

# Dignity-preserving care for persons living with dementia

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### Original article 2

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## Abstract

The overall aim of the study was to develop an empirical-theoretical model of dignity-preserving care for persons living with dementia, grounded upon the perceptions of nurses, allied healthcare professionals, and individuals living with dementia.

In study 1, we applied Noblit and Hare's meta-ethnography in order to synthesize 10 qualitative studies originating in four different countries, exploring nurse and allied healthcare professional perception/practice concerning dignity-preserving dementia care. The results showed how "advocating the person's autonomy and integrity", involving the caring aspects; having compassion for the person; confirming the person's worthiness and sense of self, and; creating a humane and purposeful environment, were identified as primary foundations for dignity-preserving dementia care. Moreover, "balancing individual choices among persons no longer able to make sound decisions, against the duty of making choices on behalf of the person", involving; persuasion; and/or mild restraint, were considered a crucial aspects in certain situations. "*Sheltering human worth – remembering those who forget*" was identified as an overarching metaphor for the comprehensive motive and core values within dignity-preserving dementia care.

In study 2, we interviewed eleven persons living with mild to moderate dementia while exploring their perceptions of personal dimensions crucial for experiencing dignity in their daily lives. Utilizing Gadamer's hermeneutical methodology, our interpretation revealed three main dimensions. First, a "historical dignity-dimension", a source of dignity experience when acknowledging one's personal life-projects and life-history, involving; valuing foundation of life through childhood and upbringing; feeling gratitude and pride in having established a family of one's own, and; appreciating honorable employment and meaningful work in their past. Second, an "intrapersonal dignity-dimension", promoting the experience of dignity when recognizing one's own human worth, and living life according to internal values, involving; acknowledging oneself; living according to personal moral virtue, and; enjoying enriching activities of daily life. Third, an "interpersonal dignity-dimension", enhancing sense of dignity when experiencing being part of a caring and confirming communion, involving; receiving recognition and respect from others, and; experiencing transcendental and spiritual meaning in daily living.

Study 3 investigated crucial qualities of relational interactions preserving dignity experience among people with dementia, while interacting with family, social network and healthcare professionals. The eleven individuals participating in study 2 were also interviewed in order to explore this subject. Gadamer's hermeneutical methodology was utilized. The study found how the main quality of dignity-preserving interactions within the family was related to "Experiencing love and confirmation", involving; feeling the love and affection from spouse; spousal support during activities of daily living, and; feeling appreciated and acknowledged as a parent, grandparent and/or great-grandparent. Second, the main quality of dignity-preserving interaction in a social network was related to "Experiencing social inclusion and fellowship", involving; perceiving friendships stay alive, and; feeling socially included, living an active life within a social fellowship. Finally, the results showed the main quality of dignity-preserving interactions with healthcare professionals. These related to "Experiencing humane warmth and understanding within a caring culture, being met as an equal human being", involving; feeling respected, listened to and taken seriously; meeting kindness; receiving health-related information in a gentle manner; adopting positive realism while feeling empowered, and; experiencing similar status and rights as other patient groups.

In developing a theoretical understanding of the empirical data collected for this research, Katie Eriksson's Theory of Caritative caring and her perspectives of dignity-preservation for the suffering human being, served as a helpful framework.

The study concludes: *Confirming human worth and equality* inherent in each person with dementia is the overall foundation for dignity-preserving care. Human worth and equality can be preserved within caring communions that *recognize absolute dignity* and *promote relative dignity* for every individual, by *supporting personal becoming* and *enhancing personal meaning* through acts of intervening that *shelter intrapersonal dignity*, *acknowledge historical dignity*, and *uphold interpersonal dignity*. On this basis a model of dignity-preserving care is developed, entitled: «Dignity Horizon Model: Caring for persons living with dementia».



## List of original articles

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## 1.0 Background

Dementia is a general term representing a syndrome of multiple related illnesses, leading to a steady decline of memory and thought processes, reduced ability for orienteering and sound judgment, coupled with a diminishing awareness of time, space, and direction. Shortly after developing dementia, the individual's ability to plan and carry out simple daily tasks becomes affected. Language impairment and diminishing ability to synthesize information often develops, and conversing coherently with others becomes difficult for many. Developing tendencies of self-neglect is common, as so alterations in emotional responses, sometimes resulting in apathy, irritability, instability, or a diminished critical sense (Qizilbash, 2002; Engedal & Haugen, 2009; World Health Organization, 2010; National Institute for Health and Care Excellence, & The Social Care Institute for Excellence, 2012). Many people experiencing dementia do however retain their positive personality traits and personal attributes (National Institute for Health and Care Excellence, & The Social Care Institute for Excellence, 2012).

Estimates show nearly 36 million people living with dementia worldwide. Within the general population, between 2 to 8 per 100 aged 60 or over experience dementia at any given time, and 2 – 10 % debut before age 65. Prevalence doubles for every five-year increment beyond age 65 (World Health Organization and Alzheimer's Disease International, 2012). In Norway, approximately 71 000 people have dementia, a number expected to double by 2040 (The Norwegian Directorate of Health, 2013). With no curative treatment at present (Engedal & Haugen, 2009), combined with increased longevity and aging population, the number of people with dementia worldwide is expected to nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050 (World Health Organization, 2012). The most common types of dementia are Alzheimer's disease, vascular dementia, Lewy body dementia, and frontotemporal dementia (Prince et al., 2013). Alzheimer's disease contributes approximately 60 -70% of all cases (World Health Organization, 2012).

People living with dementia develop an increased need for external quality care as their illness develops from mild to moderate and advanced levels (Engedal & Haugen 2009; World Health Organization and Alzheimer's Disease International, 2012). In the last 50-60 years several approaches have been developed to enhance quality of dementia care, including reality orientation, reminiscence, validation, person-centered care, snoezelen, and palliative dementia

care. Recent research suggests dignity to be an essential foundation for quality of life (Manthorpe, et al., 2010). People living with dementia are among the most vulnerable patient groups, and over time this vulnerability may threaten their sense of dignity. Healthcare professionals should therefore emphasize crucial aspects of care enhancing dignity-preservation among each individual living with dementia (Manthorpe et al., 2010; Gastman, 2013). Influential voices from the United Nations (1948), World Health Organization (World Health Organization and Alzheimer's Disease International, 2012), European Union (Matias, 2011; Alzheimer Cooperative Valuation in Europe, 2013), and UNESCO (2005) emphasize dignity as an inherent quality of each human being, an essential need and fundamental right among all people, plus a leading bioethical principle for healthcare professionals to follow. International Council of Nurses (2012) confirms dignity-preservation as a core value of caring ethics as well. Nonetheless, dignity violations occur in certain healthcare contexts (Seedhouse & Gallagher, 2002). Several countries are now preparing for the growing challenges within dementia care by developing national plans, placing dignity-preservation as a fundamental aspect. Developing dignity-preserving dementia care is crucial for meeting tomorrow's healthcare challenges (Engedal & Haugen, 2009; World Health Organization and Alzheimer's Disease International, 2012). However, there is a need for increased understanding of the underlying components of dignity-preservation to better prepare caregivers towards developing dignity-preserving interactions within these relationships (Seedhouse & Gallagher, 2002; Gallagher, 2004).

### 1.1 Dementia care

Emphasizing the Norwegian context, plus perspectives concerning the western caring culture, a brief overview of historical as well as current developments within dementia care organization will here initially be given. Leading principles and models within dementia care practice over the last 50-60 years will thereafter be portrayed, followed by a description of present ethical and political incentives within the western society, emphasizing dignity-preservation as a crucial aspect for future dementia care practices. Perspectives on human dignity among influential researchers participating in the current dignity discourse will thereafter be illuminated, before ending this chapter presenting a literature review documenting the forefront of the research on care that preserve dignity among individuals with dementia.

### 1.1.1 Contexts and organization; historical perspectives and current developments

In times past, the norm within our western cultural tradition has emphasized the family as primary caregivers for the emotional and practical needs of those unable to care for themselves (Kirkevold, 2001a). This has also been the case for individuals suffering from dementia. During the latter 1800's and early 1900's it was not uncommon however, for families to employ nurses or nuns to help care for the needs of sick still living at home. Such nurses were often guided by the principles documented by Florence Nightingale in her book "Notes on Nursing - what it is and what it is not" (1860), as they supported family caregivers when professional assistance was required (Kirkevold, 2001b).

In Norway, the first institutions dedicated to caring for the elderly were established during the mid-1800s. The building of these facilities, normally called nursing-homes or homes for the elderly, increased in number throughout the 1900's (Hauge, 2004). During this period of time, caring for the elderly, feeble and chronically ill, were viewed more as a responsibility of the public sector. From the mid-1950s, institutions now known as nursing homes were established. This included an increased focus on pathology and treatment than previously. No longer should such institutions be space where the feeble and elderly were merely quartered, but rather, places where people received treatment as well (Nygaard, 2002; Hauge, 2004).

In 1964, the Norwegian welfare state legislated the right for municipal care. This led to a massive development of public care for the elderly, emphasizing nursing home care, as well as home-based care within each municipality. From 1965-1980, a greater emphasis was placed on home-nursing, services legislated under the law for municipal health services in 1984 (Ministry of Health and Care Services, Norway, 2006). Since 1980, the government has attempted to curb further development of large institutions, adapting services so increasing numbers of people can live at home (Ministry of Local Government and Modernisation, Norway, 2011). In recent decades, the goals of civil authorities included differentiated residential-care opportunities for individuals with dementia, for example, retirement housing, assisted-living and/or nursing home facilities, according to each individual's need (Ministry of Health and Care Services, Norway, 2013).

Today, institutional long-time care is widely available in high-income countries. In UK, the prevalence of dementia among those aged 65 and above, living in nursing homes, is estimated

to be 66, 9 % (Knapp & Prince, 2007). Among individuals living in Norwegian nursing homes, approximately 80 % are affected by dementia (The Norwegian Directorate of Health, 2014). However, most people with dementia in Norway still live in their own home. Estimates show that 73% of people with dementia in developed countries live at home (Wimo, Winblad & Jönsson, 2007). In Norway, at least 50% of those living with dementia do so in their own home, a number expected to rise substantially within a few decades (The Norwegian Directorate of Health, 2007). There is now a growing provision for community-based home-care for this group (Knapp & Prince, 2007). However, whereas individuals with physical impairment continue to receive support in their home through community services, research literature documents how cognitive impairment is by far the strongest health-related predictor for institutionalization among older people (Alzheimer Disease International, 2009). Public care is today supplemented by ideal organizations, volunteers, and commercial enterprises offering support to those in need (Ministry of Health and Care Services, Norway, 2013). However, within this caring context, the family still remains the cornerstone of care for persons living with dementia (Knapp & Prince, 2007). In 2006, the government of Norway passed a resolution for developing an overall plan towards strengthening dementia care. (Ministry of Health and Care Services, Norway, 2006), and in 2007 «Dementia Plan 2015» was published. Here measures for strengthening the ability of municipal governments to meet future challenges within dementia care are emphasized. Further development of home-based care, senior activities centers and adapted living opportunities, plus measures towards increased knowledge and skills among professional caregivers as well as the general population, have all received increased priority (Ministry of Health and Care Services, Norway, 2007). In the revised «Dementia Plan 2015» (Ministry of Health and Care Services, Norway, 2011), Norwegian authorities also document how analyses and diagnosis, multi-professional follow-up, municipal planning, information availability, cooperation with important others as well as research, are emphasized in an effort to improve the lives of individuals experiencing dementia, and the lives of their families/important others, as well.

### 1.1.2 Current care practice; leading principles and models

Over the last 50-60 years several approaches aiming to enhance the quality of care for people with dementia have been developed. Below, influential principles and models will be described, namely reality orientation, reminiscence, validation, person-centered care, snoezelen, and dementia care based upon the principles of palliative care.

*Reality Orientation (RO)*. As a healthcare principle RO was first described in 1958, by psychiatrist James Folsom (Heap, 1995), and is the prototype of cognitive stimulation intervention (Woods, Aguirre, Spector & Orrell, 2012), which aims to enhance cognitive and social function through stimulation of thinking, concentration and memory processes (Clare & Woods, 2004). Typically, RO is utilized in two different forms: Either as a “classroom-activity” for small groups, led by trained staff, stimulating a small group of people to engage in discussion concerning past and present events, topics of interest, and/or engaging in music, word games, puzzles or other practical activities. Alternatively, as a 24-hour approach in which healthcare professionals take every opportunity to help orientate those in their care towards reality (Woods et al., 2012). Importantly, Asplund and Normann (2002) underline how RO is guided by the principle of helping others perceive reality as oneself perceives it. There have been some evaluations reporting positive outcome in cognitive functioning among persons living with dementia when RO is applied (Carrion et al., 2013; Salotti et al., 2013). However, a research review on cognitive training approaches failed to identify significant effects within this group (Clare et al., 2003). Additionally, RO has been evaluated as a confrontational and rigid approach (Woods et al., 2012), signaling a need for developing practical guidelines (American Psychiatric Association, 2007). Over time, the emphasis on RO is becoming less common in dementia care context (Woods et al., 2012).

*Reminiscence* is another main principle within the tradition of cognitive stimulation. First described by physician, gerontologist and psychiatrist Robert Neil Butler in the 1960’s, as a principle within general elderly care (Woods et al., 2005), the reminiscence approach was more specifically designed and introduced into dementia care practice in the 1980’s (Woods et al., 2005; Dempsey et al., 2014). Reminiscence is the process of recalling personal events or memorable experiences from one’s past (Lin, Dai & Hwang, 2003). Using “memory recallers” like pictures, photos, smells, textiles, tastes, sounds and music, individual cognition is stimulated in one’s here-and-now situation, toward reminiscing stored memories of previous life events and interactions with others (Almberg & Jansson, 2003). Today, this psychosocial intervention is commonly applied in dementia care (Wang, 2007), representing one of the most popular and highly rated approaches by both those living with dementia and their professional caregivers (Woods et al., 2005). However, research on the effects of reminiscence show contradictory results. While some studies indicate little evidence exists to support its use as effective healthcare intervention (Woods et al., 2005), others suggest a reminiscence approach may enhance cognitive activation, emotional stimulation, social

participation (Luke, Petersen & Tranvåg, 2013), well-being, identity and sense of self-worth (Dempsey et al., 2014).

*Validation.* In response to her dissatisfaction with traditional approaches, Master in social work, Naomi Feil developed Validation as a new principle in dementia care. Her first book *Validation: The Feil Method*, was published in 1982 (The Validation Training Institute, 2013). This approach represents «a way of being together» founded on the caregivers unconditional acceptance of the individual with dementia, valuing her/him as she/he is. Within this framework, healthcare professional focus is directed towards identifying the person's subjective feelings and experiences, recognizing these as true. Seeking the perspective of the person with dementia requires caregiver empathy, a key factor in this process towards validation of the other person's life-world. The purpose of validation is to enhance the individual's experience of being safe, understood and acknowledged by others. Although widely used, the efficacy of this approach is still a controversial issue, especially in comparison with other interventions. Some research has reported improved mood (Woods et al., 2005), and reduced behavioral disturbances (Deponde & Missan, 2007) among those with dementia receiving validation therapy. However, due to insufficient evidence no conclusion can be drawn about its efficacy on people living with dementia or cognitive impairment (Neal & Barton Wright, 2003).

*Person-centred care.* With an education based on science, specializing in biochemistry and a PhD in social psychology, Tom Kitwood developed innovative research projects and courses challenging the “old culture” of dementia care (Woods, 1999). In his book *Dementia Reconsidered: the person comes first*, Kitwood (1997) introduced and discussed the concepts of personhood and person-centered care, which he found crucial for developing humane dementia care practice. Recognizing individual personhood as a basic foundation for person-centered care, he defined the concept of personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being”. Moreover, personhood is perceived as a transcendent, sacred, and unique quality inherent in every human being, confirming the equal and absolute value of each individual with dementia and the obligation “to treat each other with deep respect” (Kitwood, 1997, p. 8). As a basis for person-centered care, focused attention should therefore be given towards identifying and relating to the personhood of those living with dementia. It is crucial that caregivers understand how individual feelings and wishes, experience of worthiness, dignity and life-history, plus ability

to make sense of a given situation, are inherent qualities of each human being (Kitwood, 1997). In this way, Kitwood redirected traditional views based on the bio-medical perspective, towards acknowledging the subjective experience of the person in need of care as the guiding principle for caring practice. Today, person-centered care is widely accepted and considered essential in healthcare practice (McCormack & McCance, 2006; O'Sullivan, 2013). At present, concept analysis and theory development also articulate a framework for person-centered nursing (McCormack & McCance, 2006). Empirical research documents personhood of individuals with dementia as bestowed and sustained through close, emotional bonds inherent to family caregivers and healthcare professionals (Smebye & Kirkeveld, 2013). Research on person-centered care has found positive effects on quality of life among nursing home residents with dementia (Rokstad et al., 2013). Systematic reviews document agitation reduction in care-home among dementia residents (Livingston et al., 2014), but that evidence of its effectiveness is incomplete, and more studies are needed on this area (Olsson et al., 2013).

*Snoezelen* is a term based on the Dutch words “snuffelen” (to seek) and “doezelen” (to relax) (Brown & Nicholson, 2011), first introduced as a therapeutic approach in the mid-seventies by Dutch advisor to occupational therapy Ad Verheul and music pedagogue Jan Hulsegge (World Wide Snoezelen.com., 2014; LinkedIn Corporation, 2014). These pioneers constructed their first “Snoezelen room” in 1987 (Brown & Nicholson, 2011). Snoezelen environments are purpose-built units or rooms designed for multisensory stimulation, typically using soft music, textured objects, colored lighting effect, aromatherapy, and/or serving meals with favorite food (Chitsey, Haight & Jones, 2002). The purpose is to help participants towards a “pleasurable sensory experiences in an atmosphere of trust and relaxation without the need for intellectual activity” (Hope & Waterman, 2004, p. 45-46). Snoezelen was initially designed as a healthcare approach for promoting leisure activities for children and adults with profound disabilities (Chitsey, Haight & Jones, 2002). In recent decades, the approach has been included within the foundation for dementia care (Chung & Lai 2002, updated 2008). Today, snoezelen rooms may be found in day-care centers, assisted living homes, rehab units, nursing homes and psychogeriatric units, with supportive multisensory stimulation led by nurses or other caregiving therapist (Chitsey, Haight & Jones, 2002). Empirical studies investigating the effect of snoezelen report reductions in apathy, agitation and aggression, improvement of mood, well-being, functional performance, activities of daily living, and ability of interpersonal relatedness in persons with dementia (Van Weert et al., 2005; Staal et al., 2007;



Collier et al., 2010). Recently, a theoretical framework for the snoezelen approach to dementia care (Staal, 2012), plus a tool for evaluating psycho-emotional well-being among persons with dementia receiving snoezelen stimulation (Lopez, Bolivar & Perez, 2014) have been developed. However, although encouraging results have been documented, a systematic literature review underlines the need for additional research based evidence to inform and justify the snoezelen approach to dementia care (Chung & Lai 2002, updated 2008).

*Palliative dementia care* is “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (World Health Organization, 2014). Due to inadequate pain control, and less access to palliative care services than patients with cancer, people with dementia often receive poor end-of-life care, and are often over-subjected to burdensome interventions instead (Harris, 2007). Thus, recent reports document the need for increased knowledge concerning palliative dementia care. Ten years ago, little evidence existed on this issue (Sampson et al., 2005). However, in recent years several studies have been published. Among these, studies regarding healthcare professionals’ challenges concerning existential issues within this context (Albinsson & Stang, 2002), perceptions of challenges concerning implementation of models of care, such as Advanced Care Planning (Lloyd-Williams, Abba & Crowther, 2014), plus, how and where to deliver quality palliative care for those living with dementia (Harris, 2007). While recent development on national guidelines and policies in UK (National Institute for Health and Care Excellence, 2010) set a foundation for improving palliative care for this group of people (Harris, 2007), systematic reviews document a lack of innovative palliative approaches within this area (Lloyd-Williams, Abba & Crowther, 2014), and a need for further research (Sampson et al., 2005).

### 1.1.3 Dignity-preservation; ethical and political incentives for future practice

Although the principles and models guiding current dementia care practice aim to enhance the well-being and quality of life of each individual, literature describing crucial aspects preserving dignity among those living with dementia has so far been sparse. Dignity-preservation of vulnerable and suffering human beings would intuitively seem a fundamental base for all professional healthcare practice. The explicit and focused attention on dignity-

preservation is however of a more recent date. After experiencing the Holocaust during the Second World War, in which millions of people were persecuted, interned, tortured and killed due to their personal characteristics and/or race, there has been an increased awareness on human dignity internationally. United Nations was established in 1945 to work for peace and dialogue among people of different nations, and in so doing prevent new wars and war crimes. The United Nations Charter focuses attention on human dignity and dignity-preservation, underlining the importance of reaffirming “faith in fundamental human rights, in the dignity and worth of the human person” (United Nations, 1945). The *Declaration of Human Rights*, United Nations (United Nations, 1948) states that all human beings have an inherent dignity. This understanding is the core foundation for the human rights of each human being.

During the same year, the World Medical Association (1948) confirmed that the professional practice of physicians should be based on “conscience and dignity”. Since then, dignity has been a far more frequently used concept, also in medical ethics (Van Der Graaf & Van Delden, 2009). Whereas the concept of dignity was absent in the International Council for Nurses’ (ICN) very first *Code of Ethics for Nurses*, published in 1953 (ICN, 1953), the dignity concept was part of the revised version of 1965. This dignity concept was not utilized however when referring to responsibilities “for the client”, but rather employed in the paragraph concerning responsibilities towards “the nursing profession”, stating; “The community must see the nurse as one with integrity and dignity, who can be trusted and respected” (Uys, 2007, p. 21). In 1973, the council adopted a new code, placing dignity as a core aspect of nursing, stating; “Inherent in nursing is respect for life, dignity and rights of man” (ICN, 1973). In the latest revision (ICN, 2012) the code of nursing ethics underlines; “Inherent in nursing is respect for human rights, including the right to life, to dignity and to be treated with respect”.

Since the 1990s, emphasis on developing increased understanding for patients’ dignity, and consequential implications for professional healthcare, has intensified (Van Der Graaf & Van Delden, 2009) following World Health Organization (1994) *Declaration on the Promotion of Patients’ Rights in Europe* which underscores that “patients have the right to be treated with dignity”; *Universal Declaration on Bioethics and Human Rights* of UNESCO (2005) recognizing respect for human dignity as a core principle of bioethics, and; the *European Parliament resolution of January 19<sup>th</sup>, 2011 on the European initiative on Alzheimer’s disease and related dementia and other dementias* by the European Union (Mathias, 2011), encouraging member states and the commission to promote “specific healthcare and research

programs that formulate recommendations centered on the core principles of dignity”, and to develop “an ethical approach to sufferers in order to guarantee respect for human dignity”. *Convention on the Rights of Persons with Disabilities*, Alzheimer Disease International (2009), now underscores the need for national governments to ensure a dignifying life for people living with dementia, underlining the responsibility of national authorities according to The United Nations, to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (United Nations, 2006).

The influence of these significant international organizations, along with a general concern about the quality of dementia care and the growing awareness concerning future challenges, have stimulated authorities in an increasing number of countries to develop national reports, strategies and programs. In developing new quality standards for dementia care several nations now explicitly formulate dignity-preservation as a core foundation for future practice. Considerable variation within national strategies does however exist (World Health Organization, and Alzheimer’s Disease International, 2012). In Norway, a political regulation entitled “The dignity guarantee of elderly care” came into force in January 2011. Here, dignity-preserving standards are formulated to ensure the care of older people contributes to a dignified, safe and meaningful life (Ministry of Health and Care Services, Norway, 2010). In addition, a national Dementia plan has been implemented underlining the essentiality of healthcare professionals treating each person living with dementia with respect and dignity (Ministry of Health and Care Services, Norway, 2007).

During 2011, Sweden implemented a new national value system anchored in the Social Services Act of 2001. Accordingly, national authorities encourage municipalities to implement local dignity guarantees in elderly care, in order to aid people with age-related illnesses towards living dignified lives (The National Board of Health and Welfare, Sweden, 2011). Dementia care is one of seven prioritized areas within the Swedish national strategy for health care and long-term care (Ministry of Health and Social Affairs, Sweden, 2008). The Swedish government and National Board of Health and Welfare are now developing an intervention-program, for securing dignified quality care for persons with reduced ability to make sound decisions (Ministry of Health and Social Affairs, Sweden, 2013).

In Finland, a revised version of The Act on Care Services for Older People (Ministry of Social Affairs and Health, Finland, 2013a) came into force in 2013, underlining the principle of

dignity-preserving care to enhance dignity in the everyday lives of older people in need of healthcare services. The National Memory Program, 2012-2020, entitled “Creating a ‘memory-friendly’ Finland”, has recently been implemented with an overall aim to insure that “anyone diagnosed with cognitive problems or dementia (...) can lead their lives with dignity” (Ministry of Social Affairs and Health, Finland, 2013b).

In Denmark, the Danish Health and Medicines Authority (2001) underlines how respecting the dignity of people living with dementia, while sheltering their equal right to a life in dignity, are crucial perspectives for future dementia care.

In United Kingdom, Social Care Institute for Excellence hosts the “Dignity in Care campaign”, a nationwide movement launched in 2006 to put dignity and respect at the heart of care services (National Dignity Council, UK, 2013). The Department of Health has developed a National dementia strategy (Department of Health, UK, 2009), aiming to ensure people living with dementia to be treated with dignity and respect at all times. Moreover, in their report, Nuffield Council on Bioethics (2009) underlines the treatment of persons with dementia with dignity, in the sense of ‘dignity as empowerment’, can be particularly helpful in dementia care settings. However, Northern Ireland Human Rights Commission (2012) recently published a report on human rights and a life of dignity for older people, including individuals with dementia, underlining the need for further changes in laws and regulations.

Within the international fellowship of Organization for Economic Co-operation and Development (OECD), Australia, Canada, France, Germany, Japan, Spain, Sweden, United Kingdom and United States have published the fellow report; *Dementia Care in 9 OECD Countries: A Comparative Analysis*, to “provide health policymakers with a better understanding of the variations in approaches to treating dementia that exist among OECD countries, to help them better formulate health policies for treating dementia”. The report documents how maintaining the dignity of people living with dementia is a crucial foundation for quality dementia care (Moise et al., 2004, p. 4).

National and international strategies like those documented above are crucial for developing renewed attention, increased knowledge, new directions and cultural changes within dementia care. However, albeit identifying and validating dignity-preservation as a crucial basis for future dementia care these documents do not specify *how* dignity of persons living with dementia can be preserved. Thus, national and international policies should be supplemented

by research-based knowledge, providing deeper understanding of the crucial aspects of dignity-preserving dementia care.

## 1.2 Dignity

Dignity is a phenomenon not easily placed under the microscope and defined, a point illustrated by Chochinov (2008, p. 674), who after more than 10 years of research on terminally ill and dying individuals, concluded that dignity is “different things to different people”. There is at present no consensus on the conception of human dignity (Gallagher, 2011). Critics argue that the concept of dignity within the healthcare context is vague (Billings, 2008) and useless (Macklin, 2003). It does however appear to be generally accepted that dignity can be defined as “being of value or worth because of the presence of some necessary characteristics” (Gallagher et al., 2008). Additionally, dignity is connected to shared humanity (Haddock, 1996). Dignity can thus be perceived as a fundamental human quality, anchored in personal experience relating to others, rather than a moral quality based on the judgment of others (Gallagher et al., 2008). Researchers from various disciplines have contributed to our collective understanding of dignity. Influential researchers regarding the current dignity discourse follow.

From his position as medical doctor and psychiatrist, Chochinov’s (2008) research documents the psychosocial aspects of human dignity as a subjective experience, different for each human being and affected by personal interplay with others. According to Chochinov and colleagues, dignity among the terminally ill and dying is related to their sense of self-continuity, role preservation, generativity/legacy, pride, hopefulness, autonomy/control, acceptance, resilience/fighting spirit, living in the moment, normalcy and spiritual comfort (Chochinov et al., 2002; Chochinov et al., 2006).

Anchored on his philosophical perspective on medicine and healthcare, Nordenfelt (2004) describes dignity as a complex phenomenon constituted of four varieties. First, dignity as merit, which is a dignity-manifestation based on formal positions and social rank. Second, dignity constituted of moral stature based on personal moral values. Third, dignity of identity, anchored in personal autonomy, integrity and self-respect. These three notions of dignity are changeable and violable, and may therefore vary from situation to situations or time to time. However, dignity of *Menschenwürde* (the universal human dignity), Nordenfelt’s fourth

dignity dimension, is perceived as unchangeable, inviolable and constituted by the intrinsic worth of each human being.

From his position of medical ethics, Pullman (2002) suggests that the concept of human dignity carries both moral and aesthetic connotations. He refers to “basic dignity” as an inherent, inalienable and universal moral quality of each human being, irrespective of rank, station, and of any other contingent quality. Pullman does however refer another sense of dignity which is more individual and transient in nature using the term “personal dignity”, which tends to be a more subjective and aesthetical form of dignity, tied to personal goals, and influenced by a variety of everyday circumstances.

Medical sociologist Jacobson (2007, 2009) perceives human dignity and social dignity as two main forms of dignity. She argues that human dignity is an inherent and inviolable quality and value within each human being, while social dignity is a conditional and measurable form, originated through individual social interactions, and constituted by dignity-of-self and dignity-in-relation. Jacobson describes dignity-of-self as anchored and internalized in self-respect and self-worth, and how this form of dignity is founded on the experience of personal confidence and integrity. Dignity-in-relation, on the other hand, refers to the respect and worthiness of a person conveyed through interactions with others, and involves a historical sense of dignity, status or rank.

Exploring dignity from the nursing perspective, Gallagher (2004) argues that dignity is considered both objectively and subjectively. All human beings have objective dignity purely because they are human. Thus, having human worth, each individual has objective dignity regardless of their levels of personal autonomy, dependency, utility, consciousness or ability to reciprocate within human relations. Anchored in the worth, value and common membership of all humans, objective dignity also constitutes the basis for the human rights of all people. Subjective dignity is anchored in the individual differences and idiosyncrasies among human beings. This form of dignity is bestowed by others. Subjective dignity is experienced through the thoughts and feelings of an individual as dignity is maintained or diminished. A person is dignified when there is a match between circumstantial factors and personal competencies. Gallagher (2004) underscores how dignity involves an other-regarding value and a self-regarding value, involving respect for the dignity of other people, and respect for one’s own personal dignity.

In their caring science research concerning dignity of the suffering human being, Eriksson (1995, 1996, 1998, 2006; Lindström, Nyström & Zetterlund, 2014), and Edlund (1995, 2002; Edlund et al., 2013) document how dignity forms a dualistic concept involving an absolute and a relative dignity-dimension. The former perspective perceives dignity as an absolute, inherent and inviolable dimension of human holiness. The latter perspective accounts for a relative, changeable and potentially violable dimension, influenced by external factors. While violations of relative dignity may offend the person, her/his absolute dignity and human worth can never be reduced or abolished.

Despite existing ontological and disciplinary differences, it is possible to identify similarities among the various perceptions of these influential authors. Most of them portray dignity as a dualistic concept of importance in the lives of all human beings. Each author identifies dignity as partly an inherent and lasting quality, partly a subjective and changeable quality experienced through interactions with others. Each author utilizes unique and contrasting terms: *Menschenwürde vs. dignity of identity, dignity of stature and dignity of merit* (Nordenfelt, 2004), *basic dignity vs. personal dignity* (Pullman, 2002), *human dignity vs. social dignity* (Jacobson 2007, 2009), *objective dignity vs. subjective dignity* (Gallagher, 2004) and *absolute dignity vs. relative dignity* (Eriksson (1995, 1996, 1998, 2006; Lindström, Nyström & Zetterlund, 2014), and Edlund (1995, 2002; Edlund et al., 2013). However, some authors (Chochinov et al., 2002; Chochinov et al., 2006; Chochinov, 2008) put emphasis on the latter perspective, that is, on psychosocial aspects and their influence on dignity experience among human beings.

### 1.3 Dignity within dementia care; a review of the literature

Documenting existing knowledge is essential for identifying which is already known as well as identifying questions still in need of answers. A systematic database search was therefore performed to investigate the forefront of the research concerning crucial aspects of care which preserve dignity among people living with dementia. Combining the search terms «dignity» and «dementia», previous research indexed in Scopus, published between January 1990 and June 2011, and in PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and ScienceDirect, published between January 1990 and May 2014, were explored. Additional search, utilizing available related article search column and reference list examination, were also performed. A substantial number of studies overlapped, that is, were

found in two or more databases. Several studies provided theoretical perspectives and discussions, authored by healthcare professionals and academics. A growing body of empirical research examining healthcare professionals' perspective was also found. Studies exploring the perception of persons living with dementia was however limited, especially in the context of home care. A résumé of the main results of the literature review will be presented below.

### *Dignity-preserving dementia care: Nurses and allied HCPs perspectives*

Research exploring the perspective of nurses and allied HCPs document how searching for the individual's personality, confirming their sense of self-worth (Zingmark, Sandman & Norberg, 2002; Rodriquez, 2011) and personal status (Manthorpe et al., 2010), plus supporting personal autonomy, integrity and a state of wholeness (Randers & Mattiasson, 2004) are found crucial foundations for dignity-preserving dementia care. Self-reflection upon one's own desires and needs in a similar situation, was reported to be vital aspects for increased caregiver awareness, concerning the dignity of their patients/residents living with dementia. Understanding the subjective elements of dignity in each individual, acting as the person's advocate while respecting their personal need to feel in control, and offering supportive care in a person-centered way were also emphasized. Moreover, respecting the need for intimacy and sex among people living with dementia was also part of the professional dignity-preserving perspective (Manthorpe et al., 2010).

Creating purpose built residential environments, encouraging HCPs and those with dementia to sit down and talk (Borbasi et al., 2006), providing discreet help (Zingmark, Sandman & Norberg, 2002), drawing upon resources of emotional attachment towards dignified caregiver-resident interactions (Rodriquez, 2011) and enhancing personal resources in social interaction by stimulating life-history memories (Randers & Mattiasson, 2004), were reported essential dignifying approaches. To preserve the dignity of nursing home residents, studies suggest how experiencing a loss of freedom due to locked doors, should be prevented, and how the residents' on the contrary should have the opportunity for going outside for frequent walks (Jakobsen & Sørli, 2010). Moreover, when promoting personal freedom, security and experience of self-worth in social interactions, the use of information- and communication technology was perceived a dignity-preserving approach within a caring context (Sävenstedt, Sandman & Zingmark, 2006).



When patients are unable to understand their own needs in areas such as personal hygiene or medication (Jakobsen & Sørli, 2010; Rognstad & Nåden, 2011), HCP consideration concerning individual residents needs as well as rights (Manthorpe et al., 2010), and as forbearing as possible, sometimes using persuasion or restraining orders to preserve dignity of individuals unable to make sound decisions due to their dementia illness (Jakobsen & Sørli, 2010; Rognstad & Nåden, 2011). Understanding patients' verbal and physical violence as illness-related and unintentional behavior makes it possible for caregivers to endure such events in a dignity-preserving way, avoiding dignity-violating anger or regret (Rodriquez, 2009). Acting in a calm and trusting way to avoid further agitation and aggression (Rognstad & Nåden, 2011), and sheltering the person from disrespectful treatment from others (Zingmark, Sandman & Norberg, 2002; Örluv & Nikku, 2007) have also been reported to enhance dignity-preservation while caring for person with dementia. Moreover, as part of a dignity-preserving strategy, an agreed care plan based on the cooperation between the individual with dementia, her/his relatives, and the professional caregivers, should be developed and implemented within the dementia care context (Manthorpe et al., 2010).

*The foundation for dignity in everyday life: The perceptions of persons living with dementia.*

Research exploring the perception of persons living with dementia document how they reflected upon and shared which aspects they considered significant for future end-of-life care. During interviews in early-stages of their progressive illness, being treated with respect and dignity was reported to be among their highest priorities for future care (Denning, Jones & Sampson, 2013). Experiencing understanding and respect from others was also reported to help confirm their value as human beings, and to maintain their sense of dignity (Roger, 2007; Van Gennip et al., 2013; Heggstad, Nortvedt & Slettebø, 2013a). However, individuals in this life-situation often experience an ongoing loss of personal dignity, value and security. Several studies document how experiencing cognitive decline can be a threat towards self-respect and the sense of dignity (Sørensen, Waldorff & Waldemar, 2008; Wogn-Henriksen, 2012).

Intrapsychic challenges and social challenges are both vital for maintaining dignity in persons with dementia (Johannessen & Möller, 2013). Dementia influences interpersonal interactions and relational interplay. Studies document how people living with dementia are aware of the stigma and the negative view society in general has concerning dementia, something that can undermine their dignity experience (Wogn-Henriksen, 2012; Van Gennip et al., 2013). A

gradual development of illness-related challenges is found to increase the tendency to withdraw from social interactions with others (Roger, 2007; Sørensen, Waldorff & Waldemar, 2008). Losing such interpersonal contact can divest individuals of cognitive stimulation and public value, affecting their sense of self and self-worth negatively (Roger, 2007). Their dignity experience is influenced by relational interaction with family, healthcare professionals and society as a whole (Roger, 2007; Wogn-Henriksen, 2012; Van Gennip et al., 2013). The relationship with their spouse and nearest family is most crucial. The spouse often represents a base of safety, and many living with dementia are concerned that their disease may affect spousal relationship negatively (Sørensen, Waldorff & Waldemar, 2008; Wogn-Henriksen, 2012). Although thankful, developing dependency on spousal assistance can be a dignity-violating experience when observing ones spouse become exhausted due to caregiver burden, and can cause one to question their own human value (Wogn-Henriksen, 2012).

Relational interactions are found crucial towards helping persons with dementia feel in contact with the outside world, through meaningful social interplay, sense of connectedness and recognition from others. Such experience is reported to be essential for the sense of dignity, while strengthening their relational self (Denning, Jones & Sampson, 2013; Van Gennip et al., 2013). However, remaining active in meaningful relationships has been found to be easier in one-to-one interactions than in larger groups of people (Roger, 2007). Confidence in others has been reported to be a vital foundation for dignity experience, and meaningful interactions can be experienced in relationships that are inclusive and acknowledging in nature (Wogn-Henriksen, 2012). Suffering and struggling also can help them mobilize personal resources towards being active (Wogn-Henriksen, 2012; Johannessen & Möller, 2013), and to develop adaptive strategies for coping with their new life-situation, enhancing their self-respect and dignity experience (Sørensen, Waldorff & Waldemar, 2008; Wogn-Henriksen, 2012). Involving their individual life-story in present here-and-now interactions are also shown helpful towards preserving one's personal dignity experience (Sørensen, Waldorff & Waldemar, 2008). Activities enhancing feelings of being a contributor in relational interactions, being useful, making others happy, and having the opportunity to participate in mental and physical exercise (Sørensen, Waldorff & Waldemar, 2008), plus maintaining a positive life-view, humor, courage, will and stamina (Wogn-Henriksen, 2012), have all been found vital for promoting dignity experiences while adapting to new, everyday challenges. The experiencing of being an individual human being, with meaning, continuity of

identity, autonomy, awareness and coping capacity, have also been reported to be central for the sense of dignity among individuals affected by this illness (Van Gennip et al., 2013).

Experiencing being treated with respect and dignity by healthcare professionals is found essential for quality care (Denning, Jones & Sampson, 2013). Experiencing their voice being heard and not overruled by healthcare professionals is reported essential for dignity-preserving communication within such relationships, while enhancing empowerment and coping (Wogn-Henriksen, 2012). Within the care home/nursing home context, promoting personal independence, autonomy, choice, control, privacy (Hall, Dodd & Higginson, 2014), as well as sense of freedom, confirmation and belonging (Heggestad, Nortvedt, & Slettebø, 2013a), are all reported among the highly prevalent dignity-preserving factors by persons living with dementia.

## **2.0 Study rationale**

The number of people living with dementia is increasing due to an aging population without curative treatment. The number of individuals in need of quality care is therefore expanding as persons with dementia develop an exponential need for care as their illness develops from mild to moderate and advanced phases. In order to meet tomorrow's healthcare challenges in dementia care, interventions aiming to preserve personal dignity among those affected should be emphasized (Engedal & Haugen, 2009; World Health Organization and Alzheimer's Disease International, 2012).

Promoting bioethics, human health and human rights, prominent international organizations such as The United Nations, World Health Organization, OECD, UNESCO and European Union, underline the importance of preserving dignity within every human being (United Nations, 1948; World Health Organization, 1994; Moise et al., 2004; UNESCO, 2005; Matias, 2011; Alzheimer Cooperative Valuation in Europe, 2013). Equally, the International Council of Nurses (2012) also confirms that dignity-preservation is a core aspect of caring ethics.

A growing number of countries are now developing national dementia care plans placing dignity-preservation as a core element within these strategies. However, while identifying and validating preservation of dignity as an essential foundation for future dementia care, these

documents fail to specify *how* dignity may be preserved. National and international policies should therefore be supplemented with research-based knowledge, providing deeper understanding of crucial aspects in dignity-preserving dementia care.

Research document the relevance of dignity in modern healthcare (Gallagher, 2011), showing dignity-preservation as a quality indicator of proper care, with potential to enhance quality of life among persons living with dementia (Manthorpe et al., 2010). However, dignity violations also occur in certain caring contexts. Research on preserving dignity among persons with dementia is limited, creating a void for increased caregiver knowledge on crucial aspects of dignity-preservation (Seedhouse & Gallagher, 2002; Gallagher, 2004). Moreover, research based knowledge assists scholars and policy makers responsible for quality dementia care promotion nationally and internationally, supporting their work to enhance dignity-preserving dementia care practice. The purpose of this present study is therefore an increased body of researched based knowledge within this vital area.

## 2.1 Aim and research questions

The overall aim of the study was to develop an empirical-theoretical model of dignity-preserving care for persons living with dementia, grounded upon the perceptions of nurses, allied healthcare professionals (HCPs), and persons living with dementia.

The following objectives were formulated:

- To explore and describe dignity-preserving dementia care as perceived and practiced by nurses and allied HCPs working in dementia care.
- To explore and describe crucial dimensions constituting dignity-preserving care as perceived by individuals living with dementia
- To explore and describe crucial qualities of relational interactions towards preserving dignity experience among people living with dementia.

On this basis, the following research questions were addressed:

1. Which aspects of dignity-preserving dementia care are practiced and perceived as crucial by nurses and allied HCPs employed in a variety of dementia care contexts, and documented in previous qualitative studies within empirical dementia care research?
2. Which dimensions are crucial in constituting dignity experience in the daily lives of persons living with mild to moderate dementia?
3. When interacting with family, social network, and HCPs, respectively, which qualities within these relational interactions do persons with dementia find crucial in preserving their dignity experience?

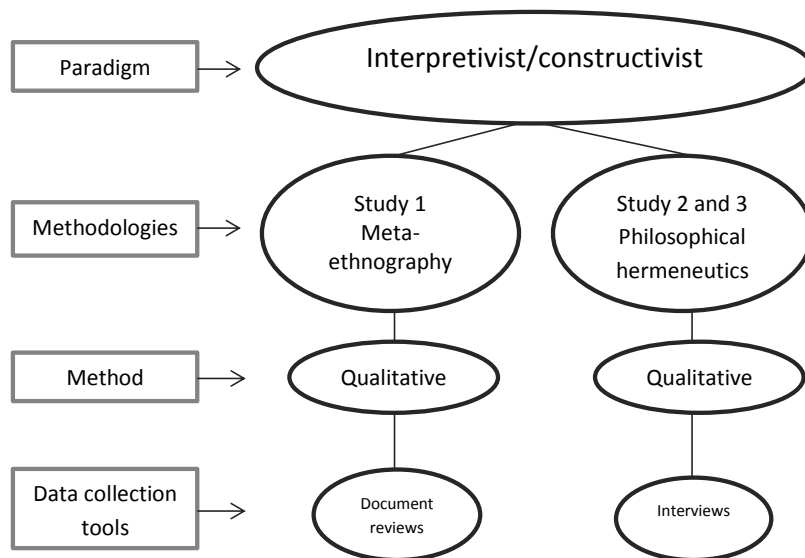
### **3.0 Epistemological foundation and study design**

Epistemology is a term referring to “the theory of knowledge, especially with regard to its methods, validity, and scope, and the distinction between justified belief and opinion” (Oxford University Press, 2014). Every research project should document its epistemological foundation to inform the reader why the chosen perspective was selected, and how this epistemology can be utilized to develop new and expanded knowledge on the subject under investigation. An explorative design, within the interpretivist/constructivist paradigm, was found an appropriate epistemological basis for this research. According to Brink and Wood (1998) the three major designs for research-based knowledge development are experimental designs, survey designs, and exploratory-descriptive designs. These designs can be subdivided further into several designs within each of the overall categories. Exploratory designs, a sub-category of the exploratory-descriptive designs, are advantageous when investigating various aspects of a distinct phenomenon, its manifestation, and the underlying processes of human behavior and interactions (Brink & Wood, 1998; Polit & Beck, 2010). Such designs are frequently used when researchers are concerned with in-depth exploration and description of the experience among people within a particular population (Brink & Wood, 1998), to “tease out” what is going on (Brink, 1998, p. 310), and develop new knowledge within uncharted areas (Brink, 1998). This was the case in this study. An exploratory design was chosen for the purpose of exploring and describing crucial aspects preserving dignity in persons with

dementia, as perceived by individuals living with dementia as well as nurses and allied HCPs within dementia care. Dignity-preserving care for persons with dementia is an area which previously has been given little attention. In line with the exploratory approach (Brink, 1998) the emphasis on this study is on developing sound descriptions of the subjective perceptions and meaning of the phenomenon under investigation.

The study was grounded on the interpretivist/constructivist paradigm (Mackenzie & Knipe, 2006), with the intention to understand "the subjective world of human experience" (Cohen & Manion, 1994, p. 36). Researchers tend to rely upon the personal perceptions of those participating in the study (Creswell, 2003), while developing interpretive understanding "of its meaning personally and theoretically" (Creswell, 2003, p. 182). In this process researchers also recognize how their own background and experience influence their research efforts (Creswell, 2003; Mackenzie & Knipe, 2006). These designs emphasize the importance of the researcher's freedom and flexibility, not being bound by rigid rules during the research process (Brink, 1998). Being able to "go with the flow" is essential to avoid using time and efforts on unfruitful areas. Such flexibility is also crucial for enabling the researcher to identify and go into depth regarding aspects not initially planned to be explored (Brink & Wood, 1998, p. 285). In this study, flexibility and creativity were crucial for the discovery of nuances, leading the research process into new directions and deeper levels of understanding how dignity can be preserved.

Documented as purposeful within the interpretivist/constructivist paradigm (Mackenzie & Knipe, 2006), the methodologies of meta-ethnography (Noblit & Hare, 1988) and philosophical hermeneutics (Fleming, Gaidys & Robb, 2003; Zimmer, 2006; Gadamer, 2010) were chosen for this study. Moreover, in accordance with literature on interpretivist/constructivist paradigm, which documents qualitative research methods to be appropriate for this kind of research (Mackenzie & Knipe, 2006), such methods were applied in this study as well; interviews and document reviews are found purposeful data collection tools in studies using qualitative methods (Mackenzie & Knipe, 2006), and were therefore chosen. A further description of the methodologies, methods and research procedures will be presented in chapter 3.1 Methodologies, methods and materials, below.



**Figure 1** The exploratory design of the study

### 3.1 Methodologies, methods and material

This research utilized Noblit and Hare's meta-ethnography (1988) and Gadamer's philosophical hermeneutics (Fleming, Gaidys & Robb, 2003; Zimmer, 2006; Gadamer, 2010) as methodologies for data material collection and interpretation. A description of methodologies, methods and materials for this research process follows.

#### 3.1.1 Noblit and Hare's meta-ethnography (study 1)

Meta-synthesis can be described as research of research (Paterson et al., 2001). Synthesizing the results of previous qualitative studies can reveal new and deeper insight (Sandelowski, Docherty & Emden, 1997; Bondas & Hall, 2007), thus, constituting a strategic way to obtain increased understanding among practitioners, scholars and politicians (Wikberg & Bondas, 2010). Meta-ethnography is a seven-step approach developed by Noblit and Hare (1988), and the most often applied methodology within this branch of qualitative nursing research (Bondas & Hall, 2007). Meta-ethnography is a methodology within the interpretivist paradigm, utilizing qualitative methods and review of previous qualitative studies as data

collection tools, in order to explore a distinct phenomenon within various cultural contexts (Noblit & Hare, 1988). Following recommendations concerning initial *getting started* phase, our research team identified first “dignity-preserving dementia care” as a theme of intellectual interest which this qualitative approach might help illuminate and develop. Since the study aim was to develop increased knowledge concerning crucial aspects inherent in dignity-preserving dementia care, as perceived and practiced among nurses and allied HCP and documented in previous empirical qualitative studies, the following research question was explored:

*Which aspects of dignity-preserving dementia care are practiced and perceived as crucial by nurses and allied HCPs employed in a variety of dementia care contexts, and documented in previous qualitative studies within empirical dementia care research?*

#### 3.1.1.1 Sample, data collection and material

The sample of this study is constituted by previous qualitative studies exploring nurse and HCP perception and practice of dignity-preserving dementia care. In the next phase our research team focused on *deciding what is relevant to the initial interest* (Noblit & Hare, 1988). Following Noblit and Hare’s recommendation of defining the study audience, nurses and allied HCPs, dementia care unit leadership, teachers responsible for dementia care education and politicians responsible for quality in dementia care, were included as target groups for this research. Studies included were empirical research, utilizing qualitative methods to explicitly explore nurse and allied HCP perceptions and practices related to dignity-preserving dementia care; written in English or Scandinavian language; published between January 1990 and August 2011 in a peer-reviewed journal available at Scopus, PubMed, or Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases. Combining the search terms “dignity” and “dementia”, the databases were investigated thoroughly during December 2010, with a follow-up search in June 2011 (Scopus) and in August 2011 (PubMed and CINAHL). Our database search yielded a total of 162 articles in Scopus, 125 in PubMed, and 127 in CINAHL. Additional database search utilizing available related article search column and reference list examination was also performed. A substantial number of studies were found across the databases. No meta-synthesis was found exploring dignity-preserving dementia care. A substantial number of studies provided theoretical perspectives and discussions. The number of studies fulfilling inclusion criteria of this present meta-ethnography, were however sparse, resulting in ten studies; Zingmark, Sandman &



Norberg, 2002; Randers & Mattiasson, 2004; Borbasi et al., 2006; Sävenstedt, Sandman & Zingmark, 2006; Örulv & Nikku, 2007; Rodriquez, 2009, 2011; Jakobsen & Sørli, 2010; Manthorpe et al., 2010; Rognstad & Nåden, 2011, totally involving empirical data from 249 nurses and allied HCPs.

### 3.1.1.2 Data interpretation

Initiating the data interpretation process we first emphasized *reading the studies* constituting our data material, conducted in four different countries on two continents: four from Sweden, three from Australia, two from Norway, and one from England. These studies generated empirical data from various dementia care settings: home care, older people's social centers, nursing home care, and hospital care. Each study was carefully read several times to identify key concepts and themes used by the original authors to formulate their results. Such constructs document the substance of each account, and are the themes which in the next research phase will be translated across studies (Noblit & Hare, 1988). These interpretations, conducted by the authors of each original study, were perceived as *second-order constructs* since they were based on the interpretation of nurses and allied HCP shared first-order construct (of their own perceptions and practice). In line with Noblit and Hare (1988), our task was to conduct a synthesis of the second-order constructs of previous studies, developing a new understanding of dignity-preserving dementia care as a whole, available for our study audience. A meta-ethnographic synthesis is therefore based upon interpretation of interpretation of interpretation of experience (Malpass et al., 2009).

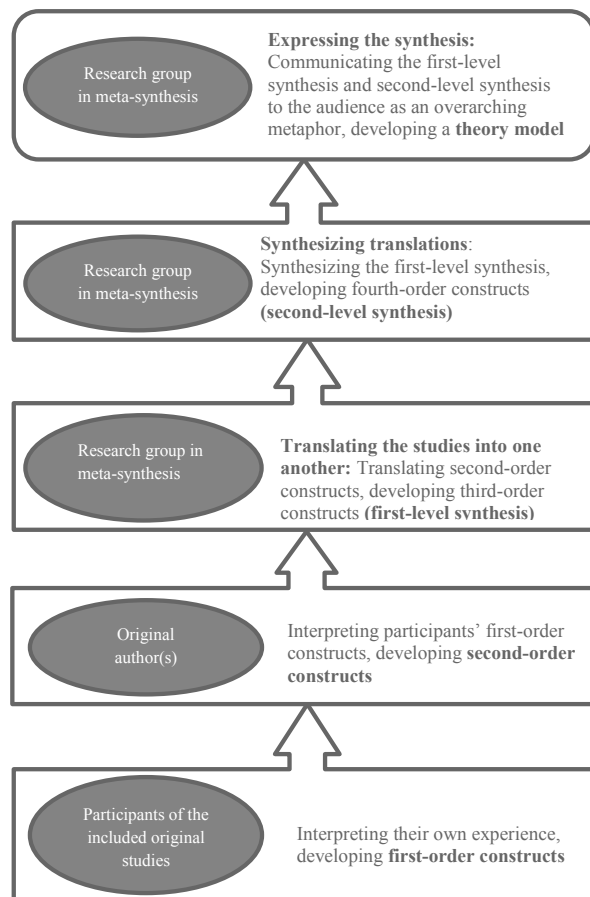
There is no standard method or consensual procedure to follow when conducting a meta-ethnographic study (Noblit & Hare, 1988; Britton et al., 2002; Lambert, Glacken & McCarron, 2011). We were encouraged by the work of Zimmer (2006), documenting Gadamer's concepts of the hermeneutic circle, dialoguing with the text, and the fusion of horizons, as a fruitful methodological foundation for conducting meta-synthesis. A broader description of these hermeneutic processes is presented in 3.1.2 Gadamer's philosophical hermeneutics. Each member of our research team investigated each study separately at first, then later in a group effort, to determine how the studies related to one another. Reading the texts over and over again while performing a reflexive dialogue with each text, and thereafter, the texts as a whole (Zimmer, 2006; Gadamer, 2010), a matrix was utilized to document the original authors' second-order constructs, in the original authors' own words whenever possible.

<ul style="list-style-type: none"> <li>• <i>Getting started</i></li> <li>• <i>Deciding what is relevant to the initial interest</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>Identifying theme of interest</i></li> <li>- <i>Formulating study aim, sample and target group</i></li> <li>- <i>Data-collection</i></li> </ul>
<ul style="list-style-type: none"> <li>• <i>Reading the studies</i></li> <li>• <i>Determining how the studies are related</i></li> <li>• <i>Translating the studies into one another</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>Identifying key concepts and themes</i></li> <li>- <i>Identifying relationship across the studies</i></li> <li>- <i>Developing an interpretive explanation (first-level synthesis)</i></li> </ul>
<ul style="list-style-type: none"> <li>• <i>Synthesizing translations</i></li> <li>• <i>Expressing the synthesis</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>Developing a holistic explanation (second-level synthesis) and an overarching metaphor</i></li> <li>- <i>Formulating the meta-synthesis in a clarifying way for the study audience</i></li> </ul>

**Table 1** The 7-step process of meta-ethnography (Noblit & Hare, 1988)

The process of *determining how the studies are related* was thereafter initiated. According to Noblit and Hare (1988), research conducted in various contexts may be related in three ways; directly related and comparable through a process of reciprocal translation; related as the studies present lines-of-argument translation, or; indirectly related due to the accounts' refutable and relative oppositional perspectives. The principles of dialoguing with the texts, and using the possibilities of the hermeneutic circle towards exploring and documenting the relationships between the parts of the texts and the text as a whole, while conducting the meta-synthesis (Zimmer, 2006) were followed during this process. We found reciprocal translations of each study into one another (Noblit & Hare 1988) to be an appropriate way for synthesizing our data-material. Although the studies represented two groups we entitled "Group A studies", and "Group B studies", we identified a reciprocal relationship between them; both groups documented practice and professional perceptions concerning dignity-preserving care, but the study results were anchored in the exploration of different ethical dementia care dilemmas.

Researchers' pre-understanding is viewed as an important foundation for interpretation, and awareness of personal pre-conception is required to obtain a deeper insight into the meaning of the phenomenon under investigation (Gadamer, 2010). Based on our professional experience in dementia care, our theoretical knowledge concerning dignity, insight gained from previous research in dementia care and/or dignity in care, our pre-understanding as a team was firmly anchored in a perspective that dignity-preserving dementia care could be developed through professional caregivers humanistic values, attitudes, and perception of worth among individuals suffering from dementia. The characteristics of these qualities were however unclear to us. Our dialogue with the text throughout this research process helped us move beyond our former pre-conceptions, opening for new insight and understanding of dignity-preserving dementia care, as perceived and practiced by nurses and allied HCPs.



**Figure 2** Developing meta-ethnographic synthesis

In the following phase we emphasized *translating the studies into one another* in order to develop an interpretive explanation, and unique first-level synthesis, protecting the particular, enabling comparison, and respecting holism towards “making a whole into something more than the parts alone imply” (Noblit & Hare, 1988, p. 28). Again, Gadamer’s hermeneutical methodology was most helpful, underscoring the importance of constant awareness on how the parts (the different second-order constructs) influence the whole, and how the whole influence the individual parts, when being translated into one another through a hermeneutic circle, towards a fusion of horizons and new understanding (Zimmer, 2006; Gadamer, 2010). When studies are translated into one another, this can imply translations that are able to encompass similar themes and results identified in other qualitative research studies. When this is the case, *synthesizing translations* in order to develop a second-level synthesis is possible (Noblit & Hare, 1988). While exploring the first-level synthesis constituted by Group A studies and Group B studies, we identified lines-of-argument relationships between them. Lines-of-argument synthesis, translates comparable similarities and dissimilarities of the first-level synthesis, into a new and holistic context. This approach is “essentially about inference: What we can say about the whole (organization, culture, etc.) based on selective studies of the parts” (Noblit & Hare, 1988, p. 62). Although anchored in different contextual situations, both Group A and Group B studies argued for dignity-preserving dementia care practice. Thus, developing a second-level synthesis helped us formulate an overarching metaphor and model for dignity-preserving dementia care as perceived and practiced by nurses and allied HCPs.

Finally, we emphasized *expressing the synthesis* (Noblit & Hare, 1988) developing a model, and overarching metaphor in a language, we believed would clarify and illustrate crucial aspects of dignity-preserving dementia care for our study audience.

### 3.1.2 Gadamer’s philosophical hermeneutics (study 2 and 3)

Gadamer’s philosophical hermeneutics is a methodology within the interpretivist paradigm emphasizing how new and expanded understanding can be gained through crucial text-interpretation processes (Fleming, Gaidys & Robb, 2003; Zimmer, 2006; Gadamer, 2010). Focused attention is therefore given on how hermeneutic exploration of a text can lead to new and expanded understanding of its meaning. According to Gadamer, enhanced understanding is possible for the reader who is willing to enter the hermeneutic circle, by reading and

exploring the texts repeatedly. This process includes simultaneous reflexive dialogue between the various parts of the text, between each part and the text as a whole, as well as the researchers pre-understanding of the subject under study (Fleming, Gaidys & Robb, 2003; Gadamer, 2010).

Gadamer (2010) is not merely conscious that personal pre-understanding anchored in individual prejudice exists, he also argues for an awareness of pre-understanding as an absolute prerequisite for obtaining knowledge beyond one's present pre-conception of a given subject. Conscientious awareness concerning personal pre-understanding of the subject under investigation is therefore crucial for the reader/interpreter to be able to see, to question and to challenge both personal horizons, as well as new and expanded understanding gained through the text interpretation process (Fleming, Gaidys & Robb, 2003; Zimmer, 2006; Gadamer, 2010).

Within this hermeneutic circle movement, the reader is viewed as a text interpreter, bringing own taken-for-granted understanding (foreground horizon) in the present, plus one's own historical experience (background horizon) into an interpretive process, aiming to gain new and expanded understanding of the text and its meaning (Zimmer, 2006; Gadamer, 2010). According to Gadamer's philosophical hermeneutics (2010), *horizon* refers to one's vista, view, or field of vision, in other words, a perspective encompassing all aspects which can be perceived from a certain point. In this study, seeking new understanding of crucial aspects in dignity-preserving care means to open up for new horizons and expand the existing ones. Exploring one's horizon, the keen observer can share important understanding concerning the various aspects found therein, grand or small. Placing oneself in another's situation, rather than observing from afar, but aligning oneself within another's field of view, allows access to new horizons. This does not entail a process in which one horizon has less value than another, but rather, a process towards expanded understanding, characterized as more meaningful than two otherwise could observe, on their own. Developing one's horizon means leaning to see beyond the obvious and close at hand. This is not done in order to overlook the near and familiar, but rather, in order to understand the entire picture within a more holistic and proper frame of reference.

Gadamer (2010) insists that the present foreground horizons are in continuous motion and change as prejudice, in which human pre-understanding are anchored, is tested. At the same

time, present foreground horizons are anchored in the past, influenced by historical background horizons. Developing present horizons entails therefore an expanded understanding of historical horizons and their historical effect. Understanding always involves a process of fusion of separate horizons, where the old and the new fuse, constituting a new and viable understanding (Gadamer, 2010).

For the purpose of further exploration regarding aspects crucial for dignity preserving care, this research also included two studies investigating the personal perceptions of individuals living with dementia. In the first of these two studies, our research group's aim was to develop increased knowledge on crucial dimensions within the foundation of dignity experience among persons living with dementia. Therefore, the following research question was explored:

*Which dimensions are crucial in constituting dignity experience in the daily lives of persons living with mild to moderate dementia?*

The aim of the latter study was to explore and describe crucial qualities of relational interactions that helped preserve dignity experience among people with dementia. Thus, the following research question was formulated:

*When interacting with family, social network, and HCPs, respectively, which qualities within these relational interactions do persons with dementia find crucial in preserving their dignity experience?*

Researchers' pre-understanding (Gadamer, 2010) should also be presented to the study audience, making the interpretive context available, increasing study transparency (Hiles & Čermak, 2007) and trustworthiness (Lincoln & Guba, 1985; Guba & Lincoln, 1994; Polit & Beck, 2010). In this present study, all researchers had professional nursing care experience among persons living with dementia. We also had theoretical knowledge of various authors' perspectives on dignity, as well as previously conducted qualitative research on dignity pertaining to dementia care. Our pre-conception and initial horizon, concerning crucial dimensions constituting dignity experience in persons with dementia, were founded upon the perception of dignity as an inherent human quality, as well as a need and right for experiencing human worth. We also shared the pre-conception that experiences from their pasts could influence their dignity experience in everyday life. The characteristics of these dimensions were however unclear to us. Our pre-understanding horizon concerning dignity-

preserving interaction was based on the assumption that interplay of this nature could be possible when informal and formal caregivers were supportive and caring, confirming the human worth of individuals affected by dementia. We were however uncertain how crucial dignity-preserving qualities of such interactions presented themselves in daily living.

#### 3.1.2.1 Sample, data collection and material

Study participants were recruited from two Hospital Memory Clinics in Norway, neither affiliated with our research team. Medical doctors responsible for diagnostic examinations and follow-up treatment cooperated with clinical nurses accountable for participant recruitment. Founded upon a strategic sampling strategy, the following inclusion criteria was formulated: Persons diagnosed with mild to moderate dementia; aged 64 years or older; living at home together with their spouse; speaking Scandinavian or English language; and willing to be interviewed concerning crucial aspects preserving their dignity experience in daily living, and on how relational interactions with family, social network and HCPs can help preserve their sense of dignity. Eleven persons participated; five women and six men. Their ages ranged from 64 to 85 years. Ten were diagnosed with Alzheimer's disease, and one with mild cognitive impairment. Eight were native Norwegians, two were born in other European countries, while one was originally from Asia. The latter three had lived their adult lives in Norway.

Previous studies have shown qualitative method utilizing interview as a useful data collection tool for exploring experiences of persons living with dementia (e.g. Clare, 2002, 2003; Preston, Marshall & Bucks, 2007; Duane, Brasher & Koch, 2013; Ericsson, Kjellström & Hellström, 2013). In our study, interviews were conducted by the first author (O.T.) from October 2011 through September 2012. At their own request, all interviews were carried out in participants' home. A temporary and modifiable interview-guide constituted a structural frame for the interviews. Examples of questions guiding the researcher-participant conversations were: What brings dignity experience into your current life-situation? How do other people affect your experience of dignity? How would you describe your interactions with healthcare professionals? How can your dignity be better preserved in these interactions? Follow-up questions added richness and depth to the data material collected. One interview was performed with each participant, lasting from 40 to 89 minutes (mean = 66 minutes). All interviews were recorded on mp3 recorder and transcribed verbatim. Data material available for interpretation totaled 190 pages (1.5 line spacing) transcribed interview-text. Participant

recruitment and data collection was limited to one-year. The number of participants interviewed reflects the sum of all who consented within the given timeframe. Towards the end of the allotted year however, we experienced data saturation, signaling that additional data would only serve to confirm our understanding.

#### 3.1.1.2.2 Data interpretation

The data interpretation was initiated by individually reading and reflexive dialogue with each interview-text (Fleming, Gaidys & Robb, 2003; Gadamer, 2010). Phrases and key words were noted during each reading. While utilizing the hermeneutic circle as a methodological framework for the interpretive process, meetings were arranged among all research group members to discuss patterns of meaning, data contradictions and inconsistencies, while simultaneously reflecting on the influence of personal pre-understanding, and questioning our interpretive understanding at all stages during this process (Fleming, Gaidys & Robb, 2003; Zimmer, 2006; Gadamer, 2010). The essence of each account was identified, investigated and formulated into themes and sub-themes. Reading each new interview-text made previously explored texts more understandable, while simultaneously adding new meaning of their own. Finally, the entire text was investigated, leading to a fusion of horizons in which new and expanded understanding of its parts, and the data material as a whole, were obtained (Fleming, Gaidys & Robb, 2003; Zimmer, 2006; Gadamer, 2010).

#### 3.2 Ethical considerations

While conducting the meta-synthesis, we felt an ethical obligation towards the original authors of the ten studies included, to be precise and loyal to their interpretations/second-order constructs, and whenever possible utilize their own formulations as data material for our meta-ethnography (study 1). We consciously followed the methodological recommendation of Noblit and Hare (1988), utilizing their recognized methodological framework while synthesizing the included studies. Moreover, including previous studies in meta-synthesis also implies an obligation to document quality criteria that strengthen study trustworthiness. These will be described in; 6.3 Methodological considerations and limitations.

The participants in studies 2 and 3 were all individuals living with dementia, and our research focus was anchored in the ethical standards of doing no harm, showing justice and respect for personal utility (Hellström et al., 2007). There is need for moral sensitivity and attention given



to the vulnerability of people with dementia participating in research (Heggestad, Nortvedt, & Slettebø, 2013b). Hence, this study was founded upon the acknowledgment of the inherent dignity of each participant, showing sensitivity towards their individual integrity, autonomy and life-history (Nordenfelt, 2004). Initially, each participant and their spouse were given verbal and written information concerning all aspects of the study. We wanted to assure that only persons capable of giving informed consent were recruited. Informing the participant spouse was therefore part of our recruitment strategy to ensure that participants had understood the implication of participating, and that their approval was given on this basis. To help increase understanding of the interview, and to strengthen their ability to either accept or decline study participation, all participants and spouses received a copy of the interview-guide containing ten main interview-questions. Moreover, all participants were informed of their right to withdraw from the study at any time, without consequence for present or future treatment and care. Each participant was informed that she/he could decide whether the interview should be conducted at home, or the researcher's office. On their request, all interviews were conducted within each participant's own home. As researchers responsible for the study, we ensured participants anonymity and confidentiality, as well as publishing study results in appropriate language style to preserve the dignity of each.

The Regional Committee for Medical and Health Research Ethics, South East Norway (ref. nr. 2010/1498, approved June 25, 2010) granted ethical approval for our study.

#### **4.0 Ontological perspective**

When exploring the nature of distinct phenomena, it is crucial to document the ontological foundation upon which the research is based. Ontology is a term referring to «the branch of metaphysics dealing with the nature of being» (Oxford University Press, 2014), and the ontological foundation of this present study will be introduced in the following.

##### **4.1. Caring science; developing a Theory of Caritative Caring**

When conducting research exploring the experiences of being, a scientific approach for exploring the ontological basis for these experiences is needed (Eriksson, 2001). This research project is anchored in the ontological foundation of caring science, its axioms, theses and methodology, as developed by Katie Eriksson, Unni Å. Lindström, and fellow researchers at Åbo Akademi University in Vasa, Finland. These researchers have developed major

assumptions concerning the core of caring, utilizing an associated caring science methodology in order to develop a theory of caring (Eriksson, 1981, 1987a, 1987b, 1990, 1995, 1996, 1997, 1998, 2001, 2002, 2006, 2013; Lindholm & Eriksson, 1993; Lindström, 1995; Lindström & Lindholm, 2003; Koskinen, & Lindström, 2013; Lindström, Nyström & Zetterlund, 2014; Edlund, 1995, 2002; Edlund et al., 2013; Nåden & Eriksson, 2000, 2004).

On this basis, Eriksson has developed the *Theory of Caritative Caring*. In this theory, *Caritas*, meaning love and charity, constitutes the fundamental motive for true caring of human beings experiencing illness and suffering (Eriksson, 1995, 1998, 2002; Lindström, Nyström, & Zetterlund, 2014). Based upon a number of major assumptions formulated as axioms and thesis and a process of continual development over several years, the theory evolved, while simultaneously establishing an autonomous caring science discipline within human science (Eriksson 2001). At present, Eriksson's *Theory of Caritative Caring* is founded upon eight axioms and six theses (Lindström, Nyström & Zetterlund, 2014, p. 177), constituting the major assumptions of the theory. Eriksson make a distinction between two kinds of major assumptions, namely axioms and theses; Axioms are regarded as fundamental truths in connection to the conception of the world. Theses are fundamental statements related to the nature of caring science in general, and the validity the thesis is tested through basic research (see Appendix 4). The Theory of Caritative Caring and associated caring science discipline are therefore part of a united and unbroken reciprocal process, utilizing empirical and theoretical studies for the testing and development of major assumptions concerning the core of caring (Eriksson 2001). While focusing on the various axioms and thesis of the caritative theory, the caring science approach can therefore be seen as a tool for systematic exploration, verification and adjustment of major assumptions upon which the theory is based (Lindström, Nyström & Zetterlund, 2014).

Eriksson (2002; Lindström, Nyström & Zetterlund, 2014) suggests hermeneutics according to Gadamer as an appropriate methodology for the caring science discipline towards penetrating the core of caring. To Gadamer, understanding perceptions and experiences of human beings is crucial for understanding the human nature. Utilizing human language transformed into descriptive texts, Gadamer shows how movement from descriptive text towards an understanding of its meaning, is possible through hermeneutical exploration (Gadamer, 2010). Such understanding also involves understanding the ontological foundation upon which people live their lives. Hermeneutics is also a valuable methodological approach since Gadamer underlines how "the truth" is never absolute or final, but should be perceived as an

understanding within the limits of our prejudice and pre-understanding at present (Eriksson, 2001; Gadamer 2010). Thus, in alignment with Gadamer (2010) this caring science tradition underscores how understanding is always a matter for revision (Eriksson, 2001).

On this basis, and in accordance with this caring science tradition, the interpretive understanding of empirical data collected for this research project was anchored in Gadamer's philosophical hermeneutics.

#### 4.1.1 Caring for the suffering human being

According to Eriksson (2001), prerequisite to ontology exist an ethos upon which ontology is based. The ethos, or core values of all human beings, becomes ethics in practice through relational interactions with others (Eriksson, 1995). In Eriksson's (2013, p. 70) own words, the mantra constituting the ethos of caring is as follows: *«I was there, I saw, I witnessed and I became responsible»*. In her theory, Eriksson is especially concerned about the suffering human being, and of the responsibility of the caregiver who is there, seeing and witnessing the suffering. Suffering is a basic category of caring, underscoring the main purpose of care as the alleviation of suffering (Eriksson, 1995; Lindström, Nyström & Zetterlund, 2014). Research concerning this caring science tradition, suggests the caring needs of those experiencing illness, are best understood through a deeper understanding of their suffering (Fagerström, Eriksson & Bergbom Engberg, 1998).

Eriksson (2006) documents how human suffering can be divided into three separate forms; suffering related to life; suffering related to illness, and; suffering related to care. Suffering related to life involves all aspects of being human, associated with circumstances, which disturb the rhythm of life, and situations threatening the experience of safety in everyday living. Suffering related to illness on the other hand, is affiliated with human experience in conjunction with illness and illness-related treatment (Eriksson, 2006), and therefore, understanding the patient's experience of suffering related to illness is crucial for the provision of care in clinical settings (Eriksson, 1997). The third form, suffering related to care, is associated with caregiver attitude and behavior within the caregiving context, which violating patients' dignity (Eriksson, 2006). Individuals experiencing suffering related to care, often feel rejected and mistrusted (Eriksson, 2006; Wiklund-Gustin, 2011), condemned and punished (Eriksson, 2006), neglected, and placed in a non-caring situation (Arman et al., 2004; Eriksson, 2006). Within this context, Eriksson and Nåden (2004) document how values and moral attitudes in Caritative caring help enhance patient participation, allow them to step

forward and become the center of attention, and thus is a crucial guiding principle towards preserving dignity among suffering human beings.

#### 4.1.2 Dignity; the origin and aim of being

According to Eriksson, *dignity* is a core concept describing the nature of human beings. Dignity constitutes the human being, and therefore has a central position within Caritative caring ethics. Dignity is present in the human origin, and in the aim of the human mission, namely to serve with love and being present for the sake of others (Eriksson, 1995, 2013; Lindström, Nyström & Zetterlund, 2014). Eriksson (1995, 1996, 1998; Lindström, Nyström & Zetterlund, 2014), and Edlund (1995, 2002; Edlund et al., 2013), document how human dignity is partly absolute, partly relative. *Absolute dignity* is inherent in all people, inalienable and granted by virtue of being human. Thus, absolute dignity involves both a need and a right for every person to be recognized as a unique and worthy individual. *Relative dignity* is however modifiable and influenced by sociocultural factors of everyday life. This form of dignity concerns feelings of self-worth and value in relation to other people. It can be strengthened through the support and confirmation of others, or torn down and violated. Eriksson emphasizes how a person's existence is a history of lifelong struggle between being and nonbeing, and that relative dignity therefore is part of the process of constantly becoming the person one desires to be (Lindström, Nyström & Zetterlund, 2014). Human beings search for meaning in their lives. Meaning is a source of energy, of transcendence, experiencing dignity through becoming a person who fulfills his or her potential (Lindström, Nyström & Zetterlund, 2014).

According to Eriksson (1995, 1996, 1998), and Edlund (1995, 2002; Edlund et al., 2013), dignity is comprised of both internal and external dimensions. Internal dignity relates to personal processes concerning self-perception and self-worth. A need to experience dignity by confirming one's self-worth is common among suffering human beings. The internal dignity dimension is connected to a personal sense of honor, reliability and morality. In the process of constantly becoming, human beings are not unfamiliar with suffering. However, while enduring suffering, internal awareness supports dignifying strength and courage (Eriksson, 1996), as it shelters dignity in times of illness and suffering (Lindström, Nyström & Zetterlund, 2014). External dignity-dimension, on the other hand, relates to attitudes and actions developed in relational interaction between individuals and those around them (Eriksson, 1995, 1996, 1998; Edlund 1995, 2002; Edlund et al., 2013). People live their lives

within the context of mystery, infinity, eternity and wholeness, and are dependent on being invited into a caring and confirming communion with others, where they can give and receive love, and experience hope, faith and meaning. Being part of a caring and confirming communion can also be experienced through feelings of connectedness towards abstract others, such as God, for example (Lindström, Nyström & Zetterlund, 2014), leading to reconciliation also among those experiencing suffering (Eriksson, 1998).

#### 4.1.3 Caritas motive and ethos; other major concepts and ethical categories

According to Eriksson (Eriksson, 1995, 1998, 2002; Lindström, Nyström & Zetterlund, 2014), the *caritas motive* anchored in *love and charity* is directed towards preserving human dignity. The caritas motive also involves several other major concepts and ethical categories which by nature are ontologically inter-related, the sum of which constitute The Theory of Caritative Caring. The caritas motive is based on an *ethical obligation for promoting that which is good and resisting that which is evil*. Since the suffering human being is in need of being invited into a *caring culture* and *compassionate communion* in order to experience *love, faith, hope and meaning* in daily life (Eriksson, 1995, 1996, 1998, 2006, 2013; Lindström, Nyström & Zetterlund, 2014), inviting individuals into such a communion is therefore an *ethical responsibility* and core foundation of each act of caring. Feeling welcome and receiving *space for suffering, rest and reconciliation* within a *caring culture* founded on *warmth and compassion, respect and tolerance*, are crucial for *alleviating suffering related to illness, preventing suffering related to care, confirming human worth* among those who suffer, and *preserving human dignity* (Eriksson, 1995, 1996, 1998; Nåden & Eriksson, 2000, 2004; Lindström, Nyström & Zetterlund, 2014).

For each human being, living means being in a lifelong process of *constantly becoming*, while simultaneously experiencing a continuous struggle between *being and nonbeing*. Human dignity is an integrated part of the history of each individual, and in the act of caring opportunities *for tending, playing and learning* help the suffering individual reach her/his true potential of becoming (Eriksson, 1998, 2002, 2006; 2013; Nåden & Eriksson, 2004; Lindström, Nyström & Zetterlund, 2014). Meaningful realization of one's inner potential strengthens a sense of *honor, reliability, morality* and feeling of *self-worth* (Eriksson, 1995, 1996, 1998; Edlund, 1995, 2002; Edlund et al., 2013), while enhancing one's sense of *dignity* through the experience of becoming (Lindström, Nyström & Zetterlund, 2014).

Freedom of becoming is a continual process in life. However, life is *a mystery of infinity, eternity and wholeness*. Within this context, the power of transcendency can be experienced as true freedom beyond the conditional freedom of daily living. Existential and spiritual experiences of connectedness to the meaning of life on a higher and more abstract level, such as in relation to one's God, is a crucial foundation for human dignity, and a pathway towards *reconciliation* while experiencing illness and suffering (Eriksson, 1998, 2006; Lindström, Nyström & Zetterlund, 2014).

## 5.0 Results

This study explored crucial aspects preserving dignity among individuals living with dementia, as perceived by nurses and allied HCPs (study 1) and those experiencing dementia in daily life (study 2 and 3). These three studies contribute to new understanding on the subject, documenting three different yet complementary horizons.

### 5.1. Horizon 1; Dignity-preserving dementia care: A metasynthesis (study 1)

The aim of this study was to develop an empirical-theoretical model concerning crucial aspects inherent in dignity-preserving dementia care. The results of 10 qualitative studies conducted within various cultural contexts, all investigating nurse and allied HCP perceptions and practices concerning crucial aspect of dignity-preserving dementia care, were explored and synthesized utilizing the meta-ethnographic methodology of Noblit and Hare (1988). An interpretive understanding of the empirical data was developed, anchored in Eriksson's Theory of Caritative caring, which emphasizing preservation of dignity as a core aspect of caring for suffering human beings (Lindholm & Eriksson, 1993; Eriksson, 1995, 1996, 1998, 2002, 2006, 2013; Nåden & Eriksson, 2000, 2004; Lindström, Nyström & Zetterlund, 2014). Based on the empirical-theoretical interpretation, a first-level synthesis was developed containing two separate groups of aspects (group A and B), both constituting primary foundation for dignity-preserving care. Within both groups supplementary sub-aspects were also identified. A second-level synthesis was thereafter performed, developing an overarching principle and metaphor for dignity-preserving dementia care as perceived and practiced by nurses and allied HCPs.

Group A studies, *advocating the person's autonomy and integrity*, was found to be a primary foundation for dignity-preserving dementia care. Three particular yet supplementary sub-

aspects were identified; *having compassion for the person*; *confirming the person's worthiness and sense of self*, and; *creating a humane and purposeful environment*, all identified as crucial prerequisites for autonomy and integrity among individuals living with dementia. From the professional caregivers' perspective, *having compassion for the person* involved a genuine interest, and empathic attitudes towards those living with dementia. This sub-aspect also included professional knowledge concerning fundamental needs of individuals with dementia in general, plus specific knowledge about each person in particular. All of the above aspects were recognized as essential qualities and competence among professional caregivers, constituting crucial foundations for autonomy and integrity advocacy. Nurse and allied HCP awareness of *confirming the person's worthiness and sense of self*, involved genuine respect for the person as a unique human being with an inherent desire and right to make choices according to their subjective needs. Emphasis on discovering the personality and authentic autonomy of each individual, recognizing their life-history, and including her/him within a caring fellowship, were all found crucial aspects towards strengthening personal resources, preserving individual sense of self and feelings of value, self-respect, sense of status and personal human worth.

Among group A studies, *creating a humane and purposeful environment*, with attention focused on establishing human-friendly surroundings towards compensating dementia-related loss of function for those who reside therein, was also found to be an essential foundation for advocating autonomy and integrity. Creating person-centered, practical and "dementia friendly" surroundings, designed to meet patients' needs for freedom and safety in everyday living, where qualified and motivated nurses and HCPs may sit down for meaningful conversation or discrete help, was reported as essential. This included creating a milieu for sheltering residents from disrespectful treatment of others, and meeting the needs for those who enjoy frequent walks outdoors. Implementing personal preferences into an individual care plan, recognizing the individual needs for assistance while establishing emotional attachment within a more homelike caring atmosphere in nursing home settings, were all perceived purposeful in developing an environment where residents might live as comfortably, enjoyably and dignified as possible.

In the process of developing and empirical-theoretical understanding, Eriksson's' and Edlunds' theoretical perspective on dignity, and Eriksson's Theory of Caritative caring for the suffering human being (Lindholm & Eriksson, 1993; Eriksson, 1995, 1996, 1997, 1998, 2001,

2002, 2006; Edlund, 2002; Näden & Eriksson, 2000, 2004; Lindström, Nyström & Zetterlund, 2014), offered helpful perspectives. According to Eriksson, Caritas, meaning love and charity, constitutes the fundamental motive for true caring (Eriksson, 1998, 2002, 2006; Lindström, Nyström & Zetterlund, 2014), and is seen as a core foundation and endeavor of caregiving, towards preserving dignity among patients/residents suffering due to their dementia illness.

Within the basic ethos concept of Caritative caring, human *dignity* exists in two forms. While *absolute dignity* is an inherent and inviolable part of human holiness, granted through creation, and involving the right to be confirmed as a unique human being, *relative dignity* is a changeable and violable dimension of human existence, influenced by external context and culture (Eriksson, 1996, 1998; Edlund, 2002; Lindström, Nyström & Zetterlund, 2014). In this study, nurse and allied HCP compassion and confirmation of each person's worthiness and sense of self, form a basis for enhancing personal autonomy and integrity. These qualities were anchored within their respect for the absolute dignity of their patients, and recognition of caregivers' responsibility for sheltering patients'/residents' relative dignity, by bringing faith, hope and charity into their daily lives. Through Caritative invitation (Eriksson 1998; Näden & Eriksson, 2000; Lindström, Nyström & Zetterlund, 2014), those living with dementia were welcomed into an intimate and stimulating caring communion, characterized by respect, warmth, closeness, tolerance and hospitality. As caregiver and patient/resident experience tending, playing and learning together, within a caring and compassionate culture (Lindström, Nyström & Zetterlund, 2014), the autonomy and integrity of their patients'/residents' were advocated, constituting crucial foundations for dignity-preserving dementia care. Moreover, based on empirical-theoretical understanding, nurses and allied HCPs aimed to preserve patients'/residents' dignity through emphasizing the creation of physical and social environments anchored in familiar design, tradition and ritual (Lindström, Nyström & Zetterlund, 2014). Thus, humane and purposeful environments with practical designs geared to meet the suffering human being's needs for easy orientation, enhancing feelings of freedom and safety, were also found to be a crucial part of dignity-preserving dementia care as perceived by nurses and allied HCPs.

Group B studies found how nurse and allied HCPs' motives towards advocating patient/resident autonomy in certain situations actually can compromise their integrity and violating personal dignity. This ethical paradoxical dilemma occurs when individuals with



dementia are unable to take care of their essential needs, and no longer able to make sound decisions, especially related to personal hygiene and vital medication. In such situations, nurses and allied HCPs reported feeling an ethical duty to protect patients/residents from harmful consequences, violating their physical integrity or integrity as a whole. Finding a way to *balance individual choices among persons no longer able to make sound decisions, against the duty of making choices on behalf of the person*, was therefore required in certain situations. While stimulating the suffering person's resources, strengthening her/his self-determination and ability to cooperate, finding the proper time to *employing persuasion in order to meet the person's essential needs*, were, in certain situations, perceived necessary to preserve patient/resident dignity. However, professional caregivers also reported how persuasion did not always solve ethical dilemmas, creating new and fundamental ethical challenges for them to solve; deciding whether the person should be allowed to decide, or not. For example; when caring for a person who is lying in bed full of excrement, unable to understand the harmful consequences, while resisting caregiver attempts at verbal persuasion. Although an ethical paradoxical dilemma, in such situations professional caregivers found certain forms of integrity violation, such as *exerting a certain degree of mild restraint in order to meet the person's essential needs*, based on authorized restraining orders according to existing laws, sometimes necessary in order to maintain the person's "integrity as a whole" while aiming for dignity preservation.

The empirical-theoretical understanding is based on knowledge of how dementia sometimes leaves suffering individuals unable to make autonomous decisions. Eriksson documents how understanding the ethos of caritative caring strengthens nurses' and allied HCPs' capabilities for ethical responsibility, promoting that which is good and resisting evil (Eriksson, 1998, 2002; Nåden & Eriksson, 2004; Lindström, Nyström & Zetterlund, 2014). While caring for individuals no longer able to make sound decisions, nurses and allied HCPs reported how they in certain critical situations felt an ethical obligation to use persuasion or mild restraint anchored in the Caritative motive of promoting what is good, to ensure the essential needs of those they cared for were met.

Based on the empirical-theoretical interpretation as a whole, a second-level synthesis of Group A studies, and Group B studies was conducted, identifying; "*Sheltering human worth*

– *remembering those who forget*”, as overarching principle and metaphor for dignity-preserving dementia care, as perceived and practiced by nurses and allied HCPs.

## 5.2 Horizon 2; Crucial dimensions constituting dignity experience in persons living with dementia (study 2)

The aim of this study was to develop increased knowledge on crucial dimensions within the foundation of dignity experience among persons living with dementia. Utilizing hermeneutic methodology, this study conducted research interviews with eleven persons living with dementia to investigate these crucial dimensions. An interpretive understanding of the empirical data was developed anchored in perspectives from Eriksson’s Theory of Caritative caring, in which the preservation dignity among suffering human beings is a core aspect (Eriksson, 1995, 1996, 1998, 2002, 2006; Lindström, Nyström & Zetterlund, 2014). Based on this empirical-theoretical interpretation, three dimensions and seven sub-dimensions, each crucial for dignity experience among our participants, were identified.

First, meaningful experiences and life-projects within their personal life-history constituted a vital foundation for retrospective dignity experience, bringing substance, meaning, and direction into their present lives. Although distant in time, *valuing foundation of life given through childhood and upbringing*, appreciating and recognizing personal values and skills internalized through relationships with significant others years ago, were still crucial sources for preserving their sense of dignity. Also, building a family was reported a crucial life-project, and *feeling gratitude and pride in having established a family of one’s own* was found to be an important source for bringing dignity experience into their present life-situation. Moreover, *appreciating honorable employment and meaningful work in their past* helped strengthen their sense of pride and self-worth, and was found to be a vital dignity-preserving aspect in their everyday lives, even after the onset of dementia. In the process of developing an interpretive understanding, perspectives of Eriksson and Edlund (Eriksson, 1995, 1996, 1998, 2006; Edlund 1995, 2002; Edlund et al., 2013) were helpful as theoretical framework, documenting absolute dignity as inherent, inalienable and granted by virtue of being human, and relative dignity; modifiable and influenced by socio-cultural factors, founded upon experiences of internal as well as external confirmation of individual worth as human beings, living their lives from birth to death, in a process of constantly becoming. As underscored by Eriksson, a person’s existence is a lifelong history involving a struggle between being or nonbeing. During this continual process of becoming, crucial life-events and achievements

can help individuals to experience meaning and become the person one desires to be (Lindström, Nyström & Zetterlund, 2014). Based on this empirical-theoretical understanding, the participants' dignity experience was found to be anchored in a *historical dignity-dimension*, recognizing personal background and *acknowledging one's life-projects and life-history*, as crucial for dignity experience in their present life-situation.

Second, subjective cognitive and emotional processes towards *recognizing one's own human worth, and living life according to internal values*, helped preserve a sense of dignity while living with their illness. In this process, *acknowledging oneself* as a worthwhile human being, while having the opportunity to continue *living according to personal moral virtue*, was crucial aspects for enhancing dignity experiences in everyday living. Having the option of *enjoying enriching activities of daily life*, be allowed to utilize both body and mind in significant ways, take part in personally relevant and valued work, plus opportunities to be outdoors and experience the pleasures of exploring their surroundings, were all found crucial towards enhancing personal meaning.

Developing an interpretive understanding, Eriksson, and Edlund, emphasize the existence of an internal dimension of human dignity (Eriksson, 1995, 1996, 1998, 2006; Edlund 1995, 2002; Edlund et al., 2013). Internal processes involving doubts of personal worthiness are common among suffering human beings. Personal processes confirming a suffering individual's self-worth through meaningful realization of inner potential, is considered crucial for dignity experience in their process of constantly becoming (Lindström, Nyström & Zetterlund, 2014). Suffering is part of the human process of becoming, and an internal awareness of aspects sheltering dignity experience, help strengthen personal endurance through suffering (Lindström, Nyström & Zetterlund, 2014), while supporting individual courage inherent in human dignity (Eriksson, 1996). Experiencing inner peace in the midst of life's demands, the suffering individual may feel closer to personal ideals, and experience of self-worth and relative dignity (Eriksson, 1995, 1996, 1998, 2006; Edlund, 1995, 2002; Edlund et al., 2013; Lindström, Nyström & Zetterlund, 2014). Within this empirical-theoretical context, dignity experience among participants of this study were found to be based upon an *intrapersonal dignity-dimension*, involving an internal evaluation of one's own self-value, and meaning in their present life-situation.

Third, our study identified how *receiving respect and recognition from others*, especially

from family, social network and HCPs, formed part of an external conformation of human worth, crucial for dignity-preservation. Among some participants, *experiencing transcendental and spiritual meaning* was an essential aspect of their caring and confirming communion. Beyond the limits of earthly concerns, feeling close and connected to nature, sensing its beauty and power, was a meaningful and dignifying transcendental experience. One participant also expressed how faith helped him feel close to his God, thus being a part of something eternal, beyond life on earth, constituting a comforting spiritual awareness, confirming his self-worth and human dignity. According to Eriksson, and Edlund, (Eriksson, 1995, 1996, 1998, 2006; Edlund 1995, 2002; Edlund et al., 2013), human dignity also contains an external dimension, involving personal attitudes and actions while relating to other individual and environmental factors. Being invited into a caring and confirming communion, with opportunities to give and receive love, experience faith, hope and meaning in daily living, are crucial for suffering individuals. Experiencing life as a mystery involving the dimensions of infinity and eternity, with a sense of existential and spiritual interconnectedness to abstract others, such as God, may help confirm one's inherent, absolute dignity (Lindström, Nyström & Zetterlund, 2014), reconciled with their own lives (Eriksson, 1998).

Based on this empirical-theoretical understanding, participants' dignity experience were founded upon an *interpersonal dignity-dimension*, giving them the opportunity of *experiencing being part of a caring and confirming communion*, constituted within their relationship to family, social network and HCPs, as well as interconnectedness of transcendental and spiritual character.

### 5.3 Horizon 3; Relational interactions preserving dignity experience: Perceptions of persons living with dementia (study 3)

The aim of this hermeneutic study was to explore and describe crucial qualities of relational interactions preserving dignity experience among people with dementia, while interacting with family, social network and HCPs. Research interviews were conducted with eleven persons experiencing dementia. An interpretive understanding of the collected empirical data was developed anchored in perspectives from Eriksson's Theory of Caritative caring, emphasizing how preserving dignity among suffering human beings is a core aspect of caring (Lindholm & Eriksson, 1993; Eriksson, 1995, 1996, 1998, 2002, 2006, 2013; Nåden &

Eriksson, 2000, 2004; Lindström, Nyström & Zetterlund, 2014). Three main qualities and ten sub-qualities within these relational interactions were found as a result of the empirical-theoretical interpretation.

First, after being diagnosed with dementia and questioning their own self-worth as a partner, *feeling the love and affection from their spouse* was reported as an essential dignity-preserving aspect within their marriage relationship. Moreover, while experiencing how dementia gradually made daily life more difficult, experiencing *having spousal support during activities of daily living* helped participants find meaning and coherence, better able to cope with new challenges, while sheltering their sense of dignity. Interactions with their children, grandchildren and great-grandchildren were also of great importance. Living with dementia affected self-esteem negatively. Feeling appreciated and acknowledged as a parent, grandparent or great-grandparent, sensing descendants' understanding of current health problems related to old age, as well as confirming one's significant and important role within the family, helped strengthen self-esteem and preserve their dignity experience.

As underlined by Eriksson, and Edlund (Eriksson, 1995, 1996, 1998, 2006; Edlund 1995, 2002; Edlund et al., 2013; Lindström, Nyström & Zetterlund, 2014), relative dignity relates to the experience of self-worth and human value in relationships with others. This modifiable form of dignity either can increase through external support and confirmation, or weaken through external violation. A core concept in the ethos of caritative caring for the suffering human being is Caritas. Meaning love and charity, Caritas constitutes the fundamental motive for true caring (Lindholm & Eriksson, 1993; Eriksson, 1995, 1996, 1998, 2002, 2006, 2013; Nåden & Eriksson, 2000, 2004; Lindström, Nyström & Zetterlund, 2014). Developing an interpretive understanding, we found the caregiving spouses' shared love for the ill partner, to be crucial Caritative quality towards preserving the relative dignity of the latter. Moreover, while questioning their own worthiness as a partner after being diagnosed, the participants' sense of dignity was activated when experiencing spousal joy, affection and everyday support, as this helped confirm their worthiness as a partner, bringing faith and hope back into their lives. Warmth, compassion, responsibility and sacrifice by the caring spouse, basic qualities within Caritative caring, were thus found to be crucial dignity-preserving features within spousal interaction. Moreover, interacting with children, grandchildren and great-grandchildren, experiencing their love and appreciation, feeling confirmation as an important contributor within their lives, also helped increase the participants' sense of relative dignity.

According to Eriksson, the qualities of such relational closeness, tolerance and respect are crucial in confirming dignity of the suffering human being (Lindholm & Eriksson, 1993; Eriksson, 1995, 1996, 1998, 2002, 2006, 2013; Nåden & Eriksson, 2000, 2004; Lindström, Nyström & Zetterlund, 2014). Based on this empirical-theoretical understanding, participants' opportunities for *experiencing love and confirmation*, was found to be the overall quality dimension of the dignity-preserving interactions within family relationships.

Second, regarding *dignity-preserving interactions within the social network*, participants' opportunities of *perceiving friendships stay alive*, while experiencing the privilege of spending time with long-time friends, was found to be a crucial dignifying source. In addition, *feeling socially included, living an active life within a social fellowship*, plus experiencing being part of an extended social network, offering them meaningful and enjoyable relational interactions with people recognizing them as worthwhile members of society, were identified as crucial qualities preserving their dignity experience in daily living. Developing an interpretive understanding, a Caritative invitation (Eriksson, 1998; Nåden & Eriksson, 2000; Lindström, Nyström & Zetterlund, 2014) is experienced as friends and individuals from extended network, welcome and include the suffering human being within a stimulating, intimate communion, characterized by Caritative caring qualities like closeness, tolerance and respect (Eriksson 1996; Nåden & Eriksson, 2004; Lindström, Nyström & Zetterlund, 2014). Invited into a caring communion with familiar values, traditions and rituals gave participants options for tending, playing and learning (Lindström, Nyström & Zetterlund, 2014), while confirming their sense of human worthiness (Eriksson, 1996, 1998, 2006; Lindström, Nyström & Zetterlund, 2014). Based on this empirical-theoretical understanding, participants' options for *experiencing social inclusion and fellowship*, constitutes the main quality of these dignifying relational interactions.

Third, humane and friendly HCPs' attitudes were found essential in reinforcing participants' feelings of being worthwhile human beings. *Feeling respected, listened to, and taken seriously* helped them feel less stigmatized or labeled as "demented", having a crucial impact on their self-perception and sense of dignity. In times of illness and suffering, living with worries and vulnerability, participants reported how *meeting kindness*, while interacting with HCPs, was a crucial dignity-preserving factor. Moreover, concerning their need for explanations related to present health condition and future outlook, participants reported *receiving health-related information in a gentle manner* to be a crucial aspect sheltering their

vulnerability, and preserving a sense of dignity. Meeting positive HCP attitudes while receiving realistic and comprehensible information concerning their health status, treatment, and how to make the most out of life in their current situation, were all identified as autonomy-promoting and dignity-preserving qualities, supporting participants towards *adopting positive realism while feeling empowered*. Moreover, *experiencing similar status and rights as other patient groups* within the national healthcare system, as well as their personal ‘interaction-with-the-healthcare-system-experiences’, impacted their sense of dignity.

Developing an interpretive understanding, Eriksson (2013, p. 70) formulate the Caritative caring mantra as: “I was there, I saw, I witnessed and I became responsible”. Anchored in love and responsibility, this mantra clearly portrays the ethical obligation within caring, to promote that which is good, and resist that which is evil (Eriksson, 1998, 2002, 2013; Nåden & Eriksson, 2004; Lindström, Nyström & Zetterlund, 2014). Nursing is an art that constitutes a healing process towards helping suffering human beings feel acknowledged, trusted, validated and confirmed (Nåden & Eriksson, 2000). Receiving care from HCPs devoted to their responsibilities is crucial (Eriksson, 2006; Lindström, Nyström & Zetterlund, 2014). The participants of this study reported how HCPs’ attitudes and behaviors influenced their dignity experience. Within the context of Caritative caring theory, the concept of *invitation* (Eriksson 1998; Nåden & Eriksson 2000; Lindström, Nyström & Zetterlund, 2014) was also found a relevant approach for describing a crucial quality of a dignity-preserving healthcare system. Welcoming suffering human beings while focusing attention on meeting their needs, is essential for developing a compassionate caring culture (Eriksson, 2006; Lindström, Nyström & Zetterlund, 2014). Within a healthcare system characterized by a caring culture founded upon warmth and compassion, respect and tolerance, suffering related to illness can be alleviated, suffering related to care can be prevented, and human dignity preserved (Eriksson, 1996, 1998, 2006; Nåden & Eriksson, 2004; Lindström, Nyström & Zetterlund, 2014).

Based on the empirical-theoretical understanding, the main quality of *dignity-preserving interactions with HCPs* was found within relational characteristics enhancing participants’ foundation for *experiencing humane warmth and understanding within a caring culture, while being met as an equal human being*.

## **6.0 Developing «Dignity Horizon Model: Caring for persons living with dementia» and Discussion**

The overall aim of this project was to develop an empirical-theoretical model of dignity-preserving care for persons with dementia, grounded on a metasynthesis of nurse and allied HCP perceptions (study 1), as well as perceptions of individuals experiencing dementia in daily life (study 2 and 3). The empirical horizon shows all three studies contribute to the collection of vital data, documenting empirical aspects crucial for dignity-preservation among people living with dementia. Perspectives of the Caritative theory of caring, emphasizing dignity-preservation of the suffering human being, documented by Eriksson and fellow researchers, represents a crucial contribution to the researchers' pre-understanding for this study and constitutes the theoretical horizon for our discussion

In this section, the empirical and theoretical horizons will be discussed towards developing a deeper understanding of the study results. Themes identified within empirical horizon are discussed, while Eriksson's theoretical perspectives form a tool for developing interpretive understanding. In this process, an association between empirical and theoretical horizons develops towards revealing of a new horizon. Working within the hermeneutical circle and engaged in dialogue with the texts of both horizons, this research sets both horizons in motion in order to create room for an assimilation process leading to their fusion and the rise of a new empirical-theoretical horizon of understanding.

The discussion of emerging perspectives below is conducted under the headings; *Crucial dignity-preserving aspects in relational interactions in general; Dignity-preserving aspects crucial within HCP-patient interactions, and; Dignity-preserving aspects crucial within relational interactions with family and social network*. Based on this discussion, the overall perspectives constitute the new empirical-theoretical understanding of this study, formulated under the heading; *Dignity-preserving care; overall perspectives*. Finally, on this basis, a new empirical-theoretical model of dignity-preserving care for persons living with dementia, is presented.

### *Crucial dignity-preserving aspects in relational interactions in general*

First, the empirical horizon suggests three aspects of dignity-preserving care which should be emphasized by all caregivers, both formal and informal. This includes a general emphasis on supporting care recipients towards: recognizing one's own human worth, and living life



according to internal values; acknowledging one's own life-projects and life-history, and; experiencing being part of a caring and confirming communion.

Dementia made everyday life more difficult. Progressive memory loss turned planning and performing daily tasks into a burdensome challenge. The empirical horizon shows how living with dementia also involved living with an inner, subjective struggle in daily life. This was often a lonesome endeavor where fighting back feelings of inadequacy were painful. Many experienced the dilemma of questioning their own self-worth, while simultaneously striving to feel adequate and retain self-esteem. While grappling through the storms of subjective thoughts and sensations, finding anchor points towards maintaining *intrapersonal dignity* was of vital importance. Throughout this process, a general emphasis on supporting the person towards recognizing his or her personal human was found to be essential within this intrapersonal dignity-dimension. The study suggests how preserving personal identity and the experience of being just as worthwhile as always, is crucial for helping these individuals protect against loss of self-esteem and dignity, within their new life situation.

On the theoretical horizon of this study, Caritative caring aims to preserve dignity among suffering human being, like those living with dementia. Eriksson envisions the *caritas* motive as being anchored in love and charity, towards the suffering human being. Recognizing the inherent and absolute dignity of each human being, true caring is motivated by devotion and benevolence grounded in an ethical responsibility, for the vulnerable individual. Recognizing the individuals struggle between being and nonbeing, an inherent part of suffering, is a core perspective here. Thus, supporting the individual in the midst of their personal struggles is seen as crucial for alleviating suffering related to illness, and vital for preserving his or her relative dignity, a vulnerable and violable form of dignity. Caritative caring recognizes and respects these processes, aiming to promote the good and resist evil (Eriksson, 1995, 1996, 1998, 2002, 2006, 2013; Lindström, Nyström & Zetterlund, 2014).

The empirical horizon illuminates the option of living according to personal internal values as crucial towards preserving participants' dignity experience after the onset of dementia. A vital foundation for identity and self-esteem, was found within the opportunity of living according to personal moral values that have guided them throughout life. A general emphasis for caregivers, informal and formal, on facilitating and supporting this need is perceived as crucial towards protecting them from loss of self-esteem and dignity. Additionally, having the opportunity to enjoy enriching activities in everyday life seemed vital for experiencing

dignity. Remaining physically active contributed meaning in their daily routine, allowing them to invigorate their bodies, receive impulses from the others, and enjoy the good feelings these activities produced. Daily walks offered the possibility to remain in contact with neighbors and community, helping to reduce passivity and loneliness. Opportunities for utilizing cognitive resources and personal reflection in daily activities they were still able to master were highly motivating, strengthening individual dignity experience. Moreover, given opportunities to perform specific household tasks helped confirm their coping abilities and inner sense of self-worth.

A fundamental element in the Caritative caring horizon lies within the necessity to live in accordance with one's "ethical consciousness" in a process of ever becoming the person one desires to be (Lindström, Nyström & Zetterlund, 2014). Experiencing inner peace at midst of life's demands, the suffering human being often feels closer to his or her deepest ideals. Thus, Caritative caring emphasizes supporting individual's internal dignity dimension towards holding onto personal moral values, preserving their sense of relative dignity, and upholding sense of honor and worthiness (Eriksson, 1996, 1998; Lindström, Nyström & Zetterlund, 2014). For our participants, enjoying enriching activities helped bring greater meaning into their everyday lives. According to the Caritative caring horizon meaningful realization of one's inner potential helps lay foundations for dignity experience within a process of constantly becoming (Lindström, Nyström & Zetterlund, 2014). Having the option to use both body and mind in meaningful ways, and take part in meaningful work activities, helped enhance participants feeling of usefulness in everyday life. Caritative caring emphasizes acts of intervening supporting faith, hope and courage in the lives of each suffering human being. A Caritative caring culture emphasizes tending, playing and learning, encouraging caregivers to develop familiarity and closeness to those who suffer, through a process of protecting, interplay and understanding, in order to alleviate illness related suffering. Opportunities for participation in activities of personal importance are also vital towards upholding one's sense of honor and self-worth, in a continual process of becoming (Eriksson, 2006; Lindström, Nyström & Zetterlund, 2014). A general emphasis among caregivers, formal and informal, on facilitating and supporting this process, is according to this study, a crucial foundation for dignity-preservation in caring for people living with dementia.

Second, this study's empirical horizon draws attention to how essential personal life-projects and life-history became, as a crucial sources for dignity-preserving experiences after onset of

dementia. Reminiscing over important milestones and meaningful projects help sustain their experience of success and accomplishment. Having the opportunity to converse with others, who showed genuine interest in their life-history, seemed essential toward confirming their personal worth as human beings. Amidst their vulnerability, memorable life-history events and successful life-projects seemed a crucial source of confirmation concerning who they really are, for themselves and others, so much more than merely one who is «demented». Talking about subjects, centered on their childhood and upbringing, gratitude and pride in having established a family of one's own, plus, experiences of honorable employment and meaningful work in younger years, affected their here-and-now dignity experience in a positive manner. Therefore, our study suggests that facets of life relating to one's historical dignity-dimension should be considered a crucial aspect when aiming to preserve dignity in daily activities among individuals living with dementia.

On the theoretical horizon of Caritative caring, human life is understood as a continual history of constantly becoming. From birth to death, living constitutes a lifelong journey in which each individual has personal need for confirmation as a worthwhile human being. In this process, crucial experiences, achievements and milestone events, are vital aspects towards bringing dignity into one's present life. While suffering is a natural part of living, the process of constantly becoming is a natural part of suffering. Knowledge on relative dignity and how it may be negatively affected through internal, subjective processes, as well as external factors in one's surrounding, is crucial for understanding the vulnerability for experiencing loss of dignity among those living with dementia. Respect and tolerance for each individual is therefore a crucial foundation for every caring act. Moreover, recognizing each person's inherent and absolute dignity as a human being is fundamental towards acknowledging the absolute value and uniqueness of each life story. Caritative caring aims to alleviate suffering brought on by illness. External support which enhances an individual's sense of honor and self-worth is a vital aspect towards promoting his or her relative dignity. Supporting suffering individuals by acknowledging their personal life-projects and life-history are ways of confirming their individual human worth (Eriksson, 1996, 1998, 2002, 2006; 2013; Nåden & Eriksson, 2004; Lindström, Nyström & Zetterlund, 2014). Acknowledging *historical dignity* as a source of dignity experience available at present, caregivers can help enhance personal meaning in the sufferer's life here-and-now. This study thus argues that caregivers can help individuals living with dementia, towards maintaining the dignifying experience of living in a process of constantly becoming.

Third, the empirical horizon of our study illuminates how experiences of being a part of a caring and confirming communion had vital impact on the participants' dignity experience. Experiencing difficulties in performing previously simple tasks often affected their self-esteem negatively, even causing some to question their value as a person. On the other hand, the feeling of being respected, recognized and included in social fellowship was experienced as a crucial dignifying aspect. We found crucial aspects or qualities within participant relational interplay with HCPs, family, friends/social network as well as a personal connection or faith in God and/or nature, forming and strengthening what we identified as *interpersonal dignity* within the interpersonal dignity-dimension. Concerning the latter aspect, we found that several participants experienced how being in the nature enhanced personal meaningfulness. The feeling of nearness to nature, sensing its power, stillness and beauty, created a feeling of transcendental, dignifying inter-connectedness with nature. One participant experienced how religious faith, and the feeling of spiritual closeness to God, brought meaningfulness and dignity into his daily life.

From the horizon of the Caritative caring tradition, life is a mystery, a reality of infinity and eternity. Each human being is holy, a wholeness of body, spirit and soul that helps them find meaning through transcendental and spiritual experiences. The suffering human being can through inter-connectedness to abstract others, such as God, experience their absolute dignity confirmed. Such experiences help maintain faith, hope and courage, and are a crucial support in the process towards finding space for suffering, rest and reconciliation (Eriksson, 1998, 2006; Lindström, Nyström & Zetterlund, 2014).

#### *Dignity-preserving aspects crucial within HCP-patient interactions*

The empirical horizon within this study shows how HCPs were often perceived as experts on participants' illness, with crucial knowledge and resources to help them make the most out of life. Their relational interactions with HCPs were therefore crucial for study participants, who after the onset of dementia felt vulnerable and sensitive concerning HCP attitudes and behaviors. In this context, experiencing HCPs kindness and gentleness was found to be a crucial dignifying aspect reinforcing the participants' sense of self-worth. Moreover, the experience of feeling respected, listened to, and being taken seriously by HCPs, had vital influence on their self-esteem and sense of dignity. In contrast to contexts where HCPs made participants feel overlooked or devalued, genuine interest among HCPs helped reinforce

experiences of feeling unique and recognized as individuals. Their need for increased understanding concerning current situation and future outlook, receiving health-related information from HCPs, within this caring context, helped stimulate participants to live their lives with a feeling of positive realism and personal growth.

On the horizon of Caritative caring, alleviating suffering related to illness is vital (Eriksson, 2006; Lindström, Nyström & Zetterlund, 2014). In this caregiving process, preventing suffering related to care is crucial, and includes preventing suffering inflicted due to the lack of care. Suffering related to care is a form of suffering caused when HCPs meet their patients with attitudes or behaviors while neglecting their dignity. When this is the case, non-caring acts or intervening, amplifies burdens among those already suffering due to illness. Within this perspective, humane warmth and compassion for the suffering human being, is therefore a crucial ontological basis for professional caregiver attitudes and behaviors, likewise, unconditional respect and tolerance for each individual needing care (Eriksson, 2006; Lindström, Nyström & Zetterlund, 2014). Anchored in the ethos of love and responsibility, the Caritative mantra «I was there, I saw, I witnessed and I became responsible» (Eriksson, 2013, p. 70) involves an ethical responsibility for promoting that which is good, as well as resisting that which is evil. Nursing as an art can help progress the healing process when the suffering individual feel acknowledged, trusted, validated, and confirmed (Nåden & Eriksson, 2000). The study found how these qualities helped support faith, hope and courage among our study participants, towards developing positive realism and personal growth, and to move on and make the most out of their lives. The study therefore suggests that our participants' need for constantly becoming (Lindström, Nyström & Zetterlund, 2014), was not hindered or incapacitated by the onset of dementia. Our research identified these facets as crucial aspects, within the interpersonal dignity-dimension, and a vital dignity-preserving foundation for HCPs care for people living with dementia.

The empirical horizon also shows how promoting personal autonomy and integrity were found essential for interpersonal dignity-preservation. Emphasized as a crucial aspect in our metasynthesis (study I), compassion for the sufferer was found to be a vital foundation for dignity in care. Compassion combined with professional knowledge and caring attitude, were identified as essential for developing genuine caring interest in persons living with dementia. The study suggests the ability to perceive each person as a unique human being, with resources, needs and rights to make choices on their own, are professional caregiver

characteristics and qualities crucial for promoting personal autonomy and integrity among those in need of care.

From the horizon of Caritative caring, promoting personal autonomy and integrity of suffering human beings can be seen as a crucial aspect of caring for one who struggles between being and not being. The ethos of caring becomes ethics in practice through HCPs relational interactions with their patients (Eriksson, 1995). Genuine respect for the autonomy and integrity of each individual with dementia is to be found vital towards establishing caregiving interactions that alleviate suffering related to illness. Respect and tolerance for the unique individual is essential towards upholding their sense of honor and confirming human worth, while promoting the person's relative dignity (Eriksson, 1995, 1996, 1998; Nåden & Eriksson, 2000, 2004; Lindström, Nyström & Zetterlund, 2014). Supporting each individual in their effort to live life according to their needs, interests and inner values, is crucial for preserving a sense of wholeness. Enhancing personal meaningfulness, while promoting individual autonomy and integrity, was found vital for our study participants in their personal process of becoming who they want to be (Lindström, Nyström & Zetterlund, 2014). These facets were identified as crucial aspects within the interpersonal dignity-dimension, and vital dignity-preserving foundations for HCP care among people living with dementia.

The empirical horizon also reveals how dignity-preservation among persons with dementia also relates to having the option of living in a humane and purposeful environment. Creating a practical environment designed to meet their needs for freedom, easy orientation, as well as safety in everyday life, were found essential for enhancing autonomy and integrity and thereby vital for preserving dignity. This study suggests therefore, that the homes of persons with dementia, as well as their living environments in a broader sense, should be designed to safeguard these crucial qualities.

Within the horizon of Caritative caring, creating space for suffering, rest and reconciliation is essential in the process of alleviating adversity related to illness. Moreover, creating a suitable milieu is crucial for vital processes related to tending, playing and learning. These crucial aspects form part of an essential caring process in which the caregiver invites the suffering human being into a caring communion and through their relational interplay seek to identify her or his needs and alleviate suffering, while stimulating personal growth, faith, hope and courage (Eriksson, 1998, 2006; Nåden & Eriksson, 2000; Lindström, Nyström & Zetterlund,

2014). The Caritative caring perspective underline how physical and social environments anchored in design, traditions and rituals familiar to the suffering human being, form part of such caring culture (Lindström, Nyström & Zetterlund, 2014). This research suggests that these facets should be considered as crucial foundations for dignity-preserving care among people living with dementia.

The empirical horizon also indicates how experiencing similar status and rights as other patient groups in the healthcare system was important for our participants with dementia. Having the similar options for training and treatment available for patient groups other than those with dementia, was experienced as crucial towards affecting their sense of dignity, since they viewed these opportunities as a standard on how the healthcare system and society at large, judged their worth as human beings.

Within the horizon of Caritative caring, a caring culture invites a suffering human being into a compassionate communion. This invitation is a crucial foundation for establishing a dignity-preserving culture of caring. If failing to make the suffering person feel welcome, the culture lacks qualities of Caritative love and charity, as well as dismissing its ethical responsibility (Eriksson, 1995, 1996, 1998, 2002; Nåden & Eriksson, 2000; Lindström, Nyström & Zetterlund, 2014). Within non-caring cultures, dignity-violations are common (Eriksson, 2006). Should this type dignity-violation occur on the macro-level, that is, an entire healthcare-system causes a group of suffering human beings to feel unwelcomed, dignity-violation on the systemic-level could be a reality. The Caritative invitation, on the other hand, recognizes the absolute dignity of all suffering individuals. This type of caring culture therefore confirms self-worth and equality towards all human beings, regardless of the illness at the root of their suffering (Eriksson, 1995, 1996, 1998; Nåden & Eriksson, 2000; Lindström, Nyström & Zetterlund, 2014). Anchored within these perspectives, this study suggests the healthcare system as a whole, establish a caring culture towards helping people living with dementia feel equally welcome as other patient groups, and a crucial foundation for dignity-preserving dementia care will be established.

Another important discovery on the empirical horizon is related to how professional caregivers' can experience certain caring situations as major ethical paradoxical dilemmas. This is the case when finding the balance between allowing people with dementia to make decision for themselves, versus, the professional duty to make wise choices on behalf of one

suffering diverse symptoms of memory loss, reduced ability for orienteering and sound judgment, or otherwise. In certain situations, supporting patient autonomy, whilst simultaneously preserving individual integrity, was found incompatible, leading to dignity-violation, for example; when a person lying in bed full of excrement refuses the helping hand of the HCP. In addition, the individual may be unable to see possible harmful consequences. Professional caregivers in this study understood their ethical duty to protect those unable to make wise choices. Paradoxically, in situations like this, some form of integrity-violation seemed in order, in an effort to maintain the individual's integrity overall. In such delicate cases, nurses and HCPs found persuasion and/or mild restraint necessary towards sheltering the suffering individuals overall integrity. This implies of course, some form of neglect concerning a patient's physical integrity (e.g. holding patient's hands), while, paradoxically, preserving their physical integrity (e.g. having excrement washed away from one's body). While the latter action was found crucial towards promoting the person's integrity overall, the act of intervening in situations like this was identified as dignity-preserving from the perspective of participating nurses and allied HCPs. Nonetheless, even when grounded in an authorized restraining order according to existing law, assisting the individual in a calm and respectful way, attempting to earn the vulnerable individuals' trust and confidence, was identified as crucial caregiver attitudes and behavior within this particular, challenging caring contexts. Thus, this empirical horizon demonstrates how demanding dignity-preserving care can be when people suffering from dementia are no longer able to make sound decisions, and at the same time, lack necessary insight concerning any harmful consequences of his or her choices. This topic also shows the need for highly qualified HCPs in this field of caregiving.

Perceiving such ethical challenges of caring from the theoretical horizon of this study, these specific situations actualize the question of whether an act of intervening, using persuasion and/or mild restraint, is dignity-preserving or not. As underlined in the Caritative caring perspective, each act should be anchored the ethos of being there for the sake of the other (Eriksson, 1995, 2013; Lindström, Nyström & Zetterlund, 2014). Based on the *caritas* motive, each act of intervention is indelibly connected to love and charity. HCPs' awareness concerning core motives behind all intervention is vital, because it constitutes a foundation for understanding whether a specific intervention helped alleviate suffering and preserve dignity, or on the contrary, is considered dignity-violating and a non-caring act causing suffering related to care. Thus, this study argues that caring should always be carried out by knowledgeable and reflective HCPs, with warmth and compassion, respect and tolerance, in



each caring act. Anchored in the Caritative ontology, the ethos of responsibility constitutes an ethical responsibility for promoting that which is good, while resisting evil (Eriksson, 1995, Lindström, Nyström & Zetterlund, 2014). What is good or what is evil, is guided by the *caritas* motive. In the previously mentioned paradoxical situations and ethical dilemma, Caritative caring is founded upon respect and recognition of the suffering human being's inherent and absolute dignity, while at the same time, aiming to preserve their vulnerable, relative dignity (Eriksson, 1995, 1996, 1998, 2006, 2013; Lindström, Nyström & Zetterlund, 2014). Suffering related to illness cannot be relieved within any context which permits suffering related to care (Eriksson, 2006). Thus, whenever responsible for caregiving within a context of balancing individual choices among persons no longer able to make sound decisions, against ones professional duty to make wise choices on behalf of the individual, this study argues for a Caritative caring perspective as a valuable genesis for reflection. Perceiving the complexity of these ethical care challenges through this ontological lens, may help caregiver efforts towards promoting that which is good, while resist what is evil, in similar situations.

#### *Dignity-preserving aspects crucial in relational interactions with family and social network*

Importantly, while exploring relational interactions crucial for dignity experience in everyday life, the empirical horizon also reveals how family, friends and extended social network constitute an essential foundation for what was identified as an inter-personal dignity dimension.

First, while feeling uncertain about their value as a partner after being diagnosed with dementia, participants sensing the love and affection from their spouse helped confirm their importance as worthwhile companions, and therefore seen as a vital dignity preserving experience. As organizing daily lives became gradually more difficult, sensing joy in one's spouse and experiencing their support, helped participants find coherence, meaning and improved coping abilities in meaningful, daily activities. Additionally, while experiencing a negative impact of illness in regards to self-esteem, the empirical horizon shows how crucial aspects of relational interactions with their children, grandchildren or great-grandchildren, seemed to reduce this burdensome experience. Feeling loved was found a vital quality for preserving participant experience of dignity. Likewise, sense of being an appreciated and

acknowledged parent and grandparent/great-grandparent, and when experiencing still having abilities to give descendants a helping hand.

On the theoretical horizon, the Caritas motive is seen as a crucial aspect in spousal relations. When founded on love and charity (Eriksson, 1995, 1996, 1998, 2006, 2013; Lindström, Nyström & Zetterlund, 2014), care provided by the spouse seemed to have a dignity-preserving impact on their partner with dementia. Experiencing the warmth, compassion and tolerance (Eriksson, 1995, 1996, 1998; Nåden & Eriksson, 2000, 2004; Lindström, Nyström & Zetterlund, 2014) of their spouse, as well as their joy and support in activities of daily living, helped towards alleviate our study participants' suffering from sickness. Anchored in the presence of fore noted relational qualities of spousal closeness, and power of caregiving spousal sacrifice while being there for the sake of the other, time and space were created for the suffering, rest and reconciliation (Lindström, Nyström & Zetterlund, 2014) of the ill partner. Essential for Caritative caring lies supporting the suffering human being towards upholding his or her sense of honor and self-worth (Eriksson, 1996, 1998; Lindström, Nyström & Zetterlund, 2014). Although aware of being a care-receiver, in need of spousal support to master daily life, caring and supportive attitudes and behaviors by ones' spouse was found crucial towards confirming the ill partner as a worthy partner. Upholding aspects related previously as inter-personal dignity dimension, helped preserve participants' relative dignity while bringing faith, hope and courage (Lindström, Nyström & Zetterlund, 2014) into their everyday lives.

In relational interactions with children, grandchildren or great- grandchildren, love and confirmation again showed its value as core aspects of caring. Experiencing descendants' appreciation and recognition helped preserve their relative dignity, while enhancing a sense of meaningfulness in life, strengthen feelings of closeness, while encouraging feelings of becoming the person they want to be in these crucial relations (Eriksson, 1996, 1998; Lindström, Nyström & Zetterlund, 2014). This research argues that the family constitutes a primary caring communion, and prime source for dignity-preservation among persons living with dementia who participated in our study.

The empirical horizon reveals as well how friends and social network had a positive impact on dignity experience when participants felt welcomed into a social fellowship. Several participants had tendencies to withdraw from social interactions with others. Reduced self-

esteem and fear of not being able to cope with social challenges was common. This in turn increased feelings of isolation and loneliness. On the other hand, experiencing sincere and encouraging inclusion by others, offered an alternative path for their lives. Recognizing the value of being included in a caring communion (Eriksson, 1998, 2006; Nåden & Eriksson, 2000; Lindström, Nyström & Zetterlund, 2014) of friends, as well as in caring communions involving ones' extended social network, seemed crucial aspects towards preserving relative dignity (Eriksson, 1995, 1996, 1998, 2013; Lindström, Nyström & Zetterlund, 2014), among our study participants.

The study argues the relevancy of participation within social fellowship of friends and social network as crucial sources of dignity experience. Nonetheless, family relationships possessed those qualities which appear to be most vital. However, one must keep in mind that participation in whatever form of social fellowship, does not guarantee the person with dementia dignity experience. The theoretical horizons of this study do suggest that relative dignity was more often than not preserved by friends and extended social network when welcomed within a caring communion, anchored in humane warmth, compassion, respect and tolerance. Moreover, in Caritative caring, the essential position of the invitation is related to the acknowledgement and confirmation of the inherent absolute dignity and equality of each suffering human being (Eriksson, 1995, 1996, 1998, 2002, 2006, 2013; Nåden & Eriksson, 2000, 2004; Lindström, Nyström & Zetterlund, 2014).

#### *Dignity-preserving care; overall perspectives*

The above discussion concerns the empirical and theoretical horizons of this study, suggesting how crucial aspects towards preserving dignity among persons living with dementia can be found in the three caring contexts; *relational interaction in general; HCP-patient interaction, and; relational interaction with family and social network*. This current empirical-theoretical horizon reveals a fresh, overarching understanding concerning foundations for dignity-preservation in caring for persons living with dementia.

The new and overarching horizon of this study, suggests the importance of both caregiver support as well as acts of intervening, help enhance personal meaningfulness in daily life, as a crucial aspects of dignity-preserving care for people living with dementia in a process of constantly becoming the person they desire to be. The intrapersonal dignity-dimension may at times, lead to the loss of dignity. However, this dimension seems to be a vital source towards

strengthening self-esteem and confirming self-worth. Thus, *sheltering interpersonal dignity within each individual is found to be a crucial aspect of dignity-preserving care.*

Supporting personal becoming and enhancing personal meaningfulness, also involve acknowledging each individual's life-history and life-projects. This historical dignity-dimension creates caregiver opportunities for focusing attention on memorable life-events and achievements of the past, occurring many years earlier, can still bring dignifying experiences into the person's present consciousness. Thus, *acknowledging historical dignity for the person living with dementia is identified as a crucial part of dignity-preserving care.*

This study finds the human processes of constantly becoming and finding meaning in life essential for each person with dementia, and that these processes are strongly influenced through inclusion and interplay within a caring social fellowship. This interpersonal dignity-dimension is influenced by qualities within relational interactions with significant others, such as family, social network, HCPs, as well as inter-connectedness of transcendental and spiritual character. Inviting each person with dementia into a caring and compassionate communion is therefore vital. Thus, *upholding the interpersonal dignity of each individual is found to be a crucial aspect of dignity-preserving care.*

This new and overarching horizon also suggests that recognizing the absolute dignity of each person with dementia is critical, for granting the foundation for dignity-preserving care on a higher-level and ontological basis. Caring for a person with dementia, means caring for a person with absolute dignity, inherent and inalienable, existing at the human origin and aim of the human mission of being there for the sake of another, and serving with love. *Recognizing absolute dignity of each individual with dementia is therefore found to be a crucial aspect within dignity-preserving care.*

Moreover, this ontological base also contributes towards understanding dignity as relative. Caring for a person with dementia means therefore, caring for a person with varying levels of dignity, influenced by relational interactions in everyday life, as relative dignity influences one's interpersonal dignity, as well as one's intrapersonal dignity. This relative form of dignity thus relates to fluctuating, subjective feelings of self-worth, as well as to the modifiable sense of human value in relationships with others. Within this context, caring for a person with dementia involves acts of intervening, towards confirming the individual as a worthwhile human being, while sheltering her/him from external violating factors. *Promoting*

*relative dignity of each person with dementia is thus found to be a crucial aspect within dignity-preserving care.*

Anchored in these overarching perspectives from the empirical-theoretical horizon, this study finds *confirming human worth and equality* of each person with dementia, as the overall foundation for dignity-preserving care. The study argues that human worth and equality can be preserved within caring communions that *recognize absolute dignity* while *promoting relative dignity* of each individual, by *supporting personal becoming* and *enhancing personal meaningfulness* through acts of intervening, that *shelter intrapersonal dignity*, *acknowledge historical dignity* and *uphold interpersonal dignity*.

Based on the discussion concerning the fusion of empirical and theoretical horizons, a model of dignity-preserving care is developed, entitled: «Dignity Horizon Model: Caring for persons living with dementia».



General emphasis on supporting the person towards:	Healthcare professional awareness concerning meeting the persons need for: establishing the foundation for:	Family and social network consciousness regarding value of:
<ul style="list-style-type: none"> <li>recognizing one's own human worth, and living life according to internal values.</li> <li>acknowledging one's own life-projects and life-history.</li> <li>experiencing being part of a caring and confirming communion.</li> </ul>	<ul style="list-style-type: none"> <li>kindliness and gentleness that stimulate positive realism and personal growth.</li> <li>feeling respected, listened to and taken seriously.</li> <li>experiencing personal autonomy and integrity.</li> <li>living life within a humane and purposeful environment.</li> <li>experiencing similar status and rights as other patient groups.</li> <li>balancing individual choices among persons no longer able to make sound decisions, against the duty of making choices on behalf of the person.</li> </ul>	<ul style="list-style-type: none"> <li>feeling spousal love, affection and support.</li> <li>experiencing respect, love and being a significant person to their children/grandchildren/grate-grandchildren.</li> <li>perceiving friendship stay alive, and feeling included in a social fellowship.</li> </ul>
<p><i>tending, playing and learning</i></p> <p><i>inviting into a caring communion</i></p> <p><i>alleviating suffering related to illness</i></p> <p><i>respect, tolerance, warmth and compassion</i></p>	<p><i>responsibility</i></p> <p><i>love and charity</i></p> <div style="border: 1px solid gray; border-radius: 50%; padding: 10px; text-align: center; background-color: #e0e0e0;"> <p><b>CARITATIVE CARING</b></p> <p>- preserving absolute and relative dignity of the suffering human being</p> </div> <p><i>respecting the mystery, infinity and eternity of life</i></p> <p><i>respecting human wholeness; body, soul and spirit</i></p>	<p><i>offering a caring culture</i></p> <p><i>recognizing the struggle between being and non-being</i></p> <p><i>supporting faith, hope and courage</i></p> <p><i>creating space for suffering, rest and reconciliation</i></p> <p><i>upholding sense of honor and worthiness</i></p>

Figure 3. Dignity Horizon Model: Caring for persons living with dementia

## 6.1 Results related to major assumptions of Theory of Caritative Caring

Among eight axioms and six theses which at present constitute the major assumptions of Eriksson's *Theory of Caritative Caring* (Lindström, Nyström & Zetterlund, 2014, p. 177), three axioms and two theses are found particularly relevant for this research.

This present study shows how essential being connected to concrete individuals was for our participants with dementia. Their spouse, children, grandchildren/great-grandchildren, friends, extended social network and HCPs were all perceived as vital people in their lives.

Experiencing an invitation into a warm and acknowledging fellowship, and given the opportunities of taking part in relational interactions confirming each as worthwhile human beings, helped toward preserving their sense of dignity. The study also shows how participants experienced inter-connection with abstract others, like God, or nature, receiving dignifying relief and strength. These results support the axiom; "*Communion is the basis for all humanity. Human beings are fundamentally interrelated to an abstract and/or concrete other in a communion*", which is one of the major assumptions of the Theory of Caritative caring.

Moreover, study results concerning participants' experiences of inter-relatedness to abstract others, through the channels of transcendental and spiritual sensations, indicates how aspects beyond the limits of earthly concerns seem to promote comforting spiritual meaning towards confirming their sense of dignity and human worth. This result is found to add meaning to major assumptions formulated as axioms in Caritative caring theory, describing; "*The human being lives in a reality that is characterized by mystery, infinity and eternity,*" and; "*The human being is fundamentally an entity of body, soul and spirit*".

This study shows how living with dementia involved living with an inner, subjective struggle in daily life. Participants questioned their own self-worth, in the midst of an exhaustive and disruptive illness. However, our study also found how participant needs for constantly becoming, was not hindered or incapacitated by the onset of dementia. While enduring their suffering, they found crucial anchor points towards maintaining intrapersonal dignity. These included: living according to personal moral virtues, and; utilizing body and mind in enriching activities of daily life. Moreover; maintaining interpersonal dignity through relational interactions with concrete significant others, as well as through inter-connectedness of transcendental and spiritual character. These crucial aspects helped enhancing personal meaning, while experiencing oneself as a whole and complete person engaged in a process of

development. These results is found to support major assumptions formulated in the thesis of Caritative caring theory, which states; *“Health means a movement in becoming, being and doing, while striving for wholeness and holiness, which is compatible with enduring suffering”*.

The study also shows how dignity-preserving care helped alleviate suffering, when relational interaction was anchored in caregiver love and compassion, being present for the sake of the suffering human being in need of care. Our participants experienced how suffering was alleviated in such interplay, while strengthening their personal growth, faith, hope and courage. These results we found to add meaning to the thesis and major assumption of Caritative caring theory, stating; *“Caring implies alleviation of suffering in charity, love, faith and hope. Natural basic caring is expressed through tending, playing and learning in a sustained caring relationship, which is asymmetrical by nature”*.

## 6.2 Results in relation to previous research

While aiming to increase the understanding of crucial aspects preserving dignity in everyday life among persons living with dementia, this study supports some of the findings identified in previous research as well as adding new insights.

Concerning research documenting life dimensions crucial for dignity experience, Sørensen, Waldorff and Waldemar (2008) previously documented how talking about personal life-story seemed an adaptive coping strategy for individuals with dementia towards preserving a personal experience of dignity. The importance of perceiving each individual with dementia as a person with a distinct family history has also been described by Roger (2007). Our study support these findings while adding new understanding of how individual dignity experience was related to a historical dignity-dimension among participants with dementia, involving acknowledgement of one’s own life-projects and life-history as crucial dignifying aspects. We specifically identified how valuing one’s own foundation of life, through childhood and upbringing, and feelings of gratitude and pride in having established a family of their own, as well as appreciating the privilege of having been honorably employed in meaningful work, all helped in forming this historical dignity-dimension.

Sørensen, Waldorff and Waldemar (2008) showed how individuals with dementia used physical activities and mental exercises to help navigate everyday challenges, while Wogn-Henriksen (2012) reported how self-respect and dignity experience among individuals with



early-onset Alzheimer's disease was reinforced by remaining active and engaged in various projects. Our result support and supplement these findings, adding perspectives concerning opportunities to take part in meaningful activities, utilizing one's mind and body, plus having the option to participate in personally valuable work activities, all seemed vital aspects enhancing intrapersonal dignity. The value of having meaningful activities and/or work is also confirmed in a recent study by Hellström, Eriksson & Sandberg (2014) exploring how older women with dementia express the importance of everyday life at home, their relationships with their husbands, autonomy and dignity. Their household chores were found to be the center of their lives, and helped these women see themselves as important individuals and "competent wives".

Wogn-Henriksen (2012), and Johannessen and Möller (2013) documented how remaining active, as well as perceiving oneself as a valuable person living in relationships with others, were identified as driving forces toward mobilizing dignity-preserving resources. Similarly, Van Gennip et al. (2013) reported how extrinsic factors related to the feeling of being connected to and recognized by others, were important dignity-related dimensions. Also, Sørensen, Waldorff and Waldemar (2008), and Wogn-Henriksen (2012), found how relationships and intercommunication with significant others affected self-respect and dignity, while Heggstad, Nortvedt and Slettebø (2013a) identified dignity experience among nursing home residents with dementia relating to feelings of belonging and confirmation. In line with these findings, this present study adds new understanding concerning how being a part of a caring and confirming communion constituted what we identified as an interpersonal dignity-dimension, vital for dignity experience among participants in our interview-studies. The results show certain qualities of relational interactions with family, social network and HCPs as having essential impact on their dignity experience. Spousal love, affection, joy and support in daily life helped preserve participant dignity while confirming their worthiness as a partner. Sensing the appreciation and love of their children, grandchildren or great-grandchildren and being involved in their descendants' lives was a dignifying experience, strengthening their feeling of acknowledgment as a parent, grandparent or great-grandparent. Moreover, our present study found experiencing friendships stay alive and an awareness that extended social network was not treating them as "demented", as crucial dignifying aspects. Such relational interactions helped strengthen feelings of being true members of society, sheltering their sense of dignity by feeling included in a confirming fellowship, with opportunities to partake in meaningful social activities. These findings support Dening, Jones

and Sampson (2013, p. 411) reporting how social interactions lay foundations for the feeling of being recognized, connected, and “in touch with the world”, and Van Gennip et al., (2013) who documents how individuals outside the immediate social circle can be a dignity-preserving source, supporting the “relational self” and “societal self”. Moreover, in a recent study, Van Gennip et al., (2014) reports how the external social environment has considerable impact on the personal dignity of people with mild to moderate dementia, recommending caregiver attention be not limited to health-related or any other single-focused aspect alone, but always within an interpersonal social context.

In his work, Norman (2008) documents that experience of illness-related challenges among individuals with dementia living at home, are affected by the way HCPs treat them. In line with this finding, our study adds understanding to how HCPs attitude and behavior influenced sense of dignity among our participants with dementia. The study reveals the essential positive impact HCPs kindness and gentleness played on participants’ feelings of being respected, listened to and taken seriously, all helped preserve experience of dignity, and simultaneously stimulated personal growth and positive realism towards present life-situation and future outlook.

Concerning HCPs’ perceptions on dignity-preserving dementia care, research exploring this perspective is rather sparse, and no previous meta-synthesis was found investigating this subject. We identified ten qualitative studies for inclusion in our meta-synthesis (study 1). The study adds understanding of dignity-preservation as perceived from a professional caregiver perspective. Advocating personal autonomy and integrity was found crucial aspects of dignity-preserving care. Attitudes and behaviors among caregivers anchored in compassion for each person, while confirming her or his worthiness and sense of self were all perceived as essential in this process. Moreover, the study also highlighted how creating humane and purposeful environments, designed to meet the needs for easy orientation and freedom, as well as safety in daily living for persons with dementia, were perceived as essential for enhancing autonomy, integrity and thereby vital for preserving dignity. New understanding concerning one of the most challenging issues in caring for individuals with dementia is also presented, identified as balancing individual choices among persons no longer able to make sound decisions, against the duty of HCPs to make choices on behalf of the person. In certain situations, supporting patient autonomy while simultaneously preserving his or her integrity was incompatible, and found to lead to dignity-violation. Ethical paradoxical dilemmas

occurred, leading nurses and HCPs to consider persuasion and/or mild restraint as necessary for sheltering the suffering individual's integrity, dignity and human worth. In a recent study investigating the ethics of coercive treatment among people with severe dementia at nursing homes, Lejman et al., (2013) explored how registered nurses ensured good, safe and legal nursing home care in order to uphold residents' dignity, without violating their integrity. The results showed how nurses, anchored in local routines, utilized three strategies; coercive treatment, coercive treatment under specific circumstances, preventing coercive treatment. However, interpretations of legal terms regarding coercive treatment, as well as inadequate gerontological nurse training and understaffing, seemed to perpetuate the utilization of coercive treatment. Lejman et al., (2013) recommend further research in person-centred care and on existing alternative approaches, to develop and implement more appropriate, nursing strategies.

This present study documents the crucial value of our participants with dementia to continue living without compromising personal moral values guiding them throughout life. Moreover, this study adds new understanding on transcendental and spiritual meaning as an important part of their dignity experience. The feeling of nearness to nature, sensing its stillness, beauty, and power, created a sense of transcendental and dignifying inter-connectedness with nature among several participants, while one participant experienced his religious faith and feeling spiritually close to God, brought meaning and dignity into daily life. The study documents as well how this aspect of interpersonal dignity-dimension, in both cases gave participants dignifying feelings of being part of a caring and confirming communion in a broader sense.

The study also adds new knowledge on how the experience of having similar status and rights like other patient groups in the healthcare system, can affect sense of dignity among people living with dementia. The study document how participants perceived this aspect as a measure of how the healthcare system and society at large, judged their worth as human beings.

### 6.3 Methodological considerations and limitations

#### *On methodology*

The meta-ethnography of Noblit and Hare (1988) was evaluated most helpful as a methodological approach for conducting our meta-synthesis (study 1). Their descriptive guidelines for conducting a meta-synthesis were beneficial from our initial idea to the final

synthesis. Based on our experiences, we believe that additional researchers will also find this methodology useful for future studies exploring ethical issues involved in caring for people living with dementia. Utilizing Gadamer's (2010) hermeneutic approach helped strengthen the study structure, providing a framework for interpretation of empirical data. In line with Zimmer (2006) we found Gadamer's description concerning the importance of dialoguing with the texts most helpful in the process of reading and exploring the ten previous studies included. We also found the hermeneutic circle and fusion of horizons most relevant during the process of interpretation and synthesis in this meta-synthesis inquiry.

For the second and third studies, we chose to conduct qualitative interviews with 11 persons living with dementia as our tool for collecting data, concerning both their similar and unique perceptions. This approach proved suitable, providing a rich data collection based on fruitful dialogue between researcher and participant. Their ability to describe personal perceptions varied. Nonetheless, all participants provided meaningful contributions. Gadamer's philosophical hermeneutic (2010) was a valuable methodological approach for our explorative research. Additionally, we found Gadamerian-based guidelines for hermeneutical research as formulated by Fleming, Gaidys and Robb (2003), and Zimmer (2006), most helpful in portraying crucial processes for this Gadamer's methodology. Hermeneutic processes initiated during the planning phases assisted each researcher as she/he contemplated personal pre-understandings of our study under investigation. The pre-conception of each researcher is a crucial lens with vital impact upon the interpretive process for understanding empirical data. The hermeneutical process was also part of our interview-setting, as dialogue with our study participants opened for deeper exploration of personal dignity experiences. Utilizing interview-guide, with the possibility to ask additional exploratory follow-up questions, contributed to informative dialogues with the participants. Upon transcription, a rich data collection gave us opportunities for increased interpretive understanding through dialoguing with each interview-texts separately, then in relation to each other, and finally as a whole, back and forth within our hermeneutic circle of interpretive understanding. This process helped our research team move beyond pre-conceptions, towards the development of new and deeper understanding concerning crucial aspects preserving dignity in persons living with dementia.

Aiming to be descriptively accurate, interpretively rich and innovative, study *credibility*, *dependability*, *confirmability* and *transferability* were sought to enhance study trustworthiness

These quality criteria for qualitative research formulated and recommended by Lincoln & Guba (1985) “represent parallels to the positivists’ criteria of internal validity, reliability, objectivity, and external validity, respectively” (Polit & Beck, 2010, p. 492).

To enhance study *credibility*, that is, establishing a foundation for developing confidence in the results while ensuring methodological fidelity was emphasized during the process of study planning, data collection, interpretation and journaling. In study 1, assuring that nurses and allied HCPs in various dementia care settings were included contributed to a greater variation. Inclusion criteria formulated for study 1 was guided by a quality assessment of each primary source, utilizing the Consolidated Criteria for Reporting Qualitative Research (COREQ) developed by Tong, Sainsbury and Craig (2007). Each of the included studies were evaluated high-quality research according to COREQ-standards concerning; research team and reflexivity, study design, data analysis and reporting. To secure participant recruitment according to the formulated inclusion criteria, the strategic sample of study 2 and 3 was recruited by doctors responsible for diagnostic examination and follow-up treatment, in cooperation with clinical nurses at two Hospital Memory Clinics. The background and pre-understanding of each researcher was described and reflected upon throughout the study. Data collection was carefully compiled over periods of nine months (study 1) and 12 months (study 2 and 3). A continuous focus on research question formulation was stressed during planning, data-collection and interpretation. In study 1, the methodological guidelines concerning the 7-step process of meta-ethnography (Noblit and Hare, 1988) was followed. Recommendations for utilizing a hermeneutical approach throughout the process of developing the meta-synthesis were also pursued. In study 2 and 3, all interviews were audiotaped to secure verbatim transcriptions for interpretation. During the process of interpretation, we emphasized questioning our initial interpretations to identify disconfirming evidence in the data material.

Study *dependability*, referring to study consistency and repeatability, was sought and emphasized through transparent documentation of the entire research process, in a language we believed would be meaningful to the reader/study audience. Throughout the data collection process, interpretation and formulation of study results, our research team discussed the crucial issues involved repeatedly, establishing an open dialogue and a transparent documentation of the research process.

Efforts were also made to avoid interpretive bias. Thus, to strengthen *confirmability*, data representing participant perspectives, was empowered by reflecting on our pre-understanding, while carefully documenting each participants' shared information. We emphasized the interpretation of empirical data towards identify any disconfirming evidence, that is, data that might contradict our pre-understanding, thus opening for alternative interpretations. A critical appraisal of each paper (study 1), and transcribed interviews (studies 2 and 3) was performed separately by each member of our research team, and then discussed within the group before being formulated as a whole. To heighten *transferability* and develop a foundation for exploring whether these qualitative findings may have applicability to other groups or settings, attention was invested towards documenting enhancement of quality criteria guiding the research, while collecting material until a point of data saturation was reached, and thick descriptions formulated. Additionally, this research focused on identifying and portraying mood, feelings, language, experience and context as expressed by the study participants themselves, in an effort towards *authenticity*, a quality criterion formulated by Guba and Lincoln (1994) in later writings, conveying the feeling or tone of study participants' shared experience, that might help readers develop a better understanding of participants' life-world.

Finally, when conducting exploratory research on unknown or understudied experiences within a certain population, research may be founded on theory derived from previous studies, and/or contribute to theory development concerning the subject under study (Brink and Wood, 1998). Therefore, a basic premise for strengthening trustworthiness of this study was the identification and utilization of an appropriate theory of caring, a framework for developing an interpretive understanding of the data material. Applying Erikssons Theory of Caritative caring, a theory developed while utilizing philosophical hermeneutics as research methodology, for continual empirical and theoretical testing of its ontological foundation and major assumptions, enhances the study quality of our present research.

### *On limitations*

In terms of limitations, although applying a systematic database search, as well as manual reference list search in study 1, additional studies may exist containing supplementary perspectives. If we had included relevant work documented in gray literature and books, including non-article based dissertations, additional aspects on dignity-preserving dementia care could possibly have been revealed. Moreover, focused attention on similar data from

various studies may have led our research team to over-represent certain second-order constructs, while other aspects may have been overlooked. We also recognize the inherent interpretive process of meta-synthesis and the possibility that a different research team may have developed an alternative model.

In study 2 and 3, all participants lived at home, together with their own spouse. All had children and grandchildren, some also great-grandchildren. If individuals living alone or those without descendants had been included, we believe this would have influenced the results, especially concerning gratitude and pride in having established a family of one's own. All participants had spousal support and the necessary personal resources to participate. We find it reasonable to believe that the foundation for dignity experience in individuals without these personal and social resources might differ from those identified in our limited sample. On the one hand, this is an inherent strength to qualitative research, given a relatively small number of participants and the opportunity for in-depth research. On the other hand, the study results cannot be generalized to include the entire population within the inclusion criteria. Crucial dimensions constituting dignity experience not revealed in study 2, and crucial dignity-preserving aspects within relational interactions not identified in study 3, are therefore likely to exist within the overall population.

Although collecting a substantial amount of empirical data, conducting only one interview with each participant is also a limitation within our study. Nonetheless, interviewing participants concerning their perceptions and experience in living with dementia was challenging. Some had emotional reactions and began to cry, while others showed signs of distress, finding it difficult to articulate. Based on ethical considerations to shelter participant dignity (Nordenfelt, 2004), do no harm, utility and justice (Hellström et al., 2007), in addition to ethical obligation for moral sensitivity in light of participant vulnerability (Heggstad, Nortvedt & Slettebø, 2013b), we determined to conduct one interview with each. Three participants requested their spouse to be present during the interview should the need for support arise. We are open to the possibility this action may have had toward influencing the data collection. Nonetheless, we found spousal assistance added valuable nuances to the data by helping participants understand and reflect upon the researcher's questions.

Within the interpretive processes of each of the three separate studies, as well as the process towards developing an interpretive understanding of the empirical data on a whole, our

chosen theoretical perspective was our theoretical lens and theoretical foundation. Thus, another research team utilizing contrasting theoretical framework would likely develop an alternative understanding of the subject under investigation.

## 7.0 Conclusion and future perspectives

This study documents how crucial aspects within: *relational interaction in general; HCP-patient interaction, and; relational interaction with family and social network*, helped preserve dignity in everyday life of persons living with dementia.

Caring and supportive attitudes and behaviors among caregivers *in relational interaction in general*, assisting the person with dementia towards; recognizing one's own human worth, living life according to internal values; acknowledging one's life-projects and life-history, and; experiencing being part of a caring and confirming communion, were found crucial aspects of dignity-preserving care.

*In HCP-patient interaction*, experiencing HCPs kindness and gentleness; feeling respected, listened to, being taken seriously; experiencing personal autonomy and integrity; living life within humane and purposeful environment; experiencing similar status and rights as other patient groups, and; HCPs balancing individual choice against the duty of making choices on behalf of the person no longer able to make sound decisions; were found to be vital aspects for dignity-preserving care.

*In relational interactions with family and social network*, crucial aspects preserving dignity among persons with dementia, thus essential in caring, were found related to; feelings of spousal love, affection and support; experiencing respect, love and being a significant person to their children, grandchildren/grate-grandchildren; perceiving friendship stay alive, and feeling included in a social fellowship.

The study concludes that *confirming human worth and equality* of each person with dementia is the overall foundation for dignity-preserving care. Human worth and equality can be preserved within caring communions that *recognize absolute dignity and promote relative dignity* of each individual, by *supporting personal becoming and enhancing personal meaning* through acts of intervening that *shelter intrapersonal dignity, acknowledge historical dignity and uphold interpersonal dignity*.



### 7.1 Implication for caring practice

There is need for increased knowledge within dementia care practice. The number of countries developing guidelines for dementia care is expanding, emphasizing dignity preservation among those living with dementia as a vital foundation for future care. It is therefore paramount to develop knowledge concerning crucial aspects of dignity-preserving care for this vulnerable group of people. This present study aims to contribute to increased knowledge relevant for nurses and allied healthcare professionals in their everyday caring practice, recommending the following crucial aspects be emphasized towards promoting dignity-preserving care for persons living with dementia:

Be willing to meet the individual in the depths of the person's inner struggle, while he or she feels the very human worth is threatened, and in this suffering, support the person towards strengthening self-esteem and personal experience of human worth.

Have courage to be together with the suffering person, without understating or ignoring their condition, but by warmth, compassion, respect and tolerance, be there for the sake of the other, in so doing, allowing them to rejuvenate faith hope and courage in life.

Help facilitate meaningful experiences of daily living through activities anchored in the interests, desires, needs and capabilities of each individual.

Engage each individual as a human being in a process of constantly becoming the person she or he desire to be, by enhancing positive realism, personalized meaning and growth.

Recognize each individual's' life-history and life-projects, applying these towards experiences of personal dignity. Themes such as childhood, upbringing, raising a family and a lifetime of work were crucial to participants in this study.

Define and develop personal attitudes and actions as a person and caregiver, ensuring the person living with dementia feels respected, listened to and taken seriously.

Engage the person with kindness and gentleness, and recognize the value of these qualities in each caring act.

Enhance personal autonomy and opportunities for individual choice in matters concerning him or her, showing respect for the individual's personal preference. Contribute towards ensuring the integrity and holistic needs of each person receive priority.

Encourage each person the opportunity to live in accordance to his or her moral principles, norms and values, which have been meaningful for them throughout life.

Ensure each individual the opportunity for transcendental and/or spiritual experiences in everyday living in accordance with his or her desire and need.

Make thorough and ongoing evaluations concerning ethical paradoxical caring dilemmas that entail balancing individual choices among persons no longer able to make sound decisions, against HCPs duty to make choices on their behalf. The individual's human worth and equality must always be at the forefront of each act of intervention. All such decisions must be grounded in rigorous professional assessment, ethical consideration and existing law.

Help create humane, practical and purposeful environments, designed to meet the individual's needs for freedom, easy orientation and safety in everyday living.

Promote the fundamental rights, and practice for each person with dementia to experience similar status and rights as other patient groups, ensuring optimal opportunities for training and treatment.

Increase consciousness of spouse, children and grandchildren/great-grandchildren concerning the importance of their love, joy, support and recognition as crucial and valuable towards enriching everyday life for family members living with dementia.

Facilitate each individual the opportunities to maintain meaningful relationships with close friends.

Provide opportunities for social fellowship activities within a caring and confirming communion that respects and recognizes the individual for the person he or she is.

Base all care within the recognition of personal dignity as an absolute, inherent and unchangeable quality of each human being living with dementia, while at the same time consciously promote his or her relative and changeable dignity, and to prevent violation of this latter form of dignity.

Consciously and continuously, develop a caring culture towards confirming the human worth and individual equality of each person living with dementia.

## 7.2 Further research

This study encourages further research to increase our understanding of crucial aspects related to dignity-preserving care for persons living with dementia.

The study documents that HCP kindness and gentleness within the caring context have crucial impact on dignity experience among persons with dementia. More research is recommended to increase our understanding of the inherent qualities of these HCP characteristics.

The study reveals having similar status and rights for training and available treatment as compared to other patient groups, had an impact on dignity experience among our study participants. To our knowledge, experience concerning system-level equality and its impact on personal sense of dignity among people with dementia, has not been previously documented. Additional research is recommended in order to expand our knowledge on this important subject.

Moreover, this study shows how HCPs, in certain situations, found balancing individual choices among persons no longer able to make sound decisions, against the duty of making choices on behalf of the person, to be a crucial aspect within dignity-preserving care. In an effort to supplement the recent research of Lejman et al., (2013), this present study recommends further research towards continually increasing our knowledge regarding dignity-preserving care in contexts involving ethical paradoxical dilemmas.

This research documents the crucial impact of family and social network on a personal sense of dignity among people with dementia. We recommend further exploration of this important subject. Moreover, additional knowledge is needed concerning HCP-interventions towards increasing family and social network consciousness concerning their crucial impact on dignity of the person living with dementia.

The study also found that participants with dementia had meaningful transcendental sensations leading to dignifying experiences when granted opportunities to interact with nature. Moreover, one participant found spiritual meaning and dignifying experience through personal religious faith. More research is needed to increase our knowledge in this important area of dignity-preserving care.

## References

- Albinsson, L. & Stang, P. (2002) A palliative approach to existential issues and death in end-stage dementia care. *Journal of Palliative Care*, 18(3), 168-174.
- Almberg, B. & Jansson, W. (2003) *Fånga stunden. Hur man bemöter och förhåller sig till personer med demenshandikapp [To seize the moment. How to approach and relate to individuals with limitations due to dementia]*. Trelleborg, Berlings Skogs.
- Alzheimer Cooperative Valuation in Europe. (2013) *Rights, autonomy and dignity in people with dementia*. Available from: [http://www.alcove-project.eu/images/synthesis-report/ALCOVE\\_SYNTHESIS\\_REPORT\\_WP7.pdf](http://www.alcove-project.eu/images/synthesis-report/ALCOVE_SYNTHESIS_REPORT_WP7.pdf) (Downloaded 17 June 2013).
- Alzheimer Disease International. (2009) *World Alzheimer Report 2009: The Global Prevalence of Dementia*. Available from: <http://www.alz.co.uk/research/world-report-2009> (Downloaded 24 December 2014).
- American Psychiatric Association. (2007) *Practical guidelines for the treatment of patients with Alzheimer's disease and other dementias*. 2. ed. Available from: <http://psychiatryonline.org/content.aspx?bookid=28&sectionid=1679489> (Downloaded 22 July 2014).
- Arman, M. Rehnsfeldt, A. Lindholm, L. Hamrin, E. & Eriksson, K. (2004) Suffering related to health care: a study of breast cancer patients' experiences. *International Journal of Nursing Practice*, 10(6), 248-256.
- Asplund, K. & Normann, K. (2002) Episoder av psykisk klarhet hos personer med svår demenssjukdom [Episodes of mental clarity among individuals with advanced dementia disease]. In: Edberg, A.K. (ed.) *Att möta personer med demens [Caring for persons with dementia]*. Lund, Studentlitteratur, pp. 82-95.
- Billings, J.A. (2008) Dignity. *Journal of Palliative Medicine*, 11(2), 138-139.
- Bondas, T. & Hall, E. (2007) Challenges in approaching metasynthesis research. *Qualitative Health Research*, 17(1), 113-121.
- Borbasi, S. Jones, J. Lockwood, C. & Emden, C. (2006) Health professionals' perspectives of providing care to people with dementia in the acute setting: toward better practice. *Geriatric Nursing*, 27(5), 300-308.
- Brink, P. J. & Wood, M. J. (1998) *Advanced design in nursing research*. 2. ed. Newbury Park, CA, Sage.
- Brink, P. J. (1998) Exploratory Designs. In: Brink, P. J. & Wood, M. J. (eds.) *Advanced design in nursing research*. 2. ed. Newbury Park, CA, Sage, pp. 308-334.

- Britton, N. Campbell, R. Pope, C. Donovan, J. Morgan, M. & Pill, R. (2002) Using meta ethnography to synthesise qualitative research: a worked example. *Journal of Health Services Research & Policy*, 7(4), 209-215.
- Brown, C. & Nicholson, R. (2011) Sensory skills. In: Brown, C. & Stoffel, V. C. *Occupational Therapy in Mental Health. A vision for participation*. Philadelphia, E.A. Davis Company, pp. 280-297.
- Carrion, C. Aymerich, M. Baillés, E. & López-Bermejo, A. (2013) Cognitive psychosocial interventions in dementia: a systematic review. *Dementia and Geriatric Cognitive Disorders*, 36(5-6), 363-375.
- Chitsey, A. M. Haight, B. K. & Jones, M. M. (2002) Snoezelen: a multisensory environment intervention. *Journal of Gerontological Nursing*, 28(3), 41-49.
- Chochinov, H. M. (2008) Dignity. Dignity? Dignity! *Journal of Palliative Medicine*, 11(5), 674-675.
- Chochinov, H. M. Hack, T. McClement, S. Harlos, M. & Kristjanson, L. (2002) Dignity in the terminally ill: A developing empirical model. *Social Science & Medicine*, 54, 433-443.
- Chochinov, H. M. Kristjanson, L. J. Hack, T. F. Hassard, T. McClement, S. & Harlos, M. (2006) Dignity in the terminally ill: Revisited. *Journal of Palliative Medicine*, 9, 666-672.
- Chung, J. C. C. & Lai, C. K. Y. (2002/2008) Snoezelen for dementia. *Cochrane Database of Systematic Reviews*, Issue 4, CD003152. DOI: 10.1002/14651858.CD003152.
- Clare, L. (2002) We'll fight it as long as we can: Coping with the onset of Alzheimer's disease. *Aging & Mental Health*, 6, 139-148.
- Clare, L. (2003) Managing threats to self-awareness in early stage Alzheimer's disease. *Social Science & Medicine*, 57, 1017-1029.
- Clare, L. & Woods R. T. (2004) Cognitive training and cognitive rehabilitation for people with early-stage Alzheimer's disease: a review. *Neuropsychological Rehabilitation*, 14, 385-401.
- Clare, L. Woods, R. T. Moniz Cook E. D. Orrell, M. & Spector A. (2003) Cognitive rehabilitation and cognitive training for early-stage Alzheimer's disease and vascular dementia. (Review). *Cochrane Database of Systematic Reviews*, (4), CD003260.
- Cohen, L. & Manion, L. (1994) *Research Methods in Education*. 4. ed. London, Routledge.
- Collier, L. McPherson, K. Ellis-Hill, C. Staal, J. & Bucks R. (2010) Multisensory stimulation to improve functional performance in moderate to severe dementia – interim findings from a randomized single blind trial. *American Journal of Alzheimers Disease and Other Dementias*, 25(8), 698-703.

- Creswell, J.W. (2003) *Research design: Qualitative, Quantitative, and Mixed Methods Approaches*. 2. ed. Thousand Oaks, California, Sage.
- Danish Health and Medicines Authority. (2001) *Demens - den fremtidige tilrettelæggelse af Sundhedsvæsenets indsats vedrørende diagnostik og behandling. Redegørelse fra Sundhedsstyrelsens arbejdsgruppe vedrørende demens [Dementia - future Health and Medicines Authority organizational efforts concerning diagnostics and treatment. Report from the Board of Health committee on dementia]*. Available from: <http://sundhedsstyrelsen.dk/publ/publ2001/demens/index.htm> (Downloaded 9 July 2014).
- Dempsey, L. Murphy, K. Cooney, A. Casey, D. O'Shea, E. Devane, D. Jordan, F. & Hunter, A. (2014) Reminiscence in dementia: A concept analysis. *Dementia*, 13(2), 176-192.
- Dening, K. H. Jones, L. & Sampson, E. L. (2013) Preferences for end-of-life care: A nominal group study of people with dementia and their family carers. *Palliative Medicine*, 27, 409-417.
- Department of Health, UK. (2009) *Living well with dementia: A National Dementia Strategy*. Available from: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/168220/dh\\_094051.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf) (Downloaded 19 June 2014).
- Deponte, A. & Missan, R. (2007) Effectiveness of validation therapy (VT) in group: Preliminary results. *Archives of Gerontology and Geriatrics*, 44(2), 113-117.
- Duane, F. Brasher, K. & Koch, S. (2013) Living alone with dementia. *Dementia*, 12, 123-136.
- Edlund, M. (1995). Värdighet - en analys av begreppets betydelse och innebörd. [Dignity – an analysis of the meaning of the concept]. In: Eriksson, K. (ed.). *Mot en caritativ vårdetik [Towards a caritative caring ethic]*. Reports from the Department of Caring Science nr. 5. Åbo, Åbo Akademi University, pp. 169–185.
- Edlund, M. (2002) *Människans värdighet - ett grundbegrepp inom vårdvetenskapen [Human Dignity – a basic caring science concept]*. PhD Thesis. Åbo, Åbo Akademi University.
- Edlund, M. Lindwall, L. von Post, I. & Lindström, U. Å. (2013) Concept determination of Human dignity. *Nursing Ethics*, 20, 851-860.
- Engedal, K. & Haugen, P. K. (2009) *Demens. Fakta og utfordringer [Dementia. Facts and challenges]*. 5th utg. [5th ed.]. Sem. Nasjonalt kompetansesenter for aldring og helse [Sem, Norway. National Center for Competence in Aging and Health].
- Ericsson, I. Kjellström, S. & Hellström, I. (2013) Creating relationships with persons with moderate to severe dementia. *Dementia*, 12, 63-79.

- Eriksson, K. (1981) *Vårdprocessen – En utgångspunkt för läroplanstenkande inom vårdutbildningen. Utvecklande av en vårdprocessmodell samt ett läroplanstänkande utgående från vårdprocessen, n. 94.* Helsinki, Finland. Helsingfors Universitet, Pedagogiske Institutionen. [*The nursing care process – an approach to curriculum construction within nursing education. The development of a model for the nursing care process and an approach for curriculum development based on the process of nursing care, number 94.* Helsinki, Finland. Department of Education, University of Helsinki].
- Eriksson, K. (1987a) *Vårdandes ide' [The idea of caring]*. Stockholm, Almqvist & Wiksell.
- Eriksson, K. (1987b) *Pausen – en beskrivning av vårdvetenskapens kunskapsobjekt. [The pause: A description of the knowledge object of caring science]*. Stockholm, Almqvist & Wiksell.
- Eriksson, K. (1990) *Pro Caritate. En lägesbestemning av caritativ vård. Vårdforskning 2/1990. [Caritative caring - A positional analysis. Caring science 2/1990]*. Institutionen för vårdvetenskap [Department of Caring science]. Åbo, Åbo Akademi University.
- Eriksson, K. (1995) *Mot en caritativ vårdetik [Towards a caritative caring ethic]*. In: Eriksson, K. (ed.). *Mot en caritativ vårdetik [Towards a caritative caring ethic]*. Reports from the Department of Caring Science 5/1995, Åbo, Åbo Akademi University, pp. 9–40.
- Eriksson, K. (1996) *Om människans värdighet [About human dignity]*. In: Bjerkreim, I. T. Mathisen, J. & Nord, R. (eds). *Visjon, viten og virke. Festskrift til sykepleieren Kjellaug Lerheim, 70 år [Vision, knowledge and influence. Festschrift for the nurse Kjellaug Lerheim, 70 years]*. Oslo, Universitetsforlaget, pp. 79-86.
- Eriksson, K. (1997) *Understanding the world of the patient, the suffering human being: the new clinical paradigm from nursing to caring. Advanced Practice Nursing Quarterly, 3(1), 8-13.*
- Eriksson, K. (1998) *Människans värdighet, lidande och lidandets ethos [Human dignity, suffering and the ethos of suffering]*. In: The Finish Association for Mental Health (ed.). *Suomen Mielenterveysseura, Tuhkaa ja linnunrata. Henkisyys Mielenterveystyössä [Ashes and the Milky Way: Spirituality in mental health care nursing]*. Helsinki, Suomen Mielenterveysseura, SMS-Julkaisut, pp. 67-82.
- Eriksson K. (2001) *Vårdvetenskap som akademisk disiplin. Vårdforskning 7/2001. [Caring science as an academic discipline. Caring science 7/2001]*. Institutionen för vårdvetenskap, Åbo Akademi, Vasa. [Department of Caring science, Åbo Akademi University, Vasa].
- Eriksson, K. (2002) *Caring science in a new key. Nursing Science Quarterly, 15(1), 61-65.*
- Eriksson, K. (2006) *The suffering human being*. Chicago, Nordic Studies Press. [English translation of Eriksson, K. (1994) *Den lidande människan*. Stockholm, Liber Förlag].

- Eriksson, K. (2013) Jäg var där, jag såg, jag vittnade och jag blev ansvarlig – den vårdande etikens mantra [I was there, I saw, I witnessed and became responsible – the mantra of caring ethos]. In: Alvsvåg, H. Bergland, Å. & Førland, O. (eds). *Nødvendige omveier. En vitenskapelig antologi til Kari Martinsens 70-årsdag [Necessary detours. A scientific anthology to Kari Martinsen's 70th birthday]*. Oslo, Cappelen Damm Akademisk, pp. 69-85.
- Fagerström, L. Eriksson, K. & Bergbom Engberg, I. (1998) The patient's perceived caring needs as a message of suffering. *Journal of Advanced Nursing*, 28(5), 978-987.
- Fleming, V. Gaidys, U. & Robb, Y. (2003) Hermeneutic research in nursing: developing a Gadamerian-based research method. *Nursing Inquiry*, 10(2), 113-120.
- Gadamer, H.G. (2010) *Sannhet og Metode. Grunntrekk i en filosofisk hermeneutikk. [Truth and Method. Original title: Wahrheit und Methode. Grundzüge einer Philosophischen Hermeneutik, 1960]*. Oslo, Pax Forlag A/S.
- Gallagher, A. (2004) Dignity and respect for dignity – two key health professional values: implications for nursing practice. *Nursing Ethics*, 11(6), 587-599.
- Gallagher, A. (2011) Editorial: What do we know about dignity in care? *Nursing Ethics*, 18(4), 471-473.
- Gallagher, A. Li, S. Wainwright, P. Rees Jones, I. & Lee, D. (2008) Dignity in the care of older people – a review of the theoretical and empirical literature. *BMC Nursing*, 7:11.
- Gastmans, C. (2013) Dignity-enhancing nursing care: a foundational ethical framework. *Nursing Ethics*, 20, 142-149.
- Guba, E. G. & Lincoln, Y. S. (1994) Competing paradigms in qualitative research. In: Denzin, N. K. & Lincoln, Y. S. (eds). *Handbook of qualitative research*. Thousand Oaks, CA, Sage, pp. 105-117.
- Haddock, J. (1996) Towards a further clarification of the concept 'dignity'. *Journal of Advanced Nursing*, 24(5), 924-931.
- Hall, S. Dodd, R. H. & Higginson, I. J. (2014) Maintaining dignity for residents of care homes: a qualitative study of the views of care home staff, community nurses, residents and their families. *Geriatric Nursing*, 35(1), 55-60.
- Harris, D. (2007) Forget me not: palliative care for people with dementia. *Postgraduate Medical Journal*, 83(980), 362-366.
- Hauge, S. (2004) *Jo mere vi er sammen, jo gladere vi blir? – en feltmetodisk studie av sjukeheimen som heim [The more often we're together, the happier we are? – a field investigative study of the nursing home as a home]*. Doctoral dissertation, Oslo, University of Oslo.



- Heap, K. (1995) *Samtal med äldre. Om kommunikation, minnen, kriser och sorg [Conversation with the elderly. Concerning communication, memory, crisis and sorrow]*. Falköping, Gummessons tryckeri AB.
- Heggestad, A. K. Nortvedt, P. & Slettebø, Å. (2013a) "Like a prison without bars": Dementia and experiences of dignity. *Nursing Ethics*, 20, 881-892.
- Heggestad, A. K. Nortvedt, P. & Slettebø, Å. (2013b) The importance of moral sensitivity when including persons with dementia in qualitative research. *Nursing Ethics*, 20, 30-40.
- Hellström, I. Eriksson, H. & Sandberg, J. (2014) Chores and sense of self: gendered understandings of voices of older married women with dementia. *International Journal of Older People Nursing*. 14 November. doi: 10.1111/opn.12062
- Hellström, I. Nolan, M. Nordenfelt, L. & Lundh, U. (2007) Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14, 608-619.
- Hiles, D. & Čermak, I. (2007) *Qualitative research: transparency and narrative oriented inquiry*. Paper presented at 10th ECP, Prague, Czech Republic, July 3-6 2007. Available from: <http://ebookbrowse.com/microsoft-word-hiles-cermak-2007-qr--transparency-and-noipdf-d57724198> (Downloaded 7 November 2012).
- Hope, K. & Waterman, H. (2004) Using Multi-Sensory Environments (MSEs) with people with dementia. Factors impeding their use as perceived by clinical staff. *Dementia*, 3(1), 45-68.
- International Council of Nurses. (1953) *International Code of Nursing Ethics*. Adopted by the Grand Council of the International Council of Nurses, Sao Paulo, Brazil, 10 July.
- International Council of Nurses. (1973) *International Code of Nursing Ethics*. Adopted by the ICN Council of National Representatives in Mexico City in May.
- International Council for Nurses. (2012) *Code of ethics for nurses*. Available from: [http://www.icn.ch/images/stories/documents/about/icncode\\_english.pdf](http://www.icn.ch/images/stories/documents/about/icncode_english.pdf) (Downloaded 3 March 2014).
- Jacobson, N. (2007) Dignity and health: a review. *Social Science & Medicine*, 64, 292-302.
- Jacobson N. (2009) A taxonomy of dignity: a grounded theory study. *BMC International Health and Human Rights*, 9: 3. doi: 10.1186/1472-698X-9-3.
- Jakobsen, R. & Sørli, V. (2010) Dignity of older people in a nursing home: narratives of care providers. *Nursing Ethics*, 17(3), 289-300.
- Johannessen, A. & Möller, A. (2013) Experiences of persons with early-onset dementia in everyday life: A qualitative study. *Dementia*, 12(4), 410-424.

- Kirkevold, M. (2001a) Familien i et helse- og sykdomsperspektiv [The family within a health and nursing perspective]. In: Kirkevold, M. & Ekern, K. S. (eds). *Familien i sykepleiefaget [The Family and Nursing Practice]*. Oslo, Gyldendal Akademisk, pp. 21-44.
- Kirkevold, M. (2001b) Familiens plass i sykepleien [The families role in the subject of Nursing]. In: Kirkevold, M. & Ekern, K.S (eds). *Familien i sykepleiefaget [The Family and Nursing Practice]*, Oslo, Gyldendal Akademisk, pp. 45-61.
- Kitwood, T. (1997) *Dementia Reconsidered: the person comes first*. Open University Press, Buckingham.
- Knapp, M. & Prince, M. (2007) *Dementia UK. A report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London, for the Alzheimer's Society*. Alzheimer's Society, London.  
Available from:  
[http://www.google.no/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0CB0QFjAA&url=http%3A%2F%2Fwww.alzheimers.org.uk%2Fsite%2Fscripts%2Fdownload.php%3FfileID%3D1&ei=AZmZVOSEMOBTyPvioDQDA&usq=AFQjCNFsbp1G1bfg1U\\_-H86KvRxYSfpNNw](http://www.google.no/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0CB0QFjAA&url=http%3A%2F%2Fwww.alzheimers.org.uk%2Fsite%2Fscripts%2Fdownload.php%3FfileID%3D1&ei=AZmZVOSEMOBTyPvioDQDA&usq=AFQjCNFsbp1G1bfg1U_-H86KvRxYSfpNNw) (Downloaded 25 June 2014).
- Koskinen, C.A. & Lindström, U. Å. (2013) Hermeneutic reading of classic texts. *Scandinavian Journal of Caring Sciences*, 27(3), 757-764.
- Lambert, V. Glacken, M. & McCarron, M. (2011) Employing an ethnographic approach: key characteristics. *Nurse Researcher*, 19(1), 17-24.
- Lejman, E. Westerbotn, Pöder, U. & Wadensten, B. (2013) The ethics of coercive treatment of people with dementia. *Nursing Ethics*, 20(3), 248-262.
- Lin, Y. C. Dai, Y. T. & Hwang, S. L. (2003) The effect of reminiscence on the elderly population: a systematic review. *Public Health Nursing*, 20(4), 297-306.
- Lincoln, Y. S. & Guba, E. G. (1985) *Naturalistic inquiry*. Newbury Park, CA, Sage.
- Lindholm, L. & Eriksson, K. (1993) To understand and alleviate suffering in a caring culture. *Journal of Advanced Nursing*, 18(9), 1354-1361.
- Lindström, U. Å. (1995) *Ensamhetskänslan sviker inte. En kvalitativ studie rörande patienters upplevelser av vårdkultur och vårdrelation på psykiatriskt sjukhus [Feeling of loneliness don't fail. A qualitative study of patients' experiences of caring culture and caring relations on psychiatric hospital]*. Reports from the Department of Caring Science 6/1995, Åbo, Åbo Akademi University.
- Lindström, U. Å. & Lindholm, L. (2003) Kontext och meningssammanhang [Context and meaning]. In: Eriksson, K. & Lindström, U. Å. (eds.) *Gryning II. Klinisk vårdvetenskap [Dawn II. Clinical caring science]*. Vasa, Institutionen för vårdvetenskap, Åbo Akademi [Vasa, Departement of Caring Science, Åbo Akademi University], pp. 35-45.

- Lindström, U. Å. Nyström, L. L. & Zetterlund, J. E. (2014) Katie Eriksson: Theory of Caritative Caring. In: Alligood, M. R. (ed). *Nursing theorists and their work*. 8. ed. (This chapter was first published in 6th edition, 2006). St. Louis, Missouri, Mosby Elsevier, pp. 171-201.
- LinkedIn Corporation. (2014) *Ad Verheul*. Available from: <http://nl.linkedin.com/pub/ad-verheul/26/277/2b3> (Downloaded 15 July 2014).
- Livingston, G. Kelly, L. Lewis-Holmes, E. Baio, G. Morris, S. Patel, N. Omar, R. Z. Katona, C. & Cooper, C. (2014) A systematic review of the clinical effectiveness and cost-effectiveness of sensory, psychological and behavioural interventions for managing agitation in older adults with dementia. *Health Technology Assessment*, 18(39), 1-226.
- Lloyd-Williams, M. Abba, K. & Crowther, J. (2014) Supportive and palliative care for patients with chronic mental illness including dementia. *Current Opinion on Supportive and Palliative Care*, 8(3), 303-307.
- Lopez, J. J. Bolivar, J. C. & Perez, M. S. (2014) COMMUNI-CARE: Assessment tool for reactions and behaviours of patients with dementia in a multisensory stimulation environment. *Dementia*, doi: 10.1177/1471301214528346.
- Luke, R. D. Petersen, K. A. & Tranvåg, O. (2013) Dementia care supported by stimulating surroundings – Caregiver experience with environmental reminiscence approach. *Nordisk Sygeplejeforskning [Nordic Nursing Research]*, 3(4), 269-286.
- Mackenzie, N. & Knipe, S. (2006) Research dilemmas: Paradigms, methods and methodology. *Issues in Educational Research*, 16(2). Available from: [https://www.google.no/?gws\\_rd=ssl#q=G:%5CMackenzie+and+Knipe++research+dilemmas+Paradigms%2C+methods+and+methodology.htm](https://www.google.no/?gws_rd=ssl#q=G:%5CMackenzie+and+Knipe++research+dilemmas+Paradigms%2C+methods+and+methodology.htm) (Downloaded 1 October 2014).
- Macklin, R. (2003) Dignity is a useless concept. *British Medical Journal*, 327(7429), 1419- 1420.
- Malpass, A. Shaw, A. Sharp, D. Walter, F. Feder, G. Ridd, M. & Kessler, D. (2009) “Medication career” or “Moral career”? The two sides of managing antidepressants: a meta-ethnography of patients’ experience of antidepressants. *Social Science and Medicine*, 68(1), 154-168.
- Manthorpe, J. Iliffe, S. Samsi, K. Cole, L. Goodman, C. Drennan, V. & Warner, J. (2010) Dementia, dignity and quality of life: Nursing practice and its dilemmas. *International Journal of Older People Nursing*, 5, 235–244.
- Matias, M. (2011) *European Parliament resolution of 19th January 2011 on a European initiative on Alzheimer’s disease and related dementia and other dementias*. Available from: <http://www.europarl.europa.eu/oeil/spdoc.do?i%419258&j%40&l%4en> (Downloaded 17 June 2013).
- McCormack, B. & McCance, T. V. (2006) Development of a framework for person-centred nursing. *Journal of Advanced Nursing*, 56(5), 472-479.

- Ministry of Health and Care Services, Norway. (2006) *St.meld. nr. 25 (2005-2006) Mestring, muligheter og mening. Framtidas omsorgsutfordringer [Parliamentary Declaration nr. 25 (2005-2006) Coping, possibilities and meaning. Caring challenges of the future]*. Available from: <http://www.regjeringen.no/nb/dep/hod/dok/regpubl/stmeld/20052006/stmeld-nr-25-2005-2006-.html?id=200879> (Downloaded 7 July 2014).
- Ministry of Health and Care Services, Norway. (2007) *Demensplan 2015. Den gode dagen [Dementia Plan 2015. The good day]*. Available from: [https://www.regjeringen.no/globalassets/upload/hod/vedlegg/omsorgsplan\\_2015/demensplan2015.pdf](https://www.regjeringen.no/globalassets/upload/hod/vedlegg/omsorgsplan_2015/demensplan2015.pdf) (Downloaded 19 June 2014).
- Ministry of Health and Care Services, Norway. (2010) *Forskrift om en verdig eldreomsorg (Verdighetsgarantien) [Regulation concerning dignified care for older people (The dignity guarantee)]*. Available from: <http://lovdata.no/dokument/SF/forskrift/2010-11-12-1426?q=verdighetsgaranti> (Downloaded 19 June 2014).
- Ministry of Health and Care Services, Norway. (2011) *Demensplan 2015. Den gode dagen. Revidert handlingsprogram for perioden 2012-2015 [Dementia Plan 2015. The good day. Revised program 2012-2015]*. Available from: [http://www.regjeringen.no/nb/dep/hod/dok/rapporter\\_planer/planer/2011/demensplan-2015-den-gode-dagen.html?id=663429](http://www.regjeringen.no/nb/dep/hod/dok/rapporter_planer/planer/2011/demensplan-2015-den-gode-dagen.html?id=663429) (Downloaded 7 July 2014).
- Ministry of Health and Care Services, Norway. (2013) *Morgendagens omsorg Meld. St. 29; 2012–2013. [Care of tomorrow. White paper 29; 2012-2013]*. Available from: <http://www.regjeringen.no/nb/dep/hod/dok/regpubl/stmeld/2012-2013/meld-st-29-20122013.html?id=723252> (Downloaded 5 August 2014).
- Ministry of Health and Social Affairs, Sweden. (2008) *Sweden's strategy report for social protection and social inclusion. National strategy for health care and long-term care 2008-2010*. Available from: <http://www.regeringen.se/sb/d/108/a/114267> (Downloaded 25 June 2014).
- Ministry of Health and Social Affairs, Sweden. (2013) *Åtgärdsprogram för god vård av personer med nedsatt beslutsförmåga [Intervention program of quality care for persons with reduced ability to make sound decisions]*. Available from: <http://www.regeringen.se/sb/d/14932/a/218038> (Downloaded 8 July 2014).
- Ministry of Local Government and Modernisation, Norway. (2011) *NOU 15: Rom for alle [NOU 15: Room for all]*. Available from: <http://www.regjeringen.no/nb/dep/kmd/dok/nouer/2011/nou-2011-15/6/3.html?id=650463> (Downloaded 10 August 2014).
- Ministry of Social Affairs and Health, Finland. (2013a) *Lag om stödjande av den äldre befolkningens funktionsförmåga och om social- och hälsovårdstjänster för äldre [Act on supporting the functional capacity of the ageing population and on social and health care services for older people]*. Available from: <http://www.finlex.fi/sv/laki/ajantasa/2012/20120980> (Downloaded 8 July 2014).

- Ministry of Social Affairs and Health, Finland. (2013b) *National Memory Programme 2012-2020. Creating a "memory-friendly" Finland*. Available from: [http://www.stm.fi/c/document\\_library/get\\_file?folderId=6511574&name=DLFE-26234.pdf](http://www.stm.fi/c/document_library/get_file?folderId=6511574&name=DLFE-26234.pdf) (Downloaded 9 July 2014).
- Moise, P. Schwarzingler, M. Um, M. Y. & The Dementia Experts' Group of OECD. (2004) *Dementia care in 9 OECD countries: a comparative analysis*. Paris: *OECD Health Working Papers no. 13*. Available from: [http://www.google.no/url?sa=t&rct=j&q=&esrc=s&frm=1&source=web&cd=1&ved=0CBsQFjAA&url=http%3A%2F%2Fwww.oecd.org%2Fdataoecd%2F10%2F52%2F33661491.pdf&ei=YYqqU\\_i1DeP8ywOg54H4Cw&usg=AFQjCNGVVG937IL2L-wCEFrc7v6e13XzKpw](http://www.google.no/url?sa=t&rct=j&q=&esrc=s&frm=1&source=web&cd=1&ved=0CBsQFjAA&url=http%3A%2F%2Fwww.oecd.org%2Fdataoecd%2F10%2F52%2F33661491.pdf&ei=YYqqU_i1DeP8ywOg54H4Cw&usg=AFQjCNGVVG937IL2L-wCEFrc7v6e13XzKpw) (Downloaded 25 June 2014).
- National Dignity Council, UK. (2013) *The Dignity in Care campaign*. Available from: [http://www.dignityincare.org.uk/Dignity\\_in\\_Care\\_campaign/](http://www.dignityincare.org.uk/Dignity_in_Care_campaign/) (Downloaded 19 June 2014).
- National Institute for Health and Care Excellence. (2010) *Dementia Quality Standard. Quality statement 9: Palliative care needs*. Available from: <http://www.nice.org.uk/guidance/qs1/chapter/quality-statement-9-palliative-care-needs> (Downloaded 7 August 2014).
- National Institute for Health and Care Excellence, & The Social Care Institute for Excellence. (2012) *Supporting people with dementia and their carers in health and social care*. Available from: <http://guidance.nice.org.uk/CG42/NICEGuidance/pdf/English> (Downloaded 17 June 2013).
- Neal, M. & Barton Wright, P. (2003) Validation therapy for dementia. *Cochrane Database of Systematic Reviews*, Issue 3. Art. No.: CD001394. doi: 10.1002/14651858.CD001394.
- Noblit, G. W. & Hare, R. D. (1988) *Synthesizing qualitative studies*. Newbury Park, CA, Sage.
- Nordenfelt, L. (2004) The varieties of dignity. *Health Care Analysis*, 12, 69-81.
- Norman, H.K. (2008) Hjemmeopplevelse hos personer med demenssykdom [Experience of home in persons with dementia]. In: Hauge, S. & Jacobsen F. F. (eds). *Hjem. Eldre og hjemlighet [Home - older people and home life]*. Oslo, Cappelen Akademisk Forlag, pp. 147-160.
- Northern Ireland Human Rights Commission. (2012) *In Defence of Dignity. The Human Rights of Older People in Nursing Homes*. Belfast . Available from: <http://www.google.no/url?sa=t&rct=j&q=&esrc=s&frm=1&source=web&cd=1&ved=0CBsQFjAA&url=http%3A%2F%2Fwww.nihrc.org%2Fdocuments%2Fresearch-and-investigations%2Folder-people%2Fin-defence-of-dignity-investigation-report-March-2012.pdf&ei=hmqmU7XsE8b8ywOa3YKoDA&usg=AFQjCNE1vAQk5OKhSIRSFKaY30BMT6cFvw&bvm=bv.69620078,d.bGQ> (Downloaded 25 June 2014).

- Nuffield Council on Bioethics. (2009) *Dementia: ethical issues*. Available from: <http://www.nuffieldbioethics.org/dementia> (Downloaded 19 June 2014).
- Nygaard, H. A. (2002) Sykehjemmet som medisinsk institusjon – et fatamorgana? [The Nursing Home as a medical institution – a fatamorgana?]. *Tidsskrift for den norske legeforening [The Journal of the Norwegian Medical Association]*, 122(8), 823-825.
- Nåden, D. & Eriksson, K. (2000) The phenomenon of confirmation: an aspect of nursing as an art. *International Journal for Human Caring*, 4(3), 23-28.
- Nåden, D. & Eriksson, K. (2004) Understanding the importance of values and moral attitudes in nursing care in preserving human dignity. *Nursing Science Quarterly*, 17(1), 86-91.
- Olsson, L. E. Jakobsson Ung, E. Swedberg, K. & Ekman, I. (2013) Efficacy of person-centred care as an intervention in controlled trials – a systematic review. *Journal of Clinical Nursing*, 22(3-4), 456-465.
- O'Sullivan, G. (2013) Ethical and effective: approaches to residential care for people with dementia. *Dementia*, 12(1), 111-121.
- Oxford University Press (2014) Epistemology. In: *Oxford Dictionaries*. Available from: <http://www.oxforddictionaries.com/definition/english/epistemology?q=Epistemology> (Downloaded 13 October 2014).
- Oxford University Press (2014). Ontology. In: *Oxford Dictionaries*. Available from: <http://www.oxforddictionaries.com/definition/english/ontology> (Downloaded 13 October 2014).
- Paterson, B. L. Thorne, S. E. Canam, C. & Jillings, C. (2001) *Meta-study of qualitative health research: a practical guide to meta-analysis and meta-synthesis*. Thousand Oaks, CA, Sage.
- Polit, D. F. & Beck, C. (2010) *Essentials of nursing research: appraising evidence for nursing practice*. Philadelphia, PA, Wolters Kluwer/Lippincott Williams & Wilkins.
- Preston, L. Marshall, R. & Bucks, R. S. (2007) Investigating the ways that older people cope with dementia: A qualitative study. *Aging & Mental Health*, 11, 131-143.
- Prince, M. Bryce, R. Albanese, E. Wimo, A. Ribeiro, W. & Ferri, C. P. (2002) The global prevalence of dementia: A systematic review and metaanalysis. *Alzheimer's & Dementia*, 9(1), 63-75.
- Pullman, D. (2002) Human dignity and the ethics and aesthetics of pain and suffering. *Theoretical Medicine and Bioethics*, 23(1), 75-94.
- Qizilbash N. (2002) Evidence-based diagnosis. In: Qizilbash, N. Schneider, L.S. Brodaty, H. et al. (eds). *Evidence-based dementia practice*. Hong Kong, Blackwell Publishers, pp. 18-25.

- Randers, I. & Mattiasson, A. C. (2004) Autonomy and integrity: upholding older adult patients' dignity. *Journal of Advanced Nursing*, 45(1), 63-71.
- Rodriquez, J. (2009) Attributions of agency and the construction of moral order: dementia, death and dignity in nursing-home care. *Social Psychology Quarterly*, 72(2), 165-179.
- Rodriquez J. (2011) "It's a dignity thing": nursing home care workers' use of emotions. *Sociological Forum (Randolph N. J.)*, 26(2), 265-286.
- Roger, K. S. (2007) It's a problem for other people, because I am seen as a nuisance: Hearing the voices of people with dementia. *Alzheimer's Care Quarterly*, 8, 17-25.
- Rognstad, M. K. & Nåden, D. (2011) Utfordringer og kompetanse i demensomsorgen: Pleieres perspektiv [Challenges and competence in dementia care: caregivers' perspective]. *Nordisk Sygeplejeforskning [Nordic Nursing Research]*, 2(1), 143-155.
- Rokstad, A. M. Røsvik, J. Kirkevold, Ø. Selbæk, G. Saltyte Benth, J. & Engedal, K. (2013) The effect of person-centred dementia care to prevent agitation and other neuropsychiatric symptoms and enhance quality of life in nursing home patients: a 10-month randomized controlled trial. *Dementia and Geriatric Cognitive Disorders*, 36(5-6), 340-353.
- Salotti, P. De Sanctis, B. Clementi, A. Fernandez Ferreira, M. & De Silvestris T. (2013) Evaluation of the efficacy of a cognitive rehabilitation treatment on a group of Alzheimer's patients with moderate cognitive impairment: a pilot study. *Aging Clinical and Experimental Research*, 25(4), 403-409.
- Sampson, E. L. Ritchie, C. W. Lai, R. Raven, P. W. & Blanchard, M. R. (2005) A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *International Psychogeriatrics*, 17(1), 31-40.
- Sandelowski, M. Docherty, S. & Emden, C. (1997) Focus on Qualitative Methods. Qualitative metasynthesis: issues and techniques. *Research in Nursing and Health*, 20, 365-371.
- Seedhouse, D. & Gallagher, A. (2002) Undignifying institutions. *Journal of Medical Ethics*, 28(6), 368-372.
- Smebye, K. L. & Kirkevold, M. (2013) The influence of relationship on personhood in dementia care: A qualitative, hermeneutic study. *BMC Nursing*, 12, 29.
- Staal, J. A. (2012) Functional Analytic Multisensory Environmental Therapy for People with Dementia. *International Journal of Alzheimer's Disease*, doi: 10.1155/2012/294801.
- Staal, J. A. Sacks, A. Matheis, R. Collier, L. Calia, T. Hanif, H. & Kofman, E. S. (2007) The effects of Snoezelen (multi-sensory behavior therapy) and psychiatric care on agitation, apathy, and activities of daily living in dementia patients on a short term geriatric psychiatric inpatient unit. *International Journal of Psychiatry in Medicine*, 37(4), 357-70.

- Sävenstedt, S. Sandman, P. O. & Zingmark, K. (2006) The duality in using information and communication technology in elder care. *Journal of Advanced Nursing*, 56(1), 17-25.
- Sørensen, L. Waldorff, F. & Waldemar, G. (2008) Coping with mild Alzheimer's disease. *Dementia*, 7, 287-299.
- The National Board of Health and Welfare, Sweden. (2011) *Hur lokala värdighetsgarantier inom äldreomsorgen kan utformas [How to develop local dignity guarantees within care for older people]*. Available from: <http://www.socialstyrelsen.se/publikationer2011/2011-5-19> (Downloaded 8 August 2014).
- The Norwegian Directorate of Health. (2007) «*Glemsk, men ikke glemt*». Rapport om demens, IS-1486 [*Forgetful, but not forgotten*]. Report on dementia, IS-1486]. Available from: <http://helsedirektoratet.no/publikasjoner/glemsk-men-ikke-glemt-rapport-om-demens/Sider/default.aspx> (Downloaded 26 June 2014).
- The Norwegian Directorate of Health. (2013) «*Ta samtalen*» [*Talk together*]. Available from: <http://helsedirektoratet.no/Om/nyheter/Sider/ta-samtalen-om-demens.aspx> (Downloaded 9 June 2014).
- The Norwegian Directorate of Health. (2014) *Demens [Dementia]*. Available from: <http://helsedirektoratet.no/helse-og-omsorgstjenester/omsorgstjenester/demensSider/default.aspx> (Downloaded 20 June 2014).
- The Validation Training Institute. (2013) *Naomi Feil Biography*. Available from: <https://vfvalidation.org/web.php?request=index> (Downloaded 10 July 2014).
- Tong, A. Sainsbury, P. & Craig, J. (2007) Consolidated criteria for reporting qualitative Research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357.
- UNESCO. (2005) *Universal Declaration on Bioethics and Human Rights*. Paris: General Conference of UNESCO: article 2c. Available from: [http://portal.unesco.org/en/ev.php-URL\\_ID=31058&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html) (Downloaded 4 February 2014).
- United Nations (1945) *Charter of the United Nations*. Available from: <http://www.un.org/en/documents/charter/preamble.shtml> (Downloaded 17 June 2014).
- United Nations (1948) *The Universal Declaration of Human Rights*. Available from: <http://www.un.org/en/documents/udhr/> (Downloaded 17 June 2013).
- United Nations. (2006) *Convention on the Rights of Persons with Disabilities*. Available from: <http://www.un.org/disabilities/convention/conventionfull.shtml> (Downloaded 4 February 2012).
- Uys, L.R. (2007) *Fundamental Nursing*. Cape Town, South Africa, Maskew Miller Longman.



- Van der Graaf, R., & Van Delden, J. J. M. (2009) Clarifying appeals to dignity in medical ethics from and historical perspective. *Bioethics*, 23(3), 151-160.
- Van Gennip, I. E. Pasman, H. R. W. Oosterveld-Vlug, M. G. Willems, D. L. & Onwuteaka-Philipsen, B. D. (2013) The development of a model of dignity in illness based on qualitative interviews with seriously ill patients. *International Journal of Nursing Studies*, 50, 1080-1089.
- Van Gennip, I. E. Pasman, H. R. W. Oosterveld-Vlug, M. G. Willems, D. L. & Onwuteaka-Philipsen, B. D. (2014) How dementia affects personal dignity: A qualitative study on the perspective of individuals with mild to moderate dementia. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*. 30 September, pii: gbu137.
- Van Weert, J. C. Van Dulmen, A. M. Spreeuwenberg, P. M. Ribbe, M. W. & Bensing, J. M. (2005) Behavioral and mood effects of snoezelen intergrated into 24-hour dementia care. *Journal of the American Geriatric Society*, 53(1), 24–33.
- Wang, J. J. (2007) Group reminiscence therapy for cognitive and affective function of demented elderly in Taiwan. *International Journal of Geriatric Psychiatry*, 22(12), 1235-1240.
- Wikberg, A. & Bondas, T. (2010) A patient perspective in research on intercultural caring in maternity care: a meta-ethnography. *International Journal of Qualitative Studies on Health and Well-Being*, 5(1), doi: 10.3402/qhw.v5i1.4648.
- Wiklund-Gustin, L. (2011) To intend to but not being able to: frequent attenders' experiences of suffering and of their encounter with the health care system. *Journal of Holistic Nursing*, 29(3), 211-220.
- Wimo, A. Winblad, B. & Jönsson, L. (2007) An estimate of the total worldwide societal costs of of dementia in 2005. *Alzheimer's & Dementia*, 3(2), 81-91.
- Wogn-Henriksen, K. (2012) “Du må...skape deg et liv.” En kvalitativ studie om å oppleve og leve med demens basert på intervjuer med en gruppe personer med tidlig debuterende Alzheimers sykdom. [“You have to... make a life for yourself”. A qualitative study on experiencing and living with dementia based on interviews among individuals with early debut Alzheimer's disease]. PhD Thesis, Trondheim, Norwegian University of Science and Technology.
- Woods, B. (1999) Editorial. The Leagacy of Kitwood. Professor Tom Kitwood 1937-1998. *Aging and Mental Health*, 3(1), 5-7.
- Woods, B. Aguirre, E. Spector, A. E. & Orrell, M. (2012) Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database of Systematic Reviews* 2012, Issue 2. Art. No.: CD005562. DOI: 10.1002/14651858.CD005562.pub2.
- Woods, B. Spector, A. E. Jones, C. A. Orrell, M. & Davies, S. P. (2005) Reminiscence therapy for dementia (Review). *Cochrane Database of Systematic Reviews*, Issue 2. CD001120. DOI: 10.1002/14651858.CD001120.pub2.

- World Health Organization. (1994) *A Declaration on the Promotion of Patients' Rights in Europe*. Amsterdam: WHO: article 5.8. Available from:  
[http://search.who.int/search?q=A+Declaration+on+the+Promotion+of+Patients%E2%80%99+Rights+in+Europe&ie=utf8&site=who&client=\\_en\\_r&proxystylesheet=\\_en\\_r&output=xml\\_no\\_dtd&oe=utf8&getfields=doctype](http://search.who.int/search?q=A+Declaration+on+the+Promotion+of+Patients%E2%80%99+Rights+in+Europe&ie=utf8&site=who&client=_en_r&proxystylesheet=_en_r&output=xml_no_dtd&oe=utf8&getfields=doctype) (Downloaded 4 February 2014).
- World Health Organization. (2010) *International statistical classification of diseases and health related problems -10 Version: 2010*. Available from:  
<http://apps.who.int/classifications/icd10/browse/2010/en#/F00.1> (Downloaded 18 November 2012).
- World Health Organization. (2012) *Dementia*. Available from:  
<http://www.who.int/mediacentre/factsheets/fs362/en/> (Downloaded 7 July 2014).
- World Health Organization. (2014) *Definition of Palliative Care*. Available from:  
<http://www.who.int/cancer/palliative/definition/en/> (Downloaded 11 July 2014).
- World Health Organization and Alzheimer's Disease International. (2012) *Dementia: A public health priority*. Available from:  
[http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf)  
(Downloaded 19 June 2014).
- World Medical Association. (1948) *World Medical Association Declaration of Geneva*. Geneva: WMA General Assembly. Last amended 2006. Divonne-les-Bains: WMA Council Session. Available from:  
<http://www.wma.net/en/30publications/10policies/g1/> (Downloaded 17 June 2014).
- World Wide Snoezelen.com. (2014) *Ad Verheul*. Available from:  
<http://www.worldwidesnoezelen.nl/en/authors-and-publishers/item/149-ad-verheul-english> (Downloaded 14 July 2014).
- Zimmer, L. (2006) Qualitative meta-synthesis: a question of dialoguing with texts. *Journal of Advanced Nursing*, 53(3), 311-318.
- Zingmark, K. Sandman, P. O. & Norberg, A. (2002) Promoting a good life among people with Alzheimer's disease. *Journal of Advanced Nursing*, 38(1), 50-58.
- Örülv, L. & Nikku, N. (2007) Dignity work in dementia care. *Dementia*, 6(4), 507-524.