Bachelor`s Thesis

Double Duty Caregiving

A qualitative literature review on nurses providing informal care to their relatives

Submitted by

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person except where explicitly defined in the acknowledgements.

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Abstract

Aim: The aim of this bachelor´s thesis was to explore the experiences of nurses being professional caregivers who provide informal care to their own relatives (Double Duty Caregivers). This paper describes which difficulties nurses had to face within their Double Duty Caregiving Role and the impact of Double Duty Caregiving on their personal lives and professional practice.

Method: This qualitative literature review used studies located by searching CINAHL, MEDLINE, Google Scholar, Google and ProQuest. 11 studies that met the inclusion criteria could be identified. Their findings were summarized and synthesized in this paper.

Results: Double Duty Caregiving was not confined to caring for elderly relatives only and rather expanded to caring for critically ill and dying family members and those with cancer-related illnesses as well. The double role of nurses was seen as a gift and a burden at the same time because of the nurses` specialized knowledge. The nurses in the studies concealed their own feelings to be able to provide emotional support to their relatives, partly with delayed emotional reactions or effects on their physical well-being. However, the majority of the nurses admit that the Double Duty Caregiving experience had shaped and had helped them to become better nurses.

Conclusion: The Double Duty Caregivers have different expectations and needs in respect of their specialized knowledge and status as health care professional. Health care providers can support Double Duty Caregivers by acknowledging their double role and assessing their wished grade of involvement in direct care. Managers, supervisors and colleagues can support Double Duty Caregivers by enabling them to reconcile their private and professional caregiving responsibilities and by enhancing their positive job-related experiences as the workplace may provide respite.

1 INTRODUCTION

The ageing of population is a great challenge for many countries throughout the developed and industrialized world. The United Nations (2013) predict that the number of older people (aged 60 years and over) will increase from 841 million people in 2013 to about 2 billion in 2050 worldwide whereas the number of working-age adults is already declining (p. XII). The reasons for this demographic trend lie within the increase in the number of older persons due to improvement in life expectancy and declining fertility in most regions of the world (pp. 3-6). The population pyramids in figure 1. illustrate the transformation from a predominately young population in 2013 to a rather aged population in 2050:

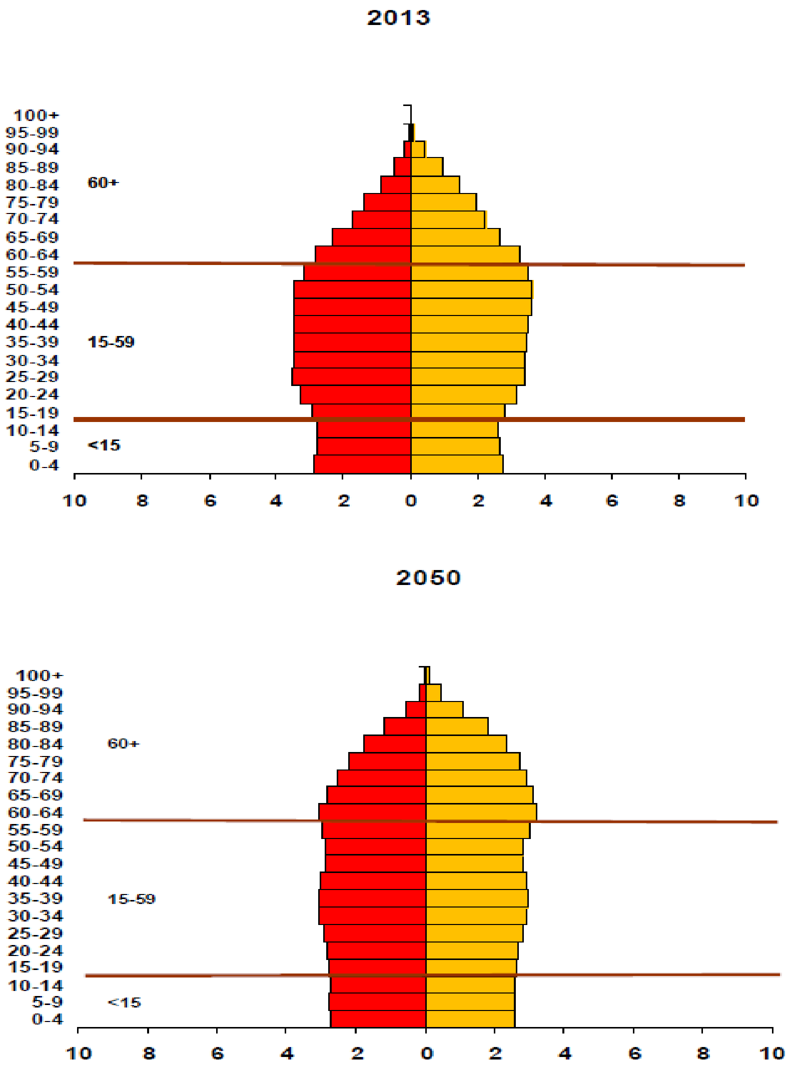


Figure 1: Population pyramid of more developed regions: 2013 and 2050: United Nations, World Population Ageing 2013

Ageing within the older population itself, meaning that the number of persons aged 80 years or over has increased as well, is another crucial aspect of population ageing. The WHO expects an increase of the “oldest age” group from 14 per cent in 2013 to 19 per cent in 2050.

However, higher life expectancy may also produce increased morbidity and years of disability and dependency (WHO 2011, pp.9-12). For example, an average of 85 per cent of older persons (aged 60 or over) worldwide died from non-communicable diseases, with more developed regions showing an average of 92 per cent. Non-communicable diseases are distinguished by their non-infectious cause and can refer to chronic diseases, such as cardiovascular diseases (heart-attack, stroke), cancer-related illness, respiratory diseases and diabetes (World Health Organisation, 2015). Non-communicable diseases are also attributable to 45 per cent of the adult disease burden, eventually causing higher demands on healthcare and hereby higher costs to the health care system (WHO 2008, p.47).

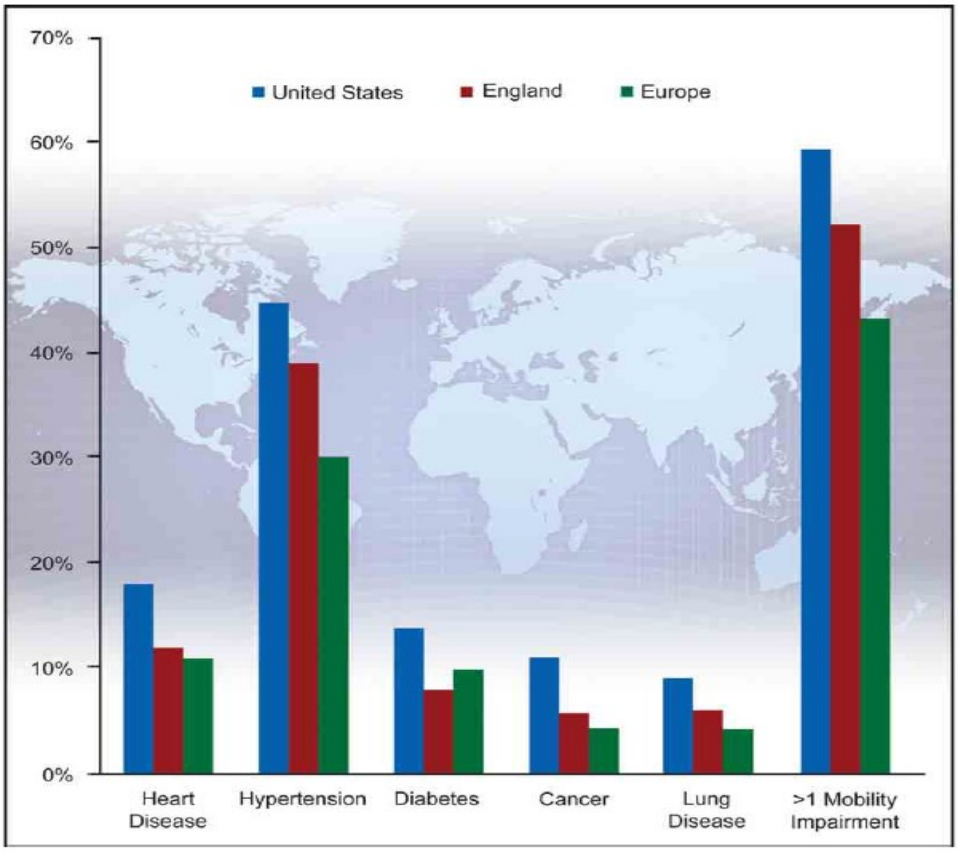


Figure 2: Prevalence of Chronic disease and disability among men and women aged 50-74 years in The United States, England and Europe: 2004: World Health Organization, 2011. Global health and ageing

Moreover, the demographic old-age support ratio, which is the number of working-age persons (aged 15-64) per older persons (aged 65 years and more), has been declining continuously from 12 working age persons for each older person in 1950 to 8 in 2013. It is expected to decline to 3 producers per older persons in 2050 in Europe, Northern America and Oceania (United Nations, 2013). Given this data, ageing may have a great sociological, economic and financial impact on the cost of health care systems. Fortunately, "the majority of the health expenditure is covered by social insurance schemes" (United Nations 2013, p. 48), but recently, health care providers and their clients are confronted with increasing cuttings in health care systems, which will have severe impacts on the services available, resulting in a higher dependence on families to assume the task of informal care

1.1 Informal care is female

Informal care is defined as unpaid care provided by relatives or friends and represents the most performed kind of long-term care throughout the world (WHO, 2003). Triantafillou et al. (2010) who conducted a European report on informal care, define informal caregiving as "care mainly provided by family, close relatives, friends or neighbours" (p.11), who are rather non-professional, do not have contracts concerning caring responsibilities, nor receive a salary for the care they provided. The reasons for adopting informal caregiving roles may lie within a sense of family obligations, driven by tradition and moral values, and in many cases is an issue of personal consideration, with focus on feelings of meaning, purpose and reciprocity (WHO, 2013).

The tasks of informal caregivers can be divided in three different groups:

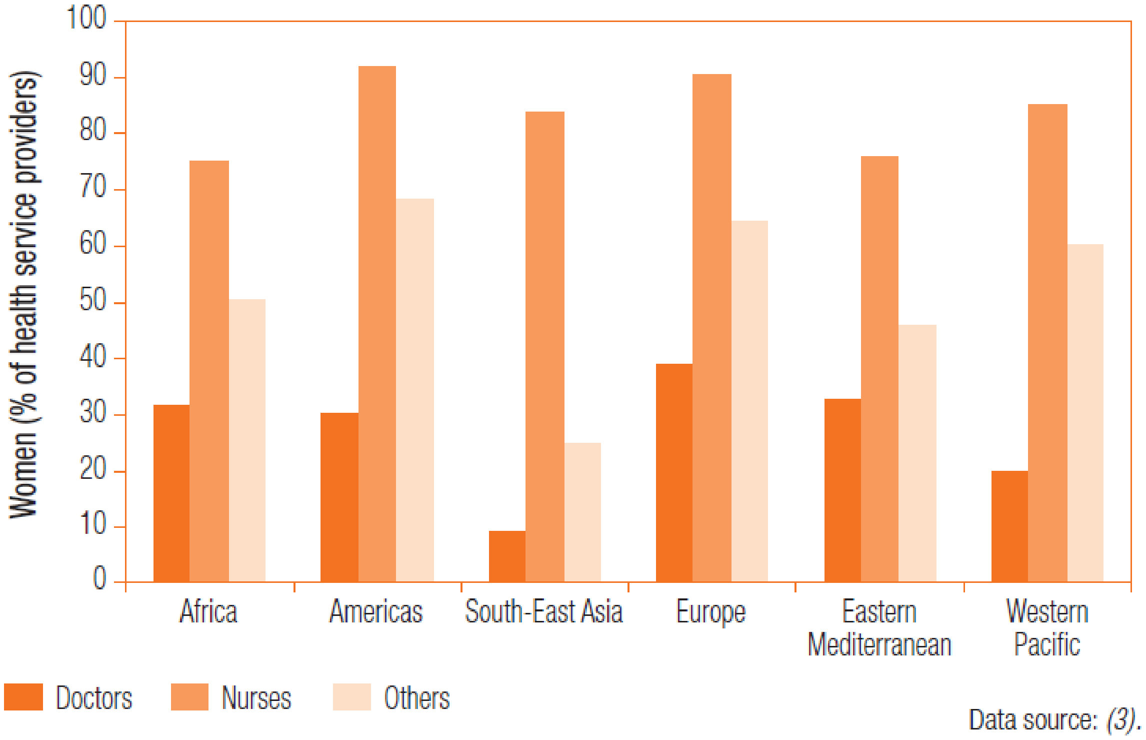
- Personal care or routine day living activities (e.g. bathing, toileting, eating, dressing)
- Household work (cooking, cleaning)
- Companionship and emotional support (Triantafillou et al. 2010, p. 14)

Considering the affinity to household activities, probably delivered by women to a large extent, it may not surprise that women are significantly dominating the field of informal care as well, representing about 76 per cent of the informal caregivers (p. 14).

Navaie-Waliser et al. (2002) found in their study that women were more likely to be primary caregivers providing more direct care relating to ADL (Activity of daily living) of elderly care recipients than men. The women in their study also were more likely to report poorer self-rated health. According to Killen (2004, p. 30) women tend to reduce their amount of their working hours due to caring responsibilities to the detriment of their income and, in the long term, of their pension entitlements (Triantafillou et al. 2010, p. 17). By contrast, Jacobs et al. (2014) did not find differences in the likelihood of being fully retired in female or male high intensity caregivers, apart from being more likely to be fully retired before the age of 65 compared to non-caregivers. Even so, Jacobs et al. (2014) state that the women in their study who provided high intensity caregiving worked mostly part-time (p.74). Overall, the findings indicate that in general women are the ones who are mostly affected by the informal caregiving responsibilities in society.

1.2 Nurses and Double Duty Caregiving

Women play a dominate role in the service delivery of health. While health service providers are predominately female, nurses represent the largest group of professional health care providers. The average distribution of women health service providers is presented in figure 3. Killen (2004) states that the majority of registered nurses in the United States work in hospitals providing direct patient care (p.20). According to the Nurses` Health study, hospital nurses involved with shift work, which has been associated with several health problems of workers, reported a higher incidence of sleep disturbances and excessive sleepiness. This study also showed a higher risk for coronary artery disease and increased risk for certain cancer-types in nurses, especially in those who worked night shifts for several years (p. 26). Nurses with worst health reported of high job demands and low job control, while those who had a better health status had lower levels of psychological demands and higher levels of social support (p. 28). As nurses also provide care for family members, such as children, parents, spouses and other relatives, these caregiving roles may have an important impact on their health (p.28).



Data source: *(3)*.

Figure 3: Distribution of women in health service profession, by WHO region: WHO 2006, The World Health Report 2006

Ross et al. (1994) suppose, that nurses` lives are shaped by the expectations and norms of our society concerning the responsibility of caring, which are absorbed due to the process of socialization all through their lives. As a consequence, women`s care in the private sphere is underrated, and so, professional caregiving remains invisible und undervalued as well. Within the formal health care system, this affects the nursing profession with respect to poorer reputation, less force in decision-making and drawbacks in the remuneration of their work (p. 45). Nevertheless, women`s lives are characterized by the multiplicity of the roles they have to perform. Nurses, trying to balance their caring responsibilities, experience various conflicts in meeting those demands. Grzywacz et al. (2006) investigated the prevalence and frequency of work-family conflicts in nurses and found, that 92 per cent of nurses reported experiencing work interference with family and 63 per cent of nurses reported experiencing family interference with work (p. 420). Nurses who reported chronic exposure to work interference with family showed poorer health, well-being and contributions to intentions to leave (p. 423). Walters et al. (1996) indicate an association between health problems and the demands of the unpaid roles within the nurses` homes, as those women who reported of time pressures and caring for a dependent adult, were more likely to report health problems, such as exhaustion, headaches, backpain and fatigue (p. 1630).

As the life expectancy increases, the lifetime risk of having to care for a disabled relative is increasing as well. Nurses, being daughters, wives and mothers trying to answer the gendered expectations of those roles are driven by the same motives to adopt informal caregiving roles like non-professional caregivers and might be more likely to assume informal caregiving responsibilities. In respect of work-family conflicts this raises questions on how nurses are effected by their Double Duty Caregiving (DDC) roles. The importance of investigating the effects is obvious. First, the nursing profession is currently suffering of nursing shortage, and the perceived work-family conflict may result in higher numbers of persons who leave the profession. Second, work-family conflicts are associated with lower job-satisfaction, burnout, fatigue and depressive symptoms, which seem to be linked to poorer job performance within health care providers (Grzywacz et al. 2006, p. 415)

Therefore, the aim of this paper is to explore the experiences of nurses being professional caregivers and providing informal care to their own relatives. This qualitative literature review tries to answer following research questions:

- What is Double Duty Caregiving (DDC)? What kinds of Double Duty Caregiving are described in the literature? Who provides DDC?
- Which problems do Double Duty Caregivers (DDCs) have to face? Which supportive factors are reported by DDCs?
- What effects does DDC have on the personal lives and professional practice of Double Duty Caregivers?

- Does DDC affect men and women in the same way?

2 METHODS

A literature review is conducted to gain an overview of existing knowledge about a particular situation, phenomenon or problem. As the description of life experiences from the involved persons are in the centre of interest, qualitative research is recommended (Grove, Burns & Gray, 2013, p. 57). In order to locate relevant literature for nursing research it is suggested to search in electronic bibliographical databases, such as MEDLINE and CINAHL using specific keywords/phrases that relate to major concepts of the topic, the population, interventions or methods that are relevant. (p. 104). The following keywords were used in this search: ***dual role/burden, dual caregiving roles, nursing / caregiving, nurse, nurse practitioner, health (care) professional, registered nurse, occupational / professional care, familiar / informal care, informal caregiving/caregiver, family caregiver, double duty caregiving, multiple caregiving***. The search was limited to qualitative literature in English and to articles with abstracts available. Nurses caring for adults (elderlies) or/and relatives/friends had to be part of the sample, therefore, articles that did not have nurses as participants at all were excluded. Time restrictions were initially set from January 2004 to December 2014 to locate current literature, but one paper from 1996 was included because it contributed relevant findings. The reference lists of relevant articles were examined carefully to track down earlier research on the topic. Additionally, further literature including *grey literature*, was found via Google Scholar and Google. A summary of the included papers is presented in table 1

Table 1 Summary of included studies (n=11)

Authors, year, title	Aim	Participants and setting	Methodology and methods	Results/Themes
Ward-Griffin (2004) *Nurses as Caregivers of Elderly Relatives: Negotiating Personal and Professional Boundaries*	To explore nurses` experiences in providing care to elderly relatives	n= 15 registered nurses of two community health-care agencies in southwestern Ontario	Qualitative, descriptive, feminist narrative In depth-interviews Analysis guidelines of Lofland and Lofland (1995)	Dimensions of Double Duty Caregiving: Caring for and Caring about. Strategies for managing family caregving responsibilities
Ward-Griffin et al. (2005) *Double Duty Caregiving: Women in the Health Professions*	To examine the experiences of women in four different health professions who provided care to elderly relatives	n=37 (15 nurses, 6 physicians, 7 physiotherapists, 9 social workers)	Qualitative, feminist narrative In depth-interviews Lofland and Lofland guidelines (1995)	Familial Care Expectations, Level of Support, Negotiating Strategies, Blurring Boundaries between Professional and Familial Caregiving, Types of Caregiving: Making it work, Working to manage, Living on the edge
Ward-Griffin et al. (2011) *Compassion Fatigue Within Double Duty Caregiving: Nurse-Daughters Caring for Elderly Parents*	To examine compassion fatigue within Double Duty Caregivers of elderly relatives	n=20 female registered nurses, identified as „living on the edge“	Qualitative, secondary analysis Transcripts of in-depth interviews Lofland et al. (2006)	Three major themes: Context, characteristics and consequences of Compassion Fatigue within Double Duty Caregiving
Mills and Aubeeluck (2006) *Nurses`s experiences of caring for their own family member*	To explore the information needs, support systems of nurses caring for a relative who has a life-threatening illness	n=5 senior nurses	Qualitative Semi-structured interviews Interpretative phenomenological analysis Smith and Osbourne (20039	4 superordinate themes: Quality of life, personal and professional boundaries, disempowerment, positive aspects of the role
Salmond (2010) *When the family member is a nurse: The role and needs of nurse family members during critical illness of a loved one*	To explore the experience of being a nurse family member of a relative hospitalised for a critical illness	n=22 nurses	Qualitative, Grounded Theory loosely structured interviews Comparative process of analysis	Core theme: Nurse role identity with six challenges were identified: masking heightened emotional turmoil, assuming the in-charge role, assessing and monitoring, seeking information and meaning, advocating, letting go to assume family roles. Strategies to facilitate meeting these challenges

Table 1 (continued)

Authors, year, title	Aim	Participants and setting	Methodology and methods	Results/Themes
Anjos et al. (2012) *Understanding Gendered Expectations and Exemptions Experienced by Male Double-Duty Caregivers: A Qualitative Secondary Analysis*	To explore how gendered expectations and exemptions enter into the caregiving of male Double Duty Caregivers of Elderly	n= 18 male nurses	Qualitative, secondary analysis Transcripts and field notes from interviews Lofland et al. 2006	Determinants of care: Familial responsibility and relationships, nursing knowledge and skills, access to resources, Gendered expectations and exemptions, personal health experiences
Wohlgemuth et al. (2013) *Advantages and Challgenges: The Experience of Geriatrics Health Care Providers as Family Caregivers*	To examine the dual role of health care professionals who are also family caregivers of older adults	n= 16 (12 nurses, 3 physicians, 1 social worker)	Qualitative Semi-structured interviews Thematic analysis approach (Crabtree & Miller, 1999)	Dual Roles Advantages and Disadvantages, Benefits of professional expertise, challenges and conflicts from expertise, emotional impact of dual roles, professional impact of dual role
Ciccheli and McLeod (2012) *Lived experiences of nurses as family caregivers in advanced cancer*	To explore lived experiences of nurses caring for a family member living with advanced cancer	n= 5 registered nurses	Hermeneutic phenomenology Semi-structured interviews Interpretative memos	Expectations of care, Balancing professional and personal boundaries, Experiencing the health care system from the perspective of a care recipient, Witnessing the illness, Decision-making for the family member
Lee (1996) *Registered Nurses`Experience of Caring for a Dying Family Member*	To examine registered nurses`experience of caring for a dying family member	n= 14 registered nurses (2 male, 12 female)	Qualitative, descriptive semi-structured interviews Content and thematic analysis (Morse & Field, 1996)	Main themes: Knowing the ropes (Connections with Health Care System, Nursing Knowledge), Caught in the middle (Conflicts with Health Care Providers, Knowledge as a burden, Juggling paid work and family caregiving responsibilities), Gaining insight (increased awareness, understanding and empathy, increased legitimacy, Advices for supporting Family Caregivers

Table 1 (continued)

Authors, year, title	Aim	Participants and setting	Methodology and methods	Results/Themes
McNamara (2007) *The meaning of the experience for IUC nurses when a family member is critically ill: A hermeneutic phenomenological study*	To gain insight into the meanings derived by intensive care nurses when a family member was critically ill	n=4 registered nurses working in an Intensive Care Unit	Qualitative, hermeneutic, phenomenological Hermeneutic interview Manen`s (1990) holistic and selective approach	A nurse`s nightmare, Knowing and not knowing, feeling torn, Gaining deeper insight an new meaning, interpretation of the results within van Manen`s existentials
McClunie-Trust (2010) *Negotiating Boundaries: The nurse family member caring for her own relative in palliatie care*	To illuminate the challenges for a nurse caring for her own relative who is dying of cancer-related illness	n=6 registered nurses	Michel Foucault`s critical history of thoughts Two interviews, first unstructured, second more structured after reviewing the previous transcripts	The call to care within the caring discourse, family discourse and discourse of expertise in knowing as a nurse, negotiating boundaries (professional and lay subjectivities, formal and informal care, professional authority and delegation of care to families

3 RESULTS

3.1 Double Duty Caregiving - The call for care

Women are the main providers in professional and informal care. Therefore, it is not surprising that women of health care professions tend to be overrepresented in Double Duty Caregiving as well. In those studies that did not investigate female nurses in particular (Ward-Griffin et al. 2005, 2011) the majority of the participants were women still. Ward-Griffin et al. (2004, 2005) indicate that the gendered expectations of women within the family caregiving discourse lead to see caregiving as women`s "natural" role and consequently, as a natural extension of their nursing duties, which is described best by this quotation:

> *"I was expected to care [for my mother] because, one, I am a nurse, two, I am a daughter, and probably three, I am a mother."* *(Ward-Griffin 2004, p. 104)*

Ward-Griffin (2005) speaks about the "gendered nature of caregiving" and highlights that women will be affected to a greater degree than men as they are usually the ones who shoulder the "bulk" of the caregiving costs because the society more and more depends on informal caregivers due to the shortages in the health care systems (p.380).

Being a professional healthcare provider was stated as a crucial determinant for taking up the caregiving role within the family. The participants felt obliged because of their professional background, not only because they had high expectations of themselves but especially because it was expected by their families who entitled them as "the nurse in the family" or the "family spokesperson" (Ward-Griffin et al. 2005). The position of the "health professional in the family" was linked to providing and explaining medical information to other family members, advocating for the relative they cared for and providing direct care themselves. Eventually, the family expectations created high pressure to provide more care than they wanted (Ward Griffin 2005, p. 384). However, these findings suggest that being a woman and a health care professional, especially a nurse, enhance the likelihood for Double Duty Caregiving.

Nurses are more likely to face different family caregiving situations within their personal lives. The participants of the studies provided care to their parents and parents in law, followed by spouses, siblings and other relatives or friends. They had to handle life-threatening and critical illnesses, such as trauma or cancer, and in many cases provided care for a dying family member. It is remarkable that this profession is expected to be in charge of a variety of informal caring situations even if the person concerned may not have the expertise or the knowledge needed. McClunie-Trust (2010) speaks also of caring as important value within the family relationships (p.110), which might explain the nurses` assumption of the family-caregiver role without hesitation (p.102). The concept of reciprocity was assigned as a large determinant for taking up the family-caregiver role by a male family-caregiver.

> *"I feel because of the way we were brought up it`s something that we want to do, make sure we have them around for a long time – because they`re your parents and they helped you, so you help back".*
>
> *(*Anjos et al. 2012, p.111*)*

3.2 The Double Duty Role of Nurses – Gift and Burden

A strong theme throughout all the storylines of the interviewed participants was the double role of the nurse being a family caregiver. The nurses distinguished precisely between their "nurse-self" and their "family member-self" but emphasized that they could not separate these two identities (Aubeeluck 2006, McNamara 2007, McClunie-Trust 2010, Salmond 2010, Wohlgemuth 2013). Moreover, their narratives give the impression of them having a kind of multiple personality, where the "nurse-identity" takes charge whenever the situation affords it, regardless if that happens consciously or *automatically:*

> *"The nurse in me came first and had to be sure that the care dad got was what it should be. I was his daughter throughout but the nurse side of me had to be satisfied for the daughter in me to give up control." (*Salmon 2010, p. 12*)*

> "*I tended to put my professional responsibility first and as a daughter that`s not what I would have chosen…the professional role overtook that."*
>
> *(*McClunie-Trust 2010, p. 105*)*

> *"…when I kissed him in the morning, I looked at the urine in his bag and felt how warm his skin was and all of those things and checked his heart rate, and probably I didn`t even do it consciously, it was more of a subconscious thing I think…(Anna)".*
>
> *(*McNamara 2007, p. 29*)*

This ability, considered as the "nursing gaze" was seen as a key aspect of nursing and a reason for not being able *not* to think as a nurse (McClunie-Trust 2010, p. 120)

Being a nurse was extremely beneficial to their personal caring experiences due to the knowledge and skills gained from their professional expertise. Knowing how to provide personal care, the ability to assess medical knowledge and their experiences with illness, dying and death helped them to build up confidence and to decrease their emotional struggle (Lee 1996, Wohlgemuth 2013). A male nurse family-caregiver stated:

> *"I wouldn`t have made his death as nearly as comfortable as I did because I was a nurse. I wouldn`t have been able to do it with as much caring and knowledge if I wasn`t a nurse. I would have still probably tried to help him out but…I wouldn`t have made his death nearly as comfortable as I did because I was a nurse and that comes from nursing. That`s not something you get from intuition. It`s not a natural ability for male, I don`t think.*
>
> *(Lee 1996, p. 68)*

Another advantage expressed by the participants was their ability to "navigate the system". They knew the infrastructure of the healthcare system, felt comfortable with the medical jargon and eventually were able to use their professional connections to gain supplies, medication or medical equipment. These connections were also helpful with acquiring specific types of support, such as home care services or appointments with medical specialists. As a consequence, using connections was a common strategy to ensure a quality care (Lee 1996, Ward-Griffin 2005, Wohlgemuth 2013) or to manage situations when their expectations did not correspond with the performance of health care providers (Chiccheli & McLeod 2012).

By contrast, "knowing" or the specialised knowledge was also recognised as a burden because of several reasons. First, the nurses had the knowledge what might happen or what could go wrong, especially when it comes to iatrogenic mistakes during hospitalisation. This knowledge triggered heighted anxiety and stress which led to a cautious observation of their ill relatives and everything around them (Salmond, 2010). Second, because of their professional knowledge base they had a different view of the prognosis, progression and potential recovery of diseases. For that reason they often could not be as optimistic and hopeful as other family members. In some circumstances they even were perceived as being negative or reacting disproportionately which made them feel isolated from the rest of the family (Salmond 2010). The terms “knowing ahead” or “thoughts jumping ahead” were used to describe those trains of thoughts (Aubeeluck 2006, Lee 1996, Chiccheli & McLeod 2012). Third, in many cases the nurses gained privileged information because of their professional status, sometimes prior to the patient and the rest of the family so they eventually had to be the “bearer of bad news” which was found difficult (Lee 1996). Last but not least, their knowledge also meant bearing a huge responsibility as the families relied on them concerning making difficult decisions about treatments, advocating on behalf of their ill family member and being information source for the rest of the family (Chiccheli & McLeod 2012).

The role of advocacy was reinforced by their professional occupation as it is “connected to understanding the patient`s condition, knowing or determining what quality care or standards of care are for the presenting condition, and actively advocating to assure that patients get the best of care” (Salmon 2010, p. 17). The nurses expressed difficulties in advocating and trying not to be too “pushy” and demanding at the same time. The communication with healthcare providers was described as a “balancing act”, a “walking on tender hooks” and a “feeling of being on very shaky ground” (Lee 1996, p. 83).

3.3 Trying to remain in control

Another remarkable theme in the storylines was described as trying to remain in control. Two kinds of trying to remain in control could be identified, first, as an emotional matter, second, concerning the caring situation itself.

Trying to remain in control emotionally was stated as not being allowed to be emotional due to expectations of others and themselves as a consequence of their professional occupation. The nurses had the strong feeling to have to stay cool-headed and calm for the sake of their families. On the one hand it helped being supportive and ensured that they could concentrate on their caring tasks, on the other hand, with someone else standing at the front lines, the other family members were able to grieve and give way to their own emotions (Salmond 2010, p. 14). In order to remain in control emotionally some nurses slipped readily into the nurse-role because there they felt comfortable and safe. The nurse-self helped them to distance themselves from emotionally challenging situations such as providing intimate care or bringing “bad news”:

> *“It was easy for me to come away and tell him what was wrong with him if I went to the place of knowledge as opposed to the place of emotion…Got the x-ray and said “See [Brother], here it is, here.” That felt easier to do than being able to go “Oh my god, you`re full of cancer, what are we going to do?”…But I think you have to, you have to dissociate yourself…I think it was a place that I needed to go to in order to be able to say it. And believe it myself, support him at the same time by not breaking down”*
> *(Lee 1996, p. 96)*

> *“I think if my emotions lead me around all the time, I don´t think I would have been able to provide care for him. I need to separate my love for him away from my, the care I need to provide for him. I couldn`t do both cause then I would just fall apart all the time and wouldn`t be able to pull it together. I`m falling apart now and it has been years right?”*
> *(Lee 1996, p. 95)*

Trying to remain in control emotionally required internalising the own anxiety and suppressing the own needs. Wohlgemuth et al. (2013) speak of a “deliberate stoicism” when trying to stand back from the own emotions and be a “professional”, which caregivers learn to do in their professional lives on an everyday basis (p. 6). Although this strategy was used by many participants, they also mentioned that it was very difficult to do so and sometimes led to delayed emotional reactions.

Trying to remain in control in the caring situation is a multifaceted task, which most of the Double Duty Caregivers (DDCs) had to manage. The control-role in the caring situation implied maintaining guard and protection of the ill/elderly family member which often proceeded to the advocacy-role. The following strategies were applied to fulfil those tasks:

- Trying to be “let in”: Being “let in” stands for a collaborative relationship between the staff of a ward and the nurse family member, where the nurse as a family caregiver was respected, consulted and kept well informed by the staff of the facility. On the one hand it contained being “let in” literally in areas that usually are not accessible for relatives such as the operating theatre. On the other hand it meant including the nurse family member in the team. The most positive experiences were made in in the own work environment, where the participants were respected as professionals and relatives. Not being “let in” generated anxiety, feelings of helplessness and powerlessness. The waiting room was named the “anxiety room” (Salmond 2010, p. 14).
- Trying to gain meaningful information was another strategy to maintain the control-role. The nurse family members` needs for information differed from those of laypersons. Therefore, the information had to be more detailed and a lack of detail was unacceptable. Gaining information and seeking meaning was performed by building relationships to the staff and was described as a cautious balancing act between being a helpful, non-critical relative and the knowing nurse, ready to advocate if the situation affords it.

> *“The information I needed is different than what another grandmother would need and I can handle it emotionally if I have the facts, no matter how bad they are. If I have the facts, the details…not just a brief explanation, I am an emotional wreck if I don`t hear the facts.”* (Salmond 2010, p. 15)

- Trying to have the lead role in coordinating and providing care was mostly performed by nurses who cared for their relatives in their home-setting (i.e. elderly or dying relatives). The nurses wanted to be the main decision makers and caregivers as they felt obliged to provide the best possible care to their loved ones. Conflicts arose when health care providers took over control of their family member`s care without consultation (Lee 1996, p. 81):

> *“A few minutes later the [palliative care] nurses has arrived. Everything just went out of our hands. I´m usually able to speak up for what I want for [my husband]. I think we just lost our voices. Even [my husband`s] brother who`s a big support, who was there as well, did sense that these nurses came in [and took over]…That was [my husband`s] couch and he was here and he wanted to be in this room cause it`s the hub of the kids and teenagers and the food and the meals and this is where he wanted to be. So this is where he was going to be. And that`s when I said so. And it was the minute they came in, well let`s get him into his bed, he needs to be into a bed…But we did say, “No, no, no, he needs to be here, this is where he wants to be, he really wants to be here.” “Let`s get him out of those clothes, let`s get him into a pajama”. And he wanted his warm favourite sweater on. It was a comfort sweater but poof that came off and it didn`t go back on.”* (Lee 1996, p. 82)

3.4 Impact of Double Duty Caregiving on personal lives

Double Duty Caregiving had a great impact on the personal lives of the participants in the studies, especially concerning the emotional level. The participants in the study of Ciccheli & McLeod (2012) reported being satisfied with their role in the caring situation and being very proud of their ability to provide care to their loved ones. That experience gave them a sense of meaning and purpose (p. 55).

On the other hand, besides feelings of anxiety and stress, the narratives also revealed certain feelings that were predominant, such as feelings of inadequacy, guilt and exhaustion. Although the nurses saw themselves as competent family care providers they also described feeling inadequate when they did not live up to their own or their family`s expectations (Wohlgemuth et al. 2013, p. 7) or had to resume too much responsibility for the care, especially when they lacked necessary knowledge (Ward-Griffin 2004, p. 105). They felt guilty because of not being optimistic (Lee 1996, p. 87), when they had the feeling that they did not “do enough” (Lee 1996, p. 91), or the family member`s health deteriorated under their care (Ward-Griffin 2004, p. 105). The feeling of emotional exhaustion arose, when they were not able to voice dissatisfaction with outside health care providers (Mills & Aubeeluck 2006, p. 162), when they struggled with multitasking the coordination and provision of care (Wohlgemuth 2013, p. 6), or were overwhelmed by maintaining guard and protection because of not wanting to “miss something” (Ward-Griffin 2004, p. 105)

As mentioned before, DDCs had to suspend their own feelings for the sake of their ill/elderly family member, partly with severe effects on their emotional and physical well-being. Especially those participants who cared for a dying family member reported about emotional breakdowns and difficulties in the bereavement period because all the suppressed emotions and grief poured out after the family member`s death (Lee 1996, p. 98):

> *“[…] And just, I just fell hard emotionally. I just couldn`t take it. I would just – I`d already, I think, I burnt myself out. I didn`t have any emotional reserve left to kind of pull back and be a clinical decision-maker. And so my emotions were at the front and that`s what I had been preventing for all the 3 and 4 months that I looked after my Dad is that my clinical decision-making came first and my emotions came second. And I found that after losing Pop, my emotions were raw and they`re right at the tip there and anything – I would bring up Pop and cry. I would talk to somebody and cry…if somebody lost a pet, I would cry. It was just, there was this non-stop crying festival that I just – it took weeks for to actually calm down.”*
>
> *(Lee 1996, p. 99)*

Effects on the physical well-being were predominately described by Ward-Griffin (2004). Ward-Griffin highlights the blurring of boundaries between the nurses` informal caregiving for elderly relatives and their occupational caregiving tasks. It is suggested that constantly negotiating the boundaries between their professional and personal caregiving roles leads to the development of compassion fatigue if the resources decrease whereas the caring needs increase. In contrast to burnout, compassion fatigue can only be experienced by people who provide care to others. In consequence, health care professionals are more likely to develop compassion fatigue when caring for a relative as well because they may not be able to “take time off from caring and always being on call 24/7” (Ward-Griffin 2011, p.). A nurse who cared for an elderly family member reported about sleep disturbances, hypertension and being tired all the time

(Ward-Griffin 2011, para. 33). Another nurse, who had cared for a dying family member mentioned heart palpitations during jogging (Lee 1996, p. 99).

Some participants reported that they were not able to perform other family roles while providing care to a relative. A nurse in the study of Lee (1996) expressed regrets because she had been so busy about caring and coordinating that she did not take the opportunity to spend some social time with her dying mother which, later on, led to difficulties in coping with the death of her mother (p. 98).

> *“[My sister] actually did a lot of playing with mom…They did more shopping trips. I know they went out and bought, both bought new dresses for Dad`s party. So, she played more, right? And I don`t think I played enough cause I was too serious. I wish I would have. If I was to change one thing I would have played more, been less serious, been less focused. Let the guard down a little bit more and played more. […]”.*
>
> *(Lee 1996, p. 98)*

Another nurse with dependent children narrates that she found it difficult to balance the caregiving responsibilities to her infant son and her dying father and that she felt guilty of having neglected the children during her caring experience (Lee 1996, p. 93).

3.5 Impact of Double Duty Caregiving on professional practice

The experience of caring for a family member seemed to have left a mark in the participants of the studies. The majority of the nurses stated that the caring experience had shaped them and had a positive influence on their professional practice (Ciccheli & McLeod 2012, p. 55, Mills & Aubeeluck 2006, p. 163).

Caring for a relative and witnessing illness or death of a loved one, seemed to raise the nurses` awareness for how patients and their relatives experience the caring situation. Thereby, the nurses changed the way they communicated with the patients, trying to be more tolerant, understanding and emphatic (Lee 1996, p. 103). Another issue was how to relay information carefully as a health care professional, to keep given promises, such as calling when conditions of the patient changed, or keeping family members well informed. A nurse acknowledged how little information the families retained in critical situations in general and the importance of being aware of this in the own clinical practice (McNamara 2007, p. 35). Some nurses felt legitimated by their own experience of a loved one`s death and felt that they had developed a better sense of what the patients and their relatives are going through and what may help them best. (Lee 1996, p. 105)

By experiencing being at the receiving end of health care services the nurses were better aware of weak points in the health care system and felt better qualified to recommend important services to their patients. Furthermore, as their skills were enhanced through the own caregiving experience the nurses felt encouraged to counsel other families and to share their “hands-on knowledge” in terms of “lessons learned” (Wohlgemuth 2012, p. 8).

Only Lee (1996) reported of nurses, who described interferences of Double Duty Caregiving with their workplace. One nurse acknowledged that the stress of family caregiving led to her inability to concentrate at work (p.102). Several nurses described being interrupted at work by other family members seeking for advice or emotional support or taking sick or holiday time to provide informal care (p. 100).

3.6 Supportive Factors

Managing the challenges of Double Duty Caregiving is a demanding task that can be handled best with support from the environment. The nurses of the studies received support from different sources: from their families, especially spouses, siblings or adult children (Ward-Griffin 2005, p. 387), and from their colleagues who covered shifts for them, changed their working schedules to help out or assisted them with their professional knowledge (Wohlgemuth 2013, p. 9, Salmond 2010, p. 16, Ward-Griffin 2005, p. 387). Participants who had an understanding manager felt blessed (Lee 1996, p. 101, Ward-Griffin 2004, p. 106). Flexible working shifts, unpaid leave of absences and working part-time were supportive as well. Ciccheli & McLeod (2012) speak of the benefits of being employed as the working place may offer respite from the family caring responsibilities and the opportunity to revitalize the spirits (p. 56). Community support such as home care and long-term care were also mentioned but seemed to be hardly available (Ward-Griffin 2005, p. 387)

3.7 Gender Issues on Double Duty Caregiving

As outlined in chapter 3.1., men seem to be underrepresented in occupational and informal caregiving situations. However, only one study was found, where gender issues in Double Duty Caregiving were discussed in particular. The study of Anjos et al. (2012) focused on male Double Duty Caregivers (DDCs) and questioned if and how gendered expectations influenced their caregiving experience.

Similar to the findings discussed before, the call for care was determined by family expectations due to their professional background. Certainly, the aspect of the birth order as an important factor for assuming the family caregiver role was outlined by a participant:

> *“I think my role would be more stressful, because they live just across town from us, so I have the geographical familiarity. I´m the oldest and I`m the only health-care-trained person.” (*Anjos et al. 2012, p. 111)

Even so, the responsibility for familial care seemed to be more negotiable and conditional to the degree of power and control of the male Double Duty Caregiver as the result of tensions caused by the gendered expectations as a son, husband or father and their expectations as a nurse. (Anjos et al. 2012, p. 112)

Another aspect reported in this study was the nuanced dedication of their nursing knowledge and skills as male caregivers. Besides providing information and advising, the male nurses used their nursing skills to be discharged from certain aspects of care. Especially tasks that clashed with their socially gendered expectations, i.e. bathing the mother in law, were refused and delegated to female family members or social services. The status of male DDCs gave them the opportunity to decide which aspects of caring were appropriate for them and to delegate those, that were not. In this sense, male DDCs could maintain the roles of health-care advisor, educator and contact person, which matched better with their gendered expectations of their role as a male nurse being a family caregiver.

4 DISCUSSION

4.1 What is Double Duty Caregiving? What kinds of DDC are described in the literature? Who provides DDC?

The term “Double Duty Caregiving” was solely used in the papers that studied nurses/ healthcare providers that provide care to elderly relatives. Nevertheless, the findings of this literature review reveal that Double Duty Caregiving might not be confined to caring for elderly relatives solely as considered by authors like Ward-Griffin (2004), but rather expands to caring for critically ill and dying family members and those with cancer-related illnesses as well. The nurses` essential issues, challenges and support needs seemed to be very similar, no matter how long or in which extent the informal caregiving situation persisted. Giles and Hall (2014) who conducted a systematic qualitative research on the topic, summarized the main issues, challenges and support needs of nurses when a critically ill family member is admitted to hospital. Having a look on their findings the similarity to the concerns and issues of Double Duty Caregivers providing care to elderly relatives is reasonable. This specifically applies to the perceived double role of nurses with the emotional costs of the dual role conflicts, their specialised knowledge and the resulting challenges and benefits, the role of advocacy and the strategies to manage the caring situation.

However, in the present studies the majority of the interviewed participants had cared for their parents or parents in law, which is consistent with findings of studies by Clark-Shirley (2012) and Boumans and Dorant (2014), where parents and parents in law were identified as main receivers of Double Duty Caregiving, followed by spouses, siblings, other relatives and friends. This data supports the assumption that the call to care and therefore the adoption of the caregiver role is linked to the grade of affection the nurses conceive for the care-recipients. Benner (2010) also speaks of the *sense of duty* as a leading motive that can be ascribed to family ties, education and culture-specific expectations (p. 175), which supports the concept of reciprocity by Anjos et al. (2012).

Women seem to be the main providers of Double Duty Caregiving as the participants of the included studies were mostly women that were registered nurses, critical care nurses, palliative care nurses or geriatric health care nurses. Other studies that investigated in Health Care Professionals who identify themselves as informal caregivers showed that the average number of female Double Duty Caregivers is about 92% – 96% (Boumans & Dorant 2014, Clark-Shirley 2012, Orzek et al., 2014, Scott et al. 2006) which confirms the prior impression of women being overrepresented in Double Duty Caregiving positions. In relation to cuts in healthcare funding and the decrease of nursing staff this development is precarious. While women already carry the bulk of the informal caregiving costs, nurses might be affected negatively twice, which may have a direct impact on their job performance. This issue is discussed in 4.3.

4.2 Which problems do Double Duty Caregivers have to face? Which supportive factors are reported by DD - Caregivers?

The most conflicts arose due to the participants` double role as nurses and informal caregivers. The feeling of being “caught in the middle” was omnipresent and “knowing” was seen as a gift and a burden as well. Sometimes the nurses said they would have preferred the state of not knowing, others disagreed by wanting to know everything in detail. The majority of the nurses stated that they could not separate from their nurse-self and that they were always monitoring, worrying and anticipating the worst. Due to their specialized knowledge their perception of what high quality care should be was heightened. They were able to see what laypersons may eventually not see, such as inappropriate care or issues concerning the hygiene, but then again, they often expressed difficulties in voicing their dissatisfaction.

Further conflicts emerged due to the expectations by the health care providers. The nurses of the studies were often not perceived as family members and eventually were expected to be an unpaid help. Others, in turn, were very suspicious and seemed to feel uncomfortable working under an expert`s eye, and as a consequence excluded the nurse family members.

The most delicate source of difficulty were their emotions. They suppressed their feelings and internalized their fears for the sake of the family member they cared for and the other family members who heavily relied on them. This task caused exhaustion and delayed reactions and in some cases had effects on their health and well-being.

Spouses, adult children or siblings were identified as supportive companions in the nurses Double Duty Caregiving – experience. They could provide emotional support, simply by being there and sometimes they could assume particular tasks in direct care. Flex time, understanding managers and co-workers were identified as strong supportive factors within the Double Duty Caregiving situation (Lee 1996, Salmond 2010, Ward-Griffin 2004, 2005, Wohlgemuth, 2013). This is reinforced by Orzeck et al. (2014) who summarized the requests of Double Duty Caregivers of a local community service in Canada. These requests include workplace flexibility (i.e. flexible work hours, caregiver leave) and work environment support (i.e. culture of work environment, organizational climate). As stated by Ciccheli and McLeod (2012), being employed seems to be beneficial because the workplace might offer respite from the informal caregiving tasks. Boumans and Dorant (2014) support that by indicating that combining informal care with occupational care may generate “self-esteem and personal accomplishment” (p. 1611). This might explain why researchers found no differences or even higher levels of job satisfaction or work motivation between Double Duty Caregivers and nurses without caring responsibilities (Boumans & Dorant 2014, Clark-Shirley 2012, Monahan & Hopkins 2002).

4.3 What effects does DDC have on the personal lives and professional practice of Double Duty Caregivers?

Basically, the participants of the studies described positive effects of the Double Duty Caregiving experience on their clinical practice. Experiencing the illness from the other perspective, the anxiety and burden of informal care helped them to improve their “soft skills” of nursing and to become better nurses. Personally, they all seemed confident with the experience of having been there for someone they loved, expressing feelings of meaning and purpose.

While they barely mentioned negative effects of Double Duty Caregiving on their physical well-being or interferences with their workplace, other studies have investigated those issues in detail:

In the study of Ward-Griffin (2004) only one nurse reported about sleep disturbances, hypertension and being tired all the time in terms of compassion fatigue, whereas the participants in other quantitative studies showed that Double Duty Caregivers suffered more from fatigue, sleepiness and perceived stress (DePasquale et al. 2014, Scott et al. 2006) and were more likely to make errors at work, whereas surprisingly working more hours per shift on average (Scott et al. 2006), which is ascribed by the authors to the financial and economic burden of family caregiving. Boumans and Dorant (2014) found that when the hours of informal care increased, Double Duty Caregivers experienced poorer mental/physical health, emotional exhaustion and more recovery needs. Dichter et al. (2012) even indicate that Double Duty Caregiving had negative impacts on working ability due to spinal diseases.

In comparison to Lee (1996), who seems to be the only author within this qualitative literature review who describes interferences of DDC with the workplaces, Monahan and Hopkins (2002) report of increased work absence, decreased productivity and increased considerations to quitting the job. In Orzeck et al. (2014) 75% of the participants who were Double Duty Caregivers missed work due to caregiving responsibilities and occasionally even reported of having missed out career opportunities. Clark-Shirley (2012) states that critical care nurses who were informal caregivers were more likely to have made at least one negative job change in the past and had poorer self-rated health which were critical predictors of higher burnout and intent to leave. Boumans and Dorant (2014) where able to detect that the caring situation resulted in an increase of presenteeism, because the Double Duty Caregivers in their study seemed to attend work more often while being sick compared with nurses without caring responsibilities at home.

The comparison of the results concerning interferences between workplace and informal caregiving responsibilities suggests that the participants of the qualitative studies did not suffer much of negative work-home or home-work interferences. An alternative explanation, however, may be that possible interferences were not severe enough to be recognized and therefore were not emphasised in the narrative interviews. Still, another possibility is that expressing negative feelings about unfavourable consequences made the participants feel uncomfortable because of fear being perceived as “selfish” (Mills & Aubeeluck, 2006). This even might be an explanation why none of the participants in the qualitative studies mentioned any negative feelings towards their care recipients. Benner (2010) reported feelings of anger, hatred and aggression resulting from family conflicts within Double Duty Caregiving and noticed that expressing those strong feelings were associated with feelings of shame and guilt. Although this kind of feelings are just natural and all too human, talking about them seems to be deemed as impious, especially, when the care recipient has passed away.

4.4 Does Double Duty Caregiving affect women and men in the same way?

As outlined in chapter 3.7, there was only one qualitative secondary analysis that focused on male Double Duty Caregivers. The men in this study seemed to be driven by the same motives to adopt the Double Duty Caregiving role but found it easier to negotiate familial care. They constantly struggled with the role of the nurse and their gendered expectations as male family member, which is a major issue in the nursing profession in general. Evans (1997) concludes that men try to meet those challenges by disproportionally occupying specialised, not to say elite positions, such as management, psychiatry, anaesthesiology, and, intensive and emergency care (p.228). In their informal caregiving role, men tended to delegate hands-on tasks to female family members and mainly performed managerial task of advocating, teaching and organizing (Anjos et al. 20120, p. 113). Due to their managerial positions, the male Double Duty Caregivers had better access to resources and benefited from their connections within the health care system.

5 CONCLUSION

5.1 Clinical implications for Health Care Providers

The findings of this review paper have shown that nurses providing informal care to their relatives are confronted with partly different challenges compared to non-professional caregivers. This results in various implications for the clinical practice of nurses, who care for patients that are relatives from nurses:

- Health Care Providers should not assume that all nurse family members want the same level of involvement in care and should be sensitive to reluctance of tasks like intimate care.
- The assessment of the desired level of involvement, of the skills and needs is crucial to build a trustful relationship between the Health Care provider and the family of the patient.
- Double Duty Caregivers should be acknowledged as nurses and family members as well, implicating possible role conflicts that may not be visible on the first sight. Health Care providers therefore can support them by offering consultations to identify possible conflicts and how to resolve them.
- The provision of meaningful information was stated as a very important claim, so Health Care Providers should try to meet the family nurse member`s needs for detailed information and being part of "the team".
- Health Care providers should be aware that advocacy is an important facet of the Double Duty Caregiving role and that expressing concerns is often not done easily.
- Last, but not least, family nurse members have to be continuously reminded of taking time for themselves as caregiving is an extremely exhausting task.

5.2 Implications for managers, supervisors and colleagues

Emotional and psychological support can be provided by colleagues, supervisors and managers. Creating an understanding working environment, which enables Double Duty

Caregivers to adjust working shifts if needed, would be highly beneficial. Support focusing on the improvement of the job satisfaction would also effect the personal well-being of Double Duty Caregivers. Some authors mentioned job sharing, caregiver leave and of course, job security (Orzeck et al. 2014, p. 5). Ross et al. (1994) also emphasize the importance of continuing educations programs to improve the level of nursing knowledge in order to support Double Duty Caregivers in maintaining their competence.

Overall, it would be recommendable to assess the status quo of Double Duty Caregivers within the own institution in order to detect possible conflicts at an early stage. That would allow managers to take action timely to prevent personnel fluctuations in the concerned departments.

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