

There is no escape from getting old

Older persons' experiences of environmental
change in residential care

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To my Mom...

“Choose topics that ignite your passion, do something that makes a difference in the world. Face the inevitable ambiguities and flow with the existential dislocation of bewilderment. Bring passion, curiosity, and care to your work. In the end, you will transform our image of studied life, and your research journey will transform you.”

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Professor Kathy Charmaz

ABSTRACT

A life of quality in residential care has to be finely balanced against the characteristics of institutionalization. Highly desirable aspects of person-hood, such as dignity, privacy, and eligibility, are bound up with satisfying and supportive living arrangements. The overall aim of this thesis was to achieve a comprehensive understanding of how environmental changes affect frail older persons' perceptions of quality of life, wellbeing, and care atmosphere, and how people create attachment and self-identity in residential care facilities. A secondary aim was to psychometrically evaluate a Swedish translation of a quality of life instrument, specifically for dementia. This thesis combines quantitative (I), qualitative (IV), and mixed method designs (II and III) to explore meaning, gain understanding, examine relationship between variables, as well as outcome effects.

Paper I (n=169), used a cross-sectional design to psychometrically evaluate a Swedish translation of the Quality of Life in Late-Stage Dementia (QUALID) Scale. Paper II (n=131), used a sequential mixed method design to follow a refurbishment aimed at enhancing the supportiveness of the physical environment. Paper III (n=155), used a concurrent mixed method design to follow an inter-institutional relocation. Paper IV (n=25), used a grounded theory method to gain an understanding of the various ways in which elderly persons create attachment in residential care, and to discover a plausible variety of real-life contingencies that affect this creation process.

The findings suggest that the Swedish translation of the QUALID provide reliable and valid information about quality of life in persons with late-stage dementia. That interior design features alone may have little importance to the care climate, and that the disruption caused by the refurbishment had negative effects on the wellbeing and quality of life of frail older persons. That inter-institutional relocation has adverse effects for those able to self-report and describe their experiences and that there is a lack of preparatory programs aimed at minimizing the adverse effects of relocation. The findings also show that frail older persons who are able to create a sense of home in the residential care facility, and thereby improve their sense of wellbeing and belonging, are those who create an attachment to the place, the space, or to someplace beyond the institution.

The results provide added insight on the complex and transactional relationship between frail older persons and their living environment in residential care facilities. There is a need for further research into how a homely atmosphere can be created in institutional contexts in order to avoid over-simplification in which a physical environment with an aesthetic appearance of a home becomes the general standard for good residential care. This work also expands existing knowledge regarding quality of life in late-stage dementia, and the methodological difficulties that surrounds measurement. Altogether, the results in this thesis might improve the lives of frail older persons in residential care by acknowledging the fundamental human need for a home. A home is more than a physical environment, and the present thesis challenge us to learn from the inside about life in residential care, which is a prerequisite for wise and supportive interventions, aimed to improve the wellbeing and quality of life in old age.

Key words; frailty, person-centeredness, older person, dementia, residential care facility, quality of life, wellbeing, attachment

ORIGINAL PAPERS

This thesis is based on the following papers, referenced in the text by the Roman numerals I- IV. Papers are reprinted with kind permission of the publishers.

- I. Falk, H., Persson, L.O. & Wijk, H. (2007).
A Psychometric evaluation of a Swedish version of the Quality of life in Late-Stage Dementia (QUALID) scale. *International Psychogeriatrics*, 19(6), 1040-1050.
- II. Falk, H., Wijk, H. & Persson, L.O. (2008).
Effects of refurbishment on residents' QoL, wellbeing, and perceived person-centeredness. *Health & Place*, 15, 717-724.
- III. Falk, H., Wijk, H. & Persson, L.O (2009).
Older persons' experiences of an inter-institutional relocation and its effects on QoL, wellbeing, and perceived person-centeredness.
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ABBREVIATIONS

GBAS	General Behaviour Assessment Scale
GDP	Gross Domestic Product
GTM	Grounded Theory Method
HRQoL	Health Related Quality of Life
MMSE	Mini Mental State Examination
NANDA	the North American Nursing Diagnosis Association
NBHW	the National Board of Health and welfare
NKI	Nöjd Kund Index
NUD	Non Ultra Descriptus (dementia diagnose without further description)
OECD	Organization for Economic Co-operation and Development
PCQ	Person-Centred Care Questionnaire
PMAS	Patient Mood Assessment Scale
QoL	Quality of Life
QUALID	Quality of Life in Late-Stage Dementia Scale
SALAR	the Swedish Association of Local Authorities and Regions
SBU	the Swedish Council on Technology Assessment in Health Care
SCU	Special Care Unit
SCB	Statistics Sweden
SOU	the Government Official Report
QUAN→qual	Sequential mixed method design
QUAN + qual	Concurrent mixed method design

INTRODUCTION

The word gerontopia has been coined to describe the ideal place where we would like to grow old and die. It is derived from the Greek roots *geron*, referring to old age, and *topia*, meaning a place (Brent, 1999). The wish expressed in the demand “I want to go home!” sometimes heard in facilities housing elderly, does not refer to a location, but to a nostalgic yearning for the feeling of home (Tofle, 2009). Everyone has his or her own notion of a gerontopia – an ideal envisioned picture (Brent, 1999). The physical environments in which most of us would prefer to age are highly personal, characterized by individuality, independence, and familiarity (Kearns & Andrews, 2005). Highly desirable aspects of personhood, such as dignity, privacy, and eligibility, are bound up with satisfying and supportive living arrangements for older persons (Zweig & Oliver, 2009). However, at some point we must move from individual imaginations of gerontopia and focus on the realistic world where institutionalized older persons may find themselves in unfamiliar environmental settings that they did not voluntarily choose (Kahana et al., 2003).

Both conventional wisdom and research evidence suggest that older persons move to residential care primarily because they have to, i.e. secondary to senescence, disease, and trauma (Andrews & Phillips, 2005). Studies of person-environment relationships have generated a rich literature that embraces social science, care science, health geography, philosophy, and architecture (Weisman et al., 2000). Residential care facilities are understandably subject to many health and safety regulations not found in our ordinary homes. The facility must function as a work place for the nursing staff, as well as a home space for its residents. The physical environment should compensate for disabilities and afford security. Going beyond mere function, the physical environment should also enable meaning, and empower will regarding preferences and control (Tofle, 2009). The need for a home is a human imperative (Pastalan & Barnes, 1999) that constitutes profound centers of human existence (Relph, 1976). The phenomena of being given a home, creating a home, sharing a home, and offering a home have been identified as important in maintaining a sense of “at-homeness” through various stages of life (Zingmark et al., 2002).

A home serves as material and symbolic sources for biographical development, and makes an essential contribution to the construction of personal self-identity (Kearns & Andrews, 2005; Kontos, 2005). A life of quality in old age ought to have the capacity to positively engage and attach the individual to the social and material fabric of everyday life on a level where the person feels secure about his or her own self-identity (Peace et al., 2005).

Whenever the subject of assisted living for older persons arises, one of the first questions raised is how much like home is it. This thesis is intended as a contribution to understanding the role of the residential care environment from the older person's perspective. There are no easy "shake and bake" solutions for creating supportive environments for older persons. Although the residential care facility has the aesthetic appearance of a home, the feeling of home, in terms individual connectedness to the place, is often missing (Dobbs, 2004). Although the all-prevailing residential care philosophy clearly stresses the importance of home-like environments and ageing-in-place, there is a need to further understand the effects of surface refurbishments, inter-institutional relocations, and the ways in which frail older persons succeed in creating a sense of home in residential care. By understanding the role of the environment from a healthcare, design, and family perspective, we might be better able to prepare the place where ageing and death occur (Tofle, 2009).

Growing old in Sweden

In proportion of Gross Domestic Product (GDP), Sweden offers more publicly financed care of the elderly than any other country in the world (OECD, 2005). During the last thirty years, public expenditures on care of the elderly has increased by 60 percent, while the number of institutional care recipients has decreased by about 40 percent. This means that the cost per care recipient has more than doubled since the 1980s (SALAR, 2006). One reason for the decreasing number of older persons in need of institutional care in Sweden is that the vast majority is in good health and able to take care of themselves into very advanced age (SBU, 2003). Between 2001 and 2008 there has also been a transfer of care from formal settings, such as nursing homes and hospitals, towards ordinary housing, which permits the great majority of older persons to accomplish the process of ageing without entering special accommodation for the elderly. The life expectancy for both men and women has increased by 10 years since the 1960s (NBHW, 2009), and it has been estimated that about 25 percent of the total Swedish population will be aged >65 years or older in the year of 2050 (SCB, 2009). Living into advanced age (at least 75 years), and thus

dying at an advanced age, means that many older persons will experience functional decline and dependency on others to accomplish the activities of daily living during their last years of life (Hallberg, 2006).

Since the beginning of the 1990s, the Swedish municipalities and county councils have been responsible for the provision and funding of care for the elderly. The Government and the Parliament legislate and formulate guidelines for care of the elderly, and determine who is to provide the various services involved. The general principles regarding care of the elderly are the same throughout the country and are primarily public sector tasks. There are also legislations requiring the care to be provided by trained and qualified staff (SOU, 2007:88). The Social Services Act (2001:453) is a framework law that emphasizes the right of the individual to receive municipal services. The Health and Medical Services Act (1982:763) emphasizes that a high standard of general healthcare has to be available to all members of society on equal terms (SOU, 2008:51). The consensus policy formed by the Swedish Government in 2008 also state that older persons should be able to live active and influential lives, and that they should be able to age in a protective environment that upholds their independence, where they are being treated with respect, and have access to good social and health care services (SOU, 2008:113; 2008:126).

Ageing-in-place

The Swedish ageing-in-place policy was formulated at the end of the 20th century as a partial solution to the problem that older persons were being forced to move between healthcare settings as their caring needs increased (NBHW, 2008; 2009). The primary objectives were to make the connections between basic and more advanced nursing care “seamless”, making aging at home possible, to increase the quality of life (QoL), and to focus on adaptable living environments that could meet the needs of more than a single stage of frailty (SOU, 2008:113; Crews, 2005; Schwarz & Brent, 1999), based on the assumption that majority of older people prefer to age in place and to stay in their own home, or at least continue to live in the community for as long as possible (Tang & Pickard, 2008). Home- and community-based services, such as home care, home health services, and home-delivered meals, have undergone extensive developments in recent years. However, when the caring need of the older person exceeds the scope of the services offered by the community, special housing for the elderly becomes a necessity (SOU, 2008:113; Tang & Pickard, 2008). The ageing-in-place policy, enabling the majority to stay in their own home, and thereby postpone institutionalization, is considered cost-effective, and results in those in

need of special housing being older and frailer, secondary to senescence, disease, and trauma (NBHW, 2007). Transfers between units within the residential care facilities, or intra-institutional relocations, based on changing caring needs, such as aggravated cognitive decline are however uncommon. Once the older person has settled in at a unit, any additional moves are avoided (SOU, 2008:51). It has been estimated that about 50 percent of those living in special housing for the elderly show significant cognitive impairment (NBHW, 2007), usually resulting in integrated populations with both cognitively intact and impaired older persons within the same unit (SBU, 2006). The priority given to older persons preferred location for ageing and death is an important quality indicator of end-of-life care (Tofle, 2009). However, older people still tend to be transferred to hospitals during the last week of their life (Hallberg, 2006).

Swedish residential care

Most facilities housing older persons in Sweden meet the international description of assisted living, emphasizing social model values that uphold choice, dignity, accessibility, security and the ability to age in place (NBHW, 2009). The basic premise of a socially based long-term care model is to combine personalized housing with nursing care (Schwarz & Brent, 1999). Compared to many other countries, the living standards in Swedish special housing for the elderly are high (SOU, 2008:113). Contemporary architectural design of residential care facilities bear the stamp of the ageing-in-place policy, by emphasizing the importance of small-scaled units and homelike environments in supporting the competencies and QoL for people as they age (Cutchin, 2005). About 95 percent of older people living in special housing have private rooms, large enough to allow a family member to stay overnight, and include a kitchenette, private telephone and full bathroom with shower (NBHW, 2008). According to the Swedish Government Official Reports (SOU, 2008:113) there are many denominations, both national and international, describing various forms of special housing for the elderly. For the purpose of this study, we will use the term residential care facility, which is a long-term care alternative that involves the delivery of professionally managed personal and healthcare services, in a group setting that is residential in character, and has the capacity to meet unscheduled needs for assistance (Regnier, 1999). In addition, there are Special Care Units (SCU), designed to meet the unique needs of older persons with dementia, usually situated within the larger residential care facility (Schwarz et al., 2004; Day & Calkins, 2002).

About 20 percent of those with a dementia diagnosis live in special care units in Sweden, housing on average 10 residents per unit. According to preliminary National Guidelines, outlining the general principles of high quality dementia care, the physical environment of Swedish dementia SCU's should be purpose-built, supportive, and small-scale. Offering private rooms or apartments, furnished with personal belongings, and shared spaces that support the residents' sense of belonging and community (NBHW, 2009). One of the most important requirements for high quality care is the educational level of the nursing staff. Between the years 2005 and 2007, 60 percent of all nursing staff in Sweden completed various forms of programs in order to meet the educational requirements needed to become a certified assistant nurse, at a total cost of about 100 million Euro (SOU, 2007:88). A recurring national survey on consumer satisfaction (NKI) and quality of care for the elderly in Sweden (NBHW, 2009), showed that the majority of older people living in residential care, as well as their relatives, were generally satisfied. However, areas that needed drastic improvements, according to this survey, were the quality of the food, the lack of meaningful daily activities, and unsatisfactory levels of information and involvement in individual care planning.

THEORETICAL FRAMEWORK

Frailty and the functional determinants of old age

When does old age begin, and what signifies its onset? Chronological age and retirement have traditionally been viewed as determinants of old age. These markers also form important forces in how old age is socially constructed, and personally experienced (Kite et al., 2005). However, to some extent chronological age has lost some of its relevance as a straightforward marker of old age (Lindenberger & Baltes, 1997). Research into different “ages” of old age is one of the new frontiers of gerontological research (Bortz, 2002). The “third” versus the “fourth” age are not directly tied to any specific age range. As phenotypic expressions (i.e. observable characteristics), the third and fourth ages are dynamic and differentiate between developed and developing countries. In developing countries, the fourth age begins and ends at younger chronological ages than in developed countries (Baltes & Smith, 2003).

Older persons in the third age are at the top of all age groups in emotional intelligence and wisdom, which represents the ideal combination of awareness and virtue (Baltes & Staudinger, 2000; Tester et al., 2004). In contrast to the fourth age, the third age is an active life period associated with good physical and mental health, as well as good potential for new learning and development (Baltes & Smith, 2003). Generally, the term old age conveys both positive and negative notions; however, in the context of residential care and institutional life, ageing is usually associated with significant functional and mental disabilities (Swartz & Brent, 1999). The transition into residential care is marked by the fact that the person can no longer look forward to recovery, but rather has to face the decline as an ongoing process (Janlöv et al., 2005).

Both conventional wisdom and research evidence suggests that older persons move into residential care primarily because they have to, secondary to weakness disease and trauma, and that it can be regarded as the final transitional step into the fourth age (Andrews & Phillips, 2005).

The fourth age usually implies loss of control and activity, which constitute important dimensions to the sense of self (Charmaz, 1983), and subsequently QoL (Knipscheer et al., 2000). It is characterized by frailty, chronic life strains, increased systemic breakdown, loss of social relations, and cognitive impairment (Baltes & Smith, 2003), accompanied by the transition from independence to dependence, which is a true challenge for the vast majority of older persons (Hallberg, 2006). Although there is no consensus definition of frailty, operational criteria for defining the concept should be based on physiological impairments such as those affecting mobility, balance, muscle strength, cognition, nutritional status, fatigue, and physical activity (Ferrucci et al., 2004). Frailty can also be defined as the intertwined and complex presentation of symptoms, functional impairments, diseases, possible drug side effects, and deterioration caused by a decline in physical activity, resulting from change of habit or disease inputs (Bortz, 2002; SBU, 2003), thereby increasing the risk of morbidity and suffering (Campbell & Buchner, 1997).

Dementia

One of the largest threats, and perhaps the best known indicator of frailty and substantial deterioration in health status in older people, is dementia (Baltes & Smith, 2003), which is a clinical syndrome that is caused by one or many underlying incurable pathologies (Weiner et al., 2009). It causes irreversible decline in global, intellectual, and physical functioning (Jeste et al., 2008), which affects all aspects of human life; both on a personal and a societal level (Smith et al., 2005). About 8 percent of those aged ≥ 65 years, and almost 50 percent of those aged ≥ 90 years have some form of dementia (NBHW, 2009; Weiner, 2009a) at a level of severity that requires continuous help and support, leading to such persons being overrepresented in residential care. Symptom clusters often overlap, thus presenting unique and individual clinical pictures (Weiner, 2009a; 2009b), closely correlated to the social and environmental context of the person (Kitwood, 1997; Weiner, 2009a; 2009b).

Central to the discourse of dementia is the relationship between being a person and awareness of existence. The assumption that cognition, memory, and rational thinking constitute selfhood, has its origins in the modern western philosophical tradition, separating the mind from body, and positions the former as superior to the latter (Davis, 2004). Explicit in the current definition of dementia is the assumption that memory impairment caused by cognitive deficiencies leads to a steady loss of selfhood (Kontos & Naglie, 2007) that “robs” people of their minds, and that those afflicted become mere “shadows” of

their former selves (McRae, 2010). With mounting empirical evidence that person-centered approaches to care enhance QoL, the key task in dementia care must be the maintenance of personhood (Kitwood, 1997). The person-centered approach in dementia care has its roots in the communicative and relational aspect of what it is to be a person (Brooker, 2004), that the self is fundamentally social in nature and that it is developed and maintained through social relations (Charmaz, 1983; 1995). Research shows that others play a crucial role in enabling persons living with dementia to construct and maintain identity. Whether or not a positive sense of self is retained is dependent not on the impact of the disease itself so much as on the response of others (McRae, 2010). Central to this perspective is that being a person is to live in a world where meanings are shared, that self-identity persists despite the presence and progression of cognitive impairment, and that the body is communicative and, as such, essential in the expression of selfhood (Kontos & Naglie, 2007).

Person-centeredness

Person-centred care is increasingly regarded as being synonymous with best quality care that upholds holistic human values and promotes wellbeing, with few reported risks (Edvardsson et al., 2008; McCormack, 2004). Without a consensus definition, most researchers seem to agree that it is a multi-dimensional concept describing care that includes people's subjective experience of illness, and permits frail older persons to be involved in decisions made about practice (Price 2006). A person-centred psychosocial environment requires the formation of therapeutic relationships between professionals, residents, and their significant others, and that these relationships be built on mutual trust, dignity, understanding, and sharing of human experiences (McCormack & McCance, 2006). The physical environment can either enhance or limit these therapeutic relationships in terms of design, ambience, and spatial layout (McCormack 2004).

A person-centered care setting is imbued with an "atmosphere of ease" (Edvardsson et al, 2005; 2008) and can be described as one in which decision-making is shared, staff relationships are collaborative, leadership is transformational and innovative practices are supported (McCormack & McCance, 2006). Feelings of wellbeing are an important outcome of person-centred care, engendered by a positive care experience, making the older person feel valued (McCance, 2003). For the purpose of this study, wellbeing is defined in terms of high levels of happiness, positive emotions, and satisfaction, and low levels of negative emotions (Berg, 2008).

QoL and the Ecological Model of Aging

Within the context of residential care and frail older persons, the concepts of QoL and health related quality of life (HRQoL) become equal, depending on the assumption that “*when a patient is ill or diseased, almost all aspects of life become health-related*” (Gabriel & Bowling, 2004). QoL in dementia comprises the same areas as in people in general (Lawton, 1994). Maintaining a high QoL in the face of frailty has long been a challenge, moving beyond meeting the medical or cognitive health needs to include multiple aspects of the fit between person and environment (Morgan, 2009a). Central to perception of QoL in frail older persons in residential care is the transaction between the psychological, social, and physical environment (Findlay & McLaughlin, 2005). Studies have shown that older people spend a lot of time within the boundaries of the residential care facility, and it is because of this the environment takes on greater significance and becomes the spatial focus of the older person’s life (Oswald et al., 2005). As such, the person-environment system of the individual is likely to be particularly important to frail older people as many depend on the environment to compensate for reduced physical and mental capacities (Parker et al., 2004).

Environmental aspects of QoL focus on design, such as windows with a view; acoustics to facilitate reflection, spiritual meditation, and intimate discussion, close links to nature and personal control that relate to privacy and independence, sensory stimulation, and connections with family and friends (Tofle, 2009). The environmental influence on QoL is evident in that environments affect individual’s wellbeing, and people select and affect their physical environments (Lawton, 1985; 1990). Frailty exists in an integrative continuum (Charmaz, 1995), making it difficult to determine when the older person is no longer able to exercise introspection and reliably report on internal states and phenomena (Lawton, 1994). Using a holistic perspective, QoL in frail older persons can be defined as a multi-dimensional evaluation of the person-environment system of the individual, using both intrapersonal and socio-normative criteria (Lawton, 1997).

Based on the principles of embodied selfhood, emphasizing a corporeal form of communicating and expressing subjective meaning (Kontos & Naglie, 2007), as well as human intentionality (Weisman & Moore, 2003), it encompasses both a subjective and an objective realm. This is based on the assumption that the individual’s subjective evaluation of each domain in life and psychological wellbeing is reflected in observable behavior and is an indicator of mental health (Lawton, 1997; 1994). This definition of QoL consists of four overlapping sectors, representing directly measurable factors – specifically “objective

environment” and “behavioral competence” – and two more holistic and integrative constructs – “psychological wellbeing” and “perceived QoL”, which “together include every aspect of behavior, environment, and experience” (Lawton, 1983:349; Weisman & Moore, 2003). Centrally situated within the model is the self, which is a dynamic process of interaction between the individual and the environment, and the most holistic and integrative of all psychological constructs (Lawton, 1997). This definition allows for discrete aspects of QoL to be defined and operationalized, while still incorporating the holistic concept of self-identity (Weisman & Moore, 2003). It also allows for each sector to be evaluated positively or negatively, building on the assumption the individuals would rather have positive than negative experiences in their lives (Weisman et al., 2000). Since the evaluation of QoL might be based on observation of behavioral competence and apparent emotional states, this definition can be useful, regardless of level of impairment (Ready & Ott, 2003).

Preserving an acceptable degree of autonomy is a primary theme of identity in old age (Parmelee & Lawton, 1990). The Ecological Model of Ageing (Lawton & Nahemow, 1973) explores the interplay between individuals and their environments. Central to this model is adaption, which can be defined as a mechanism for acquainting us with changes in the environment suggesting that human behavior and function result from the competencies of the individual, the demands of the environment, and the interaction or adaptation of the person to the environment (Wijk, 2001; Lawton, 1990). It indicates that the more vulnerable people are with failing health, and low competence, the more impact, or “stress” the environment has on them (Tofle, 2009).

In addition, the relationship is viewed as a dynamic process, where both environmental demands and level of individual competence change as part of the process of aging (Nahemow, 2000). If the environmental demands remain constant, individual behavior and function are adversely affected (Lawton, 1994), since the stress of the environment exceeds the individual’s ability to meet the demands (Verbrugge & Jette, 1994). Within the context of QoL, such an environment undermines the person’s sense of control, freedom, and subsequently their sense of self (Lawton, 1990). To compensate for reduced competences, thus improving QoL, functional accommodations in the environment with functional prosthetic equipment and design solutions can be made (Tofle, 2009), which enhance a person’s ability to make use of environmental resources and achieve a more positive outcome (Weisman & Moore, 2003; Findlay & McLaughlin, 2005). Central to QoL, successful ageing, and environmental fit is adaptation (Ettema et al. 2005a; 2005b), which in the context of frail older persons means altering life and self to accommodate to physical losses, and to struggle with illness and impairment rather than against it (Charmaz, 1995).

The balance between personal competencies and environmental demands has been called adaptation level (AL), and frail older persons require more time to reach their AL due to limited resources (Nahemow, 2000). By learning to apply choice and self-direction in the everyday use of the environment, frail older persons with any level of impairment can actively affect their overall QoL (Lawton, 1990).

Space and attributes of connectedness

One way to further extend nursing inquiry is to elaborate on the environment by using a more segmented and divided approach (Andrews et al. 2007; Andrews & Shaw, 2008). There are numerous conceptual models that offer a wide array of definitions and insights into the many spatial aspects of nursing and the environmental patterns that promote harmony within the individual (Andrews & Moon, 2005a; 2005b; Kolanowski, 1992). Geographical studies in nursing refocus on the meta-concept of environment in order to gain understanding about how nursing relates dynamically to space and place (Andrews & Shaw, 2008), and how human experiences, behavior, and activity in relation to health and wellbeing might influence and represent space and place (Andrews & Phillips, 2005). Central to most definitions of the concepts of place and space in the literature is that the investigation of place cannot be pursued alone but only in conjunction with the notion of space (Malpas, 1999). On the individual level, place is the space to which a person has assigned meaning through personal, group, or cultural processes (Low & Altman, 1992). Place has been defined as a space for a particular purpose; space as meaning position in society; and a symbolic and cultural construction (Zweig & Oliver, 2009; Andrew & Phillips, 2005).

The symbolic objects in the place have a profound impact on people's sense of self, of who they are, and feel able to be (Edvardsson, 2008; Peace et al. 2005). Places contain social qualities, and are contexts in which interpersonal, and cultural relationships occur, with regard to their particular purposes (Andrews & Shaw, 2008; Wiles et al., 2009). It is to those social and contextual relationships, not just to "*place qua place*", to which people are attached (Low & Altman, 1992:7).

The institution and the home space

Although residential care facilities usually have the aesthetic appearance of a home, the structural features of an institution are present and cannot be avoided (Dobbs, 2004). Its spatial dimensions employ both the private and the public discourse in terms of private rooms and shared spaces (Twiggy, 1999). The structural features of an institution include conducting all aspects of life in the same place under a single authority, having daily activities personally witnessed by others, following rules and schedules and having all activities brought together into a single rational plan, designed to satisfy official aims of the institution (Goffman, 1961:6). The residential care facility carries several meanings. One is that it is a space defined by social interactions related to community healthcare for those unable to provide for themselves. The dialectic relation between the formal rules and norms imposed by the institution, and the informal values and norms of the older persons home, makes it a complex and unique care site (Ward-Griffin & McKeever, 2000; Dyck et al., 2007; Angus et al., 2005).

Several studies have been engaged with institutional power-dynamics and with how nurses possess the potential to create positive counter-institutional environments (Andrews & Shaw, 2008), as well as the ways in which spatial strategies sustain the formality and function of the institution (Goffman, 1961). Human life is essentially a life of location, the development of self-identity is related to place (Malpas, 1999), and human thoughts and experiences are grounded in corporeal and concrete places (Massey, 1994). One of the strongest formative and emotive influences of place on identity is the home (Kontos, 2005). In addition, the home is also a place of self-expression and status (Tanner et al., 2008). It has been proposed that it is the relationship between a person and their dwelling that defines the essence of what “home” is, and that it can be defined as a place where people can achieve their privacy goals through personal space (Rowles, 2006), characterized by security, control, being at ease and feeling relaxed (Dyck et al., 2005).

The home-place serves as a crucial material and symbolic source of biographical development (Kontos, 2005), and a way of keeping the past alive by maintaining a sense of continuity (Rubenstein & Parmelee, 1992). The construction of home as a memory, typically consists of the concrete geographic residence shaped by function, culture, history, and the abstract meaning encompassing social relationships with significant others (Dobbs, 2004). Peoples’ memories of their former homes and their history affect their current experiences of, and meaning they give to, home (Dovey, 1985).

The desire of older persons to remain at home while they age, however, is not solely related to task and function, and has much to do with subjective feelings about what home means to them (Tanner et al., 2008).

Place attachment

A sense of attachment to place is a prerequisite to feel “at home” (Morgan, 2009b; Wiles et al., 2009). There is general agreement in the literature that there is a reciprocal relationship between the wellbeing of older persons and the place and space in which they dwell, most obviously manifested through a strong sense of attachment (Wiles et al., 2009; Rubinstein & Parmelee, 1992). Those with strong attachment are those most likely to adjust successfully to the contingencies of ageing (Andrews & Philips, 2005; Golant, 1984). Place attachment is an integrating concept comprising interrelated and inseparable aspects that contributes to individual, group, and cultural self-determination (Altman & Low, 1992). It can be defined as a set of feelings about geographical location that emotionally binds a person to place as a function of its role as a setting for experience (Rubinstein & Parmelee, 1992:139).

Attachment to places or things is an affective relationship between persons and environment that goes beyond cognition, preference, and judgment (Belk, 1992). Possessions with sentimental value contribute in making unknown surroundings familiar (Rowles, 2006), and serve as symbols of personal identity describing what is important to the person (Tofle, 2009). Place attachment is especially significant to older people for several reasons, such as keeping the past alive, maintaining a sense of continuity, fostering identity, and protecting the self against age-related changes such as functional decline and deterioration (Rubinstein & Parmelee, 1992). However, for older people who enter residential care, the last remnant of home is their private room with a few personal belongings (Williams & Warren, 2009). Routines and rituals are important aspects of the home-space, and one way to achieve attachment in residential care is to create a place that mimics the idea of one’s old home, and subsequently parts of one’s old self-identity (Lawton, 1985; Wiles et al., 2009; Reed & Royskell-Payton, 1997).

The length of time lived in a certain setting is also an important aspect of place attachment. The longer the person stays in a particular place, the stronger the connectedness to, and richer the meanings of, that place will become (Dobbs, 2004). Significance of place attachment is established through time and activities within the space (Rubinstein & Parmelee, 1992), and the actual process of

developing place attachment can be described as an accumulation of layer upon layer of personal experiences and social interaction (Dobbs, 2004).

Supportive environments for older persons

Major considerations in the design of environments for older persons are based on changing the environment to accommodate their impaired visual, auditory and kinesthetic senses, thereby enhancing their declining powers and improving their autonomy, independence, and self-perceptions of wellbeing (Crews, 2005). The goal is to provide an environment that supports and gives the older person a sense of control and choice (Stern & Carstensen, 2000). Central to the “supportiveness” of the environment is the Ecological Model of Ageing (Lawton & Nahemow, 1973) and person-environment fit, i.e. that a person’s function and abilities are congruent with the environmental demands (Kahana et al. 2003). According to Cutler (2000) an accommodating environment for frail older persons is defined as supportive by providing a substitute for loss of function, accessible by being adjusted for the use of mobility aids, adaptable by accommodating to changing conditions and secure by being protective but not restrictive (Morgan, 2009a). Area and relationship of indoor and outdoor space, materials, acoustics, lighting, legibility, and variability have been shown to be important dimensions in environmental designs for older people (Malkin, 1991). Apart from being congruent with older persons abilities, the physical environment also needs to provide its inhabitants with a sense of independence (Schwarz & Brent, 1999), and buildings that are connected to the wider community in their location and provision for visitors are associated with increased levels of activity (Parker et al., 2004).

According to a literature review by Dijkstra et al., (2006), research studies that manipulate several environmental stimuli simultaneously clearly support the general notion that the physical health care environment affects the wellbeing of patients. However, conclusive evidence is limited when the effects of specific environmental stimuli are scrutinized. To date, most design considerations have been directed towards improving environments for those affected with dementia (Crews, 2005). Way-finding cues, symbols, and proper lighting, enhance visibility, support orientation, and reduce wandering behavior and falls amongst older people with dementia (Ulrich, 1992; Day et al., 2000). Supportive environments for older persons with dementia should be small-scale with a non-institutional character, have moderate levels of environmental stimulation, higher light levels and exposure to bright light, and the possibility of concealing

door handles to reduce unwanted exiting (Lawton, 2001; Day et al., 2000). Adequate sensory input helps to maintain orientation in time and space, while overwhelming input of too novel or too numerous stimuli increases confusion and impairs self-control in persons with dementia (Weiner, 2009b). In addition, a conscious color design may enhance the spatial demarcation of the room, increase the sense of familiarity and orientation in shared spaces, which subsequently reinforces the older person's sense of independence and autonomy (Wijk et al., 2002; 2001).

For frail older persons, an environment that is characterized by conformity is likely to lead to negative outcomes, such as withdrawal and agitation (Moore, 2005), but the use of non-institutional design features, such as personalized rooms, domestic furnishings, and natural elements is generally associated with improved wellbeing (Marsden, 1999). A home-like environment has been shown to increase feelings of wellbeing and security (Cohen-Mansfield & Werner, 1990), as well as to decrease symptoms of anxiety and agitation (Zeisel et al., 2003) among persons with dementia. A supportive psychosocial environment comprises three dimensions; a climate of safety, a climate of everydayness, and a climate of hospitality (Edvardsson et al. 2008).

Paradoxically, research has also shown that a homely atmosphere does not necessarily imply a non-institutional ambience in shared spaces and that the sense of home in residential care could benefit from a sharpening of the distinction between the private and the public (Hauge & Heggen, 2007). Stringent health and safety requirements in the environment have been shown to negatively affect the QoL of those less dependent older persons living in residential care (Parker, 2004). When thinking about the residential care setting in terms of it being someone's home it becomes evident that all aspects of the environment (i.e. physical, cultural, and psychosocial) need to be addressed with the resident in mind in order to influence the supportiveness of the atmosphere (Andrews et al. 2005). The atmosphere becomes enabling and empowering when older persons experience attachment or the fulfilment of connectedness (Tofle, 2009).

Relocation

Perhaps the most difficult relocation is the movement from one's own home to a residential care facility. Some residents have described life in residential care as acceptable, whilst others describe it as both dehumanizing and constraining (Nay, 1995; Fiveash, 1998). The ability to recognize legitimate reasons for

moving into residential care, as well as playing an active role in the decision-making surrounding the move, have been shown to be important in the process of adjustment to residential life in older people (Marshall & Mackenzie, 2008; Anderson et al., 2007). The transfer of older persons from one care setting to another has been a consistent concern of researchers and practitioners for decades (Burnette, 1986; Castle, 2001; Thorson & Davis, 2000).

Inter-institutional relocation is the movement from one institution to another (Borup, 1982), for example, transfers to and from hospitals, psychiatric facilities, and residential care facilities (Castle, 2001). A literature review on relocation, with the emphasis on older people moving between institutions, revealed that the single most investigated outcome is post-relocation mortality rates (Castle, 2001). However, results from studies included in this review show large discrepancies, which raises the question whether adverse relocation effects might be determined by the nature, rather than the act itself (Lander et al. 1997). Reported mortality varies from no change in mortality post-relocation (Borup et al. 1980; Borup, 1983), to a 50 percent increase in mortality within the first three months following transfer (Laughlin et al. 2007).

“Relocation stress syndrome” is a clinical judgment about individual physiological and/or psychosocial disturbances following transfer from one environment to another (NANDA, 2006), characterized by anxiety, agitation, confusion, depression, and deteriorating social and self-care behaviors (Thorson & Davis 2000; Lander et al., 1997; Farhall et al., 2007). Those frail older persons with dementia are most likely to succumb to the stress of relocation, and the use of antipsychotics tends to increase during relocations (Hagen et al., 2005). Farhall et al., (2007) concluded that adverse relocation effects could be minimized by careful preparation and planning several months prior to moving day, and that early involvement in the relocation process gave patients a greater sense of control (Laughlin, 2005). Preparatory programs focusing on anxiety and stress reduction, such as anticipatory guidance, coping enhancement, animal assisted therapy, and security enrichment (NANDA, 2006), have shown to be associated with less stressful relocations (Laughlin et al., 2007; Laughlin, 2005; Castle, 2001; Keister, 2006). The more options old persons are given to choose among, the less negative are the effects of relocation (Bekhet et al. 2008; Thorson and Davis, 2000).

RATIONALE

QoL is an important outcome measure in dementia care. Because dementia consists of a unique set of symptoms, QoL instruments specific to dementia are needed. In addition, there are some unique methodological problems concerning reliance on subjective ratings, especially in the more severe degrees of the disease. Proxy ratings are widely regarded as a potential solution to this problem. However, in order to avoid proxy bias, it is important that the QoL measure includes ratings of observable behavior and expression. Despite a growing demand of such a measure, there are no QoL measures specific to dementia in Sweden.

There is a need for further research into how a homely atmosphere can be created in institutional contexts, such as residential care facilities, in order to avoid the over-simplification in which, for example, a physical environment with an aesthetic appearance of a home becomes the general standard for good residential care. In addition, there is a need to further understand how alterations in the physical environment, in terms of refurbishment in residential care facilities, affect those frail older persons residing there.

No one knows exactly how many frail older persons are inter-institutionally relocated each year in Sweden, and there is a lack of knowledge about how these relocations affect both residents and nursing staff (SBU, 2006). Because of the government upgrading of residential care facilities in Sweden, frail older people may find themselves forced to live in provisional transit facilities during the renovation period. Existing findings suggest that preparatory programs are important for successful relocation, but to our knowledge there is no routine in Sweden for systematically preparing those forced to relocate in order to minimize adverse relocation effects. This is a seemingly surprising disclosure since preparatory and informational interventions, directed to patients and their relatives, are central to all nursing practices. Frail older persons in residential care are a vulnerable group with diminished rights, and there is an urgent need to design health and social policies that advocate the voice of the older person.

The importance of a supportive home environment to improve quality of life in old age is well established in the literature. However, it should be acknowledged that a home is much more than a physical environment and that creating a homely atmosphere require effort. In order to facilitate such an atmosphere in residential care, the processes involved and the strategies by which older people succeed in creating attachment to place need further exploration.

PURPOSE

The overall aim of this study was to achieve a comprehensive understanding of how environmental changes affect the older person's perception of QoL, wellbeing, and care atmosphere, and how they create attachment and self-identity in residential care facilities. It comprises four papers with the following specific aims:

- I. To evaluate the validity, reliability, and responsiveness of a Swedish translation of the QoL in Late-Stage Dementia (QUALID) scale.
- II. To examine the effects of a refurbishment in two Swedish residential care facilities on residents' QoL, wellbeing, and perceived care climate, and to describe their experiences of the refurbishment in terms of environmental change.
- III. To examine the effects of an inter-institutional relocation on residents' QoL, wellbeing, and perceived care climate, and to explore the experience of relocation from the perspective of older persons.
- IV. To construct an understanding of the processes involved, and the strategies by which older persons create attachment and self-identity in residential care.

METHODS

Design and epistemological considerations

Within a transactive perspective, people and their environments are integrated and mutually defining, and knowledge sought from this viewpoint generally comprises subjective accounts of personal experience, meaning, and action (Creswell, 2009; Altman & Low, 1992). This study combines qualitative and quantitative methods that allows person and environment to be assessed both separately and transactionally (Parmelee & Lawton, 1990), using a pragmatic criterion for method acceptance, i.e. practicality, contextual responsiveness, and consequentiality (Greene & Caracelli, 2003). A pragmatic criterion for method acceptance also includes the implicit desire to modify and to influence practice (Johnstone, 2004), which makes it appealing for nursing researchers closely aligned to the complex and multifaceted life experiences of older persons in residential care. The research designs used in this study are presented in Table 1. The pragmatic ethos comprises the notion that human beings are genuinely communicative and active participants in the creation of meaning, which also includes the researcher who is part of the world he or she explores, and is thereby part of its history and future (Cherryholmes, 1988).

Society, self-identity, as well as our understanding of reality, are constructed through interaction that is dynamic and interpretative, thus relying on language and consequences. Pragmatism is a practical and applied research philosophy that embraces the use of various epistemological conceptions such as inductive or deductive reasoning being more than hallmarks of qualitative or quantitative strategies of inquiry (Morse, 2003; Creswell, 2009; Tashakkori & Teddlie, 2003). In the same way extant theoretical perspectives might sensitize the analysis, personal experience and pre-conceptions influence what we pay attention to and how we make sense of it, and in order to learn about the research participants' meanings we need to be reflexive about our own (Charmaz, 2004; 2006).

Research and its results depend on the time, place, and the pre-understanding of the researcher (Mruck & Mey, 2007). A reflexive stance informs “how the researcher conducts his or her research, relate to research participants, and how their voices are represented in written reports” (Charmaz, 2006:189). Reflexivity can be understood as a chance for researchers to rethink, ground, or justify their own decisions and to communicate the reflexive process of theory development (Mruck & Mey, 2007). Looking back on my own experiences, I acknowledge my background as a registered nurse, working with frail older persons in residential care, and as a graduate student, showing special interest to the human-environment relationship within institutional care.

Table 1. Research designs used in this study

	n	Design	Strategy	Data collection	Analysis
I	169	Quantitative	Psychometric testing	• Instrument	• Statistical
II	131	Mixed Method	Sequential QUAN → qual	• Instrument • Structured interview	• Statistical • Manifest content analysis
III	155	Mixed Method	Concurrent QUAN + qual	• Instrument • Semi-structured interview	• Statistical • Latent content analysis
IV	25	Qualitative	Grounded Theory	• Unstructured interview	• Constant comparative

Mixing Methods

The personal, existential, cultural, and political issues involved in the process of ageing, as well as its plural and enigmatic meanings, challenge single-methods attempts to understand the phenomenon (Andrews & Halcomb, 2009; Kontos, 2005). According to a pragmatic paradigm it can be presumed that the best method, or mix of methods, to use is the one that provides the most elaborate and refined answer to one’s research question (Lipscomb, 2008; Tashakkori & Teddlie, 2003). Traditionally quantitative and qualitative research have been thought of as incompatible, representing two distinct research paradigms, drawing on different bodies of thought, using different methods of data collection (Maxcy, 2003). However, there is a difference between choosing

methods and operating within paradigms (Morgan, 1998), and often the distinction between qualitative and quantitative research is outlined in terms of method of data collection and not in terms of epistemological underpinnings (Creswell, 2009).

The exploratory nature of nursing research, the complexities of the phenomena being studied, and the limitations within methods mean that there are occasions when a phenomenon cannot be described in its entirety using one single method (Morse & Niehaus, 2007). Combining qualitative and quantitative methods maximizes the ability to bring different strengths together in the same research project (Morgan, 1998), i.e. the exploration of the meaning ascribed to a social or human problem, and the examination of the relationship between variables (Johnson & Turner, 2007). Instead of focusing on the methods, i.e. qualitative or quantitative, mixed method researchers emphasize the research problem or question in terms of induction or deduction, combining methods originating from different scientific paradigms and integrating these data at some stage in the research process (Tashakkori & Teddlie, 2003).

In **Paper I**, we used a cross-sectional design to evaluate the psychometric properties of a Swedish version of the Quality of Life in Late-Stage Dementia (QUALID) scale. Despite a seemingly positivist quest for valid instruments, the pragmatist view sees “universalism” (i.e. objectivity) as agreements across a large number of communities of practices and cultures, a powerful scope and scale consensus, not an *a priori* analytical reality (Star, 2007).

The sequential explanatory design used in **Paper II** is characterized by the collection and analysis of quantitative data, followed by the collection and analysis of the qualitative data (Creswell, 2009; Johnson & Turner, 2007). The core component is quantitative, which makes the theoretical drive in this paper primarily deductive. In the supplemental component, a structured interview format was used and the analysis focused on the manifest content, i.e. the visible and obvious statements in the text (Graneheim & Lundman, 2004), thus adhering to the theoretical drive of the paper. The quantitative and the qualitative findings were integrated at the interpretation phase of the study.

In **Paper III**, we used a concurrent embedded strategy, identified by its use of one data collection phase, during which both quantitative and qualitative data are collected (Creswell, 2009). As in Paper II, this strategy has a quantitative core component that guides the project and a supplemental qualitative method that addresses other questions than the primary method. In Paper III, we used semi-structured interviews to explore the experience of relocation, whereas the quantitative data addressed the expected outcomes. The concurrent design and semi-structured interview format enabled a more inductive approach, using

latent content analysis focusing on the meaning of relocation as described by the participants. A concurrent embedded strategy, as well as the sequential explanatory design, was used to gain broader perspectives and to allow the qualitative findings to enable a deeper exploration of the quantitative findings. The quantitative and the qualitative findings were integrated at the interpretation phase of the study.

In order to gain an understanding of the various ways in which older persons create attachment in residential care, and to discover a plausible variety of real-life contingencies that affect this creation process, **Paper IV** used a grounded theory method (GTM) to construct concepts that accounted for relationships defined in the data (Dey, 2007).

Settings and Participants

In **Paper I**, all residential care facilities with dementia SCU, situated within the central part of a relatively large city in Sweden (i.e. with 500 000 inhabitants) participated in this study. In total, 209 residents, living in nineteen different dementia SCU, in eight residential care facilities (Facilities A-H) were included in the study. Each unit housed on average 11 residents. Relatives of the residents were sent a letter of consent, informing them about the study, requesting their approval for their relative's participation. No other exclusion criteria than declining to participate were applied. Six relatives declined to participate on behalf of the residents, nine residents died before data collection commenced, and one unit with 25 residents was excluded due to re-organizational issues. Thus, 169 older persons with dementia participated in this study at baseline, using proxy informants.

The intervention group studied in **Paper II** consisted of all 64 residents living at two residential care facilities undergoing surface refurbishment (Facilities I and J), one in the central part and one on the outskirts of a relatively large city in Sweden (i.e. with 500 000 inhabitants). Both facilities were originally built in the 1980s, and the refurbishment was part of the municipal upgrading of facilities housing frail older persons. Private rooms were excluded from the refurbishment, enabling residents to remain in situ. The reference group consisted of all 169 residents at one residential care facility that remained unchanged, (Facility K) and situated in the central part of the city. In order to match the intervention and the reference groups regarding morbidity, all residents with psychiatric diagnoses residing in the reference facility were excluded at baseline (i.e. schizophrenia, bipolar disorder, front temporal

dementia), leaving 139 residents from the reference group for inclusion in the study. All residents participating in the study gave their written informed consent, either by themselves or through a member of their family. No other exclusion criteria than declining to participate were applied. In the intervention group 14 residents declined participation. In the reference group, 22 declined participation and nine died before data collection commenced. Thus, 131 frail older persons participated in this study at baseline.

The intervention group studied in **Paper III** consisted of temporarily relocated residents from two facilities, all 50 residents at Facility G, and all 51 residents in two out of four units at Facility L. Both facilities were located in the central part of the city, and were originally built in the 1970s. The structural rebuilding was part of the municipal upgrading of facilities housing frail older persons. In this study, the private rooms were also subject to renovation, which required a relocation of both nursing staff and residents. The reference group used in Paper II was also used in this study for comparison. All residents participating in the study gave their written informed consent, either by themselves or through a member of their family. No other exclusion criteria than declining to participate were applied. Two residents declined participation in the intervention group, seven died before data collection commenced, and 18 moved to other residential care facilities within the municipality. Thus, 155 older persons participated in this study at baseline.

Paper IV draws on initial data from Paper III. Six out of twelve residents interviewed in Paper III, were interviewed on several occasions, resulting in 14 interviews. When analyzing these interviews, it became apparent that much of the experiences of the relocation related to general aspects of life in institutional care, such as relationships with other residents and nursing staff. The interviewees also described their inability to cope with new life circumstances, their unwillingness to conform, the feeling of homelessness, and their reorientation or maintenance of self-identity. These initial interviews opened the door to a range of questions related to the meanings ascribed to residential care, as well as to the strategies and processes involved when residential care becomes a reality in an older person's life. The following sample was purposive and convenient. Four residential care facilities also included in Paper I and II were asked to participate in this study (Facilities A, E, K and I).

Residents in these facilities, willing to share their experiences about living in residential care and without communication difficulties, were identified by the nursing staff. All residents who were invited to participate in the study gave their informed consent. Altogether, the analysis is based on interviews with 25 respondents, some of them being interviewed twice.

Instruments

The Mini Mental State Examination (MMSE)

The MMSE (Folstein et al. 1975) is a standardized test that concentrates on the cognitive aspects of mental functioning and provides information about the level of impairment on orientation in time, place and person, spatial function and short-term memory. It consists of 11 items, and ranges from zero to 30 points, where zero indicates severe impairment, and 30 no impairment. It is administered in an interview format, and the average time for completion is five to ten minutes.

The General Behavior Assessment (GBAS) Scale and the Patient Mood Assessment (PMAS) Scale

The patient mood assessment scale (PMAS) and the general behavior assessment scale (GBAS) are two proxy, informant-based instruments, providing information on general wellbeing through assessment of both positive and negative dimensions of mood and behavior in a general elderly population (Edberg, 2000). The PMAS comprises three domains (strength, satisfaction, and security) and the GBAS two domains (confidence and accessibility). According to Edberg (2000), the scales have good overall internal consistency, with a reported Cronbach alpha coefficient of 0.85 for the PMAS, and 0.70 for the GBAS.

The Person-centered Care Questionnaire (PCQ)

The person-centered climate questionnaire (PCQ) is a 17-item self-report assessment scale originally developed to provide information about the extent to which the climate of acute to sub-acute hospital care settings is experienced as being person-centered; that is supporting the patient as a person and placing their needs and expectations at the centre of the care (Edvardsson et al. 2008; Edvardsson et al. 2009). It encompasses three domains (e.g. safety, everydayness, and hospitality), regarded as important for patients' wellbeing and recovery. According to Edvardsson et al. (2008) the scale has good overall internal consistency, with a Cronbach alpha coefficient ranging from 0.64 (hospitality) to 0.94 (safety).

The Quality of Life in Late- Stage Dementia (QUALID) Scale

The QUALID is a domain-specific, brief, proxy-based instrument with a one-week recall period. It is designed for use specifically with patients with late-stage dementia in institutional settings. The original English version of the instrument has demonstrated good internal consistency and adequate construct validity (Weiner et al. 2000), as well as sensitivity to change (Martin-Cook et al. 2005). The scale consists of 11 items, comprising both positive and negative dimensions of concrete and observable mood and performance, thought to be indicative of QoL (QoL) in late-stage dementia. The items are rated as to frequencies of occurrence on a five-step scale, and scores are summed to range from 11 (best QoL) to 55 (worst QoL). The instrument is administered in a structured interview format and the average time for administration is five minutes. The proxy informants need to be well acquainted with the person with dementia, and to have spent a significant amount of time with the person during the week before the QUALID assessment.

Procedure

In **Paper I**, the data collection lasted from March to August 2006. After obtaining permission from the original authors, a cyclic process of forward translations, back translations, and evaluation of translation correspondence by a bilingual expert was conducted to achieve conceptual equivalence between the original English version and the Swedish translation of the QUALID. The care provided in all dementia SCU included in the study was organized in such a way that each resident was assigned his/her own contact person (assigned healthcare provider with extensive knowledge about the resident). These contact persons provided proxy assessments of QoL, and to minimize any assessment inconsistencies, the same informant was used at both baseline and follow-up. Assessing 40 patients twice by the same informants allowed test-retest reliability to be examined. The time between these assessments was three weeks. Inter-rater reliability was investigated in a subset of 26 patients who were assessed by two different informants on the same occasion.

In **Paper II**, data were collected between February and August 2007. Baseline data were gathered one month prior to the refurbishment and follow-up data two months after its completion. In **Paper III**, data were collected between March 2008 and October 2009. Baseline data were collected one month prior to

the relocation, and follow-up data six months post relocation. Information about residents' age, psychotropic drug treatment and dementia diagnosis was gathered from medical records. In Paper II, a comprehensive assessment of visual, communicational, and mobile abilities (including the use of walking aids), provided information about how reliant the resident was in terms of utilization of the shared spaces in the residential care facility.

An initial assessment of the participants, using the MMSE, divided the residents into one of two groups according to cognitive functioning (Nirenberg, 1983), dichotomized as ≤ 20 points (low-functioning group) and ≥ 21 points (high-functioning group). In the intervention group in Paper II, 27 residents were low-functioning and 23 high functioning. In the relocation group in Paper III, 62 residents were low-functioning and 12 high functioning. The same reference group was used in both studies, showing 55 low functioning and 26 high functioning residents. Data from the reference group were gathered over the same period of time (7 months between baseline and follow up). The high-functioning groups provided self-report assessments using the PCQ in a face-to-face interview format. The low-functioning groups were assessed by their contact person (assigned healthcare provider with extensive knowledge about the resident) using the QUALID. In order to obtain a joint assessment of both groups on general behavior and mood, all residents were assessed by their contact person, using the PMAS and the GBAS. To minimize any assessment inconsistencies, the same informants were provided proxy reports at both baseline and follow-up.

Thus, in order to provide additional information to address the research question and to obtain an enhanced description of our quantitative findings, in Paper II, all eligible residents in the intervention group, i.e. high functioning group, were asked to answer three questions about the refurbishment at follow-up: *"Have you noticed any changes?" "Have these changes affected you in any possible way?" "What is your personal opinion about this refurbishment?"* Some residents denied participating in an interview, and some reported they had not noticed any refurbishment, leaving 12 residents who participated in a structured interview, conducted in the private rooms of the residents. In Paper III, all residents in the high-functioning group (n=12) were asked to spontaneously describe their experiences of the inter-institutional relocation 10 to 12 weeks post relocation. The opening question in each interview was: *"Can you tell me about the relocation?"* Interviews lasted on average for 30 minutes, and were conducted in a secluded area of the facility, usually the private room of the residents. In order to minimize the difference between the oral and written discourse, the interviews were recorded digitally and transcribed verbatim by the first author (Kvale & Brinkman, 2009).

In **Paper IV**, data were gathered using face-to-face interviews aimed at illuminating experiences of residential life, the actions and strategies used to create a sense of home and feeling of comfort, but also how frailty and dependence, and institutional life could affect self-identity. The opening question in each interview was “Can you tell me what it is like to live in residential care facilities?” Based on the reply to this question, follow-up questions were asked that further explored the person’s experiences. All interviews took place in the respondents’ private rooms at the residential care facility and lasted between 20 and 80 minutes. The interviews were digitally recorded and transcribed verbatim. Consistent with the emergent character of the grounded theory method used in this study the analysis evolved as data were collected and interpreted. Saturation of data was claimed when new data no longer revealed new properties concerning the core theoretical categories, and the constructed model conceptualized and provided an understanding of the processes involved and the strategies by which older people create attachment and reconstruct self-identity in residential care.

Methods of analysis

Statistical analyses

The SPSS statistical software version 15.0 was used in all data analyses. Missing items were extrapolated as the mean of the completed items, using a half scale-criterion. If the half-scale criterion was not reached, the total scale score was set to be missing and excluded from analysis. Descriptive statistics were used to characterize the sample. Frequencies and percent were calculated for categorical variables, and means and standard deviations were used for continuous variables. Statistical significance was set at .05 (two-tailed) for all analyses. Parametric statistical analyses were used throughout the study.

In **Paper I**, QUALID score distribution was examined regarding skewness, kurtosis, proportions of respondents scoring at maximum (ceiling) or minimum (floor) levels and the extent to which the full range of possible scores was used. Internal consistency reliability and of the 11 items were examined by the Cronbach alpha coefficient and the unidimensionality with principal components analysis. Item-scale correlations, corrected for overlap, were also computed. The criterion level for acceptable reliability was set to $\alpha \geq 0.7$ (Nunnally, 1978; Altman, 1999). Catell's scree test, absorption of variance and face validity of potential dimensions (Gorsuch, 1983) were used as criteria for multidimensionality. Test-retest and inter-rater reliability were calculated using

intra-class correlation (single-rater, absolute agreement). Criterion validity was tested by calculating Spearman correlations of the QUALID with the GBAS and PMAS, as well as global assessment of wellbeing. Clinical validity was assessed by correlating the level of cognitive impairment as determined by the MMSE and total score on the QUALID. It was expected that high levels of cognitive impairment would be inversely related to quality of life. To further investigate the clinical validity of the QUALID, residents prescribed antipsychotics and antidepressants were compared with those not receiving any psychotropic drug treatment. It was hypothesized that residents taking antipsychotics and/or antidepressants would have lower levels of quality of life. The sensitivity of the QUALID was examined in those residents whose overall wellbeing had changed over the three-week period. These comparisons were performed using the Mann-Whitney U-test. Finally, the sensitivity of the QUALID was examined in those residents whose overall wellbeing had changed over the three-week period. Changed scores, p-values, and Standardized Response Means (SRM) were calculated for this sub-group of patients.

In **Papers II and III**, descriptive statistics were used to characterize the sample. Internal consistency was calculated using Cronbach α (Altman, 1999; Nunnally, 1978) for all multi-item domains measured by the instruments used in the studies. Differences between groups at baseline were tested using independent samples t-test for continuous variables and Chi2 for frequency data. Two-way repeated measures ANOVA was used to investigate changes between groups and within groups over time. Two-way indicates that there are two independent variables (i.e. the individual score on one of the instruments used and repeated measure indicate that there is a pre-test/post-test design). The SPSS statistical software package (version 15.0) was used for all statistical analyses. Statistical significances were set at 0.05 (two-tailed) for all analyses.

Qualitative content analysis

The basic assumption of all content analysis is that cultural forms of expression in the broadest sense can be written down and expressed in texts, which means that the content analysis of texts is concerned with *social reality* and that the results of the analysis and their interpretation are correspondingly dependent (Bos & Tarnai, 1999). A basic issue when performing qualitative content analysis is to decide whether the analysis should focus on manifest or latent content (Graneheim & Lundman, 2004). Analysis of what the text says deals with the content aspect of the text, and describes the visible, obvious components, referred to as the manifest content. In contrast, analysis of what the text talks about deals with the relationship aspect of the text, and involves an interpretation of the underlying meaning, referred to as the latent content (Kondracki et al., 2002). Both manifest and latent content deal with

interpretations varying in depth and level of abstraction (Graneheim & Lundman, 2004).

In **Paper II**, the unit of manifest analysis was based on the structured interview text concerning experiences related to the refurbishment. The interviews were read through several times to gain a sense of the whole. Meaning units describing the residents' experiences related to the refurbishment were extracted, condensed, and labelled with a code. The codes formed four categories describing the manifest content of the interviews.

In **Paper III**, the unit of latent analysis was based on the semi-structured interview text concerning experiences related to the inter-institutional relocation. The text was analyzed in several steps (Kvale & Brinkman, 2009). Initial reading of the interviews provided a sense of the whole. Meaning units that were relevant to the research questions were identified and shortened, while preserving their core. The condensed meaning units were coded into short and immediate descriptions of the experiences related to the relocation. In order to preserve the temporal sequence in the original interviews, codes were categorized into three content themes; experiences related to the actual move, experiences of the transit facility, and expectations related to the move back. Within each latent content area, codes were compared, sub-categorized, and categorized, leaving the qualitative content analysis on a descriptive level, thereby maintaining the role of a supplementary strategy.

Grounded Theory Method

Action and process are central units of analysis in GTM, and the major stance in choosing direction is that of which meaning one ascribes action (Patton, 2002). In this study the approach was a constructivist GTM, where meaning and action are dialectical in that actions impart meaning, and meaning shapes action (Charmaz, 2004; 2007), and can be seen as the result of relations, rather than originating from within the individual herself or himself (Star, 2007). By seeing both the researchers' and respondents' actions, recordings, and reports as constructs (i.e. as opposed to objectives), positioned in specific situations, spaces and times, the process of generating theory, rather than structuring the data, is emphasized (Patton, 2002). Another central tenet in constructivist GTM is that it allows a simultaneous incorporation of formal and informal understandings of the world (Bryant & Charmaz, 2007).

The thrust in theoretical sampling is to develop and refine the categories, and to identify their properties and parameters (Charmaz, 2006; Hood, 2007) by abstracting the data so that it both adds and subtracts from the original experience described in the data (Star, 2007). Theories are interpretations of

reality, subsequently dependent on complex interactions between the researcher and the research participants, within their personal and professional backgrounds (Mruck & Mey, 2007). However, gaining multiple views and reaching across substantive areas strengthens our claims to understand the world (Charmaz, 2004). In **Paper IV**, the first step in the data analysis, the transcribed interviews were coded and segments of the data were selected, sorted, and labeled in order to move beyond the concrete statements in the data and begin an analytical account. The transcribed interviews were read several times in order to obtain a holistic view and understanding of the various ways in which older persons create attachment in residential care, and to discover a credible variety of real-life contingencies that affect this creation process. The transcribed data were then read line by line and segments of data that included statements about experiences, actions, thoughts, feelings and events related to life in residential care were marked out and labeled.

In this study the spatial dimensions of place and space were used as a starting point for the examination (Charmaz, 2004), to illuminate the life world of older people in residential care. This extant theoretical perspective sensitized the analysis, enabled us to pose questions and explore aspects of the developing categories that otherwise would probably have remained unexplored. The danger of forcing the data, and abandoning the basic inductive principle of GTM, was avoided by choosing theoretical concepts with limited empirical content as “heuristic devices” for constructing empirically grounded categories (Kelle, 2007). Place and space can be viewed as sensitizing concepts that move beyond the meta-paradigm of nursing environment (Andrews, 2005), which can be applied to a wide array of settings in developing novel theories grounded in empirical data (Kelle, 2007; Mruck & Mey, 2007).

The continuing iterative process of moving back and forth between empirical data and developing theory gradually brings focus to the data collection (Bryant & Charmaz, 2007). A crucial point is when to stop. Saturating theoretical categories requires paying attention to the theoretical sampling, which is to be considered as a tool for theoretical exploration, not confirmation (Dey, 2007). In line with constructivist GTM, saturation is an interpretation of data that emphasizes the density of categories (Charmaz, 2006).

Ethical considerations

The ethical principles in this thesis follow the World Medical Association Helsinki Declaration (WMA, 2008). Ethical principles for research which protect frail older persons state that the risks and benefits of research participation should be properly distributed, that choices made by an autonomous person should be respected, and that those incapable of autonomous choice are protected (Weijer, 1999).

In this thesis, the rights of both residents and nursing staff acting as proxy informants were protected throughout the project, based on the principles of informed consent. The will of those who refused to participate was respected, without reprisal. In cases where the resident was unable to independently provide informed consent, due to cognitive impairment and dementia, this was obtained from a relative of the resident.

The participants' descriptions of experiences relating to the refurbishment and the inter-institutional relocation in Papers II and III were potentially sensitive since the structured or semi-structured interviews partly evolved around the resident's attitudes towards facility administrators and the nursing staff. All interviews and self-assessments were, therefore, carried out in secluded areas, such as the private room of the resident or outdoors, on a bench in the park surrounding the facility.

The unstructured interviews in Paper IV sometimes aroused strong emotions, both in participants and researchers. In such cases, follow-up interviews could provide comfort by letting the participants talk about what they thought was important or frustrating, regardless of whether it had anything to do with the purpose of the study. All personal identification was removed to ensure confidentiality. Data are saved on USB flash drives and stored in accordance with good research ethics in a locked filing cabinet.

The Regional Ethical Review Board approved the proposal for Paper I on January 9, 2006 (575-05), and for Papers II-IV on November 13, 2006 (572-06).

RESULTS

Paper I

Demographic and clinical characteristics

The psychometric evaluation of the Swedish version of QUALID demonstrated a good validity and reliability. The tests were accomplished on persons in residential care with a diagnose of dementia. The mean age of the 169 residents included was 86 years (SD±6; range 66-99), and 88 percent were female. Forty-nine percent were diagnosed with non-specified dementia (NUD), and 53 percent were treated with antidepressants. The majority of the 107 proxy informants used in this study were assistant nurses (71%), and female (90%). They had a mean length of health care work experience of 12 years, and had been acquainted with the resident on average for two years. The distribution was relatively normal, as indicated by the proximity of the mean (23.9, SD±8) and median (22, range 11-44), as well as by the low skewness (0.54) and kurtosis coefficients (-0.52).

Validity, reliability and sensitivity

Proportions of patients rated at the floor or ceiling were low, suggesting that the scale adequately covered the possible range of QoL scores in the sample. The Cronbach's alpha coefficient of the 11 QUALID items was 0.74, indicating a satisfactory level of internal consistency. Principal component analysis revealed no strong evidence for multi-dimensionality according to the chosen criteria. Correlations between items and scale ranged between 0.73 (appears calm and comfortable), and 0.09 (cries), with a mean of 0.39. However, removal of the item concerning crying did not increase Cronbach's alpha correlate. This item also showed the lowest correlation with total score in the original study by Weiner et al. (2000). Of the 40 residents who were assessed twice over time, 23 were rated as having stable global wellbeing between the two assessment points. The intra-class correlation (ICC) between assessments among those residents was 0.86, indicating good test-retest reliability. Inter-rater reliability, estimated by

intra-class correlation in those 26 residents who were judged by two independent informants on the same occasion, was also satisfactory (ICC = 0.69). The correlation between the QUALID and the other QoL indices (GBAS, PMAS, and global wellbeing) were positive and high indicating good criterion validity. The QUALID also correlated as expected (weak but significant) with the MMSE, suggesting that lower levels of cognitive functioning were related to lower levels of QoL (Table 3).

Those residents who were prescribed antipsychotics and/or antidepressants showed lower QoL compared to those without psychotropic drug treatment, indicating good clinical validity of the QUALID. The sensitivity of the QUALID was assessed in those residents who were rated as changed in global wellbeing between assessments. This subgroup consisted of 10 residents who had deteriorated and 7 who had improved. These two groups were merged and the QUALID scores for the improved residents were inverted in order to increase the sample size. A paired sampler t-test of change scores for this merged subgroup showed a significant but moderate decrease ($p = .015$). The SRM 0.66 suggested moderate responsiveness of the QUALID scale.

Paper II

Changes between groups at baseline and over time

In the intervention group, the mean age was 88 years (SD ± 6 ; range 78-104), and 74 percent were female; in the reference group, the mean age was 86 years (SD ± 6 ; range 72-99), and 78 percent were female. Differences between the intervention group and the reference group were compared at baseline, and no significant differences were found for any of the dimensions in QUALID, PMAS, GBAS, and PCQ. Differences between the groups were also tested regarding age, sex, visual ability, physical mobility, and communication skills at baseline, showing no significant dissimilarities. A significant difference was found for the MMSE test score (Mann-Whitney; $p = 0.005$), with the reference group being more cognitively impaired than the intervention group at baseline. To test changes in QoL, wellbeing, and person centeredness over time between the intervention group and the reference group, repeated measures ANOVA were performed on QUALID, PMAS, GBAS, and PCQ.

The individual changes from baseline to follow-up were compared between the two groups. In these analyses, the MMSE score at baseline was used as a covariate, since the groups differed concerning this variable.

A significant differences in change between the groups were found for quality of life (QUALID; $F=8.36$; $p=.007$), and wellbeing (PMAS; satisfaction, $F=5.38$; $p=.02$, GBAS; confidence, $F=6.99$; $p=.01$). The changes indicated a deterioration for the intervention group compared to the reference group, suggesting that residents might be more frail and sensitive to change per se than has been assumed. No significant changes were found for the remaining factors in PMAS (strength and security), GBAS (accessibility). No significant changes were found for perceived person centeredness as measured by the PCQ, indicating that interior design features alone have little importance for the care climate in terms of supporting the patients and placing their needs and expectations in the centre of care.

The qualitative supplemental component of the study revealed that the residents ($n=12$) felt unaffected by the refurbishment. However, most appreciated the improvement of general aesthetic impression. The new and more inviting dining room milieu did not increase sense of community amongst the residents, and most still preferred to be in their private rooms, but did at the same time report that they lacked a sense of friendship with the others. These qualitative findings could explain the non-significant change in care atmosphere at follow-up, since the same residents (high functioning) self-reported on the PCQ and participated in the interviews.

Paper III

Differences between groups at baseline and over time

Demographic/clinical data and questionnaire results at baseline are presented in Table 2. The mean age and proportion of females were similar in both the relocated group and the reference group – 86 years of age and 77 percent females, respectively. Sixty-eight percent had a dementia diagnosis in the relocated group, while the corresponding proportion in the reference group was 77 percent. Concerning regular psychotropic drug prescriptions, the only significant difference between the groups was found for cholinesterase inhibitors (symptomatic treatment for mild to moderate Alzheimer's disease).

Significantly more residents in the reference group had such prescriptions (24 percent compared to 10 percent; $p=0.020$). Otherwise, no significant differences were found. Thus, the relocation group and the reference group were quite comparable regarding distributions of age, sex, cognitive functioning, dementia diagnoses and drug prescriptions. However, significant difference at baseline between the groups was found for PMAS strength ($p=.039$) and security ($p=.030$); GBAS confidence ($p=.017$); and on all scales of the PCQ ($p=.000$). These differences indicate that the relocation group tended to have lower levels of wellbeing and perceived person-centeredness before the relocation move.

Table 2. Residents characteristics and differences between groups at baseline

	Relocation (n=74)	Reference (n=81)	
Female <i>n</i> %	57 (77)	63 (77)	<i>ns</i>
Age <i>M</i> (<i>SD</i>)	86 (8.5)	86 (8)	<i>ns</i>
MMSE <i>M</i> (<i>SD</i>)	10 (9.5)	11 (10)	<i>ns</i>
Psychotropic treatment <i>n</i> %			
Antipsychotics	10 (14)	9 (11)	<i>ns</i>
Antidepressants	37 (50)	50 (62)	<i>ns</i>
Sedatives	18 (24)	24 (30)	<i>ns</i>
Cholinesterase inhibitors	7 (10)	19 (24)	$p=0.020$
PCQ total score <i>M</i> (<i>SD</i>)	57.3 (14.6)	84.2 (10.8)	$p<0.000$
Safety	34.8 (9.1)	49.7 (5.3)	$p<0.000$
Everydayness	12.1 (4.8)	19.8 (4.6)	$p=0.001$
Generosity	10.4 (2.6)	14.8 (2.5)	$p<0.000$
PMAS total score <i>M</i> (<i>SD</i>)	25.3 (7.4)	22.4 (7.8)	$p=0.017$
Strength	10.7 (3.6)	9.4 (3.9)	$p=0.039$
Satisfaction	6.7 (2.6)	6 (2.3)	<i>ns</i>
Security	8 (2.6)	7 (2.8)	$p=0.030$
GBAS total score <i>M</i> (<i>SD</i>)	21.6 (6.5)	19.7 (7)	<i>ns</i>
Confidence	9.7 (3.9)	8.3 (3.5)	$p=0.017$
Accessibility	11.8 (4.1)	11.4 (4.5)	<i>ns</i>
QUALID total score <i>M</i> (<i>SD</i>)	22.5 (7.2)	20.9 (6.5)	<i>ns</i>

To test changes in QoL, wellbeing, and person-centeredness over time between the relocation group and the reference group, repeated measures ANOVA were performed on QUALID, PMAS, GBAS, and PCQ. The individual changes from baseline to follow-up were compared between the two groups. Significant group effects were found indicating that the relocation group had significantly lower scores compared to the reference group in perceived person-centeredness and wellbeing over the whole assessment period. Significant time effects were found, suggesting that perceived person-centeredness decreased over time for both groups. Mortality also tended ($p=0.08$) to differ between the relocated group and the reference group. Between baseline and follow-up, 16 (24%) patients died in the relocated group and nine (11%) in the reference group. Significant interaction effects were only found for perceived person-centeredness (PCQ, $F=7.308$; $p=.015$, everydayness, $F=9.969$; $p=.005$), suggesting that the relocated group showed a significantly larger deterioration of perceived person-centeredness over time than the reference group.

The qualitative results were presented in three themes that emerged from latent analysis of the participants' descriptions of the relocation. Participants faced conditions that were "beyond their control", experienced the transit facility as having an "obstructive and institutional ambience", and "the future as fraught with uncertainty". The relocation was impelled by reasons beyond the residents' control. The actual move to the transit facility was described, by some of the residents, as well executed. The preparations prior to the actual move were carried out by others at a fast pace without the participation of the residents. Information about the purpose and execution of the relocation, as well as about the transit facility, was described as limited and insufficient. Lack of awareness, in combination with limited participation in the preparations, created feelings of exclusion and apprehension. Having no other option than to merely "*follow the course of events*", and "*having no saying*" evoked feelings of powerlessness. The daily routines at the transit facility were described as unchanged in comparison with those in the old facility, leaving the residents indifferent towards their new living environment. Others reported that they found the physical and psychosocial environment in the transit facility institutional, confined, and cold. Although the old nursing staff accompanied the residents to the transit facility, new staff members and altered floor-level routines contributed to feelings of confusion and uncertainty.

Some speculated that a prevailing discontent amongst the nursing staff seemed to have a negative influence on their work performance. The spatial layout of the transit facility, with long corridors and great distances between units, contributed to feelings of loneliness and being deserted. Some expressed disappointment in those persons responsible for the relocation, as well as the "social apparatus" in general. Some longed for the return to the rebuilt facility, and had high

expectations that it would be attractive, spacious, and homelike. However, the awareness of their advanced age, frailty, and of their “days being numbered”, darkened their hopes for the future. Some said that they felt certain that they would not live to experience the rebuilt facility, and that the reconstruction was intended for future residents, not themselves. Others refused to speculate about their future, taking one day at the time, and were reluctant to reflect about their current living environment and the remaining time in the transit facility.

Paper IV

Our findings show that the creation of attachment in residential care involves strategies that can be related to three dimensions of the environment; attachment to place, attachment to space, and attachment beyond the institution. Our findings also show that the circumstances and conditions under which older persons either manage or fail to create attachment, consist of psychosocial processes involving both individually and collectively held attitudes, beliefs, and symbolic meanings (Figure 1).

Strategies creating attachment to place

Personalizing the environment, making room for personal belongings, for furniture and memorabilia transformed the private room to a place of recognition and familiarity that symbolized and strengthened one’s self-identity, distilled from a lifetime of memories, experiences, and the meanings attached to them. However, by reconciling the inherent ambiguity of the institutional place, and to furnishing the room in ways that compensated for loss of function, respondents successfully incorporated their aged and frail self-identity into the environment. Central was spending time at home and being able to set the agenda for the day independently. Another aspect in creating attachment to place was that of being in charge, and able to independently decide whom to include and to exclude, which was regarded as an important representative aspect of the home. Although the nursing staff had keys, the locked door symbolized privacy. Nursing staff were welcome when the respondents needed assistance. Breaching that rule was experienced as an infringement. However, when respondent were ill, tired, weak, and in need of more assistance than usual, the nursing staff’s ability to freely enter the private room contributed to a sense of safety and caring.

Strategies creating attachment to space

The ability to independently decide when and how to interact with co residents and nursing staff was imperative for the creation of attachment. Socializing with others made respondents aware of their physical appearance, and the opportunities to dress up and to have one's hair set was important in maintaining continuity of the sense of self, in expressing identity, and personal values. Another way of expressing independence and personal dignity was to set boundaries regarding the nursing staff, perceiving oneself as equal to, and respected by, the nursing staff. Shared understandings about the residential care facility being someone's home preserved the continuity of the respondent's normal lifestyle, and strengthened their sense of self-worth and dignity. Making friends was an important aspect of attachment to space. However, there was a clear demarcation between being acquainted with the nursing staff, and being real friends with co-residents. Friendships were characterized by trust and a desire to confide in one another.

Strategies creating attachment beyond the institution

Being active in everyday life despite impairments was reported as important. By constructing attachment beyond the institution, respondents viewed the residential care facility as a place where they slept and ate, but did not live. The notions that home was some other place was related to the view that one's domicile at the residential care facility was temporary, making settling in unnecessary and uncalled for. The respondent's old home, either kept for various reasons or sold, would always be the place called home, and despite the fact that being housed at the residential care facility was permanent, returning home could be a possible alternative if things did not work the way one wanted. Actively refraining from personalizing the private room strengthened the notion that home was somewhere else. Despite, its seemingly illogical nature, attachment constructed beyond the institution provided the respondents with a sense of both control and belonging

Psychosocial processes supporting attachment

Respondents viewed the course of ageing, and its subsequent feebleness, as a natural and anticipated part of life, related to an understanding that the residential care facility symbolized loss and infirmity as well as being a place of protection and respite. Experiencing symmetric power relations to the nursing staff was an important dimension of feeling valued, and was experienced as reliant and well inclined, which contributed to sense of self-worth. Another

fundamental aspect of processes contributing to attachment was the ability find pride in managing even the smallest chores by your own. The ability to downplay the negative aspects of institutional living and to decide to make the best of things could partly be associated with having no other option than to accept the situation. However, it was also described in relation to an understanding that creation of attachment requires effort, and that such creation needs support. Both nursing staff involved in the day-to-day care and those in charge of the residential care facility were regarded as doing their best with the limited resources they had. By becoming reconciled to one's biography, the respondents described a calm and assertive acceptance of the inevitable end. Waiting for death was regarded as the final natural stage in life and whenever one's time was up, death was welcome to pay a visit.

Psychosocial processes hindering attachment

Unwillingness to accept growing old and becoming frail resulted in a state of emotional limbo, leaving the respondents well aware of their need for assistance, but at the same time mourning over their losses in terms of the capability and independence ascribed to their old self-identity. Much that once was, was now lost. The sadness of losing one's sense of self-identity and youthful looks made respondents ashamed of their physical decay, which in turn contributed to isolation and strengthened their feelings of being an outsider. Negative self-conceptions about being a burden to others, diminished the respondents' self-esteem and self-confidence. The discrepancy between their desire to cope independently with everyday life, and their limited ability to do so, contributed to feelings of bodily imprisonment, which had little to do with the spatial dimensions of the residential care facility per se. With low self-esteem and self-confidence, the respondent felt insecure and afraid that their remaining abilities would fail them if they tried to cope independently, which strengthened the feeling of imprisonment and isolation. When evaluating life in residential care, respondents judged their needs and expectations as unmet, which in turn gave rise to disappointment, frustration, and dissatisfaction.

Respondents described that they had expected that residential care would imply a higher degree of being looked after, that it would mean access to physiotherapists and rehabilitative training, and that the proximity to physicians and registered nurses would guarantee optimal care.

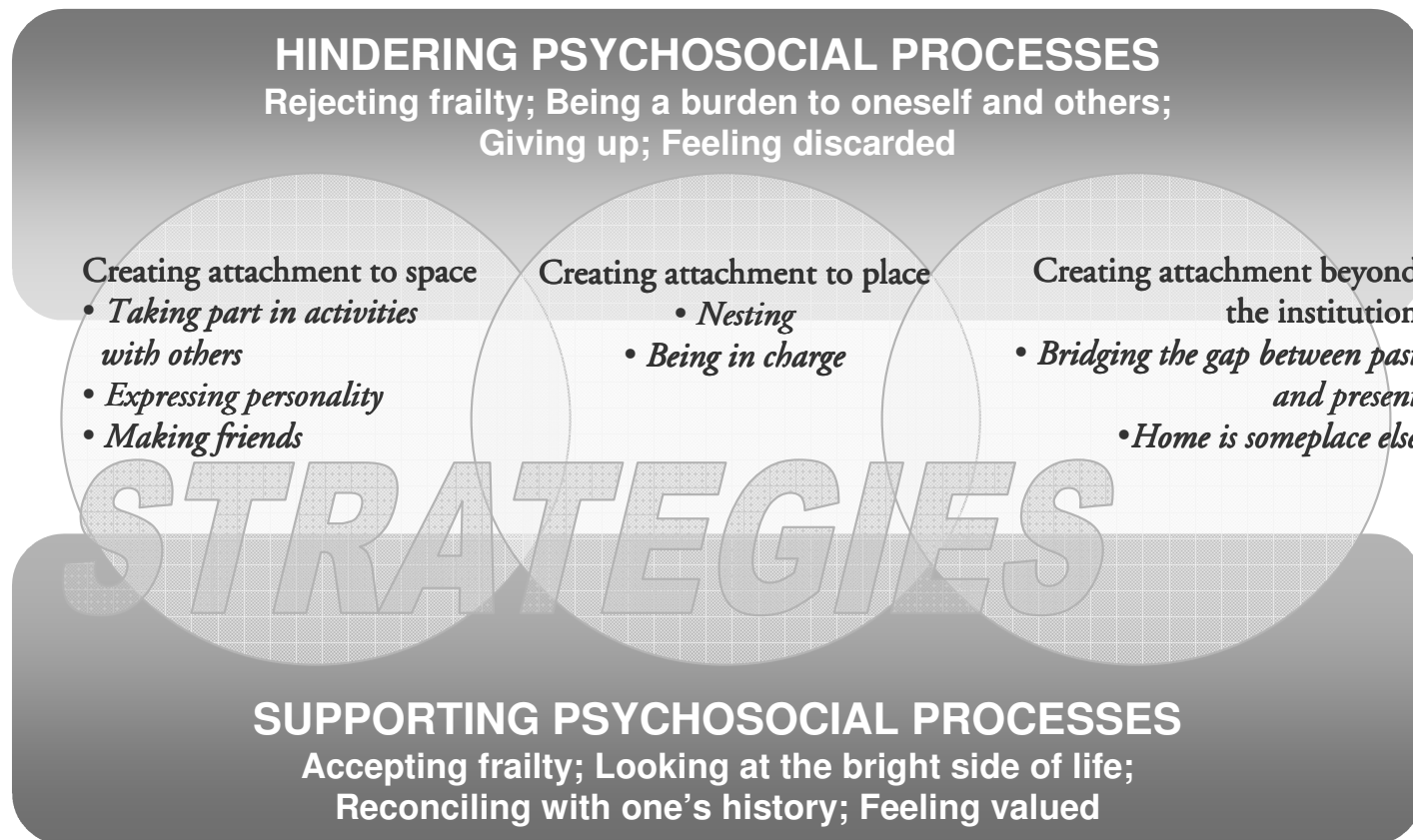


Figure 1. The residential care attachment model

DISCUSSION

Whether or not we like to think about the residential care facility as an institution, it is a place that characteristically involves loss of privacy, adherence to uniform treatment and fixed schedules imposed by nursing staff and facility administrators (Goffman, 1961; Kahn, 1999), which for some might signify confinement, whilst for others feelings of safety and respite. Regardless of one's attitudes towards the residential care facility, it should be safe to say that moving into such a place require a great deal of adaptation and adjustment to an environment and lifestyle that is entirely different from that of one's previous life (Marshall & Mackenzie, 2008). It might also be safe to say that institutional settings often have physical and social features that are more or less incongruent with the needs and preferences of its residents (Kahana et al. 2003). The residential care facility can be seen as a place along a continuum, where the institution and the home constitute the endpoints, and is places. Residential care facilities is places where some must live and experience life, and the problems associated with reconciling the dual nature of this environment is one that residents and nursing staff encounter in their everyday lives (Peace et al. 2005, Kahn, 1999).

In recent years, several steps have been taken to “de-institutionalize” the care for the elderly, and Sweden has come a long way in the “de-medicalization” of old age. The vast majority of facilities housing frail older persons in Sweden meet the requirements of “assisted living”, in terms of individualized care planning, needs assistance, and aesthetic appearances (Brooker, 2004). In the end of January 2010, The Swedish Government announced an official ethical standpoint that will be implemented to safeguard the autonomy of elderly persons (Ministry of Health and Social Affairs, www.sweden.gov 2010-02-15), and the main concept guiding the care is that the older persons are to be enabled to continue living in their own homes. Studies of person-environment relationships have generated a rich literature. The results in this thesis bring to mind that this relationship is complex and that some attributes of the institution, as described by Goffman (1961) some fifty years ago, still apply despite attempts to create “homely” residential care settings.

This thesis is about quality of life in frail older persons with late-stage dementia. It is about the complex person-environment relationship in terms of a refurbishment aimed to enhance the supportiveness of the physical environment, and it is about an inter-institutional relocation to temporary transit facilities due to extensive renovations at the home facility. It is also about the strategies older persons use to create emotional attachment to their new environment, as well as the psychosocial processes that either supports or hinders this creation. A basic premise underlying this thesis is that a need for a home is a human imperative, regardless of age and functional ability, recognizing frail older persons as unique individuals, with qualities distilled out of a lifetime of experiences, consequences and wisdom.

Although QoL has become a major topic of studies in dementia research (Ettema et al., 2005a; 2005b), frail elderly persons with late-stage dementia are a neglected group, mainly because of the methodological challenges that arise in gathering reliable data. In **Paper I**, a psychometric evaluation of a Swedish translation of the QUALID scale (Weiner et al. 2000), showed good validity, reliability, and sensitivity to change. In order to minimize proxy bias, QUALID items target observable and concrete aspects of life. Some argue that it is impossible to stipulate whether observable displays of affect actually index feelings in persons with severe dementia (Kolanowski et al., 2002; Byrne-Davis et al., 2006), whereas others believe that, the most effective way is to describe behavior and affective state, with the subjective tinge that it implies (Rabins & Kasper, 1997, Lawton, 1994). However, caution is appropriate when using proxy informants to estimate the QoL of persons with dementia. People tend to use their current affective state to judge how content and happy they are with their lives (Selai, 2001), and the main drawback of proxy ratings are that they filter an experience through the opinion of another person (Rabins & Kasper, 1997). There is also a tendency that nursing staff underestimate residents QoL (Novella et al., 2001). However, proxy bias might be minimized when the information sought is concrete (Novella et al., 2001). Observable emotional and behavioral responses are a major key to enhance our knowledge about the preferences of persons with late-stage dementia, and their responses to our nursing interventions.

The refurbishment evaluated in **Paper II** was initiated and carried out by facility administrators, following a routine time plan for maintenance. Nursing staff from both facilities undergoing refurbishment made educational and inspirational visits to exemplary settings in both Sweden and Denmark, involving them in the decision-making. A small number of residents were also invited to participate in the planning of the refurbishment. With the intention of evaluating the effects of a routine refurbishment, as it was performed in real life

by facility administrators with limited insight in evidence-based knowledge, the researchers had no influence on the refurbishment plan and execution.

The manifest analysis of the interviews revealed that most residents appreciated the refurbishment in terms of a general aesthetic impression, but that changes in the physical environment left them unaffected. One goal of the refurbishment was to enhance the visibility in hallways, enabling residents to move around the facility more independently. According to the interviews, no one stated that the enhanced visibility affected them in terms of utilization of the shared spaces and most residents returned to their rooms as soon as they finished their meals. According to this data, it can be argued that the refurbishment was not extensive enough to improve visibility and way finding. It could also be argued that more extensive refurbishment than improved visibility and general aesthetic appearance is needed to enhance the social interaction amongst residents in the shared spaced of the facility.

The quantitative findings suggested that residents QoL, as measured by the QUALID, and wellbeing, as measured by the PMAS (satisfaction) and GBAS (confidence), significantly deteriorated between baseline and follow-up in the intervention group compared to the reference group. It should be noted, that the scales used in this thesis are relatively new, with limited amount of reference data. Besides methodological issues related to the procedure, there might be several explanations to these results. One suggestion could be that the disruption caused by the refurbishment outweighed any possible outcomes of the new physical environment, and that frail elderly persons, perhaps, are more vulnerable to the “muddle” caused by the refurbishment than previously assumed. Another explanation might be that interior design features alone have little importance to the care climate in residential care.

The physical environment and peoples “doing and being” are in fact inseparable, both place and space need considering in order to improve the person-centred care climate (Edvardsson, 2008). On a methodological note, using QoL and wellbeing as outcome measures when evaluating this type of refurbishments might be to “make a mountain out of a molehill”. Maybe other, more direct and concrete outcome variables such as the residents’ actual utilization of the shared space would be more suited when examining environmental changes of this type. Another noteworthy point is that that when standards are relatively high prior to refurbishment, the changes that are measurable post- refurbishment become less noticeable. One could assume that the effect on QoL and wellbeing would have been more explicit if the need of refurbishment was extensive and the change after refurbishment more obvious.

The inter-institutional relocation evaluated in **Paper III** was also initiated and carried out by facility administrators, without any involvement on behalf of the researchers. The North American Nursing Diagnosis Association (NANDA, 2006) definition of relocation stress, states that dependency, confusion, depression, and withdrawal are associated with inter-institutional relocations, and that these adverse effects need to be further recognized and addressed (Mallick & Whipple, 2000; Brugler et al., 1993).

However, our results showed only few significant changes. Residents in the relocation group showed a larger change for the worse over time than the reference group concerning perceived person-centeredness. The PCQ instrument is a self-rated assessment tool that was only used in the minority high-functioning groups in the study, and the residents who were able to report their experiences themselves perceived their transit facility as less person-centered, and described it as obstructive. In addition, residents described the relocation as being beyond their control, that they had no saying, and that the future was fraught with uncertainty. Despite attempts to decorate the environment with non-institutional and everyday objects, such as paintings, flowers, and furniture, the residents described the climate at the transit facility as deserted, confined, and cold in comparison with that in the old facility. A further finding, possibly indicating an adverse effect of the relocation, was the differences in mortality between the relocating group and the reference group during the assessment period.

Twenty-four percent in the relocating group deceased between baseline and follow-up compared to 11 percent in the reference group. This difference was close to be significant ($p=0.08$). The assessments of the wellbeing and QoL in low-functioning participants did not show any significant changes over the assessment interval. One might speculate that those most affected by the relocation in terms of lack of control and dependency, were those that prior to the move experienced control and independence at the home facility (i.e. the high-functioning group). The ability to function independently in residential care is primarily associated with the person's cognitive and intellectual abilities. A further explanation to the lack of significant changes in the low-functioning groups could be that the nursing staff and the residents relocated together, which has been shown to minimize the disruption of daily routines associated with relocations (McAuslane & Sperlinger, 1994), thereby sheltering those most frail and vulnerable. In retrospect, additional measures, such as nutritional status, body mass index, sleeping behavior, or need of sedatives would have strengthened the study, since previous research have shown significant weight loss in elderly persons with dementia, up to three months (Lander et al., 1997).

A methodological problem that needs considering when analyzing the results from the present study is that the relocation group tended to be significantly worse off regarding perceived person-centeredness (self-rated) and wellbeing (proxy-rated) compared to the reference group already at baseline. The differences were consistent also at follow-up. One explanation could be that baseline data was collected too close to the actual moving day, i.e. that the imminent relocation influenced the care climate and resident's wellbeing even four weeks prior to moving day. Another explanation could be that the nursing staff's own attitudes towards the relocation might have influenced their assessments about the resident's mood and behavior (Novella et al., 2001). As far as we know, the nursing staff was engaged in, and positive to, the rebuilding of their residential care facility and to the temporary relocation. However, in some of the interviews, the residents described that they experienced a certain discontent amongst the nursing staff regarding how facility administrators organized the relocation, as well as the housing standard of the transit facility.

It is a well-known fact that proxy assessments have less validity than self-assessments (Rabins & Kasper, 1997). However, in the context of late-stage dementia there is a lack of optional means of assessment. According to a review of the literature, the accuracy of proxy ratings is higher when the information sought is concrete and observable (Novella et al., 2001). We used three proxy assessment tools in the present thesis – QUALID, PMAS and GBAS. Of these, the QUALID is the most explicit in terms of rating concrete and observable behavior. QUALID did not show any significant group-effects between the relocated group and the reference group, in contrast to the PMAS and GBAS. Thus, it is possible that the significant group effects found for PMAS and GBAS, at least partially, might reflect the proxy informants' own emotions towards the relocation. However, this does not explain the significant group effects also found for self-rated care climate, as measured by the PCQ. Particularly, since controlling for cognitive impairment, as measured by the MMSE, did not change the results obtained for the PMAS and GBAS.

The core component in Paper III was quantitative. It can be argued whether the sampling procedure used adheres to the methodological rigor associated with quantitative research. However, the relocation was not research driven and would have been realized regardless of our participation as researchers. For that reason, we had no influence on selection of participant, nor procedure for relocation. Caution is always urged in claiming that an intervention caused an observed change (Richardsson & Bartlett, 2009). In naturalistic inquiries, like paper III, it can always be questioned whether the relocation, or some other uncontrolled effect modifiers, accounts for the changes observed. In order to control for potential maturation we used a reference group representing the "natural history" of frail elderly in residential care. Naturally, randomized intervention/control

designs are more efficient in determining potential effects, as well as controlling for potential confounders. Unfortunately, in real-life practice, it is quite impossible to randomly assign frail elderly persons to experimental and control groups of a project, in order to study the effects of inter-institutional relocations. However, a possible design would be to randomly assign to groups using different preparatory approaches prior to relocation, since it is an established fact that preparatory programs that inform and involve elderly persons prior to relocation are associated with successful relocation (Laughlin, 2007; Castle, 2001; Bourestrom & Pastalan, 1981). However, when planning such preparatory interventions one should not forget that most frail elderly living in residential care are cognitively impaired, posing great challenges.

Another limitation of paper III was that we were not able to follow the relocation group when they returned to their rebuilt and refurbished home facility. One year is a long time when you are frail and old. The time between baseline and follow-up was 7 months and during that time 16 residents out of 74 deceased. If we extrapolate this mortality to 12 months, more than half of the residents that participated at baseline would have deceased. The minority that was cognitively intact expressed feelings of uncertainty about their health, their advanced age, and being alive irrespective of the relocation, as illustrated by the following quotation, made by one of the participants: *“Well...we’ve already done one third of the time here...I’m counting the days...but still there’s nine months left and that’s a long time if you are old and sick. After experiencing this, you really come to appreciate the old place. Now all you can do is to hope to live to see that.”*

The purpose of **Paper IV** was to construct an understanding of the processes involved, and the strategies by which older people create attachment and self-identity in residential care facilities. Our findings showed that the creation of attachment in residential care involved strategies related to three dimensions of the environment; attachment to place, attachment to space, and attachment beyond the institution. Our findings also showed that the circumstances and conditions under which older people either managed or failed to create attachment, consisted of psychosocial processes involving both individual and shared attitudes, beliefs, and meanings. In this study, those residents that were able to create attachment, accepted their frailty and tried to make the best of things. Ten years ago, Kahn (1999) stated that those able to adapt to life in residential care were those recognizing the ambiguity of the environment, in terms of being in a place where they had to live until they died, trying to get as much satisfaction as possible from what remained of their lives. This duality will always remain in the context of frailty and old age.

However, besides making the best of things, our findings moved beyond the mental state and determination of older people, and into the realm of

practicality, action, and strategies. By assuming that attachment is of vital importance to human existence regardless of age, attention must be paid to optimize the conditions and circumstances under which attachment is created in residential care.

The spatial dimensions of the residential care facility employ both the private and the public discourse (Twig, 1999). It cross-sections place in terms of the shared areas and private rooms, and space in terms of social relationships being either intimate, acquainted, or professional. Adding a “private versus public” perspective on top of place and space, the diversity and complexity of the semi-public environment was captured. According to our findings, the act of inviting someone into one’s private sphere was the practical application of one’s ability to independently include and exclude. In a study on home-based nursing care (Öresland et al. 2008), patients perceived themselves as guards, protecting their independence and home-space from others. Within the private sphere, those invited usually take on a friendly and personal attitude in order to maintain a good relationship. According to our findings, nursing staff was regarded as welcome when assistance was needed. Without an articulate and clear purpose of assisting them, nursing staff violated their privacy. However, when respondent were sick, tired, weak, and in need of more assistance than usual, the nursing staff’s ability to enter the private room single-handedly contributed to a sense of safety and being looked after.

The central tenet of making new friends, and thereby create attachment to space, was that of having the ability to independently decide when and how to interact. It is well known that independence and control are prerequisites for quality of life (Gabriel & Bowling, 2004). The neutral and permissive aspects of the shared spaces seemed to support social interaction, and entering each other’s private rooms could be controversial even with an invitation. The private room was clearly restricted to one’s self, family, good friends, and nursing staff with the intention to assist.

Building on the pragmatist underpinnings, the constructivists’ believe that reality are constructed within social relationships, repeated performance, and shaped by discourse (Öresland et al. 2008; Charmaz, 2006). Place possesses meaning through human agency, intentionality, essence, authenticity, and embedded knowledge. An important aspect of the creation of attachment to place, as well as to construct privacy, was that of spending time alone in one’s room. Routines and rituals are important aspects of the home-space, and according to our findings, domestic activities and habits within the private sphere were important in constructing a sense of normality. By decorating the room in a way similar to that of the old home with private symbols, such as photographs and personal belongings, the residents claimed a piece of the institution as their own, which

bridged the gap between their old and new life situation. Another way of bridging the gap between the old and the re-constructed self-identity was to create attachment beyond the institution. The residential care facility was regarded as a “hotel” where the nursing staff was experienced as prosthetic, acting like substitutes, thus compensating for lost abilities of the person.

There is general agreement in the literature that there is a reciprocal relationship between wellbeing of elderly persons and their ability to experience place-attachment (Wiles et al., 2009; Low & Altman, 1992). The literature also shows that older people with strong attachment are those most likely to successfully adjust to the contingencies of ageing (Andrews & Philips, 2005; Golant, 1984), and that a sense of attachment to place is a prerequisite for feelings of homeliness that enables older people to draw meaning, security, and sense of belonging (Wiles et al. 2009). There are apparent limitations in perceiving shared spaces as private. In general, public spaces offer opportunities for social interaction and participation in activities. According to Hauge and Heggen (2007), the semi-public nature of the residential care facility would benefit from a re-orientation in terms of enhancing the public aspects of the shared spaces. A clearer demarcation between public and private would not only support the creation of attachment to place, but would also provide less ambiguous signals to nursing staff, which according to our findings were those that violated most of the privacy of the residents.

A consequence of the 'aging-in-place' policy is that older people moving to residential care today are more frail and dependent, in terms of decreased functional and cognitive capacity, than before. The vast majority of Swedish residential care facilities are designed according to guidelines established in 1992, embracing purpose-built and small scale environments, adapted to accommodate declining visual, auditory, and kinesthetic senses (Crews, 2005), with single rooms and private bathrooms (NBHW, 2006). Well rooted in our Western individualist culture, is the assumption that status invariably derives from ability. Based on our findings, strategies used by older people to create attachment required some degree of effort. In relation to the fact that those moving into residential care are frailer and, subsequently, less able to gather the strength needed for nesting and making new friends, nursing interventions that support the creation of attachment needs to be acknowledged.

CONCLUSION

Some concluding thoughts about the findings presented in this thesis and how it can be related to prior knowledge, future research, and practical applicability. The QUALID scale has shown to provide reliable and valid information about quality of life in late-stage dementia. It can be used to evaluate treatment and intervention effects, as well as to compare between groups, given that other knowable and perhaps influencing variables are controlled for. QUALID is the first QoL instrument in Swedish especially designed for late-stage dementia. However, it should be remembered that QUALID provides a snapshot of the older persons QoL, and that it should be used manageable and measurable glimpse of reality. It is quite obvious that residential care facilities are places that consists of social, cultural, historic, political, economic, and physical features, which subsequently call for multidimensional perspectives in research, construction of new buildings, as well as refurbishments of old ones. Although the residential care facilities have the aesthetic appearance of a home, its structural features of the institution cannot be avoided, and the physical environment must meet the functional requirements of a work-place for nursing staff and as a home-place for residents. Quality of life in old age encompasses both the intrapersonal as well as the socio-normative evaluation of the person-environment relationship (Lawton, 1983). The basic premise of supportive environments is to reduce the demands of the environment to a level congruent with the abilities of those living in the environment. Based on previous research, it might be safe to say that frail older persons generally react negatively to change. However, whether it is the change “per se” or the inconveniences associated with the change that adversely affect frail older persons need further study. Based on our findings, it seems like interior design features alone may have little importance to the care climate, and that the disruption caused by the refurbishment outweighs any possible advantages with a more supportive environment. Also based on our findings, it seems safe to say that temporary inter-institutional relocations of frail older persons entail serious risks for those able to self-report about their experiences. Places and things are important symbols of self, cues to memories of important life experiences, and a means of maintaining one’s sense of self. The findings in this thesis support the general notion that sense of self is maintained and that an attachment to some dimension of one’s present or past place helps counter the threats to personhood that is associated with change, frailty, and dependence. Loosing sense of control diminishes sense of self. Assuming that the self is the core of quality of life, maintaining a sense of continuity with one’s personal past by knowing the individuals environmental history, seems to be a powerful tool for viewing and understanding frail older persons in residential care. The environments in which we dwell consist of space and place. The basic assumption underlying homelike

settings, or so called recalled environmental features, is that it should provide appropriate environmental stimuli for the residents in recollection of meaningful environments from the past. In order to recall a sense of home, it becomes apparent that more is needed than a homelike physical environment. Dignity, control, and safety is prominent features of the home place. In order to support the sense of self-worth and control of the older person, we need to create residential care facilities in which decision-making is shared, staff relationships are collaborative, leadership is transformational and innovative practices are supported. Refurbishments need systematic evaluations for us to learn “best practice”. Frail older persons must be prepared prior to relocation. The time is ripe for the National Board Of Health and Welfare to formulate preparatory programs that minimizes adverse relocation effects. A person-centred approach is crucial for the delivery of high quality care. In order to support the creation of emotional attachment and sense of home in residential care, the uniqueness of the person must be respected as well as protected.

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