 314-324.

II. Lundman, b., Årestedt., K. Norberg, A., Norberg, C., Santamäki Fischer, R. & Lövheim, H. (2015). Psychometric properties of the Swedish version of the Self-Transcendence Scale among very old people. *Journal of Nursing Measurement, 23*(1), 96-111.

III. Norberg, A., Lundman, B., Gustafsson, Y., Norberg, C., Santamäki Fischer, R. & Lövheim, H. (2015). Self-transcendence (ST) among very old people – Its associations to social and medical factors and development over five years. *Archives of Gerontology and Geriatrics, 61*(2), 247-253.

IV. Norberg, C., Santamäki Fischer, R., Isaksson, U. & Lämås, K. Spirituality as it is perceived and expressed by the very old people. *In manuscript*.

Introduction

The ontological assumption for this thesis is that a human being has bodily, psychological, social and spiritual needs. Spiritual needs are independent of gender, age, culture and epoch. To be human is to be vulnerable; in some situations during a life-span the vulnerability will emerge, for example in periods of illness, grief and in advanced age. If a person's suffering is ignored it may lead to spiritual distress. The very old are a particularly vulnerable population and may have difficulties catering for their spiritual needs on their own; their need for care therefore includes a need of spiritual care.

Spirituality can be defined as a religious system of beliefs and values, as perceived meaning, purpose and connection to others, or as a nonreligious system with beliefs and values (Sessanna et al., 2007). Spirituality is universal and personal, whereas religion is often linked to culture and society (McEwen, 2005). Spirituality is understood in this thesis as an overarching term and a core of a person's being; religiosity is seen as one of many expressions of spirituality. Through spirituality an individual can find meaning and purpose in life, a sense of peace and connection to other people, to a higher being and to nature. This approach implies that all people are spiritual by virtue of being human. With a holistic view in nursing, a person will be met as a whole, with spiritual as well as bodily needs, based on their personal view of life. Spirituality can be studied within different perspectives, for example experiences related to nature, art, music, and meditation. In this thesis the main focus has been to study spirituality in relation to a higher being and religiosity.

To understand spirituality and religiosity, it needs to be studied in different ways. To gain an understanding of spirituality and religiosity among the very old and to identify associations to other factors, valid and reliable assessments are required. This thesis contributes with knowledge about psychometric properties of instruments for assessing religiosity and spirituality (religious orientation and self-transcendence), and associations between spirituality and factors known to strengthen or threaten well-being. Furthermore, the thesis adds knowledge about how very old people perceive and express spirituality.

The age group in focus in the thesis is people aged 85 and older, the term used for the age group is “very old”. “Older” people refers to people 55 years and older. Particularly in study IV there were many expressions of an external force that had significance for the participants' spirituality, for example higher being, divine one and something bigger than oneself. All these expressions are referred to as ‘God’ in this thesis.

Background

Spirituality and religiosity seem to have a relation to health. Even though Sweden is assumed to be secularised, based on the national Society, Opinion and Media survey (SOM) (Bromander, 2013) that included individuals aged 16-85 years old, 45 percent reported that they believe in God. Among those aged 65 to 85 years, 54 percent reported that they believe in God. The fact that spirituality and religiosity seems to increase later in life are confirmed in a longitudinal study where it was found to increase significantly from mid-fifty to late adulthood (Wink & Dillion, 2002). Spirituality and religiosity were found to increase more among women than men. An identification as religious, having a religious social network (Ysseldyk et al., 2013), participating in religious activity (Fry, 2000), experiencing existential well-being, and to pray (Lawler-Row & Elliot, 2016) have been found to be positively related to health among older people.

Frailty and challenges in advanced age

When very old, the risk of frailty is high and there is a need for adaption to new life circumstances. The risk of health problems, being dependent in activities of daily life, and dependence on healthcare services are common in old age (Næss et al., 2017). In a sample of very old people in Sweden (n=992) in whom multimorbidity was common, 34% were diagnosed with angina pectoris, 29% with heart failure, 27% with dementia and 20% with previous stroke (Boström et al., 2016). Fear of being dependent on care has been reported, and to be independent was regarded important (Larsson et al., 2009). Among very old people (n= 392), 67% were living in a residential care facility and 75% were dependent in Activities of Daily Living (ADL), (Boström et al., 2014) and thereby dependent of care. Furthermore, it is common to live alone in older age in Sweden; findings in Niklasson et al. (2015) show that 80.2% were living alone, and among people 60-90 years old 44.2% reported feelings of loneliness (Koc, 2012). In an interview study, loneliness was found to be living with loss of bodily function and of independence, and mourning of significant others (Graneheim & Lundman, 2010). In a review (Luanaigh & Lawlor, 2008), loneliness was found to have associations to depression, physical health and cognition, and in another study loneliness had a significant positive association with depression (Bergdahl et al., 2011). Together, the picture of older age seems to imply risk of frailty and the need for adaption to life circumstances (Jopp & Rott, 2006), and spirituality is suggested to have an impact on the possibility to adapt (Dalby et al., 2011, Manning, 2012).

Spiritual care

Caring for the whole person, including one's spiritual needs, has been a reality for the nursing discipline since it was founded. Florence Nightingale emphasised the need for nurses to honour the spiritual as well as the physical aspects of patients to promote their health (Macrae, 2001). Henderson (1991) categorised nursing activities into 14 components, based on human needs. Beside bodily needs, she also highlighted psychological and spiritual needs. According to the International Council of Nursing (2012), nurses are expected to provide care with respect to individual spiritual beliefs. However, it is difficult to recognise and handle existential issues (Sundler et al., 2016). In focus group interviews, nursing staff requested more knowledge to deal with patients' existential questions, and discussed the lack of documentation about existential or psychosocial concerns (Browall et al., 2010). Høgsnes et al. (2016) studied healthcare professionals' documentation about end of life care for patients with dementia disease living in nursing homes. The result showed that physical symptoms particularly were documented, but only one notation was interpreted as being related to existential/spiritual needs. There were no notes about dialogue with residents about end of life care and death. However Strang et al. (2014) identified living, dying and relationships as common topics in conversation with patients close to death, and stated that it is a responsibility for nurses to open up for spiritual conversations. Findings in Rykkje et al. (2013) show that spiritual support may be of greater importance in crisis and near the end of life, because severe illness fosters inner turbulence and struggle with existential thoughts and religious questions. Spiritual support was connected to feelings of dignity, which can also be described as feeling like a whole person. The findings revealed that spiritual care, including religious support, could be met by the healthcare personnel or by the chaplains, and that it was important for experiencing human dignity in old age.

The concept of spirituality and religiosity

In a study (Torskenæs et al., 2015) among health professionals and unhealthy adults the meanings of the words spirituality, religiousness, and personal beliefs were studied and found to be interconnected; spirituality included religiousness and personal beliefs included personal values. Spirituality was expressed as being an important element for a person to experience wholeness in life; religion was said to give an existential meaning to life; and personal beliefs were found to be impacted by personal view of life and culture. According to Koenig (2008) there are various approaches to understanding and defining religiosity and spirituality. From *a traditional-historical perception,* spirituality is embedded in a religious context, being religious is necessary but not enough for being spiritual. Individuals described as spiritual are those who dedicate their lives to religion, individuals deeply involved in religious activity or sincerely seeking to develop a

religious view and way of life. *The modern perception of spirituality* is a broad, overarching, inclusive construct and a popular term for describing a wide range of people and experiences almost always referring to something good. Religion is included in spirituality but spirituality expands beyond religion. Spirituality applies to persons from diverse religious backgrounds and to those with no religious background at all. *The tautological perception of spirituality* is similar to the modern, but extends out even further to include positive mental health and human values as part of the definition. *The modern clinical perception of spirituality* includes not only religiosity and positive indicators of mental health, but also secular spirituality. In this model everyone is spiritual (Koenig, 2008). The distinction between spirituality and religiosity has a short history (Cohen et al., 2012). For the very old spirituality and religiosity might be understood as mostly the same.

Spirituality in a health care context

There are a variety of ways to conceptualise spirituality. Weather et al. (2016) identified three attributes of spirituality in the nursing research literature (n=47) published from 1972 to 2005. Three defining attributes for spirituality were identified: namely, a feeling of *connectedness* (to self, to others, to God or to a higher power); *transcendence* (beyond self, everyday living, and suffering); and a sense of *meaning in life*. A review of research articles (n=40), among people with varying religious affiliations, and atheists, the most common attributes include: meaning, beliefs, connection, self-transcendence and value (Stephenson & Berry, 2015). According to a conceptual analysis by Vachon et al. (2009) spirituality yield 11 dimensions. The most frequent dimensions of spirituality in research articles (n=71) published 1996-2007 were meaning and purpose in life, self-transcendence, and transcendence with a higher being. The dimension of meaning and purpose was an inevitable part of spirituality of almost all definitions reviewed, self-transcendence was the second most cited dimension of spirituality, and transcendence with a higher power was the third most cited dimension, characterised by a feeling of connection and a mutuality with a higher being (Vachon et al., 2009). In a concept analysis of spirituality, Haase et al. (1992) described spirituality as an inherent characteristic in all human beings. Love and understanding are described as enablers to spiritual growth, while fundamental life events can trigger the development of spiritual perspective. Spirituality can be expressed through an organised religion or in other ways. Among older people the concept of spirituality was connected to an intrinsic sense of being (Williams, 2008; Shaw, 2016), a belief system (Creel & Tillmann, 2008), a personal experience (Shaw, 2016), and as a connectedness to an outside force (Schwarz & Fleming Cottrell, 2007). Spirituality was further connected to a belief about a higher power (Creel & Tillman, 2008), a relationship with God (Shaw et al, 2016; Williams, 2008; Kotrotsiou-Barbouta, 2006), and with other people

(MacKinley, 2006). Spirituality was connected to religion but at the same time beyond religion (Rykkje et al., 2013). However, being spiritual or religious was described as independent of the church building (Shaw et al., 2016). Together, in studies among older people, spirituality is interconnected to religion, a feeling deep inside, independent of affiliation to a church. The concept of spirituality is multifaceted and there appear to be personal experiences around why it cannot be easily defined.

Religiosity and religious orientation

According to MacKinley (2006), spirituality can be seen to include religion. Allport & Ross (1967) define religiosity as being intrinsically or extrinsically oriented. Intrinsic religiosity is characterised by mature, committed, and internally motivated religion. Needs and motives are brought into harmony with religious motives and prescriptions, which are organised and integrated in the deeper life of a person. Extrinsic religious orientation is utilitarian in the sense that religious behaviours are employed to secure positive rewards. A person with a mature religiosity – conceptualised as intrinsically motivated – "lives his religion". A person with an immature religiosity – conceptualised as extrinsically motivated – "uses his religion" (Allport and Ross, 1967, p. 434).

Religiosity has been found to have positive as well as negative associations with well-being. For example, spirituality can ease stressful life events if God is seen as a supportive partner (Pargament et al., 1998). However, religious struggle with a troubling relationship to God or a higher power was, in a meta-analysis, linked to anxiety, guilt, depression, loneliness, social withdrawal and isolation (Ano & Vasconcelles, 2005). Furthermore, self-assessed well-being among older widowed people was found to have a negative relationship with prayer (Lee Roff et al., 2007). The negative relationship was suggested to depend on the fact that praying may be used as a coping strategy during crises and thereby occur more frequently. Several studies also report positive relationships; for example, less depression, anxiety and distress (Ano & Vasconcelles, 2005). Religiosity has been studied in relation to fear of death among older people. It was found that people scoring as highly religious had less fear of death than people who scored low or moderate religiousness (Wink & Scott, 2005). Among students, church attendance have been found to contribute to perceived social support and well-being (Doane et al., 2014). In summary, the studies above describe religious activities from different perspectives; on one hand, to have a relationship with a higher being and on the other hand companionship in a social context. These perspectives can be expressed in terms used by Allport (1956) and seen as an example of intrinsic and extrinsic oriented religiosity (Allport, 1956). Distinguishing between intrinsic and extrinsic ways of being religious are suggested to contribute to our understanding of the impact of religion in people's

lives (Koenig et al., 2001). For example, among older people admitted to intermediate care for rehabilitation, Yohannes et al. (2008) found that intrinsic religiosity was significantly related to older age and to less severe depression, and that church attendance was related to positive perception of health. The authors suggest that it can be understood either that those who are healthy may be more able to attend church or as those who attend church derive benefits of being a part of it, and may get support from other church members. Ardelt (2003) found that intrinsic religious orientation correlated significantly to purpose in life, subjective well-being, and acceptance of death among older people. Furthermore, people rated with extrinsic religious orientation feared death more, and had lower subjective well-being (Ardelt 2003). Pooja and Shabana (2017) examined the relationship between intrinsic and extrinsic religious orientation among adolescent in India. Findings revealed the intrinsic religious orientation was significantly and positively correlated with self-acceptance, which is one domain of psychological well-being. Hovemyr (1994) constructed and evaluated a Swedish scale to measure religious orientation in relation to success and failure among religious and non-religious students. The religious students who attributed success to God's help and/or an answer to prayer, had significantly higher self-esteem than those who did not (Hovemyr, 1998). The Swedish religious orientation scale has not previously been tested for validity in a group of very old people.

Self-transcendence

Spirituality is also described to include self-transcendence (ST) (Vachon et al., 2009). Within nursing, Pamela Reed developed the ST theory using three sources: an inspiration from Marth E. Rogers' Life Span Development Theory (1994); disequilibrium between person and environment as an important trigger of human development as a life-long process; and evidence from clinical experiences among depressed older people. ST refers to the capacity to expand self-boundaries in a variety of ways; *intrapersonal* through reflections and awareness of beliefs, values and dreams, *interpersonal* refers to the environment relations to others, *temporal* domains refers to an integration of past and future in the present, and *transpersonal* domains refers to a capacity to connect with dimensions beyond the visible world (Reed, 2008). ST is described as a vital resource for well-being in vulnerable older adults (Haugan et al., 2014; Nygren et al., 2005; Reed, 1991b). According to Reed (2009) individuals who face human vulnerability and life-threatening experiences obtain an increased capacity for self-transcendence.

ST has been studied in a variety of perspectives and contexts. In a study (Garcia-Romeu et al., 2015), 15 healthy adults were asked to tell about experiences of ST understood as a feeling of connectedness to something larger than an everyday

sense of self. Certain situations, contexts and activities were connected to ST experiences; for example, stress, being outdoors in nature, religious/spiritual ceremonies, prayer, meditations and dance. They described bodily experiences, for example, shivering, hyper-ventilation, out of body experiences or direct revelation. The experiences were reported as being followed by decreased anxiety, increased concern for others, and a shift in world-view. Furthermore, Coward (1990) studied the lived experiences of ST in women with breast cancer. Self-transcendence was expressed in terms of reaching out beyond self, to help others, to permit others to help them, and to accept the present unchangeable events. ST has also been studied according to associating factors among old people and has been found to be positively related to resilience (Nygren et al., 2005), successful ageing (McCarthy et al., 2013), well-being (Haugan et al., 2013), and quality of life (Haugan et al., 2016) and had a negative association to depression (Kim et al., 2014; Stinson & Kirk, 2006). Findings in McCarthy et al. (2015) show that ST explained 47% ($p<0.001$) of the variance in successful ageing. Ageing successfully involves one's mind, body, and spirit, understood as an individual's perceived favourable outcome in adapting to changes associated to very old age (Flood, 2006).

Haugan et al. (2013) reported that interpersonal ST, comprising for example, of involvement with other people and sharing wisdom and helping others, directly affected social and emotional well-being. Intrapersonal ST, comprising, for example, self-acceptance and adjustment to the present situation, directly affected functional well-being and indirectly influenced physical, emotional and functional well-being. Among the same sample, Haugan et al. (2016) showed that participants scoring high on intrapersonal ST comprising, for example, self-acceptance and adjustment, were nearly four times more likely to report better quality of life. In summary, ST has been identified as a developmental resource for well-being, a feeling of purpose in life and for adjustment to life-circumstances, and is associated with decreased depression, social relations, being active, and believing in something greater than oneself. However, it is unknown if ST changes during a life-span and whether it is associated with negative life events and longevity.

Assessing spirituality and religiosity in a health care context

There are several ways to assess spirituality and religiosity within nursing research; Cohen et al. (2012) conclude that much of the existing literature uses a single or few questions to study the topic. The existing measures have diverse approaches. Cohen et al. deemed that the researcher needs to decide whether to assess belief, behaviour or outcome of spirituality or religiosity based on the purpose of the study. Hall et al. (2008) reviewed measures most commonly found in the health research literature, and found instruments that had various

approaches; religious attendance, private religious activities, religious orientation, multidimensional measures that combine attendance and private activities, functional measures of religiosity, religious well-being, religious coping, quest, belief and value, affiliation, maturity, history, and experiences. In a review by Monod et al. (2011) the findings show that among 35 instruments used in clinical research, only three had been validated in older people, and that only one was validated with nursing home residents. The lack of validated instruments is problematic and may impede the production of trustworthy knowledge about spirituality and religiosity; the knowledge in turn is of utmost importance in developing qualitative nursing care to the rapidly growing population of older people.

Experiences of spirituality

Additionally, experiences of spirituality among older people have been studied from different perspectives. Spirituality is reported to be perceived as being connected to religiosity and to God or a higher being (Dalby, et al., 2011; Manning, 2012; Shaw et al., 2016). Several studies describe the meaning of spirituality. For example, older women attribute their relationship with and belief in God as a resource for support, resulting in strength and ability to cope with life's challenges (Manning, 2012). Participants in Williams (2008) also related spirituality as a resource for dealing with life challenges. For older people with dementia disease, a relationship with God was a source of comfort, strength and a means of coping with their illness. They also expressed support from religious communities and a network of prayer (Dalby et al., 2011). In Schwarz and Fleming Cottrell's study (2007) participants expressed their reliance and dependency on spirituality during their rehabilitation period. Spirituality helped them to define their true meaning and purpose in life, to cope and acquire an optimistic outlook about their future and recovery from illness. In a study among women undergoing breast diagnosis, God was experienced as one who nurtures, guides, watches over, cares, heals and helps. For women with a firm belief in God, praying was a strategy to meet their spiritual needs; their own prayers and those of others aided the women (Logan et al., 2006). The knowledge of experiences of spirituality among the very old (85 years of age and older) are scarce. Within the Umeå 85+/GERDA study, very old people's health and life-situation have been studied from different perspectives (Weidung, 2016; Hörnsten, 2016; Niklasson, 2015; Mathillas, 2013; Molander, 2010; Hedberg, 2010; Lövheim, 2008; Santamäki Fisher, 2007; Nygren, 2006 & Alex, 2007); however, the experiences of spirituality among the very old included in the Umeå 85+/GERDA study have not earlier been studied. In order to facilitate older people to attain spiritual development, professionals need to recognise and give space for spiritual activities. However, to be able to recognise spiritual needs, professionals need to know how very old people perceive and express spirituality.

Rationale

The elderly population is an increasingly growing group. Spirituality as described above is suggested to play an important role for successful and good ageing. Being a very old person can imply vulnerability in both a physical and a spiritual way. The influence of spirituality on well-being for the very old is well-documented, and for the very old, a relationship to God and spiritual experiences seem to be of crucial importance in their life. Meeting spiritual as well as physical needs is claimed to be an important part of everyday nursing care and a requirement to enhance holistic and individual care. In order to learn and understand more about the impact of spirituality, valid and reliable questionnaires are needed. However, there is lack of questionnaires relating to religiosity and self-transcendence tested for validity and reliability among very old people. Furthermore, knowledge about how religious and spiritual beliefs are perceived and expressed among very old people is scarce.

Aim

The overall aim of this thesis was to assess psychometric properties of instruments and to gain understanding about associations and experiences in relation to spirituality and religiosity among very old people.

The specific aims of the studies

Study I: To test the appropriateness, feasibility and ability of the shortened version of the Swedish Religious Orientation Scale (SROS) to distinguish between intrinsic and extrinsic religious orientation among very old people.

Study II: To evaluate the psychometric properties of the Swedish version of the Self-transcendence Scale (STS), with focus on factor structure.

Study III: To describe the associations between ST and psychological and physical well-being, and to test the influence of negative life events on ST, and the predictive value of ST for mortality.

Study IV: To illuminate how very old people perceive and express spirituality.

Methods

The thesis is built on three studies using quantitative design, and one study using qualitative design.

Study designs

As this project is part of the Umeå 85+/GERDA study, analyses in study I-III are built on data drawn from the GErontological Regional DAtabase. Participants in study IV are a sub-sample of participants in the Umeå 85+/GERDA study. An overview of the studies is given in Table 1.

***Table 1**. Overview of studies, participants, design, data and analysis*

	Participants	Design	Data	Methods of analysis
Study I	Umeå 85+/GERDA study (n=43). All participants considered themselves as Christian believers.	Quantitative Cross-sectional	SROS	Descriptive statistics. Boot-strap resampling. Hierarchical cluster analysis.
Study II	Sample 1 Umeå-85+/GERDA study (n=198). Sample 2 Convenience sample (n=60).	Quantitative Cross-sectional	STS RS SOC PIL PGCMS	Descriptive statistics. Principal component analysis (PCA). Confirmatory factor analysis (CFA). Ordinal alpha. Spearman's rank correlation. Inter-item & item-total correlation. Test-retest reliability.
Study III	Participants from the Umeå 85+ /GERDA study. Base-line (n=190). Five-year follow-up (n=55).	Quantitative Cross-sectional and longitudinal	STS revised version MMSE PGCMS GDS Barthel's Index of ADL Katz' index of ADL Medical diagnosis Index of negative life events	Descriptive statistics. Independent sample *t*-test. Paired sample *t*-test. Bivariate Pearson's correlation. Multiple Cox proportional hazard regression. Linear regression analysis.
Study IV	The Umeå 85+/GERDA study. (n=12). Purposive sampling.	Qualitative	Narrative interviews	Qualitative Content Analysis.

Settings

The thesis is conducted within the Umeå 85+/GErontological Regional DAtabase (GERDA), which is a multi-professional collaboration between the Department of Nursing and the Department of Community Medicine and Rehabilitation at Umeå University (cf. von Heideken Wågert, 2006). The Umeå 85+/GERDA study has been conducted every five years since 2000. The data were originally collected in the city of Umeå and five rural municipalities in the county of Västerbotten in northern Sweden. In the second and third wave of the study, 2005-2007 and 2010-2012, Ostrobothnia in Western Finland was also included. Participants were selected from the population register from the National Tax Board in Sweden and the population Register Centre in Finland. Half of those aged 85, all 90 years old, and all aged 95 and older was invited to participate. Potential participants were initially sent a letter with information about the study. These individuals were later contacted by phone in order to collect informed consent to participate. If necessary, due to cognitive impairment, informed consent was additionally collected from next of kin (cf. Näsman et al., 2017).

Participants

Inclusion criteria in this thesis, as well as being included in the Umeå 85+/GERDA study, was the ability to complete Likert-type questionnaires. The specific inclusion criteria for study I (SROS), was their own identification as Christian believers. Before administrating the SROS, the interviewer asked whether they considered themselves Christian. Out of 71 potential participants who were asked to participate, 43 answered positively and were included in the study. Their age was 87-101 years old, with an average age of 92. Of these, 86% (n=37) were women. Data collection was performed in the year 2005.

Study II (STS) was based on two different samples: sample 1 (n=198), was 85-103 years old, average age 88.9 years (sd. 4.1); of these 63.6% (n=126) were women. The specific inclusion criteria was that they had completed the STS. Sample 2 (n=60), was a convenience sample with no specific inclusion criteria other than being Swedish speaking. Their ages ranged from 21 to 69, with a mean age of 39.2 (sd. 9.6); of these 26% (n=39.2) were women. Data collection was performed in the year 2000.

Study III (STS) is a cross-sectional and longitudinal study. Participants at base-line (n=190), had an average age of 88.8 years (sd. 4.1.); of these 65% (n=123) were women. At a five-year follow-up, 55 people were still alive and able to complete the STS a second time. Participants at follow-up had an average age of 91.3 (sd. 2.4); of these 81.8% (n=45) were women. At base-line 147 (77.4%) participants were living in their own house or apartment, At the five-year follow

up 17 (31.5%) were living in residential care facilities. Data collection was performed in the year 2000 and 2005.

Participants in study IV were a sub-sample of the participants in the Umeå 85+/GERDA study, included in 2015 and living in an urban area in Västerbotten County of Sweden (n=12), aged 86-99 years of age, average age 89.7 years. Of these, 10 were women. The specific inclusion criteria for participating were self-reported membership in a spiritual or a religious society or church, experiencing spiritual or religious activity as significant for their well-being, and scoring 20 points or more on the MMSE. Data collection was performed in the year of 2017.

Procedure and data collection

In this thesis, questionnaires (study I, II, III, sample 1) as well as narrative interviews (study IV) were used in order to collect data. Data collection took place in the participants' homes. The interviewer read aloud the items included in the questionnaires, and participants indicated responses on a large-print copy of the alternatives. The participants indicated responses on the scale either verbally or by pointing to an option on the answer sheet. When the participant indicated their responses, the interviewer filled them in on the questionnaires (cf. Isaksson et al., 2007). For test-retest reliability, the STS was distributed to and collected from the participants in person or by mail; they completed the STS on two occasions with an interval of three to four weeks (study II, sample 2).

In order to illuminate perceived and expressed spirituality, narrative interviews were conducted. The topics were: their personal interpretation of the concept of spirituality, spiritual/religious development from childhood to old age, and situations of connectedness to a higher power. The opening question was "Please can you tell me how you perceive spirituality?" Their narratives were followed up with clarifying questions, for example, "when you said... what did you mean?", "Can you tell me more about that?", "What do you think about that?", and "What does that mean to you?" All interviews were tape-recorded and transcribed verbatim. Interviews ranged 26-60 minutes, with an average time of 40 minutes (study IV).

Descriptions of questionnaires and assessments

Swedish Religious Orientation Scale (Study I)
The Swedish Religious Orientation Scale (SROS) was developed to identify and measure religious orientation in a Swedish context (Hovemyr, 1994). It is a 28-item likert-type scale aimed to measure intrinsic religious orientation (SROSI) (10 items), extrinsic religious orientation (SROSE) (12 items), and Quest (6

items). The SROS includes items from the Religious Orientation Scale (Allport & Ross, 1967), the Religious Life Inventory (Batson & Ventis, 1982), the Intrinsic Religious Motivation Scale (Hoge, 1972) as well as new items specially written to reflect Swedish conditions (Hovemyr, 1994). In this study, only the subscales SROSI and the SROSE have been used. The response alternatives range from 1 (strongly disagree) to 5 (strongly agree). The possible range of scores for the SROSI was 10-50 and for SROSE 12-60, with 50 and 60 representing a high degree of SROSI and SROSE respectively. Cronbach's alpha for intrinsic (I)-items in a Swedish context was .89 and for extrinsic (E)-items .82 (Hovemyr, 1996a).

Self-Transcendence Scale (Study II & III)

The Self-Transcendence Scale (STS) was developed to identify characteristics of later life that reflect expanded boundaries of the self (Reed, 1991b). It is a 15-item Likert-type scale with response alternatives for individual items ranging from 1 (not at all) to 4 (very much). The possible range of scores is 15-60, with 60 representing the highest degree of self-transcendence (ST). The STS was translated to Swedish by Nygren et al. (2005). Cronbach's alpha in the original version of the STS was over .90 (Reed, 1986), and in the Swedish version .70 (Nygren et al., 2005). The revised STS is a revised version with 10 items. The possible range of scores is 10-50, with 50 representing the highest degree of ST.

Resilience Scale (Study II)

The RS was developed to identify personality characteristics that moderate the negative effects of stress and promote positive adaption (Wagnhild & Young, 1993). It is a 25-item Likert-type scale with response-alternatives from 1 (totally disagree) to 7 (totally agree). The possible range of scores is 25-175 with 175 representing the highest degree of resilience (Wagnhild & Young, 1993). The RS has been translated to Swedish (Nygren et al., 2004). Cronbach's alpha in the original version of the RS was .91 (Wagnhild & Young; 1993) and the Swedish version ranges from .85 to .88 (Nygren et al., 2004).

Sense of Coherence Scale (Study II)

Focus on the Sense of Coherence Scale (SOC) is salutogenesis (Antonowsky, 1987), with items related to comprehensibility, manageability and meaningfulness (Lindblad et al., 2016). The original scale comprises 29 items. The Umeå 85+/GERDA study uses the 13-item scale with response-alternatives ranging from 1 (never) to 7 (always). The possible range of scores is 13-91 with 91 representing the highest degree of sense of coherence (Antonowsky, 1987). The SOC has been translated to Swedish by Langius and Björvell (1993). Cronbach's alpha in the original version with 13 items ranges between .74 and .91 (Antonowsky, 1993). The Swedish version with 13 items has shown an alpha of .80 and above (Lindblad et al., 2016).

Purpose in Life Scale (Study II)
The Purpose in Life Scale (PIL) was developed to quantify the existential concept of purpose in life. It is a 20-item Likert-type scale with response alternatives from 1 (low degree) to 7 (high degree). The possible range of scores is 20-140 with 140 representing the highest degree of purpose in life (Crumbaugh, 1968). The PIL has been translated to Swedish by Åkerberg (1987). Cronbach's alpha for the Swedish version is reported as .84 (Hedberg et al, 2010).

Philadelphia Geriatric Center Morale Scale (Study II & III)
The Philadelphia Geriatric Center Morale Scale (PGCMS) was developed as an indicator of psychological well-being. It has 17 questions with response alternatives yes or no. The possible range of scores are 0-17. Lawton (1975) considered a total score between 0 to 9 points to indicate low morale, 10-12 intermediate, and 13-17 high morale. The PGCMS has been translated to Swedish (von Heideken Wågert et al., 2005). Cronbach's alpha in the original version was .81 (Lawton, 1975) and for the Swedish version .74 (Niklasson et al., 2015).

Mini-Mental State Examination (Study III)
Participants' cognitive state in study III was assessed using the Mini Mental State Examination (MMSE), which is a test of cognitive aspects of mental function, e.g. orientation, memory, ability to follow verbal and written commands. The possible total range of score is 0-30 and the higher the score the better the cognition (Folstein et al., 1975). A total score of 18-23 indicates mild cognitive impairment, a score of ≤ 17 indicates severe cognitive impairment (Tombaugh & McIntyre, 1992). The English version of the MMSE has good test-retest reliability (0.89) (Folstein et al., 1975) and among very old people with cut-off ≤ 24, an acceptable sensitivity (0.85), and specificity (0.80) (Kahle-Wrohleski et al., 2007).

Geriatric depression scale (Study III)
Depressive symptoms were screened using the Geriatric Depression Scale (GDS), the possible total range of score is 0-15. A score of 0-4 indicates no depression, 5-9 indicate mild depression, and 10 or more indicates moderate to severe depression (Yesavage et al., 1983). Cronbach's alpha in a group of very old people ranged from 0.636 (MMSE 28-30) to 0.821 (MMSE 5-9) (Conradson et al., 2013).

Barthel's Index of Activities of Daily Living (Study III)
Barthel's Index of Activities of Daily Living (ADL) is a 10-item measure for assessing self-care and mobility of daily living. The possible range of score is between 0-20 and the higher the score the better ADL-function, with the maximum score of 20 indicating total independence in personal ADL (Mahoney & Barthel, 1965).

Katz Index of ADL (Study III)

The Katz Index of ADL, including both instrumental and personal ADL, was used for assessing functional status, specifically ability to independently perform activities of daily living. The index ranks adequacy of performance in the following six functions: bathing, dressing, toileting, transferring, continence, and feeding. If no supervision, direction or personal assistance is required, 1 point is given to that functional activity. If the individual needs personal assistance, or total care is required, then a 0 is assigned to that functional activity A total score of 6 indicates full function, 4 indicates moderate impairment, and 2 or less indicates severe functional impairment (Katz et al., 1963).

Medical diagnosis (Study III)

Medical diagnoses were collected from the participants in person, cross-checked in their medical records at hospital clinics and primary healthcare centres, and reviewed by an experienced geriatrician. Some of the medical diagnoses are included in the index of negative life events described below.

Index of Negative Life Events (Study III)

The index of negative life events (Lövheim et al., 2013) is based on 13 items included in the Umeå 85+/GERDA study and was designed to cover a wide range of events that might be considered as major negative life events. Four common and serious medical conditions (stroke, myocardial infarction, hip fracture and depression), two items concerning loss of close relatives, two items (decrease in ADL functioning and institutionalization) representing loss of independence, three items concerning cognitive and communicational abilities, and two items of subjective negative events (occurrence of loneliness and crisis in life) were included. The Barthel's ADL index and MMSE scale were continuous variables where all the others were dichotomous and scored one point for each affirmative answer. Hence the calculated negative life event index scored 0-15 points, where a higher score means more negative life events.

Analysis

Statistical analysis

Descriptive statistics were used for participant's characteristics and for items range, mean and median (study I, II & III). Resampling with boot-strap technique and hierarchical cluster-analyses were used to identify inter-related items in the SROS (study I), (Suzuki & Shimodaira, 2006). The Mann-Whitney U-test was used to compare mean STS among men and women. To explore the association between age and STS score, linear regression analyses were used (study II).

Since uni-dimensionality is a requirement for Classical test theory, the separate dimensions in the STS were treated separately. For structural validity, principal component analyses (PCA) were used. The PCA were estimated using a weighted least square means and variance adjusted method, based on polychoric correlations. Before interpretation of the factor structure, an oblique rotation method was applied. Statistics used to assess goodness-of-fit were chi-square (χ2GoF), root mean square of approximation (RMSEA), standardised root mean square residual (SRMR), comparative fit index (CFI), and Tucker Lewis Index (TLI). For concurrent criterion validity, Spearman's *r* correlation was calculated between the STS and RS, SOC, PIL and PGCMS (study II).

Internal consistency was estimated with ordinal alpha, inter-item correlation and item-total correlation with polychoric correlation. Test-retest reliability for each item was evaluated with Agreement (%), weighted Cohen Kappa statistics (Kw), and polychoric correlation coefficient. Boot-strapping with 1,000 replications was conducted before estimation of a 95% confidence interval. Test-retest on scale level was evaluated with intra-class correlation coefficient (ICC) and Lin's concordance correlation coefficient (CCC). Test-retest for individuals was evaluated with the absolute reliability measure and the repeatability coefficient. The heteroscedasticity of the scale was investigated with rank correlation coefficient (study II).

For identifying differences between groups in study III, Independent sample *t*-tests were used; for comparing STS scores between base-line and follow-up, paired sample *t*-test were used, and correlation between physical and mental function, medical disorders, living arrangements, social contacts and feelings of loneliness and pharmacological drug use and STS score, bivariate Pearson's *r* were used. Finally, regression analyses were used for associations between STS score, mortality and for negative life events. A *p*-value of <0.05 was considered significant (study III).

In study I, where 13 values (1.4%) were missing in 10 different items, missing values were replaced with the mode value for the actual item. In study II, 10 values (0.3%) were missing in nine different items; missing values were replaced with mode value for the actual item. For statistical calculation in study I, the Statistical Package for Social Sciences (SPSS) version 12 and R, were used. SPSS version 22 was used in study II and III, and Stata 13.1, Mplus 7.1, and R 3.0.3 for Mac OSX in study III.

Qualitative analysis

For analysis of narratives in study IV, qualitative content analysis (QCA), (Graneheim & Lundman, 2004; Graneheim et al., 2017), was chosen, since it offered the opportunity to answer the aim of the study about experiences of spirituality in a systematic way. QCA is a method for analysing qualitative data and is commonly used in nursing research (Elo et al., 2014). QCA emphasises similarities within, and differences between, parts of the text (Graneheim et al., 2017). The interviews were transcribed verbatim; thereafter the text were read through several times to get a sense of the whole. Text related to spirituality constituted the unit of analysis. The essential features of the text were placed into meaning units and these were condensed without losing the central meaning, and labelled with codes. The codes were thereafter, through mind-mapping, sorted into 16 categories. A category is a group of content that shares something in communality (Graneheim & Lundman, 2004). In the next step these categories were transformed into preliminary sub-themes and themes. Throughout the analysis, the research team reflected on and discussed the codes, sub-themes and themes. The results of the study have been discussed in research seminars at the Department of Nursing, Umeå University.

Ethical considerations

All data collection in the Umeå 85+/GERDA study was conducted by interviewers in the home of the very old people. The interviewers were used to communicating with very old people with functional difficulties (Isaksson et al., 2007). Before an appointment was made for a home visit, a letter was sent out to the participants with information about the purpose of the research study, the voluntary participation, their right of withdrawal and that they could abstain from answering questions, and about confidentiality. Before the data collection started, the same information was given verbally.

Very old people are a particularly vulnerable group in research, with restricted strength to participate in extensive data collection. The interviewers were observant of whether the interview was becoming too tiring for the participant and in such cases offered to take a pause or come back another day. When

gathering data, the interviewer proceeded gently, respectfully and were sensitive to the participants' needs. The participants were also invited to contact the researcher after the home visit if he or she had any questions.

Sharing experiences, thoughts and feelings on becoming and being very old and about personal faith/beliefs may be a sensitive topic and cause discomfort. However, most of the participants expressed the view that it was interesting and valuable to participate. In the interview-study the participants expressed their appreciation for being asked to share their story; spirituality is an uncommon topic to talk about and some of their experiences had not previously been told. They also expressed a sense of relief that somebody actually listened. Other studies have noted that the act of narrating can result in relief for the participants (cf. Gaydos, 2005; Buckley et al., 2013). The study was approved by the Regional Ethical Review Board in Umeå, Sweden (99-326; 05-063M; 09.178M; 2017-26-32M).

Results

Religious orientation among very old people (Study I)

The results show that the very old scored high according to both intrinsic and extrinsic religiosity. The mean value for the intrinsic subscale, with 10 items, was 41.1 (s.d. 8.5; Md 43; IQR 35-49) and for the extrinsic subscale, with 12 items, it was 42.2 (s.d. 6.9; Md 43; IQR 38-46). Among the very old, the mode-value for intrinsic subscales was 50 and for extrinsic subscale, 44.

For the items in the intrinsic subscale, the median ranged from 4 to 5 (IQR 2-5), the mode value for all items was 5, indicating a high agreement in all items. The items in the extrinsic subscale median were spread more widely and ranged from 1 to 5 (IQR 1-5). The mode values for extrinsic items were 1 to 4. Item E10, statement about motivation to pray, had a median of 2.0, while E11 and E12, statements about religiosity as being beneficial and securing positive rewards, had a median of 1, which indicates that many of the participants disagreed with the statements. The items are presented in English and Swedish in Table 2 and 3.

The ability to distinguish between intrinsic and extrinsic values were analysed by means of cluster analysis, which revealed three clusters of interrelated items, (Figure 1). As expected, the intrinsic and extrinsic items loaded in different clusters. One cluster included items measuring intrinsic religious orientation and two clusters emanated from items measuring extrinsic religious orientation. The first cluster included items I5, I9, and I10, and was interpreted as characterising a religious faith that influences the individual's attitude to life. The second cluster included items E6 and E7, and was interpreted as a religious faith that is expected to give help, protection, comfort and reassurance. The third cluster included items E11 and E12, and was interpreted as a religious faith that is shallow but useful in times of distress.

Table 2. *Mean, median (md), mode value and interquartile range (IQR) for each item in the SROSI subscale (n=43)*

Intrinsic items (I)	Mean	Md	Mode	IQR
I1. I would probably be a Christian even if there were no hope of life after death. *Jag skulle nog gärna vara Kristen även om det inte fanns hopp om evigt liv.*	4.5	5	5	5-5
I2. If unavoidable circumstances do not prevent me from doing so, I attend church. *Om jag ej hindrats av oundvikliga omständigheter går jag i kyrka*	4.0	5	5	3-5
I3. Religion is important to me because it gives an answer to many of the most important questions in life. *Religionen är viktig för mig därför att den besvarar många av de viktigaste livsfrågorna*	4.5	5	5	4-5
I4. Praying is for me a way to seek stillness and the presence of God and not primarily an opportunity to ask for something. A*tt be är för mig ett sätt att söka stillhet och Guds närvaro och inte i första hand ett tillfälle att be om något*	4.6	5	5	5-5
I5. It is probably wise to seek the guidance of God before making an important decision. *Man bör nog söka Guds ledning innan man fattar ett mycket viktigt beslut*	3.6	4	5	3-5
I6. There have been moments in which I have experienced the presence of God in a tangible way. *Det har funnits tillfällen då jag upplevt Guds närvaro på ett påtagligt sätt*	4.0	5	5	3-5
I7. It is important for me to find time for religious reflection and meditation. *Det är viktigt för mig att få stunder då jag kan ägna mig åt religiösa reflektioner och meditation.*	3.9	5	5	3-5
I8. If you are to be a member of a church, it is important that you believe in what you do and dare to stand up for it. *Ska man vara med i en kyrka så är det viktigt att man tror på vad man gör och vågar stå för det*	4.6	5	5	5-5
I9. My religious conviction actually lies behind my whole attitude to life. *Min religiösa övertygelse ligger i själva verket bakom hela min inställning till livet*	3.9	5	5	3-5
I10. I really try to make my religious conviction influence everything I do in life. *Jag försöker verkligen få min religiösa övertygelse att påverka allt jag gör I livet.*	3.5	4	5	2-5
Intrinsic subscale; sum	41.1	43.0	50	35-49

Response ranging from 1, which represents 'strongly disagree', to 5 which represents 'strongly agree'. Possible range of score 10-50, with 50 representing high degree of intrinsic religious orientation.

***Table 3**. Mean, median (md), mode value and interquartile range (IQR) for each item in the SROSE subscale (n=43)*

Extrinsic items (E)	Mean	Md	Mode	IQR
E1. If one could be certain that praying produced results, it should be worthwhile to pray more often. *Om man kunde vara säker på att bön ger resultat skulle det vara värt att be lite oftare*	*3.4*	*4*	*4*	*1-5*
E2. The meaning or purpose of prayer is the feeling of security and harmony it can give the individual *Meningen med bön ligger i att den kan ge individen en känsla av trygghet och harmoni*	4.2	*5*	*0*	*5-5*
E3. Even if my religious faith is important to me, I feel that there are other things in life more important to me. *Även om min religiösa tro är viktig för mig känner jag att det finns många andra saker här i livet som är viktigare för mig*	*3.3*	*4*	*3*	*2-5*
E4. The turmoil in the world these days makes that you can feel safe having a religious conviction. *Oroligheterna i världen på senaste tiden gör att det kan kännas tryggt att ha en religiös övertygelse*	4.4	5	1	4-5
E5. It doesn't really matter what you believe in, as long as you live in a morally impeccable way. *Det spelar inte så stor roll vad man tror på så länge man lever på ett moraliskt oklanderligt sätt*	2.8	3	3	1-4
E6. The most important reason for praying is to get help and protection. *Den viktigaste anledningen till att be är att få hjälp och beskydd*	4.1	5	2	3-5
E7. It is good that there is a church since all of us can get into situations when we need comfort and reassurance. *Det är bra att kyrkan finns för alla kan ju råka ut för situationer då man behöver få tröst och uppmuntran*	4.6	5	0	5-5
E8. Even if I see myself as a religious person, I do not let religious views influence my daily behaviour. *Även om jag betraktar mig som religiös låter jag inte religiösa synpunkter påverka mitt dagliga handlande.*	3.4	4	4	1-5
E9. More than anything, religion gives you comfort, when you are struck by grief of misfortune. *Vad religionen framför allt ger är tröst när man drabbas av sorg och olycka*	4.6	5	0	5-5
E10. I pray mainly because I have been taught to do so. *Jag ber främst därför att jag fått lära mig att göra så.*	2.7	2	3	1-4
E11. The church really does not give very much, but it is good to go there occasionally to get to know the pastors, just in case. *Kyrkan ger i och för sig inte så mycket men det kan vara bra att gå dit då och då för att lära känna prästerna för säkerhets skull.*	2.1	1	2	1-3
E12. Now and then I find it necessary to compromise with my religious conviction in order not to end up in social or financial difficulties. *Då och då finner jag det nödvändigt att kompromissa med min religiösa övertygelse för att inte råka i sociala eller ekonomiska svårigheter*	2.0	1	2	1-3
Extrinsic subscale; sum	42.2	43	44	38-46

Response ranging from 1, which represents 'strongly disagree', to 5 which represents 'strongly agree'. Possible range of score 12-60, with 60 representing high degree of extrinsic religious orientation.

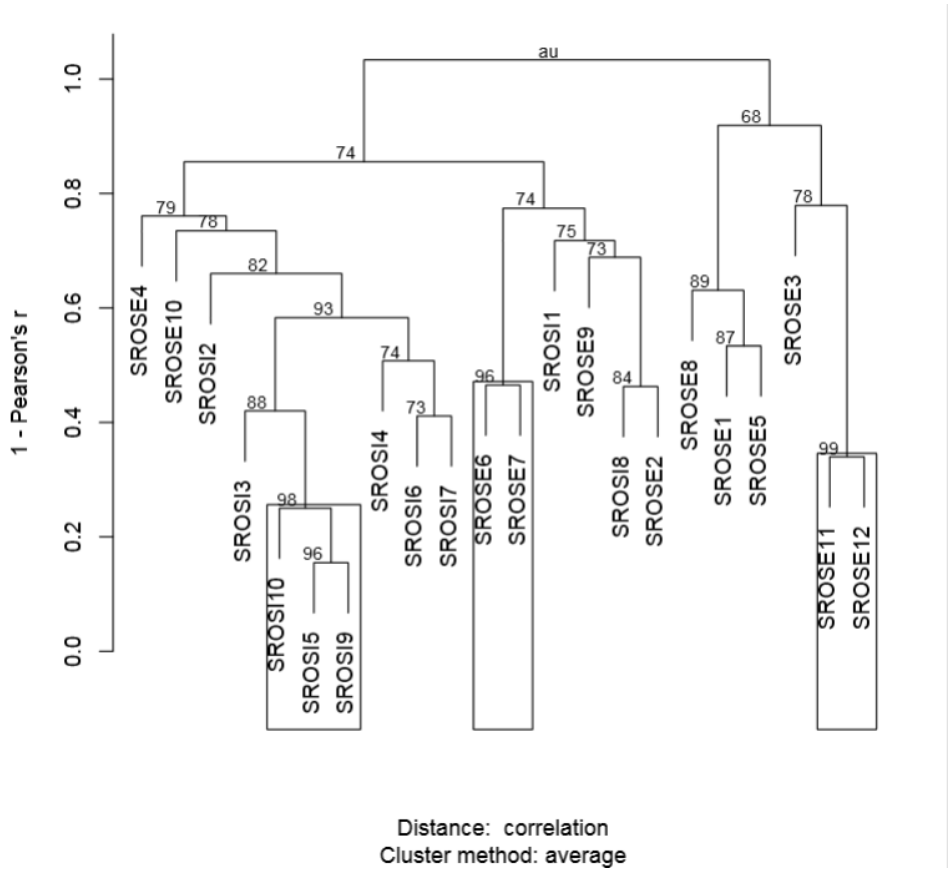

Figure 1. *Cluster diagram including all items from the SROS. Distances are measured as 1 – Pearson's r. The numbers at each connection are AU (approximately unbiased) p-values, which were computed multiscale bootstrap resampling the rectangles indicate clusters of high probability (>0.95) probability.*

Self-Transcendence Scale, psychometric properties (Study II)

The results show that both the very old and the convenience sample scored high on STS, for the original STS. The median score for the very old was 48 with no significant differences between gender and age. The convenience sample, who answered the STS on two occasions (test-retest), scored 47 on both occasions. The items are presented in English and Swedish (Table 4).

Structural validity for the original STS, evaluated with explorative factor analysis, resulted in a five-factor solution. Based on the factor loading and the item-total correlation, five items were excluded (item 7, 10, 12, 13 & 15); item 7 due to lack of significant factor loading in the five factor solution, and items 10, 12 and 13 due to low correlation with the total STS score. Item 15 had a combination of these problems. The revised STS including 10 items resulted in a two factor solution with acceptable fit indices. The correlation between the two factors was 0.63. After excluding five items, the possible range of scores in the revised STS was 10-40, with 40 representing the highest degree of self-transcendence. The items in English and Swedish and factor loadings for the revised STS are presented in Table 4.

Concurrent criterion validity was based on four questionnaires measuring related concepts. The revised STS correlated as expected between the revised STS and RS (r = .50); SOC (r =.25); PIL (r =.64); and PGCMS (r =.37).

Internal consistency was strong for both the original STS (0.82), and the revised version with five items removed (0.83).

According to Dawson and Trapp (2000), the test-retest reliability for each item demonstrated: moderate (0.41-0.60) for items 1, 2, 3, 4, 5, 7, 9, 14 and 15; good (0.61-0.80) for items 6, 8, 10, 11 and 13; or very good (0.81-0.92) test-retest reliability for item 12. Test-retest reliability on scale level shows an acceptable level for the original STS with intra-class correlation coefficient (ICC) and Lin's concordance correlation coefficient (CCC) over 0.7.

Table 4. *STS-items and factor loadings*

In this period in life I think of myself as a person who are: *I den här perioden av mitt liv ser jag mig som en person som:*	Factor 1	Factor 2
1. Having hobbies or interests I can enjoy		.454
Har hobbys eller intressen som skänker mig glädje		
2. Accepting myself as I grow older	.507	
Accepterar mig själv allteftersom jag blir äldre.		
3. Being involved with other people or my community when possible.		.606
Engagerar mig I andra människor och I samhället när det är möjligt.		
4. Adjusting well to my present life situation	.628	
Anpassar mig väl till min nuvarande livssituation		
5. Adjusting to the changes in my physical abilities	.760	
Anpassar mig till mina fysiska förutsättningar		
6. Sharing my wisdom or experience with others.		.687
Delar med mig av min livsvisdom och mina livserfarenheter		
7. Finding meaning in my past experiences.	X	
Upplever mina tidigare erfarenheter som meningsfulla		
8. Helping younger people or others in some way.		.668
Hjälper både yngre personer och andra på ett eller annat sätt		
9. Having an interest in continuing to learn about things.		.685
Är intresserad av att fortsätta lära mig saker		
10. Putting aside some things that I once thought were so important	X	
Kan bortse från saker som jag tidigare tyckte var så viktiga.		
11. Accepting death as a part of life	.460	
Accepterar döden som en del av livet.		
12. Finding meaning in my spiritual beliefs	X	
Finner mening I min religiösa tro		
13. Letting others help me when I may need it	X	
Kan ta emot hjälp av andra när jag behöver det.		
14. Enjoying my pace of life	.413	
Njuter av att ta livet I min egen takt		
15. Dwelling on my past unmet dreams or goals	X	
Grämer mig över mina tidigare drömmar och mål som inte förverkligats.		

X = removed from analysis. English version in plain text, Swedish in italics.

Self-transcendence, associations and development (Study III)

The revised STS was used in study III. At base-line the STS scores ranged from 17-40 with a mean of 31.4 (sd. 4.5). At the five-year follow up STS scores were 31.8 (sd. 4.1). The mean difference between the first and second measurement was 0.42 (sd. 4.2).

Among participants at base-line a significant negative association was found between a lower STS score and living in an institution (*p* .005), not being able to go outdoors independently (*p* .004), feeling lonely (*p* .013), dementia (*p* .039), osteoporosis (*p* .007) and depression (*p* .007); and pharmacological treatment with anxiolytics, hypnotics or sedatives (*p*. 013). In the same sample, a significant positive association was found between higher STS scores and having a good friend (*p*. 050) or someone in their family to talk with (*p* .002), and among those who did not take any drugs at all (*p* .003). Those with better cognitive function (*p* .004), better balance (*p* .021), better nutritional status (*p*. <.001), higher morale (*p* <.001), less symptoms of depression (*p* <.001), higher self-rated health (*p* <.001), an amount of outdoor walking (*p*. <.001), and visits to other places in the previous week (*p* .001), had a higher STS score.

STS score at base-line did not relate to survival over five years (*p* .173). The analysis of the STS score and its association to index of negative life events shows a significant correlation (*p* <.005), the more negative life events the larger decline in STS score (p .049).

Perceptions and expressions of spirituality (Study IV)

The results of study IV contain three themes and eight sub-themes. The themes are 'feeling connectedness', 'transcending life's circumstances' and 'living in a spiritual reality'. The themes and sub-themes are presented in Table 5.

Experience of spirituality was expressed as *feeling connectedness*. The participants talked about their feelings of connectedness with something they could not explain but still recognised. They expressed a trusting relationship to God where they experienced how God had been giving them support through their life-span. The trusting relationship had been affected by experiences in childhood or from important others. The participants expressed their desire to talk about their experiences of God and about their faith but they usually did not; they were *shielding the relationship with God*. The experiences of spirituality were described as a sensitive topic and difficult to share with somebody, and they described a fear of being ridiculed if they talked about these experiences and about their relationship with God. Experience of connectedness was also expressed as *feeling affinity with others*; they told about their feelings of

closeness to people in various situations. For example, they told about situations from childhood when they had experienced a close connectedness with parents or grandparents, about activities that opened up for feelings of connectedness when singing together. Attending church and being helpful to other people was also described as a way to obtain affinity with other people.

The participants told about demanding situations and difficult conditions during their life-span without bitterness. The interpretation was that they had *transcended life's circumstances* and expressed *reconciliation with life*. They told about believing that life and health was a gift from God and therefore they expressed a responsibility to be grateful and accept life the way it had been and the way it was. They also expressed an *awareness of mortality* and a preparedness for changes in health and that life will end.

The participants described *living in a spiritual reality*; they told about situations when they had *perceived mysteries in daily living*. They described visions, unnatural and bodily sensations, and feelings of a spiritual reality always presence and close by. The spiritual reality was expressed as something greater than which they could really understand. They talked about being *amazed about the Creator,* they interpreted nature as an announcement of God's greatness. But they also expressed *querying an inconceivable God*. God was described as on one hand being a loving and caring God but on the other as having allowed the world to be afflicted by cruelty and evil. The duplicity was told to be difficult to understand and accept.

***Table 5**. Overview of sub-themes and themes revealed in the analysis*

Sub-themes	Themes
Having a trusting relationship with God	Feeling connectedness
Shielding the relationship with God	
Feeling affinity with others	
Reconciliation with life	Transcending life's circumstances
Living in awareness of mortality	
Perceiving mysteries in daily living	Living in a spiritual reality
Being amazed about the Creator	
Querying an inconceivable God	

Discussion

This thesis has focused on religiosity and spirituality among very old people. Psychometric tests of questionnaires for religious orientation (SROS) and self-transcendence (STS) was conducted. The associations between the revised ST and psychological and physical well-being, negative life events, and mortality was explored. Furthermore, expressed and perceived spirituality was also illuminated.

In the psychometric test of SROS, the SROS clustered as expected. One cluster included intrinsic items, which represent an inner force for religiosity, and two clusters with extrinsic items which represent an external motivation for religiosity. The result thereby shows that the SROS has the potential to distinguish between intrinsic and extrinsic religiosity among very old people. The separation of intrinsic and extrinsic factors was also found by Hovemyr (1996b) in a previous study of the psychometric properties of SROS among Swedish students. In contrast to Hovemyr (1996b), the extrinsic subscale in our study produced two separate clusters. However, the same deviation of the extrinsic subscale into two parts have been found in earlier studies (Darvyri et al., 2014; Ghorbani et al., 2002; Kirkpatrick, 1989), which supports the idea that the extrinsic subscale has two factors. In our study, items included in the second cluster were interpreted as the extrinsic personal aspects of religiosity, and the third cluster was interpreted as the extrinsic social aspect of religiosity (c.f. Gorsuch & Pherson, 1989). An extrinsic personal aspect concerns importance of having support from other people in church and from God, while an extrinsic social aspect concerns relations that could be useful in times of distress.

Corresponding results to statements in SROS were found in study IV. Intrinsic aspects concerning praying as a way to seek stillness and the presence of God, experiencing God in a tangible way, and finding time for religious reflection and meditation corresponds to findings in study IV. The participants (study IV) expressed having a constant ongoing communication with God; they expressed the feeling that God cared for them and helped in everyday challenges. Extrinsic personal aspects, which concern support from God and other people, were also found in study IV. The participants (study IV) expressed the significance of being enclosed in a community with people with whom they can share experiences and beliefs. The participants also described a trustful relationship with a supporting God. Thus, the relevance of the extrinsic personal statements in SROS are supported by the results from the interviews. According to statements in the extrinsic social subscale, there are no obvious connections with findings in study IV.

Results from study I show that the very old scored high on both subscales in SROS, which indicates that the very old people included in this study were religious in both an intrinsic and extrinsic manner. The fact that the participants scored high on both subscales contradicts the assumptions by Allport and Ross (1967), who suggest that an individual either has a mature religiosity, i.e. scoring high on intrinsic subscale, or immature religiosity, i.e. scoring high on the extrinsic subscale. Allports and Ross's suggestions have, though, been criticised by Hill and Hood (1999), who proposed that the same person can have high values on both subscales, thus having both intrinsic and extrinsic religious orientation, which is in line with findings from study I.

Due to the result of the factor structure (study II), five items were excluded from the original STS, and the revised version include ten items. The revised version of the STS was found to be reliable and valid, and can be recommended for measuring ST among very old people. Internal consistency in the revised version of STS was 0.83. Corresponding results were found in the Korean version of STS 0.85 (Kim et al., 2012). Internal consistency for the factor with intrapersonal items was 0.78 and for the interpersonal factor, 0.73, compared to the Norwegian version of Haugan et al. (2012) with a Cronbach's alpha of 0.75 intrapersonal and 0.64 for interpersonal factor. In the literature, an acceptable range of alpha value from 0.7 to 0.9 is proposed (Streiner et al., 2015), which strengthens the assumption that the items in ST are measuring the same construct. Furthermore, the result revealed an overall good reliability of STS. Since there are no "golden standards" to measure ST, scales supposed to measure similar phenomena were used in study II to assess concurrent criterion validity. The STS correlated with RS, SOC, PIL and PGCM, which supports the concurrent criterion validity. According to Koenig (2011), correlations (*r*) between psychosocial and behavioural variables such as spirituality – which are difficult to measure precisely – a correlation of 0.1-0.2 might be considered small, 0.2-0.3 moderate, and everything above 0.3, strong. That means that STS is suggested to have strong associations with RS, PIL, PGCMS, and a moderate association with SOC, as expected.

STS is suggested to have four dimensions (Reed, 2009). A factor analysis in study II resulted in a two factor solution with no cross-loadings; one factor including items about adjustment to old age and acceptance of death (intrapersonal ST), and the other factor including items about being involved with other people (interpersonal ST). In the factor structure, statements about integration of one's past and future in the presence (temporal ST), and to connect to a spiritual reality (transpersonal ST), loaded in the intra- and interpersonal factors and did not load separately. The same results were reported in a Norwegian study among nursing home residents, despite the fact that the original version of STS, including 15 items, was used (Haugan et al., 2012). In contrast, in a Korean study which used

STS with 15 items, the factor analysis ended up in a four-factor solution, thus the four dimensions in the original scale were supported by Kim et al. (2012). The reason why five items did not load in our cluster analysis is unknown; one reason could be cultural aspects in the translation, more precisely, depending on diverse meaning of words in different languages. Some of the items may not have relevance for very old people, for example 'letting others help me when I may need it'. However being very old may imply decreased functions and increased dependency of help in daily living, and thereby receiving help can be of necessity.

SROS and STS have been constructed within a western culture and a Christian context. An inclusion criteria in study I was that the participants were Christian believers. In study I, seven items congregated, with a high probability in three different clusters. Those seven items are expressed in a general way without any clear connection to Christian religion. With a few adaptions in wording (God, Church), SROS could probably be used in other contexts and religions. The Allportian ROS has been translated and used in a group of Muslim students in Iran, where the study supported the cross-cultural validity of the Allport's intrinsic and extrinsic religious orientation (Ghorbani et al., 2002). This suggests that there are features in religiousness that are universal. According to spirituality in study IV, the participants expressed that spirituality includes a connectedness to a trustful God and people. Corresponding findings have been reported in studies among older people with varied cultural and religious back-ground, an essential characteristic of spirituality among all included groups was found to be a deep connection to God and others (Cohen et al., 2008). The similarities between results in study IV and the Cohen et al. (2008) study supports earlier findings that spirituality is a universal phenomenon (McEwen, 2005). Even if religions differ and are linked to culture and society, the religiousness and spirituality may have universal features (cf. McEwen, 2005).

In study III, the results revealed a negative association between spirituality and depression, assessed with GDS, which includes statements about, for example, dissatisfaction with life, activities and interests, worries about the future, etc. There are statements in STS that have commonalities with statements in GDS; enjoying life, having and enjoying interests, and adjustment to old age, etc. According to Koenig (2008), there are instruments assessing spirituality which are contaminated with mental health indicators, which of course will correlate and thereby show a positive association with mental health. Maybe the fact that spirituality is a multifaceted concept that is difficult to capture in a definition (c.f. Sesanna et al., 2007) has an impact on the construction of questionnaires, and risks an influence of related concepts and thereby contamination. However, several statements in STS correspond to descriptions in study IV that illuminated perceptions and expressions of spirituality. The STS statements about adjusting well to life-situations and the ageing process, finding meaning in past

experiences, and accepting death as a part of life, correspond well with results in study IV. In study IV the participants talked about reconciliation with life circumstances, experiences of life that they afterwards found meaningful, and about death as a natural part of life. Findings in study IV support the fact that topics in STS concern spirituality.

In study III, the results show that having a friend or family to talk to, or a number of visits in the previous week, were significantly associated with a higher degree of ST. Furthermore, study III showed a significant negative association between ST and living in a geriatric care institution. Living in institutions has been reported to bring experiences of being abandoned due to poor communication with staff, and a lack of autonomy and privacy (Anderberg & Berglund, 2010), and being trapped and confined in institution, no longer a part of a larger community (Namkee et al., 2008). On the other hand, if the resident manages to create a private space in the institution, where they feel safe and have a possibility for interaction with other people, they could experience the institution as their home (Nakrem et al., 2011). To be living at home has been found to be connected to autonomy, privacy and self-identity and made it possible to continue living with essential values. Living at home offers time and space for thoughtful reflections on both sad and joyful times. Home held memories of shared experiences with loved ones and enabled the very old to having a presence in the present as well as in the past (Stones & Gullifer, 2016). The descriptions about living at home correspond to descriptions of self-transcendence by Reed (2008). Self-transcendence has been described as a capacity to expand bodily limitations by reflections about the past and future, in the present. Together, the findings in the literature (Anderberg & Berglund, 2010; Nakrem et al., 2011; Namkee et al., 2008; Stones & Gullifer, 2016), show a disparate picture of living in an institution. It is therefore difficult to know if it is the living in an institution per se or if it is other factors that explain the association between ST and living in geriatric care institutions.

A higher score of ST did not affect longevity (study III), but ST is suggested to be of importance for successful ageing (McCarthy et al., 2013). ST has previously been found to have positive associations with well-being (Haugan et al., 2013) and quality of life (Haugan et al., 2016) among very old people. This indicates that ST may be of importance to quality in life rather than quantity in years. The results in study III also revealed that an accumulation of negative life events was significantly associated with lower ST. In the theory of self-transcendence (Reed, 2009), it is supposed that negative life events trigger the development of ST. However, there seems to be a point where life challenges are too overwhelming and instead of being a developmental factor, ST decreases. There is an increased risk that very old people experience several negative life events: decline in physical and mental function (Boström et al., 2016); lose independence and move

to care facilities (Neass et al., 2017); experience bereavement around the death of significant others (Lee-Roff, 2007), etc. All these factors may increase vulnerability among the very old and thereby present a risk for a declining ST. In an attempt to increase ST, some care programs have been tested, however, with weak results. With a purpose to strengthen ST Coward (2003) tested an intervention among women with breast cancer. The interventions included for example relaxation training, assertive communication skills and problem solving. However, no significant differences were identified between intervention (n=22) and control group (n= 17). In a study among older women (n=24), structured reminiscence group sessions for six weeks resulted in a non-significant increase in ST (Stinson & Kirk, 2006). McCarthy et al. (2015) developed the Psychoeducational Approach to Transcendence and Health (PATH) Program, which included group processes, mindfulness practice, and creative experiences. The effectiveness of the PATH program was evaluated and showed a positive non-significant result (McCarthy et al., 2017). These studies (Coward, 2003; McCarthy et al., 2017; Stinson & Kirk, 2006) included few participants (n=18-39) and it is therefore difficult to draw conclusions if the interventions were ineffective or if the small study groups was the reason for the lack of significant results.

The results from study IV – where very old connected spirituality to a belief in God and religion – showed that the very old had an ongoing and trustful relationship with God. These results are in accordance with previous research indicating that a belief in God is very central to the life of very old people. Santamäki Fischer et al. (2007) found the relationship with God as a basis for consolation in old age and in a study among older women belief in God was a resource for support, resulting in strength and ability to bounce back from adversity (Manning, 2014). Results from Dalby et al. (2011) show that old people with dementia continued to live out their pre-existing spirituality and faith, and that it was a source of comfort and strength, helping them to cope with the difficulties of having dementia. Creel and Tillman (2008) found that even among younger people who had declared themselves as non-religious, the participants who uttered beliefs about a higher being, expressed that their belief led to a positive internal feeling. In study IV, the participants talked about death as a natural part of life; none of them expressed fear of death and they expressed a conviction about an immortal soul and about reunion with loved ones. This is in accordance to results in Santamäki Fisher et al. (2007), where death was described as being on the move to a better land; in Shaw et al. (2016), the results described death as another part of life and, in Creel and Tillman (2008), death was related to belief about an afterlife. The participants in study IV expressed a belief and experiences of a spiritual reality, they told about experiences of mysteries in life and a conviction about guardian angels, watching and caring about them. This is in concordance with Santamäki Fischer et al. (2007) who

found that very old people also expressed a belief about having a personal protector, a guardian angel who accompanied them.

In study IV, spiritual experiences were not commonly related to attending church but a part of everyday experiences. Some of the participants had limited opportunities to attend church due to physical health problems and lack of strength. For some of the participants their relationship with God had never been dependent on activities in the church during throughout their lives. The description in study IV shows a multifaceted picture of spirituality. Several studies use affiliation and attendance as measures of spirituality (Moberg, 2008); however, this may be too limited to gain an understanding of the significance and the impact of spirituality among the very old, and instead might lead to a risk for bias (c.f. Hall et al., 2008).

Methodological considerations

Study I-III

The quantitative studies (Study I-III) are based on cross-sectional data. There are some well-known advantages and disadvantages with such a design; some problems are that data provide just a snap-shot in time and it is impossible to differentiate cause and effect from simple associations, for example, if ST is a protective factor for depression or if depression leads to lower ST. However, advantages of this kind of data collection are that it is possible to identify associations that can be used for designing further studies (Mann, 2003).

Data was collected in study I, II and III via home visits via face-to-face interviews in the participant's home. With this method, people with impaired hearing, impaired vision or a decline in cognitive function could be included in the study (cf. DeVellis, 2012). In a face-to-face interview, attributes of the interviewer may affect the responses given, partly caused by interviewer bias; the interviewer may have prejudices or ask leading questions, and subtly communicate what answer they want to hear (Streiner et al., 2015). Isaksson et al. (2007) elucidated support given to very old people in the Umeå 85+/GERDA study, according to the process of completing the research questionnaire. The result revealed that it was possible to gather valid data from very old people using face-to-face interviews. The interviewers were trained to talk to very old people with functional disabilities, which is suggested to minimise the risk of interviewer bias. A common problem with survey research is to obtain sufficiently large response rates; the data collection method using face-to-face interviews minimised the risk for incomplete data, and the extent of missing data was low (cf. Isaksson et al., 2007).

To gain reliable results in studies including questionnaires, there are certain requirements for the statements included. In SROS, the meaning of some of the

items was unclear and may have been confusing for the respondents (I5, I9, E3, & E9), some of the items are lengthy statements (I4, I7, I8, E3, E7, E11, & E12), some have negations or negative prefixes (I1, I2, I4, E5, E8, & E11), and some are double-barrelled (E3, E4, E5, E11, & E12.). In the literature, item construction is discussed (DeVellis, 2012). Items should be clear and not ambiguous, and should not require reading skills beyond that of a 12-years old, which means short words and short sentences that are simpler to read and understand. According to Fry cited in DeVellis (2012) items with less than 15 to 16 words and 20 syllabus are recommended. Negatively worded items, such as not, never, or words with negative prefixes should be avoided (DeVellis, 2012; Streiner et al., 2015). In light of DeVellis (2012) and Streiner et al. (2015) the ambiguity in the items will be a risk for confusion and thereby produce questionable results. However, in this study the respondents had the opportunity to have the items clarified in dialogue with the interviewer (cf. Isaksson et al, 2007), which may have compensated for unclear item construction.

Study IV

As a follow-up of the quantitative studies we chose a qualitative design for study IV, which allows the participants to describe what is meaningful or important to them about spirituality. In study IV, narrative interviews and qualitative content analysis were used. The choice of design and method stems from a desire to illuminate spirituality as described by the very old. There is always some degree of interpretation when approaching a text (Elo et al., 2014). The first author discussed all the steps in the research process with the co-authors to ensure trustworthiness. Trustworthiness will be discussed below in relation to the following aspects: credibility, dependability, and transferability (Graneheim & Lundman, 2004).

To enhance credibility, participants were chosen on the basis that they had something to tell about experiences of spirituality and that they should be able to discuss it. Two pilot interviews were performed and the analysis method was pre-tested in one of the pilot interviews (not included in this study). In the analytic process the researchers repeatedly returned to the original text to check whether the interpretation reflected the participant's voice and to check how well the themes were covering the data (cf. Elo et al., 2014). There is a risk that pre-understanding will influence the analysis; the findings in study IV have commonalities with the scales used in study I-III. The author's knowledge about religious orientation and self-transcendence theory may have influenced the analysis in study IV.

However, two of the co-authors have been less involved in studies I-III and all co-authors repeatedly discussed interpretations and all steps in the analysis process

to increase credibility. There are no recommended sample sizes in qualitative research (Elo et al, 2014), and data were considered to be rich, and covered variations.

The participants are a sub-sample of the Umeå 85+/GERDA study, before selection of participants' inclusion criteria were decided. To ensure dependability all the interviews started with the same opening question, and the narratives of the interviewees were followed up with clarifying questions. To strengthen the dependability, the interviews were conducted by one interviewer. Though interviewing is a co-creation between the interviewed and the researcher, the interviewer tried not to steer the participants' stories thus minimising the influence of the interviewer's pre-understanding. During the analytic process, categorising and divergent opinions concerning the themes and interpretation of the data have been discussed (cf. Elo et al., 2014), the analysis process ended when the research group reached consensus (cf. Graneheim et al., 2017).

It is the readers' decision whether or not the findings are transferable to another context. To facilitate transferability, the context, selection procedure and characteristics of participants have been described and the result has been discussed in relation to other contexts.

Conclusion, clinical implications, and further research

Spirituality is a complex phenomenon and this thesis contributes to increasing the understanding of the phenomenon within the context of the very old. The results propose that the Swedish version of SROS and STS, aiming to measure religious orientation and self-transcendence have satisfactory psychometric properties and are feasible to use among very old people. Furthermore ST is positively and significantly associated and correlated to a number of factors known to enhance well-being. Spirituality was understood as including religiosity, a belief in God, connectedness to other people and conviction about a spiritual reality.

The very old expressed a desire to talk about spirituality but their fear of being considered as dubious was an obstacle. However within nursing care spirituality almost always is omitted in the care planning among very old people (Høgsnes et al 2016), or reduced to notification about affiliation and attendance. Spiritual needs can be met in various ways. Spiritual care is a responsibility for health care professionals (ICN, 2012). To encourage activities that support spiritual development and a transcendent perspective on life, an openness for spirituality and a readiness to give spiritual care are required. In order to meet spiritual needs it is essential to be open and non-judgmental, to recognise spiritual needs, and to encourage narratives about personal understanding of spirituality.

In this thesis, mostly ethnic Swedes with Christian affiliation are included. Since Sweden is a multi-cultural country with immigrants with various religious affiliations, it is important to further study spirituality and religiosity among these groups. A possible future research could focus on developing an intervention aiming to facilitate spiritual care among very old people.

Acknowlegdement/Tack

Nu när avhandlingen ska gå till tryck vill jag tacka alla de som på ett eller annat sätt bidragit till denna avhandlings tillblivelse. Mitt varma tack går till:

Samtliga deltagare i studierna för att ni trots hög ålder och minskad ork så tålmodigt delat med er av er tid och av era berättelser. Mötet med er har burit mig genom avhandlingsarbetet och bidragit med värdefulla insikter.

Mina högt värderade handledare; *Kristina Lämås, Regina Santamäki Fischer och Ulf Isaksson*, som på olika sätt stöttat mig i mitt arbete. Utan er intet!

Berit Lundman som var min handledare från allra första början, du har alltid fått mig att fatta mod när kraften och modet svikit.

Astrid Norberg som öppnade upp för avhandlingens ämne inom omvårdnads-forskningen.

Samtliga medförfattare i artiklarna; *Sture Eriksson, Yngve Gustafsson, Ulf Isaksson, Berit Lundman, Kristina Lämås, Hugo Lövheim, Astrid Norberg, Regina Santamäki Fischer och Kristoffer Årestedt* för att ni delat med er av ert rika kunnande.

Tidigare och nuvarande *doktorander* vid Institutionen för omvårdnad och *doktorander och forskare* inom Umeå 85+/GERDA studien.

Tidigare och nuvarande *arbetskamrater* vid Campus Skellefteå, Umeå och Ö-vik. Ert stöd har varit ovärderligt, nu ska det bli roligt att åter arbeta tillsammans i kursteam och undervisning.

Människan lever i ett sammanhang; så också jag! Mina tankar går nu till släkt, vänner och familj som på olika sätt har funnits med mig under mitt liv.

Mamma, tack för din kärlek och omtanke. När jag besöker dig är jag ofta såsom en ”Marta”, jag ränner runt och fixar och donar, men mest av allt har jag uppskattat att liksom ”Maria”, sitta vid dina fötter och lyssna. Din berättelse har gett mig en djupare insikt om vad det kan innebära att vara mycket gammal.

Mina syskon, Johan och Viveca med familjer, tack för att ni finns.

Birgitta och Olle, ni gav min barnatro näring så att den kunde utvecklas. Tack vare ert stöd vågade jag kliva över tröskeln för teologistudier vid universitetet. Idag knyter jag ihop säcken!

Brita min kära vän och ”korrelator”. I mer än 30 år har du troget funnits vid min sida. Tack för alla goda samtal, de har burit och bär.

Daniel och Anna, mina älskade barn. När ni föddes trodde jag att jag skulle lära er om livet. Nu när ni är vuxna inser jag vad ni lärt mig.

Emily, my daughter of law, I love you! Now it will be time to visit you and Daniel in your home in Alaska.

Hannes och Elis, ni kom senare in i mitt liv. Jag är tacksam för att få vara innesluten i den Holmqvistska familjen. Om ni inte kommit i min väg skulle jag inte heller fått lära känna familjen Simpson, Seinfeld och Larry.

Mats, för din kärlek och omsorg, och för att du delar det viktigaste med mig – livet.

Sources of funding and support

This work was supported by The Swedish Research Council (grant no. K2014.99X-22610-01-6); the Vårdal Research Foundation; the King Gustav and Queen Victoria's Foundation; a regional agreement between Umeå University and Västerbotten county council in cooperation in the fields of medicine and Odontology at Umeå University; the Detlof Research Foundation; the Swedish Dementia Association; and the European Union and the Regional Development Fund; the Interreg IIA Mitt-Scandia and the Bothnia-Atlantica Program; the Kempe Foundations, the Anna Cederbergs foundations & Foundation of Medical Research, Skellefteå. The Medical faculty & Department of Nursing, Umeå University.

References

Allport, W.G. & Ross, J. M. (1967). Personal religious orientation and prejudice. *Journal of Personality and Social Psychology, 5*(4), 432-443.

Allport, W.G. (1956). *The individual and his religion.* New York, NY: Macmillan.

Aléx L. (2007). *Äldre personers berättelser utifrån ett genus-och etnicitetsperspektiv*. Umeå University Medical Dissertations New series no 1081. Department of Nursing, Umeå University, Umeå, Sweden.

Andersberg, P. & Berglund, A-L. (2010). Elderly persons' experiences of striving to receive care on their own terms in nursing homes. *International Journal of Nursing Practice, 16*(1), 64-68.

Ano, G.G. & Vasconcelles, E.R. (2005). Religious coping and psychological adjustment to stress: A meta-analysis. *Journal of Clinical Psychology, 61*(4), 461-480.

Antonowsky, A. (1993). The structure and properties of sense of coherence scale. *Social Science Medicine, 36*(6), 725-733.

Antonowsky, A. (1987). *Unravelling the mystery of health. How people manage stress and stay well.* San Francisco: Jossey-Bass, 1987.

Ardelt, M. (2003). Effects of religion and purpose in life on elders' subjective well-being and attitudes toward death. *Journal of Religious Gerontology, 14*(4), 55-77

Batson, C.D. & Ventis, W.L. (1982). *The religious experience. A social-psychological perspective.* New York: Oxford University Press.

Bergdahl, E., Allard, P. & Gustafsson, Y. (2011). Depression among the very old with dementia. *International Psychogeriatrics, 23*(5), 756-763.

Boström, G., Hörnsten, C., Brännström, J., Conradsson, M., Nordström, P., Allard, P., Gustafsson, Y. & Littbrand, H. (2016). Antidepressant use and mortality in very old people. *International Psychogeriatrics, 28*(7), 1201-1210.

Boström, G., Conradsson, M., Rosendahl, E., Nordström, P., Gustafsson, Y. & Littbrand, H. (2014). Functional capacity and dependency in transfer and dressing are associated with depressive symptoms in older people. *Clinical Interventions in Aging, 9,* 249-257.

Bromander, J. (2013). Religiositet i Sverige. In Weibull, L., Oscarsson, H. & Bergström, A. (red). *Vägskäl, Göteborgs universitet*: SOM-institutet.

Browall M, Melin-Johansson C, Strang S, Danielson E, Henoch I. (2010). Health care staff's opinions about existential issues among patients with cancer. *Palliative Support Care, 8*(1), 59-68.

Buckley, C., McCormack, B. & Ryan, A. (2013). Valuing narrative in care of older people: a framework of narrative practice for older adult residential care settings. *Journal of Clinical Nursing, 23*(17-18), 2565-2577.

Cohen, M.Z., Holley, L.M., Wengel, S.P. & Katzman, R.M. (2012). A platform for nursing research on spirituality and religiosity: Definitions and measures. *Western Journal of Nursing Research, 34*(6), 795-817.

Cohen, L. H., Thomas, L.C. & Williamson, C. (2008). Religion and spirituality as defined by older adults. *Journal of Gerontological Social Work, 51*(3-4), 284-299.

Conradsson, M., Rosendahl, E., Littbrand, H., Gustafson, Y., Olofsson, B. & Lövheim, H. Usefulness of the Geriatric Depression Scale 15-item version among very old people with and without cognitive impairment. *Aging and Mental Health, 17*(5), 638-645.

Coward, D.D. (2003). Facilitation of self-transcendence in a breast cancer support group: II. *Oncology Nursing Forum, 30*(2), 291-300.

Coward, D.D. (1990). The lived experience of self-transcendence in woman with advanced breast cancer. *Nursing Science Quarterly, 3,* 162-169.

Creel, E. & Tillman, K. (2008). The meaning of spirituality among nonreligious persons with chronic illness. *Holistic Nursing Practice, 22*(6), 303-309.

Crumbaugh, J.C. (1968). Cross-validation of purpose in life test based on Frankl's concepts. *Journal of Individual Psychology, 24*(1), 74-81.

Dalby, P., Sperlinger, D.J. & Boddington, S. (2011). The lived experiences of spirituality and dementia in older people living with mild to moderate dementia. *Dementia*, *11*(1), 75-94.

Darvyri, P., Galanakis, M., Avgoustidis, A.G. Pateraki, N., Vasdekis, S. & Darviri, C. (2014). The revised intrinsic/extrinsic religious orientation scale in a sample of Attica's inhabitants, *Psychology, 5*(13), 1557-1567.

Dawson, B. & Trapp, R.G. (2000). *Basic and Clinical Biostatistics.* 3rd. ed. New York: Lange Medical Books/McGraw-Hill.

DeVellis, R.F. (2012). *Scale development. Theory and applications.* 3rd. ed. London: SAGE.

Doane, M.J., Elliot, M. & Dyrenforth, P.S. (2014). Extrinsic religious orientation and well-being: Is their negative association real or spurious? *Review of Religious Research, 56*(1), 45-60.

Elo, S., Käärinäinen, M., Kanste, O., Pölkki, T., Utriainen, K. & Kyngäs, H. (2014). Qualitative content analysis: focus on trustworthiness. *SAGE Open,* 1-10.

Flood, M. (2006). A mid-range nursing theory of successful aging. *The Journal of Theory, Construction and Testing, 9*(2), 35-39.

Folstein, M.F., Folstein, S.E. & McHugh, P.R. (1975) "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*(3), 189-198.

Fry, P.S. (2000). Religious involvement, spirituality and personal meaning for life: Existential predictors of psychological wellbeing in community-residing and institutional care elders. *Aging and Mental Health, 4*(4), 375-387.

Garcia-Romeu, A., Himelstein, S.P. & Kaminker, J. (2015). Self-transcendent experience: a grounded theory study. *Qualitative Research, 15*(5), 633-654.

Gaydos. H. L. (2005). Understanding personal narratives: an approach to practice. *Journal of Advanced Nursing, 49*(3), 254-259

Ghorbani, N., Watson, P.J., Framarz Ghramaleki, A., Morris, R.J. & Hood, R.W. (2002). Muslim-Christian religious orientation scale: Distinctions, correlations, and cross-cultural analysis in Iran and the United States. *The International Journal for the Psychology of Religion, 12*(2), 69-91.

Gorsuch, R.L. & McPherson, S.E. (1989). Intrinsic/extrinsic measurement: I/E-revised and single-item scale. *Journal of the Scientific Study of Religion, 28*(3), 348-354.

Graneheim, U.H. & Lundman, B. (2010). Experiences of loneliness among the very old: The Umeå 85+ project. *Aging & Mental Health, 14*(4), 433-438.

Graneheim, U.H., Lindgren, B-M. & Lundman, B. (2017). Methodological challenges in qualitative content analyses: A discussion paper. *Nurse Education Today, 56,* 29-34.

Graneheim, U.H. & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24*(2), *105-112.*

Haase, J.E., Britt, T., Coward, D.D., Leidy, K.N. & Penn, P.E. (1992). Simultaneous concept analysis of spiritual perspective, hope, acceptance and self-transcendence. *Journal of Nursing Scholarship, 24*(2), 141-147.

Hall, D. E., Meador, K. G. & Koenig, H. G. (2008). Measuring religiousness in health research: Review and critique. *Journal of Religion and Health, 47*(2), 134-163.

Haugan, G., Moksnes, U.K. & Löhre, A. (2016). Intrapersonal self-transcendence, meaning-in-life and nurse-patient interaction: powerful assets for quality of life in cognitively intact nursing-home patients. *Scandinavian Journal of Caring Sciences, 30*(4), 790-801.

Haugan, G., Rannestad, T., Hammervold, R., Garåsen, H. & Espnes, GA. (2013). Self-transcendence in cognitively intact nursing home patients: A resource for well-being. *Journal of Advanced Nursing, 69*(5), 1147-1160.

Haugan, G., Rannestad, T., Garåsen, H., Hammervold, R. & Espnes, G.A. (2012). The Self-Transcendence Scale. An investigation of the factor structure among nursing home patients. *Journal of Holistic Nursing, 30*(3), 147-159.

Hedberg, P., Gustafson, Y. & Brulin, C. (2010). Purpose in life among men and women aged 85 years and older. *International Journal of Aging and Human Development, 70*(3), 213–229.

Hedberg P. (2010). *Purpose in life among very old people.* Umeå University Medical dissertations New series no 1384. Department of Nursing and Department of Community Medicine and Rehabilitation, Geriatric Medicine, Umeå University, Umeå, Sweden.

von Heideken-Wågert, P., Rönnmark, B., Rosendahl, E., Lundin-Olsson, L., Gustafsson, J.M.C., Nygren, B., Lundman, B., Norberg, A. & Gustafsson, Y. (2005). Morale in the oldest old: the Umeå 85+ study. *Age and Ageing, 34*(3), 249–255.

Henderson, V. (1966). *The nature of nursing: a definition and its implications for practice, research, and education.* New York: Macmillan.

Hill, P.C. & Hood, R.W. (1999). *Measures of religiosity*. Birmingham, Ala: Religious Education Press.

Hoge, R. (1972). A validated intrinsic religious motivation scale. *Journal for the Scientific Study of Religion, 11*(4), 369-376.

Hovemyr, M. (1998). The attribution of success and failure as related to different pattern of religious orientation. *The International Journal for the Psychology of Religion, 8*(2), 107-124.

Hovemyr, M. (1996a). Forms and degrees of religious commitment: intrinsic orientation in a Swedish context. *Journal of Psychology and Theology, 24*(4), 301-312.

Hovemyr, M. (1994). *A Swedish religious orientation scale.* Report from the Department of Psychology, no 787. Stockholm University, Stockholm, Sweden.

Høgsnes, L., Danielsson, E., Norbergh, K-G. & Melin-Johansson, C. (2016). Healthcare professionals' documentation in nursing homes when caring for patients with dementia in end of life – a retrospective record review. *Journal of Clinical Nursing, 25*(11-12), 1663-1673.

Hörnsten C. (2016). *Stroke and depression in very old age.* Umeå University Medical Dissertations New series no 1800. Department of Community Medicine and Rehabilitation, Geriatric Medicine, Umeå University, Umeå, Sweden.

International council of nursing (ICN). (2012). *The ICN code of ethics for nurses*. https://www.scribd.com/doc/23056204/The-ICN-Code-of-Ethics-for-Nurses#

Isaksson, U., Santamäki Fischer, R., Nygren, B., Lundman, B. & Åström, S. (2007). Supporting the very old when completing a questionnaire. Risking bias or gaining valid results. *Research on Aging, 29*(6), 567-589.

Jopp, D. & Rott, C. (2006). Adaption in old age: Exploring the role of resources, beliefs and attitudes for centenaries' happiness. *Psychology and Aging, 21*(2), 266-280.

Kahle-Wrobleski, K., Corrada M.M., Li, B. & Kawas, C.H. (2007). Sensitivity and specificity of the Mini-Mental State Examination for identifying dementia in the oldest-old: The 90+ Study. *Journal of the Geriatric Journal Society, 55*(2), 284-289.

Katz, S., Ford A.B., Moskowitz, R.W., Jackson B.A. & Jaffe, M.W. (1963). Studies of illness in the aged. The index of ADL: a standardized measure of biological and psychosocial function. *Journal of the American Medical Association, 185*, 914–919.

Kim, S.S., Hayward, D. & Reed, P. (2014). Self-transcendence, spiritual perspective, and sense of purpose in family caregiving relationships: a mediated model of depression symptoms in Korean older adults. *Aging and Mental Health, 18*(7), 905-913.

Kim, S.S., Reed, P.G., Youngmi, K. & Jina, O. (2012). Translation and psychometric testing of the Korean versions of the Spiritual Perspective Scale and the Self-transcendence Scale in Korean elders. *Journal of the Korean Academic Nursing, 42*(7), 974-983.

Kirkpatrick, L.A. & Hood, R.W. (1989). Intrinsic-Extrinsic Religious Orientation: The Boon or Bane of Contemporary Psychology of Religion? *Journal for the Scientific Study of Religion, 29*(4), 442-462.

Koc, Z. (2012). Determination of older people's level of loneliness. *Journal of Clinical Nursing, 21*(21-22), 3037-3046.

Koenig, H.G. (2011). *Spirituality and Health Research. Methods, Measurement, Statistics and Resources:* Templeton Press. West Conshohocken, USA.

Koenig, H.G. (2008). Concerns about measuring "spirituality" in research. *The Journal of Nervous and Mental Disease, 196*(5), 349-355.

Koenig, H. G., McCullough, M., & Larson, D. B. (2001). *Handbook of religion and Health*. Oxford: Oxford University Press.

Kotrotsiou-Barbouta, E., Soountzi-Kreptia, D., Roupa-Darivaki, Z., Psychogiou, M., Dimitriadou, A., Paralikas, T., Tzounis, T. & Sgantzos, M. (2006). The meaning of spirituality as it perceived by hospitalized elderly people in a small city of Greece. *ICUS Nursing Web Journal, 28*, 1-7

Langius, A. & Björvell, H. (1993). Coping ability and functional status in a Swedish population sample. *Scandinavian Journal of Caring Sciences, 7*(1), 3-10.

Larsson, Å., Haglund, L. & Hagberg, J-E. (2009). Doing everyday life – experiences of the oldest old. *Scandinavian Journal of Occupational Therapy, 16*(2), 99-109.

Lawler-Row, K.A. & Elliott, J. (2016). The role of religious activity and spirituality *in* the health and well-being of older adults. *Journal of Health Psychology, 14*(1), 43-52.

Lawton, M.P. (1975). The Philadelphia Geriatric Center Morale Scale: A revision. *Journal of Gerontology, 30*(1), 85-89.

Lee Roff, L., Durkin, D., Sun, F. & Klemmack, D.L. (2007). Widowhood, religiousness, self-assessed well-being among older adults. *Journal of Religion and Aging, 19*(4), 43-59

Lindblad, C., Sandelin, K., Petersson, L-M., Rohani, C. & Langius-Eklöf, A. (2016). Stability of the 13-item sense of coherence (SOC) scale: a longitudinal prospective study in women treated for breast cancer. *Quality of Life Research, 25*(3), 753–760.

Logan, J., Hackbusch–Pinto, R. & DeGrasse, C.E. (2006). Women undergoing breast diagnostics: the lived experience of spirituality. *Oncology Nursing Forum, 33*(1), 121-126.

Luanaigh, C.Ó. & Lawler, B.A. (2008). Loneliness and the health of older people. *International Journal of Geriatric Psychiatry, 23*(12), 1213-1221.

Lövheim, H., Graneheim, U.H., Jonsén, E., Strandberg, G. & Lundman, B. (2013). Changes in sense of coherence in old age – a 5-year follow-up of the Umeå 85+ study. *Scandinavian Journal of Caring Sciences, 27*(1), 13-19.

Lövheim H. (2008). *Psychotropic and analgesic drug use among old people. With special focus on people living in institutional geriatric care.* Umeå University Medical Dissertations New series no 1157. Department of Community Medicine and Rehabilitation, Geriatric Medicine, Umeå University, Umeå, Sweden.

MacKinley, E. (2006). Spiritual care: Recognizing spiritual needs of older adults. *Journal of Religion Spirituality & Aging, 18*(2-3), 59-71.

Macrae, J-A. (2001). Nursing as a Spiritual Practice. *A Contemporary Application of Florence Nightingale's Views.* Springer publishing company. Available: http://site.ebrary.com/lib/umeaub/reader.action?docID=10265402

Mahoney, F.I. & Barthel, D.W. (1965). Functional evaluation: the Barthel Index. *Maryland State Medical Journal, 14*, 56-61.

Mann, C.J. (2003). Observational research methods. Research design II: cohort, cross-sectional, and case control studies. *Emergency Medicine Journal, 20*(1), 54-60.

Manning, L.K. (2014). Enduring as lived experience: Exploring the essence of spiritual resilience for women in late life. *Journal of Religion and Health, 53*(2), 352-362.

Manning, L.K. (2012). Spirituality as a lived experience: exploring the essence of spirituality for women in late life. *International Journal of Aging Human Development, 75*(2), 95-113.

Mathillas J. (2013). *Dementia, depression and delirium in the very old: prevalence and associated factors.* Umeå University Medical Dissertations New series no 1595. Department of Community Medicine and Rehabilitation, Geriatric Medicine, Umeå University, Umeå, Sweden.

McCarthy, V.L., Hall, L.A., Crawford, T.N. & Connelly, J. (2017). Facilitating Self-transcendence: An intervention to enhance well-being in late life. *Western Journal of Nursing Research, 6*(17), 1-20.

McCarthy, V.L., Ling, J., Bowland, S., Hall, L.A. & Connelly, J. (2015). Promoting Self-transcendence and well-being in community-dwelling older adults: a pilot study a psychoeducational intervention. *Geriatric Nursing, 36*(6), 431-437.

McCarthy, V.L., Ling, L. & Carini, R.M. (2013). The role of self-transcendence: a missing variable in the pursuit of successful aging? *Research in Gerontological Nursing*, *6*(3), 178-186.

McEwen, M. (2005). Spiritual nursing care. State of the Art. *Holistic Nursing Practice*, *19*(4), 161-168.

Moberg, D.O. (2008). Spirituality and aging: Research and application. *Journal of Religion, Spirituality & Aging*, *20*(1-2), 95-134.

Molander L. (2010). *Blood pressure in advanced age: with focus on epidemiology, cognitive impairment and morality*. Umeå University Medical Dissertations New series no 1372. Department of Community Medicine and Rehabilitation, Geriatric Medicine, Umeå University, Umeå, Sweden.

Monod, S., Brennen, M., Rochat, E., Martin, E., Rochat, S. & Bula, C.J. (2011). Instruments measuring spirituality in clinical research: a systematic review. *Journal of General Internal Medicine*, *26*(11), 1345-57.

Nakrem, S., Guttormsen, Vinsnes, A. & Seim, A. Residents' experiences of interpersonal factors in nursing home care: A qualitative study. *International Journal of Nursing Studies*, *48*(11), 1357-1366.

Namkee, G.C., Ransom, S. & Wyllie, R.J. (2008). Depression in older nursing home residents: the influence of nursing home environmental stressors, coping, and acceptance of group and individual therapy. *Aging & Mental Health*, *12*(5), 536-547.

Niklasson, J., Conradsson, M., Hörnsten, C., Nyqvist, F., Padyab, M., Nygren, B., Olofsson, B., Lövheim, H. & Gustafson, Y. (2015). Psychometric properties and feasibility of the Swedish version of the Philadelphia Geriatric Center Morale Scale. *Quality of Life Research*, *24*(11), 2795-2805.

Niklasson J. (2015). *Morale in very old people: With focus on stroke, depression and survival.* Umeå University Medical Dissertations New series no 1750. Department of Community Medicine and Rehabilitation, Geriatric Medicine, Umeå University, Umeå.

Nygren, B. (2006). *Inner strength among the oldest old*. Umeå University Medical Dissertation, New Series No 1065. Department of Nursing. Umeå University, Umeå, Sweden.

Nygren, B., Alex, L., Jonsén, E, Gustafsson, Y., Norberg, A. & Lundman, B. (2005). Resilience, Sense of coherence, Purpose in life and Self-transcendence in relation to perceived physical and mental health among the oldest old. *Aging and Mental Health, 9*(4), 354-362.

Nygren, B., Björkman Randström, K., Lejonklou, A.K. & Lundman, B. (2004). Reliability and validity of a Swedish language version of the resilience scale. *Journal of Nursing Measurement, 12*(3), 169-178.

Næss, G., Kirkevold, M., Hammer, W., Straand, J. & Wyller, B.T. (2017). Nursing care needs and services utilized by home-dwelling elderly with complex health problems: observational study. *BMC Health Services Research, 17*(645), 1-10.

Näsman, M. Niklasson, J., Saarela, J., Nygård, M., Olofsson, B., Conradsson, M., Lövheim, H., Gustafson, Y. & Nyqvist, F. (2017). Five-year change in morale is associated with negative live events in very old age. *Aging and Mental Health, 21*, 1-8.

Pargament, K.I., Smith, B., Koenig. & Perez, L. (1998). Patterns of positive and negative religious coping with major life stressors. *Journal for the Scientific Study of Religion, 37*, 710-724

Pooja, S. & Shabana, B. (2017). Effects of Intrinsic-Extrinsic Religiosity on the psychological well-being of adolescents. *Journal of Psychosocial Research, 12*(1), 137-145.

Reed, P (2009). Demystifying self-transcendence for mental health nursing practice and research. *Archives of Psychiatric Nursing, 23*(5), 397-400.

Reed, P.G. (2008). The theory of self-transcendence. In. Smith. M.J. & Liehr P.R. *Middle Range Theory for Nursing.* 2nd. ed. Chapter 6, 105-129. Available: https://ebookcentral.proquest.com/lib/umeaub-ebooks/detail.action?docID=423419

Reed, P. G. (1991b). Self-transcendence and mental health in oldest-old adults. *Nursing Research, 40*(1), 105–111.

Reed, P.G. (1986) Developmental resources and depression in the elderly. *Nursing Research, 35*(6), 368-374.

Rogers. M.E. (1994). The science of unitary human being. *Nursing Science Quarterly, 7*(1), 33-35.

Rykkje, L., Eriksson, K. & Råholm, M-B. (2013). Spirituality and caring in old age and the significance of religion – a hermeneutical study from Norway. *Scandinavian Journal of Caring Sciences, 27*(2), 275-284.

Santamäki Fischer R. (2007). *Living in consolation while growing old*. Umeå University Medical Dissertations, New series No 1087. Department of Nursing, Umeå University, Umeå, Sweden.

Santamäki Fischer, R., Nygren, B., Lundman, B. & Norberg, A. (2007). Living amidst consolation in the presence of God. Perceptions of consolation among the oldest old. *Journal of Religion, Spirituality & Aging*, *19*(3), 3-20.

Schwarz, L., & Fleming Cottrell, R.P. (2007). The value of spirituality as perceived by elders in long-term care. *Physical and Occupational Therapy in Geriatrics, 26*(1), 43- 62.

Sesanna, L., Finell, D. & Jezewski, M.A. (2007). Spirituality in nursing and health-related literature. *Journal of Holistic Nursing, 25*(4), 252-262.

Shaw, R. Gullifer, J. & Wood, K. (2016), Religion and spirituality: A quantitative study of older adults. *Ageing International, 41*(3), 311-330.

Steiner, D.L., Norman, G.R. & Cairney, J. (2015). *Health measurement scales. A practical guide to their development and use.* 5th ed. Oxford University Press.

Stinson, C.K. & Kirk, E. (2006). Structured reminiscence: an intervention to decrease depression and increase self-transcendence in older women. *Journal of Clinical Nursing, 15*(2), 208-218.

Stones, D. & Gullifer, J. (2016). At home it's much easier to be yourself: older adults' perceptions of aging in place. *Ageing and Society, 36*(1), 449-481.

Strang, S., Henoch, I., Danielsson, E., Browall, M. & Melin-Johansson, C. (2014). Communication about existential issues with patients close to death – nurses' reflections on content, process and meaning. *Psycho-Oncology, 23*(5), 562-568.

Stepenson, P.S. & Berry, D.M. (2015). Describing spirituality at the end of life. *Western Journal of Nursing Research, 37*(9), 1229-1247.

Sundler, A.J., Eide, H., van Dulmen, S. & Holmström, K. (2016). Communicative challenges in home care of older persons – a qualitative exploration. *Journal of Advanced Nursing, 72*(10), 2435-2444.

Suzuki, R. & Shimodaria, H. (2006). Pvclust. An R package for hierarchical clustering with p-values. Department of Mathematical and Computing Sciences Tokyo Institute of Technology. *Bioinformatics Application Note, 22*(12), 1540-1542.

Svenska kyrkan. https://www.svenskakyrkan.se/statistik

Tombaugh, T.N. & McIntyre, N.J. (1992). The mini-mental state examination: A comprehensive review. *Journal of American Geriatric Society, 40*(9), 922–935.

Torskenæs, K.B., Kalfoss, M.H. & Sæteren, B. (2015). Meaning given to spirituality, religiousness and personal beliefs: exploring by a sample of Norwegian population. *Journal of Clinical Nursing, 24*(23-24), 3355-3364.

Vachon, M., Fillion, L. & Achille, M. (2009). A conceptual analysis of spirituality at the end of life. *Journal of Palliative Medicine, 12(*1), 53-59.

Wagnhild, G.M. & Young H.M. (1993). Development and psychometric evaluation of the resilience scale. *Journal of Nursing Measurement, 1*(2), 165-178.

Weather, E., McCarthy, G. & Coffey, A. (2016). Concept analysis of spirituality: An evolutionary approach. *Nursing Forum, 51*(2), 79-95.

Wiedung B. (2017). *Blood pressure in very old age. Determinants, adverse outcomes, and heterogeneity*. Umeå University Medical Dissertations, New series no 1868. Department of Community Medicine and Rehabilitation, Geriatric Medicine, Umeå University, Umeå, Sweden.

Williams, B.J. (2008) an exploratory study of older adults' perspectives of spirituality. *Occupational Therapy in Health Care, 22*(1), 3-19.

Wink, P. & Scott, J. (2005). Does religiousness buffer against the fear of death and dying in late adulthood? Findings from a longitudinal study. *Journal of Gerontology, 60B*(4), 207-214.

Wink, P. & Dillion, M. (2002) Spiritual development across the adult life course: Findings from a longitudinal study. *Journal of Adult Development, 9*(1), 79-94.

Yesavage, J.A., Brink, T.L., Rose, T.L., Lum, O., Huang, V., Adey, M.B., & Leirer, V.O. (1983). Development and validation of a geriatric depression screening scale: a preliminary report. *Journal of Psychiatric Research, 17*(1), 37-49.

Yohannes, A.M., Koenig, H.K., Baldwin, R.C & Conolly, M.J. (2008). Health behaviors, depression and religiosity in older patients admitted to intermediate care. *International Journal of Geriatric Psychiatry*, *23*(7), 735-740.

Ysseldyk, R., Haslam, S.A. & Haslam, C. (2013). Abide with me: religious group identification among older adults promotes health and well-being by maintaining multiple group membership. *Aging and Mental Health*, *17*(7), 869-879.

Åkerberg,H. (1987). *Livet som utmaning existentiell ångest hos svenska gymnasieelever*. Stockholm, Sweden: Norstedts.