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FAMILY CAREGIVERS' EXPERIENCES IN NURSING HOMES;
NARRATIVES ON HUMAN DIGNITY AND UNEASINESS.

Running headline: A life in dignity

Abstract

This qualitative study is focusing on dignity in nursing homes from the perspective of family caregivers. Dignity is a complex concept and central to nursing. Dignity in nursing homes is a challenge, according to research. Family caregivers are frequently involved in their family members' daily experiences at the nursing home.

This Scandinavian cross-country study has a descriptive and explorative design. Twenty-nine family caregivers were included. A phenomenological-hermeneutic approach was used to understand the meaning of the narrated text.

The interpretations revealed two main themes: "One should treat others in ways that one would like others to treat oneself" and "Uneasiness due to indignity".

The main reason for dignity was experiences as respect, confidence, security and charity.

The uneasiness occurred when indignity aroused.

The voices of the family caregivers are usually taciturn, but still important in nursing homes.

It seems therefore important to further investigate experiences of family caregivers in the context of nursing homes.

Dignity, family caregivers, nursing home, hermeneutics

Introduction

This study focuses on contextual experiences of dignity in nursing homes, from the perspective of family caregivers. Dignity is a complex concept, central to nursing science. When facing vulnerability in a context of dependency, dignity is viewed as ethical demanding (Cochrane 2010). In one aspect, all human beings possess dignity, as an inner and absolute property. Additionally, another aspect of dignity is relative and relational, and influenced by culture and society (Cochrane 2010, Edlund 2002). This study examines carefully the relative aspect of dignity in nursing homes, based on close examination of the narratives delivered by the family caregivers.

The increase of elderly patients in western countries will represent a major future challenge in the next thirty years (Dahle et al. 2011). As institutions, nursing homes are faced with exceedingly demanding ethical challenges in interaction between protecting vulnerable adults in need of excessive care, professional shortage and rigid routines (Dreyer, Førde & Nortvedt 2011, Forbes-Thompson & Gessert 2006). Ethics in caring for older people is therefore an important issue (van der Dam et al. 2011). At the same time perceptions differ about ethical issues among different groups, such as health professionals, patients and their relatives (Suhonen 2010). A focus on dignity in nursing home from different perspectives may therefore be essential since dignity is an ethical important issue.

Family caregivers are situated both inside and outside the nursing home, usually positioned close to the patient, socially as well as emotionally. Therefore, family caregivers are both observers and participants in nursing homes, alternating between being familiar and stranger, and with a continuous concern of what is happening to their close ones. Even though the family has neither juridical obligations in Scandinavian nursing homes, nor legal privileges or rights, the family still wish to be included by the health professionals in the care of the elderly. Caring for elderly people is often a challenging balance between dependency and

dignity, which is the main concern in this research (Dale et al. 2011, Jacobsen & Sørli 2010). Only a few research papers have been found so far that focus on dignity in the context of nursing homes, from the perspective of the family caregivers.

Background

Bredland et al. (2002) distinguishes between objective and subjective dignity. The objective aspect of dignity is a basic human right, according to international declarations of human rights: “*All human beings are born free and equal in dignity and rights*” (Universal Declaration of Human Rights). On the other hand, the subjective aspect of dignity is based upon personal experiences with other people as well as their own interpretation of dignity values. According to Edlund (2002, 3), and in correspondence with Bredland (et al. 2002), human dignity has two aspects: Absolute dignity (or objective dignity), which is an inalienable and inviolable dignity and relative dignity (or subjective dignity), which is mutually interdependent on others and, based upon relative and changeable experiences. According to Eriksson, central values in human dignity are autonomy, equality, integrity, uniqueness, freedom and credibility as individual qualities, and respect, responsibility, protection, and kindness as relational beneficence. Human dignity as an individual and inalienable value implies an inner freedom which is available to everyone. Nevertheless, respect, kindness and protection as interdependent qualities are not necessarily available to patients, due to contextual attributes (1996).

Human dignity may be associated with experiences of significance or importance, indicating to matter for or having meaning towards other people. Experiences of the relative and subjective aspect of dignity are related to experiences of feeling safe, and being acknowledged and interpreted as a credible person (Eriksson 1996, Nåden 1999, Edlund 2003). Being respected and recognised as a unique and competent individual was found as

essential for older patients (Dale et al. 2011, Jacobsen & Sørli 2010, Randers, Olson & Mathiasson 2004, Woolhead et al. 2004 Walsh & Kovanko 2002), while disrespect and paternalism within healthcare was considered as violation (Dreyer, Førde & Nortvedt 2011). The concept of power is an important and present circumstance in caring, especially in a context of helplessness and vulnerability. Power may be potentially constructive or destructive, depending on how it is performed in close and intimate nursing care relations (Juritzen & Heggen 2009). Relative dignity can be transformed, destructed or rebuilt, according to Edlund (2002).

Family caregivers are frequently involved in both their family members' daily experiences of dignity at the nursing home, as well as in their own experience and interpretation of human dignity as a family caregiver. This dualistic role is complicated and may create and increase vulnerability and discomfort in spite of the family caregivers' general competency and autonomy outside the nursing home. Through focus group and individual interviews with family caregivers Duncan and Morgan uncovered the relatives' emphasised wish for an on-going relationship with staff members, based on emotionally sensitive care, which may increase experiences of dignity (1994). From a Canadian study, based on participatory action research approach, examining relationships between families of residents and the health-care team, findings indicated that the family members described their attempts to form and sustain individual relationships within a system marked by limited resources, increased patient flow and personnel draught. Families expressed their desires to be trusted for their knowledge of the residents, which is a premise for individual nursing care. Also incidents of lost clothing or damage to personal items appeared to be a source of much distress. According to the participants, clues of caring often lie in 'little' things, because little things represent personalised care which is important concerning human dignity (Austin et al. 2009). Less time resources and reduction of work force is the enemy of sensitive and individual care. A

phenomenological study of the ethical environment in a nursing home in Sweden based on observations of twelve residents revealed experiences of being together without meeting, illuminating the emptiness of the social relations between the patients. Findings reported that the residents had unfulfilled desires of autonomy (meaning being dependent and not in a position of deciding) and also unfulfilled desires for being respected, noticed and for receiving help (Bolmsjö, Sandman & Andersen 2006). According to research, ethical problems arose in different situations where resident's interests were considered to be in conflict with the interests of the other residents or the interest of staff (Dam et al. 2011, Suhonen et al. 2010, Dreyer, Førde & Nortvedt 2011, Nolan et al. 2004). There are many moral issues concerning care in nursing homes. These issues again relate to the concerns of the residents, the family caregivers and the staff. This article, however, highlights narratives from the perspective of the family caregivers.

Aims of the study

The main purpose of this study was to illuminate narratives on how family caregivers experience that human dignity is respected and taken care of by health care personnel in Scandinavian nursing homes.

The following research questions were investigated:

- 1 How do family caregivers describe and explain experiences of dignity in nursing homes?
- 2 How do family caregivers narrate their understanding of their experience of dignity and violation in the context of nursing homes?

Design

This qualitative Scandinavian study has a descriptive and explorative design, based on qualitative individual research interviews. The overall purpose of this cross-country Nordic

study was to gain further knowledge about how dignity is maintained, promoted and neglected in nursing home residents through cooperation with residents, family members, health care personal and nurse administrators. A phenomenological-hermeneutic approach, inspired by Ricoeur (1981, 1976) was used to understand the meaning of the narrated text. This theory of interpretation includes a reading to gain a sense of the whole, followed by the identification of meaningful parts as well as interpretations of meaning in the text as a whole. Narratives describe not only past actions, but how individuals understand those actions. Narratives are related to context and the process of interpretation is aiming at going deeper into the text, seeking a deepening understanding of the meaning of the human phenomena (Ricoeur 1999).

Ethical approval

This study is a part of a larger study which has been evaluated and approved by the Norwegian Ethical Committee and the Norwegian Social Science Data Services and within the respective countries in Scandinavia. The family caregivers were recruited by the staff nurses. All caregivers received both oral and written information about the purpose, content and extent of the study, and their written consent was obtained. Participation in the study was voluntary and the anonymity of the participants and the duty of confidentiality were respected during the research process and in publishing.

Participants

This Scandinavian study was carried out in six nursing homes: three in Norway, two in Sweden and one in Denmark. Twenty-nine adult family caregivers were included in this study, all closely related to the residents. The relatives constituted of 17 women and 11 men, and were aged between 47 and 89 years, and were either a parent, a sibling, a cousin or a spouse. The residents at the institution defined their family care caregivers and were recruited by the staff. The sample was homogeneous and purposive.

Data collection

This empirical study is part of a larger Scandinavian study with a research focus on experiences of dignity from different perspectives of patients, family caregivers and health personnel. Data in this part of the study were collected from family caregivers by personal research interviews. The interviews, focusing openly on personal experiences of daily situations containing dignity and indignity at the nursing home, were collected during autumn 2009 and spring 2010. The interviews were first tape-recorded and then transcribed verbatim. The interviews followed a semi-structured guide. The focus for the interviews was their encounter with health services, what they considered important concerning dignity, and their experiences of how dignity was respected and taken care of at the nursing home. Focus was on experiences involving also violation and offences.

Table 1 about here

The context

Data were collected by ten researchers and were performed in the six nursing homes or at a quiet and private place that was most appropriate to the participants. The interviews lasted from thirty to ninety minutes. The amount of data was very rich and the relatives were highly motivated to participate in this study; they had plenty of stories to tell.

Data analysis

The hermeneutic analysis was performed inductively by twelve researchers. The interviews were read several times to get an overview. Substantial themes were written in the margin of the text. The purpose of the data analysis was to extract meaningful content from the patients' experiences. Interpretation of a text moves forward from naïve understanding to deeper understanding of the text. The analysis was performed in several steps: In the first step (the naïve readings), the researcher attempts to understand the meaning of the whole text. The second step involves a number of structural analyses to grasp the most probable interpretation

and explanation of parts of the text. At this level, comprehension is a mode of understanding. The final step is to make a comprehensive and understandable interpretation of the whole text, taking into account the naive reading and the structural analysis towards appropriation (Ricoeur 1976, 1981, 1999). The first author moved between different parts and the whole text. Throughout the analysis and the interpretation process, the research group discussed themes face to face until consensus was obtained.

Findings and interpretations

According to the narratives given by the participants, most family caregivers spent several hours daily, or at least weekly, together with the residents (patients living in the nursing homes). Therefore they were in a position of both being frequent guests and observers of the daily life at the nursing home, as well as participants in the inner life of the nursing home, sharing frequent experiences with their older family member.

In this study, the interpretations revealed two main themes:

“One should treat others in ways that one would like others to treat oneself” (I) and *‘Uneasiness due to indignity’* (II).

Theme I: “One should treat others in ways that one would like others to treat oneself”

This comprehension, in accordance with the golden rule (Lukas 6.13), which is similar in every culture, was bilateral, indicating that the relatives were using themselves and their own sensitivity to understand the residents’ experiences *as if* it was happening to them.

Additionally, the family caregivers paid continuous attention to ‘the other’, meaning that the wellbeing of their dear one was vital for their own welfare, which is also in accordance with

the golden rule. From this inside perspective, the family caregivers also lived experiences of dependency at the nursing home. Through this insight, the family caregivers were forced to face their own vulnerability.

Several of the relatives explained human dignity as individuality and integrity. Dignity means respect and love, according to one participant:

“They (the staff) do not need education to treat people with respect or to talk properly to others (the patients), it is just common sense. But health personnel without love for human beings should never be permitted to work here” (F).

The golden rule is based upon respect and love for the other. Dignity, meaning individuality as an inalienable human right in a context of vulnerability, was also narrated to be important as well as a decisive relational quality:

“Dignity is a very complex phenomenon, having an inner as well as an outer or external dimension: Different individuals are not in need of identical dignity. Neither are their individual needs equal, but when they (residents) are feeling humble or exhausted they are in need of being appreciated and praised” (R).

The golden rule is also based on individuality for each individual. Most participants experienced dignity on behalf of their relative as “*feeling autonomous*”, “*being seen*”, “*being confirmed*” and “*being heard*” in a context of “*predictability*” and especially when the personnel did “*the little extra on a voluntary basis (U)*”. According to a busy son, “*dignity is safety and prosperity for both the residents and their family*” (O). Several participants emphasized the importance of health personnel taking their time to “*be conversation partners in a warm, friendly atmosphere*” (S). According to this, human dignity was understood as

“caring togetherness in a context of heartfelt acknowledgement, helpfulness and confidence”

(B). The golden rule is based on the conviction that even though we are created differently, we still have equal needs. Common human needs illuminated in the narratives are autonomy, safety and acknowledgement.

Theme II: Uneasiness due to indignity

Usually the family caregiver experienced relief when their old parent was allocated a room at the nursing home, but later on, the relief changed into frequent uneasiness. In one sense the family caregivers constituted a bridge between the two different worlds; the system and the residents', meaning living in-between the 'doing' and the 'being' at the nursing home. This position was a major cause of the uneasiness among the family caregivers. While the main concerns of the staff were running the system, carrying out the daily routines and taking care of their duties, the relatives had a continual focus on the residents' daily living. These different positions created conflicts between the staff, the family caregivers and the residents. From the position of the family caregivers, the needs of the older residents were not always met by the staff, due to these different perspectives. The uneasiness was due to their continual concern for their older parent, sibling or spouse and experiences on behalf of their relative concerning indignity or dignified care. The uneasiness was due to or provoked by violation when they lost their confidence to the service, on which they also were completely dependent.

The participants narrated the nursing home as an infinite waiting room, illuminating situations of emptiness and feelings of loneliness. One daughter described her mother's daily life like this. *“She is just sitting here, hidden and lost”*. According to the daughter, her mother felt *“thrown away”* (K).

Another participant experienced her mother as

“being ignored, which made her mother feeling very lonely”(A). Some narratives were even about inexcusable situations: *“sometimes when visiting, we would see that residents were suddenly about to stand up from their chairs. We knew that they recently had broken the neck of their femur. Our hearts were in our throats”* (L). Situations involving waiting, like when their dear ones were *“having to wait an hour for visiting the toilet because the permanent staff was too busy”*(D) increased their uneasiness.

When the patients experienced being abandoned in the toilet or left alone in their room over time, the family caregivers felt severe uneasiness. Some unease was also due to the relatives' experiences of illnesses and medical treatments at the nursing homes.

Several of the relatives spoke on behalf of the residents about the residents' situation: Experiences of guilt and despair sometimes overwhelmed the participants due to previous experiences: *“How will she feel when we have left her, because in the beginning, she always wept when we were leaving? Did she want us to stay longer? Who is there to ask? Nobody knows”* (E). In this perspective, a son narrated: *“To be a family caregiver is like being continually frightened”* (G). He visited his father every day to ensure himself that his father did not suffer. Nevertheless, the participant felt that his father was suffering due to uncaring episodes. A daughter, experiencing suddenly being in the role of her mother's mother, was filled with sorrow due to the staff's lack of attention towards her mother: *“My heart is crying”* (I), she reported. In spite of this, family caregivers had no other choice than *‘fighting the small battles’* (T). Sometimes the relatives were feeling reluctant to ask about their

residents, “*apprehending that her mother was spending too much time in bed*” (V), which again induced the uneasiness.

Different situations gave rise to different narratives of uneasiness: Unpredictability was a common source for the uneasiness, like when belongings were lost or promises were broken: “*a lot of clothes disappear. And my mother should have had her hair cut. I believe that there is a little too much of absent-mindedness, (H)*” emphasizing the importance of the ‘little’ things. Another common occasion was lack of information, which caused the relatives strong uneasiness. The children of the residents also felt an extreme role conflict concerning intimate questions like the use of napkins because of incontinence, which constituted reversed roles between the old parent and their younger children. Furthermore, conflicts and struggling with the staff resulted in a bad atmosphere and paternalism, which again reinforced experiences of disappointment and uneasiness. Paternalism, as a destructive aspect of power, then resulted in powerlessness and fatigue among the family caregivers.

Still several relatives seemed to accept the fact that since they were in need of having professional help and assistance for a parent or a relative, they had to release their own right of self-determination as well as to endure some conflicts of interests. To conclude the findings, one daughter working as a healthcare professional gave this opinion:

“Well, people often say that it is worse being a family caregiver than it is being a patient. And maybe this is true enough” (M).

Being a family caregiver is like being continually worried on behalf of ones dear one, as well as experiencing indignity on behalf of their relative *as if* it was happening to themselves.

Discussion

Limitations and strength of the study

The aim of this study was to explore and describe family caregivers' experiences of dignity. A phenomenological-hermeneutic approach (Ricoeur 1981) was used to reach a comprehensive and understandable interpretation of the narratives. Some methodological limitations have to be raised. Ten researchers from three different Scandinavian countries collected the data through personal interviews. Because of the large amount of family caregivers, as well as due to the richness of the data, we decided only to do one interview with each participant. In spite of a common semi structured guide, the considerable numbers of researchers may have influenced the interview situations in different ways through individual focus of interest, different age, gender and nationality. However, Scandinavian countries are considered having much more in common than differences, also in the area of elderly care and nursing homes. This was confirmed through the interviews as well. The analysis of the text was performed by twelve, experienced researchers (two were unable to participate in the data collection) and the interpretations were shared and discussed. The reason for choosing different Nordic countries and the respecting nursing homes were that the data material from different contexts in Scandinavia strengthens the entire study's theory-generating potential of the larger study, as well as the methodological approach (Lindholm et al. (2006). Additionally, every researcher has been educated within caring and nursing science, and was additionally experienced as researchers.

Findings

The findings of this study revealed two main themes: one should treat others in ways that one would like others to treat oneself (I), and uneasiness due to indignity (II). The interpretation of the narratives regarding human dignity was understood as the scriptural command "to do unto others as you would be done unto" in accordance with the Bible

(Lukas 6.31, Matthews 7, 12). This Bible quotation is in accordance with the golden rule which is similar in every culture and all religions. The narratives given by the family caregivers indicated situations of individual respect (being seen and confirmed), confidence (the little extra), security (safety and prosperity) and charity (in a warm and friendly atmosphere), all values belonging to this scriptural command. In agreement with the ICN Code of Ethics for Nurses, nurses should provide care that respects human rights and provide sensitivity to values and safety (ICN 2011).

The participants' comprehension of the concept of dignity was in line with central research on dignity within the care of elderly. The most common descriptions of the inner and absolute human dignity among the family caregivers were individuality, respect and integrity which are highlighted in the literature (Dale et al. 2011, Jacobsen & Sørli 2010, Cochrane 2009, Randers, Olson & Mathiasson 2004, Woolhead et al. 2004 Walsh & Kovanko 2002, Edlund 2002, 2003, Bredland et al. 2002, Nåden 1999, Eriksson 1996). When the body loses its ability or capacity to meet its own demands, the person may contemporarily experience being in need for help. In other words, an indigent fragile body challenges individual experiences of freedom and significance. Therefore, and in accordance with Edlund (2003), serving persons require unlimited liability. Some narratives however, balanced the antagonism between paternalistic care as a result of the elderly's physical needs for help or fluctuating cognitive capacity and autonomy. In accordance with Christoffersen (1977), unconditional human dignity can never be the reason for the ability or possibility of independency. What a person *is* can never be comprehended as a product of what the person concerned *does*. The basic equality between humans means that nothing can make one person more valuable than another. Human worth is absolute (Edlund 2002) but the ability to make decisions is contextual (Jacobsen, Sorlie 2010). The concept of autonomy is based on

individuality and respect and is the most important value in caring (Nortvedt 2012) and the basic assumption in the golden rule. In addition, Edlund also emphasises the importance of inner individual freedom and dignity (2003) when illness and suffering are inhibiting external dimensions of life. However, if this shift of perspective does not occur, contextual experiences will change from dignity to indignity, in agreement with Edlund (2003).

Concerning the relative aspect of human dignity, some narratives illuminated longings for professional protection and kindness on behalf of both the residents and the caregivers. The fundamental issue in the text concerning their wish for protection and kindness towards themselves or towards residents was not the actions themselves, in the sense of method or technique, but rather how, or in what way, activities were performed or carried out. The essence of the outside perspective was by that means not the tasks or obligations as is, but the way things were performed, narrated as 'the little things', yet carrying the meaning *main things*. The families' desire for emotionally sensitive care and not just for technically competent performance of tasks was also found by Duncan & Morgan (1994). Robinson et al. interviewed twenty-nine family members (2010) and results pointed to the importance of relationships in creating a homelike environment with a relational orientation. The need for belonging and being appreciated is basic to all humans. But when dependency on other people seems to constitute a limitation of both freedom, and autonomy, and when vulnerability is aroused by a system error like paternalism and ignorance, the result is experiences of desperate loneliness and powerlessness (Jacobsen & Sorlie 2010). System errors were frequently narrated among the family caregivers at nursing homes in Scandinavia and were also a main reason for their uneasiness.

The concept of uneasiness is understood as a sort of suffering; like a discomfort in the body or mind, trouble or anxiety or as confusion, disturbance, interruption, worry, alarm, gnawing, apprehension or a burden (Oxford Advanced Dictionary of Current English). A quality study of the residents' life in nursing homes uncovered significant suffering due to profound losses, like the loss of home, most possessions, privacy, control and capacity, activity and autonomy, which again resulted in the loss of personal meaning among the residents (Forbes-Thomson, Gessert 2006). Experiences of sorrow, guilt and despair were narrated by the participants in this study. Patients and their families belong together in the sense that when the patients are in suffering, their family caregiver suffers as well. Family caregivers experienced dependency and vulnerability due to relative aspects of dignity and indignity at the nursing homes. The uneasiness was also caused from observed incidents of disrespect and violation towards the residents at the nursing home. Such situations often ended up in different dilemmas including situations involving anxiety, ignorance and disappointments on behalf of their family member as well as feeling insecure about the staff. Injustice creates mistrust, according to Løgstrup (1991). Poor relationships between the family and the staff seemed to occur when uncertainty and distrust arose between the staff and the families, according to Hertzberg and Ekman (2000). Abrahamson et al examined the influence of conflicts between the nursing home staff and family members, which indicated that conflicts with family members increased staff burnout and decreased staff satisfaction (2009). These studies indicate the importance of relation-centered approaches to prevent the threat of a vicious cycle.

Nursing homes are professional health institutions, encompassing vulnerability and dependency, which indeed require complex ethical attitudes (Jacobsen & Sørli 2010). In this Scandinavian study, written from the position of the relatives, we found narratives involving

ignorance, inexcusability, sorrow and despair. Unpredictability and lack of information was a common experience, which at the same time expressed an antagonism of interest. Family caregivers had no formal power to decide and they were all dependent on the system. Different types of relationships between family and staff was identified as collegial, professional, friendship, distanced and stressful, or as collaborative or carative relationships, according to Austin et al. (2009). Relationships in caring should involve security, belonging, continuity, purpose and significance, according to Davies et al. (2004). The authors emphasises that the family caregivers should feel confidence, maintain valued relationships as well as to maintain dignity and integrity. Dialogical ethics involves a learning process in which participants require openness and engagement to acknowledge one's own limits and to change in interactions through development of new and richer understanding (van der Dam et al. 2011). Different types of relationships were identified and narrated by participations in this study.

Relational ethics, or relative, according to Edlund (2002), involves attempts to understand the other's situation, perspective and vulnerability, and require a true engagement with the other, according to Austin et al. (2009). This may indicate a need for stronger ethical attention in nursing homes and an evident focus on dignity. Relatives may assume a responsibility that they do not want but that they feel obliged to take to ensure that their family member receives help. However, conflicts that arise may also be caused by misunderstanding (Dreyer, Førde & Nortvedt 2009, 11). According to an extensive literature review, empirical research on ethics in nursing care for older people seems to be fragmented, multifaceted and focused on selected ethical concepts arising in particular areas rather than from a fundamental knowledge base from which continuous development can proceed (Suhonen et al., 2010). These findings contributed to the identification of gaps in nursing knowledge and understanding, which

might be of great contextual importance for the future. Few studies focus on older patients' relatives, though both patients and their families are captured in the system in different ways. Therefore the question of what should be the proper role of the family in caring for older should be addressed.

Conclusions

This study of family caregivers' experiences in the context of nursing homes highlights narratives on human dignity and uneasiness due to violation. The main reason for dignity, spoken by the family caregivers, illuminated situations of respect, confidence, security and charity, in accordance with the golden rule and in agreement with the ICN Code of Ethics for Nurses. Uneasiness occurred when indignity was experienced, which again arose the conflicts between the family and the staff, usually on behalf of the residents. A main issue of the conflicts, from the perspective of the relatives, was the different types of relationship and the attitudes at the nursing home. Family caregivers' are in a unique position to express their experiences from their outside perspective, in the context of nursing home. Based on this study, it seems important to further investigate family caregivers' experiences of uneasiness due to sorrow, guilt and despair in nursing homes, to promote dignity and confidence in the care of the elderly.

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References

- Abrahamson, K., Suito, J. J. & Pillemer, K. (2009). Conflicts between nursing home staff and residents' families. *Journal of Aging and Health*, 21 (6), 895-912.
- Austin, W., Goble, E., Strang, V., Mitchell, A., Thompson, E., Lantz, H., Balt, L., Lerner, G. & Vass, K. (2009). Supporting relationships among family and staff in continuing care settings, *Journal of family Nursing*. 15, 360-82.
- Bolmsjö, I.Å., Sandman, L., & Andersson, E. (2006). Everyday Ethics in the care of elderly people. *Nursing Ethics*, 13 (3), 249-63.
- Bredland, E.L., Linge, O.A. & Vik, K. (2002). *Det handler om verdighet: ideologi og praksis i rehabiliteringsarbeid*. (It is all about dignity; ideology and practice in rehabilitation work) Oslo: Gyldendal Akademisk.
- Edlund (2002). *Människans värdighet – et grundbegrepp inom vårdvetenskapen*. (Human dignity – a basic caring science concept). *Doctoral thesis*. Åbo: Åbo Akademis Förlag.
- Edlund, M. (2003). Värdighet i et kliniske perspektiv. (Dignity in a clinical perspective). In: Eriksson, K. & Lindström, U. (eds) *Gryning II Klinisk Vårdvetenskap (Clinical Caring Science)*, 123-45.
- Christoffersen, S.A. (1997). *Handling Person Samfunn (Activity Person Society)* Otta: Tano-Aschehoug.
- Cochrane, A. (2010). Undignified Bioethics. *Bioethics*, 24 (5), 234-241.
- Dale, B., Sævareid, H.I., Kirkevold, M. & Söderhamn, O. (2011). Older home-living patients' perceptions of received home nursing and family care. *Nordisk sykepleieforskning*, 3 (1), 219-235.
- Dreyer, A., Førde, R. & Nortvedt, P. (2011). Ethical decision-making in nursing homes: Influence of organizational factors, *Nursing Ethics*, 18, 5-14. doi: 10.1177/0969733011403553

- Duncan, M. T. & Morgan, D.L. (1994). Sharing the caring: Family caregivers' views of their relationships with nursing home staff. *The Gerontologist*, 34 (2), 235-244.
- Eriksson, K. (1996). Om människans värdighet. (On human dignity). In: Bjerkreim, T., Mathisen, J. & Nord, R. (eds) *Visjon, viten og virke* (Vision, knowledge and profession). Oslo: Universitetsforlaget.
- Forbes-Thompson, S. & Gessert, C.E. (2006). Nursing homes and Suffering: Part of the Problem or Part of the Solution? *Journal of Applied Gerontology*, 25, 234-51.
doi:10.1177/0733464806288561
- Gallagher, A. (2004). Dignity and respect for dignity – two health professional values: implications for nursing practice. *Nursing Ethics*, 11 (6), 587- 329.
- Gallagher, A., Li, S., Wainwright, P., Jones, I.R. & Lee, D. (2008). Dignity in the care of older people – a review of the theoretical and empirical literature. *British Medical Nursing*, 11, 7-11. doi:10.1186/1472-6955
- Hertzber, A.& Ekman, S. (2000). “We, not them and us”. Views on the relationships and interactions between staff and relatives of older people permanently living in nursing homes. *Journal of Advanced Nursing*, 31, 614-22.
- Jacobsen, R. & Sørlie, V. (2010). Dignity of older people in nursing home: Narratives of care providers. *Nursing Ethics*, 17(3), 289-300. doi: 10.1177/0969733009355375
- Juritzen, T. I. & Heggen, K. (2009). Produktive maktpraksiser i sykehjem. (Productivity power practising in nursing homes). *Tidsskrift for velferdsforskning*, 12 (2), 94-104.
- Kalb K.A. & O'Connor -Von S. (2007). Ethics education in advanced practice nursing: respect for human dignity. *Nursing Education Perspectives* 28, (4), 196-202.

- Lindholm, L., Nieminen, A. L., Mäkelä, C., Rantanen-Siljamäki, S. (2006). Clinical application Research: A hermeneutical Approach to the Appropriation of Caring Science. *Qualitative Health Research* 16 (1), 137-150.
- Løgstrup, K.E. (1991). *Den etiske fordring*. (The ethical request). Copenhagen: Nordisk Forlag A.S.
- Nolan, M. R., Davies, S., Brown, J., Keady, J. & Nolan, J. (2004). Beyond 'person-centered' care: a new vision for gerontological nursing. *Journal of Clinical Nursing*, 13 (3), 45-53.
- Nortvedt, P. (2012). *Omtanke (Concideration)*. Oslo: Gyldendal Akademisk / Oxford Advanced Dictionary of Current English.
- Randers I., Olson, T. H. & Mathiasson, A.C. (2004). Confirming older adult patients' views of who they are and would like to be. *Nursing Ethics*, 9 (4), 416-431.
- Ricoeur, P. (1976). *Interpretation Theory. Discourse and the Surplus of Meaning*. Fort Worth: Texas Christian University Press.
- Ricoeur, P. (1981). *Hermeneutics and the Human Sciences*. (J.B. Thompson, ed. and transl.). Cambridge: Cambridge University Press.
- Ricoeur, P. (1999). *Eksistens og Hermeneutikk (Existence and Hermeneutics)* (Ystad, H.H. transl). Oslo: Aschehough & Co.
- Robinson, C.A, Reid, R.C & Cook, H.E. (2010). A home away from home: The meaning of home according to families of residents with dementia. *Dementia*. doi: 10.1177/1471301210381679.
- Shotton, L. & Seedhouse, D. (1998). Practical dignity in caring. *Nursing Ethics*, 5 (3), 246-255.
- Suhonene, R., Stolt, M., Launis, V. & Leino-Kilpi, H. (2010). Research on ethics in nursing care for older people: A literature review. *Nursing Ethics*, 17 (3), 337-52. doi: 10.1177/0969733010361445

- Van der Dam, S., Abma, T.A., Molewijk, A.C, Kardol, M.J.M, Schols, & J.M.G.A.,
Walsh, K. & Kovanko, I. (2002). Nurses' and patients' perceptions of dignity. *International Journal of Nursing Practice*, 8, 143-151.
- Widdershoven, G.A.M (2011). Organizing moral case deliberation experiences in two Dutch nursing homes. *Nursing Ethics*, 18 (3), 27- 40. doi: 10.1177/0969733011400299
- Woolhead, G, Calnan, M., Dieppe, D. & Tadd, W. (2004). Dignity in older age. What do older people in the United Kingdom think? *Age and aging*, 33, 2, 165-70
- Yrkesetiske retningslinjer for sykepleiere (2011). (The ICN Code of Ethics for Nurses).