

# **Dignity Work of Older Women Caring for a Husband with Dementia at Home**

## **ABSTRACT**

In this study, we explored perceptions of dignity, and sources preserving dignity of six older Norwegian women caring for a home-dwelling husband with dementia. Through hermeneutic interpretation of in-depth interviews, ‘having personal integrity’, ‘mastering everyday life’, and ‘giving of one self’ were identified as crucial intrapersonal aspects of dignity – while ‘acknowledging worthiness and uniqueness of each human being’ was found to be an essential interpersonal aspect. Nine dignity-preserving sources identified suggests that the wives engaged in ‘dignity work’ to preserve their own dignity as a caregiver, as well as to safeguard the dignity of their husbands who were vulnerable to dignity loss.

**Keywords** Dignity, caring, wives, husbands, dementia

In some countries, marriage vows explicitly refer to caring for one’s partner ‘for better or worse, in sickness and in health.’ When a husband receives a diagnosis of dementia there is likely to be an expectation that his wife will honor such a promise to care for him. Whilst there has been a good deal of attention to the dignity of care recipients with dementia (Tranvåg, Petersen & Nåden, 2013; 2014a; van Gennip et al., 2014), there has been little attention to the dignity of family caregivers. In this qualitative study, we set out to remedy this research gap by giving voice to, and listening to, the generally unexplored perceptions of dignity among older women caring for a husband with dementia at home. Such knowledge is important in order to improve interdisciplinary caring practice, emphasizing dignity-preserving care for these caregiving wives.

## **Background**

Dementia is a condition characterized by progressive and irreversible cognitive decline with no curative treatment as of yet (World Health Organization, 2017). Many people living with dementia retain positive personality traits and personal attributes. However, memory loss, confusion, language impairment and self-neglect are common illness-related challenges which make activities of daily living gradually more demanding for those affected (National Institute for Health and Care Excellence, 2006, updated 2016). Worldwide, approximately 50 million people are living with dementia, projected to rise to 82 million in 2030 and 152 million in 2050 (World Health Organization, 2017). Estimates show that in developed countries around two thirds of people with dementia live at home (Alzheimer Disease International, 2015).

People experiencing dementia develop increased need for quality care as their illness develops from mild to moderate and advanced levels. Dementia thus influences the lives of the informal caregivers – in particular the person with the primary role of providing everyday care. Although public care today is supplemented by care services delivered by private enterprises and voluntary organizations, family caregivers still remain the cornerstone of the provision of dementia care (World Health Organization and Alzheimer’s Disease International, 2012; Alzheimer’s Society, 2014). From an economic perspective, unpaid informal caregiving constitutes a crucial cost-reducing component within dementia care (Wimo, Winblad & Jönsson, 2007).

A cultural expectation exists assuming that women will take on caregiving roles within the family (Godfrey & Warshaw, 2009). Women spend more time on caregiving than men (Kim et al., 2012, Friedemann & Buckwalter, 2014), and number of hours devoted to caregiving is found to be a significant predictor of caregiving burden (Kim et al., 2012). Global Alzheimer’s and Dementia Action Alliance (2017, p. 23) argue that; “dementia should be seen as a global women’s health, social care and rights issue”. The needs of women caring

for a person with dementia are extensive and varied, and they need to be supported and acknowledged. Thus, health policies must be established ensuring that the interdisciplinary healthcare workforce is skilled and knowledgeable about how to support these caregiving women (Erol, Brooker & Peel, 2016).

Around two thirds of primary caregivers are women, and most of them are spouses (World Health Organization and Alzheimer's Disease International, 2012; Alzheimer Disease International, 2015). Caring for a home-dwelling spouse with dementia involves dealing with multiple tasks as the condition progresses. Initially, support for activities of daily living such as household, social activities and financial assistance – expanding to personal care support in additional personnel – and in the course of time, continual supervision assistance (World Health Organization and Alzheimer's Disease International, 2012). While wives define spousal caregiving for a husband with dementia as an extension of their existing household activities (Calasanti & Bowen, 2006), caregiving husbands more often utilized formal in-home services (Sun et al., 2008). Spending more time on caring activities, and often having a more burdensome emotional reaction pattern, have been identified factors making female spouses particularly vulnerable to caregiver burden and strain (Friedemann & Buckwalter, 2014). Due to lack of knowledge about dementia, and what causes their husband's changing behavior, caregiving wives may experience loss of control and incomprehensibility during early phases of their new life-situation (Potgieter & Heynes, 2006). Research comparing caregiving female and male spouses, as well as female and male adult children, identifies female spouses as the most vulnerable group – experiencing more burden, depression, and less optimal physical health than the other groups (Friedemann & Buckwalter, 2014). Additionally, older female spouses living in the same household with the person cared for have reported higher caregiver burden than other informal caregivers (Kim et al., 2012).

Caregiving wives may experience how identity changes in their husbands influence their own marital perception and identity – leading to disruption of their marital closeness (Boylstein & Hayes, 2012). Love, commitment and the desire to repay are suggested as core components of motivation among women caring for a family member with dementia (Dunham & Cannon, 2008). Caregivers with positive perceptions concerning their role are less likely to report depression, burden or poor health (Cohen et al., 2002), and more likely to continue providing homecare for the person with dementia (Mausbach et al., 2004). While experiencing spousal love, compassion and support help preserve dignity of married persons with dementia (Tranvåg, Nåden & Petersen, 2014b), knowledge of crucial sources preserving dignity experience among older wives caring for a home-dwelling husband with dementia is limited.

### **Study rationale and aim**

Dementia disproportionately affects caregiving wives, generating a need for increased knowledge on what dignity means to them and how it can be preserved in their everyday life. Such improved understanding can support interdisciplinary caring practice, policy development and research specifically relevant to the numerous older wives caring for a home-dwelling husband with dementia. In this present study, our aim was to explore and describe perceptions of dignity and sources preserving dignity experience among older women caring for a home-dwelling husband with dementia. The following research questions were addressed: (1) How do older women caring at home for a husband with dementia describe their perception of dignity? (2) Which aspects are crucial sources preserving everyday dignity experience among older women caring at home for a husband with dementia?

## **Methods**

An exploratory design employing qualitative interviews was chosen since this is an advantageous approach when investigating the manifestation and underlying processes of a distinct phenomenon where knowledge is limited (Polit & Beck, 2010; Brink & Wood, 1998). The study was founded upon Gadamer's philosophical hermeneutics (2004), in which interpretation is fundamental for developing new understanding.

### ***Pre-understanding and theoretical framework***

Researchers' pre-understanding should be available to increase study transparency (Hiles & Čermák, 2007) and trustworthiness (Polit & Beck, 2010; Lincoln & Guba, 1985; Guba & Lincoln, 1994), to help the reader identify the interpretive context. Regarding the authors of this article, we had both similar and different preconceptions regarding female spouses' dignity perceptions. All three authors had contributed to scholarship and research relating to dignity and care, as well as sharing a commitment towards care that respects the dignity of both caregiver and care recipient. However, the gender focus of this paper – female caregiver and male care recipient in a heterosexual marriage – led to some different foci. AG was drawn to insights from dignity scholarship and research in relation to caregiving whereas OT and DN were anchored in the understanding of dignity as an ontological and ethical aspect of humanity, in addition to a core concept of caring practice as well as a fundamental value in caring science.

There is an abundance of literature relating to the meaning and implications of dignity in care. A summary review containing a portion of this was presented in the journal *Nursing Ethics* in 2013 (Nåden, Råholm Lohne & Eriksson, 2013). Before discussing three theoretical perspectives with the potential of casting light upon this topic, we offer some working definitions that have appeared in the nursing literature. In their report 'Defending Dignity:

Challenges and Opportunities' (by Leslie Baillie, Ann Gallagher & Paul Wainwright) the Royal College of Nursing, UK. (2008, p. 8) suggested the following:

Dignity is concerned with how people, think, feel and behave in relation to the worth or value of themselves and others. To treat someone with dignity is to treat them as being of worth, in a way that is respectful of them as valued individuals.

Another formulation of patient dignity, derived from empirical data, is by Baillie (2007, p. 247):

Patient dignity is feeling valued and comfortable psychologically with one's physical presentation and behavior, level of control over the situation, and the behavior of other people in the environment.

The idea of feeling and being valued are important elements of both these definitions on dignity.

Three theoretical perspectives on dignity we considered to best illuminate the area of 'caregiving wives of husbands who have dementia' were: Nordenfelt's four varieties of dignity; Gallagher's self-regarding and other-regarding dignity; and Woodruff's perspective on dignity and dementia:

The first perspective, 'the four varieties' or types of dignity as described by Nordenfelt (2009) are: dignity as merit; dignity as moral stature; dignity of identity; and *Menschenwürde*. *Dignity of merit* is a special dignity that comes from a person holding a special role or status, for example, the dignity of a monarch or a judge. This variety of dignity can be lost, however, if the person should do something shameful. People might refer to 'a fall from grace'. The second variety of dignity is *dignity of moral stature* and this is bestowed on a person earning value by good deeds, for example, a leader who has self-respect and who is motivated by ethical ends. An example might be someone such as the late Nelson Mandela, a person

admired for his ethical standing. *Dignity of identity* is the third variety of dignity and relates more to the subjective aspect of dignity, what it is that enables the person to feel that they are able to express their identity and to feel valued. Disrespect by others can result in dignity of identity being compromised and in an individual feeling embarrassed, humiliated and devalued as a person. The fourth and final variety of dignity, described by Nordenfelt, is *Menschenwürde* or ‘human dignity’ relating to a more objective or universal perspective. Humans have this type of dignity solely by being human. They have no need to do or prove anything and it cannot be taken from them, regardless of the behavior of others (Nordenfelt, 2009). It has been argued that the two most important varieties of dignity inherent in care work are dignity of identity and *Menschenwürde* (Wainwright & Gallagher 2008).

The second perspective on dignity is from early scholarship by Gallagher (2004). She argued that dignity should be considered as a two-pronged professional value – as a subjective value directed towards self, related to self-respect, and as a value directed towards ‘respect for dignity’ inherent in others. This perspective is helpful in drawing attention to a potential reciprocal relationship between self-regarding and other-regarding dignity which may manifest itself in care relationships. A third and complementary ‘two-tiered model of dignity’, from our perspective, proposed by Woodruff (in Scarre, 2016, p. 225-245) who writes of:

[...] *a basic dignity* possessed equally by all members of a species, and a *refined dignity* requiring individual effort and social support to exercise one’s species-specific capacities (p. 230).

Woodruff suggests also a conception of human dignity which ‘is grounded in the possession and exercise of the capacities to create meaningful lives for ourselves’ (p. 232). Another distinction made by Woodruff, which is helpful as we consider dignity in relation to care of people who experience dementia, is between two selves: the ‘then self’ (prior to dementia) and the ‘now self’ (after the onset of dementia). We will return to these perspectives in the

discussion. We shall now examine the details of study participants, data collection, interpretation, and ethical considerations, before presenting the findings.

### ***Participants***

Participants were recruited from two Norwegian Hospital Memory Clinics, where neither affiliated with our research team. Medical doctors responsible for diagnostic examinations and follow-up treatment of the participants' husbands, in cooperation with clinical nurses, assisted with participant recruitment. Utilizing a strategic sampling strategy we formulated the following inclusion criteria: Women caring for a home-dwelling husband diagnosed with mild to moderate dementia; aged 60 years or older; living at home together with the husband; speaking a Scandinavian or English language; willing to be interviewed concerning dignity experiences as a caregiving wife. Six Norwegian women aged 61 to 81 participated in the study.

### **[Insert Table 1 Caregiving wives – socio-demographic data](#)**

### ***Data collection***

Qualitative research interviews (Brinkmann & Kvale, 2015) were carried out in the caregiving wives' home. We used a modifiable interview guide to structure the interviews, including the following main questions: Please tell me what dignity means to you? How may your dignity be preserved – in everyday life? What brings dignity experience into your current life situation? How do other people affect your experience of dignity? Can you describe a situation in which your sense of dignity was preserved through interactions with others? Can your dignity be preserved when interacting with healthcare professionals (HCPs)? Can you tell me about a situation where HCPs helped preserve your dignity? Based on active listening to participants' reflections, follow-up questions were posed – adding further depth and richness into the data collection. All interviews were recorded on an MP3 recorder. One



interview was carried out with each participant, lasting from 53 to 125 min (mean = 83.5 min), constituting 184 transcribed interview-text pages available for analysis.

### ***Interpretation***

The hermeneutical interpretive process was initiated by reading and reflecting upon each interview-text, while keywords and phrases were noted during each reading.

While dialoguing with the various parts of the text, and the text as a whole, awareness of personal preconception guided us toward critically identifying and understanding the text as well. Each new interview-text made those already explored more understandable, while simultaneously adding new meaning of their own. Emerging patterns of meaning, data inconsistencies and contradictions were also explored. The essence of each account was identified, investigated and formulated into themes and sub-themes. This process of hermeneutic circle expansion, moving back and forth – from the parts to the text as a whole (Gadamer, 2004) – helped us move beyond our pre-understanding gaining new understanding of the subject under investigation.

### ***Ethical considerations***

In recruiting caregiving wives as study participants, sensitivity toward preserving their integrity and dignity was essential for us as researchers. Following the ethical standards for medical research involving human subjects, formulated in the Declaration of Helsinki (The World Medical Association, 2013) these ethical principles, alongside with moral sensitivity to their vulnerability, doing no harm, showing justice and respecting their personal utility, guided our research. All participant provided informed consent after receiving verbal and written information of all aspects of the study, including their rights to withdraw without any consequences. Each of the caregiving wives received a copy of the interview-guide containing ten main interview-questions to help increase their understanding of the interview and strengthen their position to either accept or decline to participate. Each participant decided

whether the interview should be conducted in their own home or at the researcher's office. As researchers, we assumed responsibility for ensuring participant anonymity and confidentiality, and to communicate the study results in an appropriate language style toward preserving the dignity of each participant (The World Medical Association, 2013). The study received ethical approval from South-East Regional Committee for Medical and Health Research Ethics, Norway.

## **Results**

### *Caregiving wives' perceptions of dignity*

We identified four crucial aspects constituting dignity as perceived by the caregiving wives: *Having personal integrity*; *Mastering everyday life*, and; *Giving of oneself* were identified as intrapersonal (internal) aspects, while *Acknowledging the worthiness and uniqueness of each human being* were found as an interpersonal (relational) aspect by nature:

#### *Having personal integrity*

First, on the intrapersonal or internal level, the caregiving wives perceived dignity as related to the quality of conducting personal self-observation and self-reflection concerning one's own choices and actions. Dignity was also affiliated with personal self-care, positive self-presentation as well as being a fair and open-minded human being – all identified as vital aspects of personal integrity:

Being aware of one's own actions, how far a person is...is willing to go... to be open minded and fair...not only concerning one's words and actions, but also in taking care of oneself...dressing properly...and putting your best foot forward (...) behave in an orderly manner. This means so important for dignity.

### *Mastering everyday life*

The caregiving wives' dignity perspective was also related to having the power and means to accomplish their plan for the day. In daily living, this involved caring for their husband and home – according to their personally defined plan and responsibilities:

To be able to accomplish...my tasks for the day...is of great value to me, both in caring for him (husband) and necessary household chores.

Second, on the interpersonal or relational level, the women's perceptions of dignity were founded upon certain values and standards constituting dignified human relationships:

### *Giving of oneself*

Another vital aspect of dignity was related to giving of oneself willingly – based on genuine love and concern for other people. When this level of compassion for fellow beings exists, intrapersonal dignity was present:

Doing that which is praiseworthy...must also be part of dignity as well... to help others feel appreciated... that my small gesture assists another's wellbeing.

To have the opportunity to do something for the one you love, it means so very much – this, I believe, is dignity.

### *Acknowledging the worthiness and uniqueness of each human being*

Dignity was also perceived as a quality enabling human beings to see, accept and confirm one another as worthy individuals, by virtue of being human. Being allowed to be the person you are was identified as vital for preserving one's personal identity, preventing personal alienation, enhancing experience of respect and equality – all vital aspects of caregiving wives' interpersonal dignity perceptions:

Dignity is being able to be...to be who I am without being concerned about what others think... in a way it's being myself... without anyone attempting to defame my sense of dignity.

Moreover, mutual respect was perceived as an important feature of acknowledging the humanity of all. In their view, sharing respect for each individual was a crucial foundation for establishing dignifying relationships:

There is something very basic about being respectful towards one another ... dignity and respect are so closely connected.

[Insert Figure 1 Caregiving wives' perception of dignity](#)

The participants went on to detail strategies they utilized to preserve their intrapersonal and interpersonal dignity:

***Crucial sources preserving caregiving wives' intrapersonal dignity***

We identified three main sources vital for preserving their intrapersonal dignity:

*Experiencing personal growth; Maintaining aspects of continuity in daily life, and; Living in the moment:*

*Experiencing personal growth*

Doubling in roles as both wife and caregiver for their husband resulted in new and demanding personal challenges. Confronted by the husband's worsening health and increased vulnerability, the female caregivers became more conscious and reflective of their own behavior and performance. Many experienced greater personal growth and maturity during this time – with their human capacity as caregiver developing in positive ways, leading to increased experience of dignity on the interpersonal level:

I feel I have become very patient... one who has always been a little impulsive... now I feel I have become just that, and it's because of course...I do not want him to feel...burdened because of his forgetfulness.

Personal growth was experienced in relation to developing compassion for their husband's functional decline. In this process, the wives experienced that their personal sensitivity, as well as gentleness became more present in their relationship with the spouse – giving them a sense of intrapersonal dignity in everyday interactions with their husband:

You think more carefully over how you respond, and what you say ... when I repeat myself for the second or third time – I just continue as if I have not done so... I used to say things like 'Good Glory, I have already told you that before!' ... but it's been a long time since I stopped doing that.

The wives were in a life-situation where they experienced the gradual health decline of their husbands. Being a firsthand witness to this, and acknowledging the dramatic changes brought into their everyday lives, was demanding. This sometimes led to days marked by pessimistic thoughts – a negative development which influenced the dignity of their spouse as well. To prevent their daily lives from degrading, and uphold their intrapersonal dignity, the wives consciously tried to meet everyday challenges with a positive mindset:

To turn it to something positive ... I must concentrate to be able to watch my words and avoid sounding negative or accusing, so not to increase his burdens – then he feels better, and this is important to me.

#### *Maintaining aspects of continuity in daily life*

Experience of dignity were connected also to continuity in caring for one's own needs, interests and treasured personal activities in everyday life. For participants who were still

active in the workforce, the opportunity to continue at their jobs or careers was an important source of experience towards intrapersonal dignity in their daily lives:

To be able to continue at work... gives me a great deal of happiness... satisfaction.

Not because I do not enjoy being at home, but because I believe he... both of us benefit... with the way our situation is now – that I am not... that we're not in the same room 24 hours a day.

Allowing themselves to take part in meaningful daily activities was of great worth to them, contributing to maintain continuity in their lives – lives that in many ways were now constantly changing:

At my age... I am able to sew, have good eyesight and a steady hand. I feel a certain dignity... when I have sewn for my daughter-in-law, grandchildren and even my great grandchildren.

### *Living in the moment*

Their husbands dementia illness worsening and new challenges frequently immersing, these caring wives avoided wasting time and energy worrying about the future. They tried instead to take care of, and enjoy, positive experiences found here-and-now. This proved to be an important source for dignity experience in everyday life:

I try not to think too far ahead... to enjoy the present instead. I cannot worrying about what will happen a year from now, two years, three years, four years down the road... that only leads to negative thoughts.

Shared love, closeness and devotion to one another – encountering happy moments with the husband was important for their dignity experience of daily life:

Dignity for me is being able to be together with (husband's name), to share our lives together, this is my dignity at the present time ...the joy (husband' name) shares with me.

The caregiving wives went on describing crucial aspects preserving their interpersonal dignity:

***Crucial sources preserving caregiving wives' interpersonal dignity***

Within their spousal and social relationships, we identified three main aspects essential for their sense of dignity; *Being a good wife and good caregiver*, *Sheltering the husband's dignity*, and; *Experiencing true understanding*:

***Being a good wife and good caregiver***

Being attentive to their husbands, whose dementia illness required close attention was a caregiver task each of the participant wives identified as their own – as part of their marriage responsibilities. They felt it was important for them personally to fulfill these additional responsibilities in the best possible way for their spouse. Even though their tasks were tiring and time consuming, they mostly did not want to ask their children for help as *they* already had a busy life. The wives felt their responsibilities towards the husband meaningful – something they also felt an honor to do – and thereby also a source of experience towards interpersonal dignity in daily life:

They (their children) are worried about me wearing myself out... that I ought to engage homecare specialists, perhaps utilize a temporary care center for weekend help... and they have wanted him (her spouse) placed in a nursing home due to our current situation – but I cannot do it... and he has no desire for it either. There is

some... dignity... in my opinion it would be undignified of me not to be able to manage this.

### *Sheltering the husband's dignity*

Witnessing the increase in their spouses' vulnerability encouraged them to take on additional responsibility. Protecting the husband when his dignity was threatened became a central task in their daily lives. Although this often meant laying their own personal needs aside, the wives felt their attitudes and actions helped confirm their own dignity during this challenging time:

My concern is with his dignity. I utilize a great deal of time to preserve it, so that he receives the dignity he is entitled to, and, then, mine is not so important ... my dignity is very solid. We are supposed to care for one another, and that has become a part of me.

In their unfolding life-situation, the caregiving wives and their husbands had to determine whether they should inform others about the dementia illness or keep this information private. How other people would react to information about the dementia illness was a major question of concern for them. The common understanding among the wives was how this choice would affect their husband's dignity and their dignity as a couple:

He has Alzheimers. Alzheimers, this... this has a great deal to do with dignity... people will be looking at you in a completely different way... This is what dignity is all about. We want to be perceived as a well-functioning couple, yes ... still, this is a concern for him.

However, for some of the wives (and husbands), withholding information from others was not natural for them. In these cases openness concerning reality was perceived as dignity preserving since dementia was an illness and nothing they should be ashamed of:



In my opinion, one need not lose their dignity because of dementia ... and he is completely open about it, so it is not difficult for me to talk about it either, with our friends and acquaintances.

### *Experiencing true understanding*

The wives often experienced a sense of loneliness – feelings that no one could truly understand how they felt and what their daily lives entailed. The opportunity to attend discussion groups designed to help spouses prepare for some of the challenges associated with dementia gave them a unique opportunity to be acquainted with others who found themselves in similar situations. Sharing common experiences, fears and frustrations with another, become an important source of dignity-preserving empowerment for some, which helped reduce their experience of loneliness.

Sitting in groups of 6-7 (caregiving spouses), we were given the opportunity to chat with one another... it was there I became acquainted with one, and we have been in touch ever since, meet at restaurants, drink coffee, talk together; ‘oh yes, that’s my experience too’ ... ‘oh yes, I agree’. It has been an unexpected blessing.

The wives also outlined how their interpersonal dignity could be preserved in relational interactions with healthcare professionals:

### *Dignifying interaction with healthcare professionals (HCPs)*

Within their HCP interaction we identified three main sources essential for preserving their sense of dignity: *Experiencing HCPs’ genuine interest and compassionate care; Being a respected partner in dialogue, and; Receiving acknowledgement and encouragement:*

### *Experiencing HCPs' genuine interest and compassionate care*

In their challenging situation, meeting compassionate, positive, open minded and listening HCPs was very important. This helped them feel they were dealing with a healthcare system that had their best interests in mind, enabling them to find help and support. Building relationships in this manner encouraged confidence and a sense of greater safety – thus being an important relational source for strengthening their dignity experience:

You find certain HCP who strive to do their very best for you, find solutions they believe the patient will benefit from and make our lives together the best for me as well ... thoughtfulness ... real understanding for the situation at hand (...) open minded HCP with a good sense of humor, honest, compassionate, helpful ... someone you feel you can talk with about the most difficult things, and then receive a decent answer to your question. I need to feel the individual is interested in me personally... willing to listen to what I have to say, and what I desire to ask.

### *Being a respected partner in dialogue*

Dealing with HCPs who paid attention, who respected their inner need to participate in decisions concerning their present circumstances strengthened the caregiving wives sense of dignity in this crucial HCP-relation – experiencing the privilege of participating as an equal partner in dialogue with HCPs who acknowledged their prospective and need for autonomy:

HCPs should strive to understand how his illness affects him now, and ask my opinion about what is best for him – recognize you for what you are, without categorizing you in anyway – merely explain the possibilities, so I can understand and choose what I feel is best. They should never tell you what you must or must not do... of course they may make suggestions, but go no further; 'Here are your options:...?'

### *Receiving acknowledgement and encouragement*

The wives' efforts to facilitate their spouses' ability to function as best as possible were often acknowledged by the HCP responsible for the husband's treatment and follow-up. Supportive and laudatory comments helped strengthen their sense of dignity, as were acknowledging the wives as being valuable and appreciated:

I always get a little encouragement: 'And the two of you are able to care for yourselves, still?' I think this is positive. They know it, and I know that I can do it. It is very encouraging for me to hear that they are impressed with what I am able to accomplish ... that they acknowledge this means a lot that they understand, and for me, this is dignity.

[Insert Figure 2 Crucial sources preserving caregiving wives' intrapersonal and interpersonal dignity](#)

### **Discussion**

Our findings in this study illuminate a too often neglected perspective in health policies and within the interdisciplinary healthcare workforce; dignity and dignity in care – as perceived by older women caring for the husband with dementia at home. A central theme concerning interpersonal aspects of dignity, as perceived by the caregiving wives, was acknowledging the worthiness and uniqueness of each human being. Royal College of Nursing, UK. (2008), underline that dignity is about how people think, feel and behave in relation to the worth of value of themselves and others. There is something critical in this message; it concerns values of oneself and others, behaving to others in a way that you want them to encounter you. However, human beings are diverse – hence this does not mean that what is best for one individual is necessarily best for all. Royal College of Nursing, UK. (2008) point towards a very important aspect concerning dignity in addition to behaving, namely how people *think* in relation to the worth of values of others. This means, in our opinion, treating and respecting

others as unique individuals, even though their values or views differ from ones' own. This is how we interpret the message from our female participants as they share respect for others in a variety of ways. As a professional or family caregiver, these values are crucial and of utter importance for the art of caring, representing a living and caring presence (Nåden, 1997). In our understanding, this aspect of caring is revealed within the results in two ways, where the women focus, not only towards the other, in this case their spouse, but also towards their inner self, leading to meaningful, dignifying and personal growth. Through self-observation and being aware of one's own actions, they demonstrate personal integrity and the ability to be a good wife and caregiver, by preserving and promoting the dignity of their husband and their own dignity as well. Overall, such self-observation is not self-realization primarily for oneself. In our opinion, it is rather the opposite, turning away from oneself towards another, fulfilling their own standards where dignity is equivalent to giving of oneself. Promoting what is good (Nåden & Eriksson, 2004), the wives were able to give of themselves and strive for the best of the other – so their spouse might feel appreciated. The act of turning towards another human being is an active act, according to Lindström (1994). Preserving and promoting one's own dignity might seem as a prerequisite for this creative act. Calasanti and Bowen (2006) previously found that although time-consuming and emotionally draining, caregiving wives may find meaning and pride in enhancing the wellbeing of their home-dwelling husband with dementia, helping him maintain identity and sense of self.

Acknowledging the expression or appeal in the face of another, may be necessary to make oneself responsible, even though such a responsibility is fundamental to being human.

According to the philosopher Levinas, the expression on another person's face, not only in a figurative sense, makes the caregiver responsible (Kemp, 1992). In this present study, we believe the wives sense of responsibility to identify and recognize how dementia formed an appeal in the face of their husbands, enabled the women to live in the moment, share their

love, closeness and devotion; a dignifying source for encountering happy moments in the here-and-now.

Mastering everyday life was found to be a dimension of the wives' perception in dignity, and according to our interpretation connected with their need for maintaining continuity in daily living – a dignity-preserving source also expressed by the caregiving wives. However, mastering everyday life also promoted positive consequences for others, in this case the spouse. Attitudes and behaviors of others in the near proximity is important (Baillie, 2007), particularly when the person in need of help is so vulnerable. Previous studies have documented the vulnerability of persons living with dementia, how the gentleness and kindness of others, being attentive while recognizing their needs, are required from caregivers – in order to understand, as far as possible, the individual's situation (Tranvåg et al., 2014a; 2014b). In this present study, themes constituting the wives' perception of dignity, showing evidence through quotations, bear witness of these inherent qualities in the care of their spouse, where their compass seems to be the 'good and beautiful'. It is as if they are equipped with true wisdom and joy, working on an archeological scene, to use a metaphor (Nåden, 1997), defining the material-at-hand as fragile and vulnerable, easily destroyed. Both the archeologist, as well as the caregiver, must act with utmost prudence, so the phenomenon-in-hand be not fractured (Nåden, 1997; 2000). Through dignifying attitudes and behavior of this nature, the women seemed to live their intrapersonal ethos and responsibility, anchored in their personal integrity – letting their husbands feel valued and appreciated.

Our study findings regarding interpersonal and intrapersonal dignity resonate with definitions proposed in the Royal College of Nursing, UK. (2008), as well as Baillie (2007). The perspectives found among wives of those experiencing dementia were in step with insights suggesting: Dignity *'is concerned with how people, think, feel and behave in relation to the worth or value of themselves and others'* (Royal College of Nursing, 2008, p. 8), and;

dignity relates to *'feeling valued and comfortable psychologically with one's physical presentation and behavior, level of control over the situation, and the behavior of other people in the environment'* (Baillie, 2007, p. 247). The data illustrate how wives would take control of situations, for example, protecting their husband in situations where his dignity was threatened. It is not difficult to grasp the importance of Nordenfelt's (2009) exposition of 'Menschenwürde' or human dignity, afforded to all care recipients and caregivers, simply because they are human. It is clear from the data that wives viewed both themselves and their spouses possessed this fundamental worth or value. This perspective was apparent in their views and interpersonal dignity. More particularly, it is also not difficult to appreciate the subjective importance of Nordenfelt's 'dignity of identity' in relation to the care recipient whose identity is undermined by dementia. The role of the wife in reminding others of the value of his past and current identity seems crucial. Considering also the role of dignity as a self-regarding and other-regarding value, resonates with elements of this project's findings (Gallagher, 2004). The female caregiver has an important role in underlining the worth or value of her husband, regardless of the severity of his dementia. She also has to remind herself and others of her own value as a committed caregiver; a role too often devalued, considered a work that 'anyone' can do (Gallagher, 2017).

Woodruff's distinction (in Scarre, 2016), between 'basic dignity' and 'refined dignity' and between the 'then self' and the 'now self' helpfully illuminate the experiences of the wives who strive to preserve their own dignity and the dignity of their husbands. In our opinion, data supports the view that whilst all have basic dignity, the focus of caregiving were on the reclamation and sustainability of the 'refined self'. Strategies to keep the 'then self' and the 'now self' integrated as far as possible were realized through the development of creative communication strategies. This also shelters the husbands' dignity and can compensate the husbands' loss of health. In our judgement, the work to develop virtues such

as patience, gentleness and sensitivity (being ‘a good wife and good caregiver’), and their creative behavioral strategies designed to preserve the dignity of their spouses (for example observing and intervening whenever their husbands dignity were threatened), qualifies to be labeled ‘Dignity work’. Woodruff’s conception of human dignity *‘is grounded in the possession and exercise of the capacities to create meaningful lives for ourselves’* (p. 232) resonates with the wives’ efforts to maintain a valuable – dignifying – identity as conscientious caregivers.

Awareness of the difference their quality care makes is found to increase caregiver rewards among spouses caring for a partner with dementia (Savundranayagam, 2014). In this present study, the wives seem all too aware that the role of caregiver was both challenging and rewarding. Previous research documents that this group of caregiving wives focus on making sense of the situation, and maintain a positive outlook on daily living (Paun, 2003). In a recent systematic review, Quinn and Toms (2018) document that informal caregivers can experience positive aspects of providing care and that caregiving thus may have beneficial influence on their well-being. There is also some evidence suggesting that higher positive aspects of caregiving is associated with higher self-efficacy. According to Bandura (1982), self-efficacy relates to an individual’s belief in one’s own ability to achieve goals – a personal judgement of "how well one can execute courses of action required to deal with prospective situations" (Bandura, 1982, p. 122). Accordingly, in this study we found that the caregiving wives experienced positive aspects of caregiving – a beneficial influence on their self-efficacy and intrapersonal dignity, strengthening their belief in being able of giving of oneself to improve everyday life for the husband and themselves. In another study, Woolhead et al. (2004) found dignity as salient to the concerns of older people, and dignity of identity as a core dimension affecting their self-respect/esteem – as dignity affects the self. Being patronised, treated as an ‘object’, and excluded from decision-making, were identified as

crucial aspects leading to loss of self-esteem. Care researcher Eriksson (2006) argues that these aspects are examples of dignity-violation often experienced by vulnerable people. And importantly, when caregivers violate the dignity of the other, they also violate their own dignity. In our study, we found that treating their husbands, who were experiencing dementia, as worthy and beloved ‘subjects’ and involving them as equal partners in meaning-making decisions in everyday life, had positive consequences. This ‘Dignity work’ also helped preserve the wives’ own self-esteem, self-efficacy and intrapersonal dignity as these aspects are so closely related.

Caregivers’ positive self-regard, and life satisfaction, have also been linked with having the opportunity to talk about their caregiving efforts (Kaufman, et al., 2010). Based on the findings of this present study we argue that the wives’ self-esteem, self-efficacy and intrapersonal dignity may be strengthened when experiencing true understanding in a group of caregiving spouses at the Memory clinic. As reported by one of the participants, this helped her to maintain her dignity and reduce the sense of loneliness she had experienced beforehand. Although the other wives did not participate in such a group, it is important that caregiving wives receive an open invitation to join in whenever they feel for it, since their need for being part of a support group may develop later as the disease progresses. Additionally, with implication for interdisciplinary dementia care practice we argue that the wives’ self-esteem, self-efficacy and intrapersonal dignity were strengthened when experiencing HCP’s genuine and compassionate care, acknowledgement, encouragement, and the sense of being a respected partner in dialogue.

### ***Methodological considerations and study limitations***

The rich data obtained in this study originated from a participant group not previously consulted concerning dignity as caregivers. However, the study has several limitations; only six wives gave their consent to participate in the study within the 24-month timeframe set for



participant recruitment. Extending the recruitment period would have increased the possibility of recruiting a larger sample, which most likely would have added further breadth and depth to the empirical data. Restrictions in extending the recruitment period did however exclude this option. However, qualitative studies, even with small samples, can generate new in-depth understanding of phenomena we have limited knowledge of (Brinkmann, 2012). The participating wives were resourceful middle-class women, sharing well-articulated reflections. They seemed to master their present life-situation well, also aiming to reduce the worries and the amount of help from their children as *they* had busy lives of their own. However, it is important to stress that these wives had been caregivers for a relatively short period of time, from six months to three years, to husbands who had mild to moderate dementia and no need for community healthcare support like day care center or home based care. The only support received was the follow-up from the Hospital Memory clinic. The wives perceptions and behavior may therefore change with time – and as the disease progresses. It is also important to underline that caregiving wives not giving their consent to participate in this study, may have other experiences and feelings than those participated. Although we as researchers guided the medical staff to recruit a broad sample, there is a chance that the staff can have recruited wives they could see were coping very well in their current life situation, while leaving out those who were struggling and more vulnerable. The data may therefore give a biased perspective towards more resilient and resourceful wives, and the results cannot be generalized into a broader population of wives caring at home for a husband with dementia.

Although an interesting dimension, the number of wives who refused participating in the study were not recorded. As in most self-reporting research the phenomenon of presenting oneself in a more positive way in order to gain or maintain respect may also have occurred in this study. However, our participants were asked to describe their perception of dignity, as

well as the sources preserving their dignity in everyday life – questions asking them to describe their experiences of the positive aspects of caregiving.

It is possible that other female partners – married, unmarried, gay or from other more diverse groups – may have different perspectives on dignity-preservation in caregiving relationships. In future research, it is important to study the experience of caregiving wives in more severe stages of dementia, caregiving wives perceptions in other countries, as well as non-married co-habitant partners care for one another in the case of long-term severe illness. Male caregivers and people in non-heterosexual relationships also deserve equal consideration.

## **Conclusions**

The findings in this study give voice to a previously silent group. Their creativity and commitment towards dignifying caregiving for themselves and their husbands, is admirable. These were wives who, on the whole, coped extremely well with challenging circumstances. They responded to opportunities to improve the situations they and their husbands found themselves in, examples from which we believe others can learn. The data presents a strong argument for mutual respect between formal and informal caregivers. Caregiving described by the wives appears to be of a high ethical standard, enabling people experiencing dementia to live as well as possible. There would appear to be a scope of understanding for caregivers such as these, suggesting advice and support for partners also caring for spouses with dementia. The fact that the study participants were a self-selected group of wives, who had provided care for their husbands with mild to moderate dementia during a relatively short period, is an important contextual dimension to be considered as this may have had impact on the study findings. Regarding future research, in addition to studying the experience of more diverse caregivers, it would also be helpful to study the perceptions and obligations of partners from other cultures. We do not assume that all will be as diligent as the participants

in this study appear to be, in honoring their marital promise to care ‘for better or worse, in sickness and in health.’

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