The experience of being an informal dementia caregiver in the Danish healthcare system.

Rapportens samlede antal tegn
(med mellemrum & fodnoter): 169954
Svarende til antal normalsider à 2400 tegn: 70,82

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10th. Semester, Psychology,
Thesis report

Aalborg Universitet
Dato: 29/05-20

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Abstract

Dementia has increasingly become a part of the daily lives of many citizens world wide, who care for, or are relatives to a person who has dementia. In Denmark it is estimated that 300.000-400.000 people are close relatives to a person with dementia (Nationalt videnscenter for demens, 2020). The current thesis had the aim of investigating the experience of being an informal caregiver, for a person with dementia, in the danish caregiving setting. This was investigated with regard to the caregivers experience of grief through the Marwit and Meuser (2005) *caregiver grief index - short form*; the caregivers individual differences with regard to attachment through Fraley's (2012) *Experiences in Close relationships - Revised* scales and with regard to disease progression in the form of a modification of the Reisberg (1982) © *Global deterioration scale*. The study further included caregiver demographics and a few open ended questions relating to the caregivers' experiences. However, no statistically significant results could be obtained, and power analysis indicated a low power. Nonetheless, the thematic analysis of the open-ended questions indicated further need for support of the caregivers with regard to how to care for relatives with dementia; that caregivers generally focus on communication and adequacy of caregiving and that positive aspects of caregiving could be found for some of respondents. Generally it is concluded that further research is needed, especially with regard to the low sample size, vastly different effect sizes and alternative methods that had to be utilized in order to investigate any potential differences.

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1.0 Introduction

According to the *Nationalt videnscenter for demens* (Danish research and treatment organization with specialization in dementia) an estimated 36.000 to 82.000 people above the age of 65 had been diagnosed with dementia by the year 2015. Since then an estimated 8.000 people have annually been diagnosed with dementia, and by 2050 an estimated 131 million people worldwide will be diagnosed with dementia (Nationalt videnscenter for demens, 2020a).

When a family member, or other relative, is diagnosed with dementia, the people closest to that person often take upon them the huge task, of caring for and guiding that relative through the course of the (underlying) disease. As such the syndrome that is dementia has informally been termed as “the relatives’ disease” (Danish: *De pårørendes sygdom*).

In Denmark an estimated 300.000-400.000 people are close relatives to a person diagnosed with dementia (Dansk videnscenter for demens, 2020a).

Dementia is a general descriptive term for a cluster of usually chronic and progressive brain disorders. These disorders produce widespread deterioration of an individual's mental and social functions. The most widely known disease is probably Alzheimer’s disease (Ogden, 2005, p. 304). Dementia is usually diagnosed from the presence of some degree of amnesia (retrograde or anterograde) along with some impairment of at least one or more of the higher cognitive functions. The underlying diseases that cause dementia have their own diagnostic criteria (Ogden, 2005, p. 305). Therefore, it seems likely that dementia is a syndrome that already has, and will continue to have a large impact on many families and social circles world wide. But what happens to a family (or social circle) when dementia is diagnosed in one or more family-members? This thesis will investigate what impact dementia exacts on the affected person’s (PwD; Person with dementia, Abbreviated) relatives. This will be done with a specific focus on how dementia affects the different types of caregivers. By different types of caregivers, I refer to some of the many ways in which caregivers as individuals may differ, in terms of the roles as primary and secondary caregivers; the different relational positions that a caregiver can have, e.g.

spouse, adult-child of PwD, and other factors. Before continuing with the investigation of this topic, we must first determine, *who* is a caregiver, and what characterises a caregiver? - This will be done with special relation to dementia, under the assumption that the caregiver-role can change, with regard to the care-receivers condition, and with regard to whether or not the caregiver is a hired professional or a relative.

A caregiver then is a person who provides assistance to a person. The role of caregiving can be further divided into two distinct subgroups: The formal caregiver, and the informal caregiver. The *informal* caregiver is often used synonymously with the family caregiver and is defined as: *someone who provides care*, without financial compensation, and as someone who at the same time has an informal relation to the care-recipient (Ostwald, 2006). The informal caregiver can then be anyone who has a relationship with the care receiver, but is usually a spouse, children, siblings or other friends and family members (Ostwald, 2006, p. 29). The other type of caregiver, the *formal* caregiver, by extension is a caregiver that receives financial compensation for their services, and who does not necessarily have a prior relationship with the PwD. I am here putting emphasis on the *prior* relationship, to avoid claiming that one cannot develop an informal relation (e.g. friendship) with someone they are caring for. Thus the formal caregiver could be nursing home staff, nurses, professionally hired caregivers etc.

In this project I will be focusing on the informal caregivers, such as spouses and children, and specifically their experience with being caregivers. Informal caregivers can, as previously mentioned, also be divided into different levels of caregiving (i.e. primary or secondary caregiver). A primary caregiver is the caregiver(s), who provides the majority of the care for the PwD, excluding the type of care that can only be provided by healthcare professionals (such as nurses). A secondary caregiver, in regard to this project, is an informal caregiver, that provides care at times where the primary caregiver is unable to, or who provides care simultaneously with the primary caregiver, but not with the same frequency or time spent caring. With regard to this thesis all informal caregiver subtypes will be included if they meet the respondent requirements, which will be elaborated further on.

The caregivers' "workload" is expected to change with time. The level of care that is needed by the PwD is assumed to increase, until a point, where placement in a nursing home or hospitalization becomes necessary.

By the very nature of this phenomenon, it can be hypothesized that there will be differences in the experiences of caregivers, depending on the relationship between the caregiver and PwD, and as previously mentioned, the progression of the disease. This could perhaps be exemplified in the PwD being moved to a nursing home, which presumably will affect a spouse in a different way than that of an adult child of the PwD. During this thesis these potential differences will be investigated both with regard to the caregivers relation to the PwD and inter-individual differences.

1.1 The Cultural setting of caregiving in Denmark

Contingent upon the hypothesis, that the caregiving setting will vary depending on different cultural settings such as public healthcare economy, cultural norms etc., this thesis will begin with an exploration of the cultural caregiving setting in Denmark.

In the danish caregiving setting, before the PwD is moved to a nursing home, a number of options are available to alleviate the problems associated with assisting PwD's with their daily living activities. Different options are given throughout the course of the disease to support the relatives of the PwD, in coping with the situation. As an example, doctors are expected to keep some routine checkups every 6-12 months; a dementia-coordinator can provide the family with useful information about what offers are available in the family's city/area; formal caregivers can aid with daily living tasks and nurses can visit the PwD's place of residence. A number of assistive devices are also available to both the PwD and caregivers to assist daily living, such as GPS-trackers and stove-timers. Other than that most larger cities also organize caregiver support groups, where caregivers of people with dementia can meet and discuss the challenges they experience (Nationalt videnscenter for demens, 2020b; 2020c). With all of these assistive devices and interventions one could ask how danish caregivers of dementia experience the caregiving situation, compared with other caregivers worldwide. A study by Jakobsen, Poulsen, Reiche, Nissen and Gundgaard (2011) investigated the resources that are used in informal caregiving for people with dementia in Denmark. The study showed that informal primary caregivers typically spend 4.97 to 6.91 hours daily on caregiving, while secondary informal caregivers spend 0.70 to 1.06 hours daily on caregiving for their relative with dementia. The cost of care ranged between 160 to 223 euros per day for primary caregivers and 23 to 34 per Euros day for secondary caregivers. With regard to the participant-caregivers 67% of the respondents in the study were women, and 76% of the respondents were spousal caregivers (Jakobsen et al., 2011). As can be seen from this, even though a lot of support is available to relatives of people with dementia, there is still a significant caregiving culture and a significant amount of informal personal resources, that are being spent on the care of people diagnosed with dementia. All of this embeds the danish caregiver experience in a context that is specific to the cultural and historical situatedness in Denmark. Therefore, as is probably already evident, a certain amount of emphasis must necessarily be put on the cultural context, in which dementia caregiver research is carried out. Danish caregivers do at least have some different options, when it comes to alleviating their burden as caregivers. But are these options adequate in regard to the challenges that danish caregivers face? - And do all caregivers perceive the same amount and type of challenge? In this project the challenges of being a caregiver will be explored both with regard to caregiver type and relation to the PwD. The study will be emphasizing measures of caregiver grief and burden, along with different measures that are aimed at differentiating the caregiver dyad. This is done more so with regard to the syndrome's progression, than with regard to the different underlying diseases that might have caused the dementia. The study will also include some more open ended measures of what the Danish caregivers experience as challenging in the year 2020. Why is it important to research caregiving psychology? Not only is a considerable amount of money and time being put into informal caregiving, but caregivers have also been shown to experience chronic stress, and decreased physical and psychological health in association with the caregiving duty (Fonareva & Oken, 2014; Bremer et al., 2015). Some of these consequences of caregiving may even extend long past the end of the caregiving relationship (Corey & McCurry, 2018). Furthermore, caregiving is expected to be highly situated to the target groups' social, cultural and healthcare related situation. Therefore, even though studies may have been made previously, or in other cultural settings, this may not necessarily be representative of all other caregiving circumstances.

Another important point to make comes from a survey made by YouGov (2019) made for the danish Alzheimers society (*Alzheimerforeningen*), in this survey, it was concluded that the majority of the general danish population did not have the necessary knowledge, to help people diagnosed with dementia. Hence it will be important to identify where the population needs more knowledge. Though, presumably the caregiving population will be a bit more informed.

The study of caregiver experiences might also potentially provide implications for practitioners of psychology in the examination of, which areas might be beneficial to further explore with clients, for whom informal caregiving of a person with dementia is an essential part of their daily life.

In the section above has been explored some of the more general knowledge of dementia caregiving and the caregiver setting in Denmark.

1.2 Synthesis of research question and subquestions

Above, the current caregiving setting for relatives of people with dementia in Denmark has been explored. Through the exploration it became evident that the danish general population appeared to have limited knowledge of dementia, but that a lot of assistance can be provided to caregivers of people with dementia. Contingent on the information that has been elaborated above, a research question that can be proposed, is as follows: “What is the experience of being a caregiver, for a person with dementia, in Denmark?”

This research question can be further be divided into 3 general subquestions:

1) What is the experience and consequences of being a caregiver to a person with dementia?
2) How does different individual characteristics affect the caregiving experience?
3) Is the experience similar or different to what is experienced in other non scandinavian cultures?

This will be further elaborated throughout the thesis. In the next section will be reviewed some of the research that has already been carried out with regard to this subject, in order to further specify and theoretically embed the current thesis.

2.0 Review of literature

2.1 Pre-death grief and different construct definitions for the experience of loss in dementia caregiving.

While caring for a PwD, the caregiver often goes through a range of emotions and conditions. Naturally, it is possible that watching a cherished relative decline in cognitive-, social- and sometimes physical abilities can invoke some negative feelings in the caregiver. These feelings have sometimes been labeled as grief, or anticipatory grief. Lindauer and Harvadt (2014) explored the different labels for the negative feelings that occur in the context of dementia related family caregiving, through content-analysis. In their analysis they comprise research from 49 peer reviewed papers published in the timespan of year 2000 till 2013. The authors arrive at the terminology of pre-death grief, but suggest that the term is linguistically immature, since the terminology used to describe the dementia-caregiver's grief has been inconsistent in the literature thus far. The term is described as overlapping with anticipatory grief, and chronic sorrow, while to some degree being distinct from them. Lindauer and Harvardt set out to clearly define and distinguish the somewhat unique feeling that caregivers of people with dementia have, during the course of the disease. Their reason was to investigate the terminology, so that caregivers may be better understood and supported through the caregiving process.

The authors provide the following definition for pre-death grief in the context of dementia:

> Pre-death grief (...) is the caregivers emotional and physical response to the perceived losses in a valued care recipient. (...) This pre-death grief is due to (a) (the) care recipient's psychological death, which is asynchronous with

> physical death; (b) (the) lengthy and uncertain disease trajectory; (c) (the) compromised communication between the person with dementia and the family caregiver, and (d) (the) changes in relationship quality, family roles and caregiver freedom. Pre-death grief can contribute to caregiver burden, depression and maladaptive coping (Lindauer & Harvath, 2014, p. 2203).

The definition is given the antecedents that 1) there will be an emotional attachment between the PwD and the caregiver. Either due to love, respect or familial obligation; 2) that the caregiver perceives the functional and relationship-related changes as losses (Lindauer & Harvadt, 2014). As such this definition is likely to be limited to informal caregivers compared with formal caregivers.

Lindauer & Harvath (2014) propose that pre-death grief differentiates from the related concepts of anticipatory grief and chronic sorrow with regard to its revocability, nature of loss and communication issues. With regard to the irrevocability of the loss, the authors describe that PwD's from time to time can reveal some of their "original" personality and function, giving a glimpse into the person "they were". The nature is also described as being differentiated, as the caregiver in pre-death grief experiences a sense of the PwD having died, while they are still alive, the "psychological death being asynchronous with the physical death"(Lindauer & Harvadt, 2014). This is contrasted with anticipatory grief, which is more related to the knowledge of loss that will occur instead of grieving over the current losses that occur asynchronously with death. Lastly they point to communication in pre-death grief being limited and thus distinct from anticipatory grief, where communication may be possible, and chronic sorrow where communication - at least in its common sense - is inaccessible (Lindauer & Harvadt, 2014). The authors also contend that the term, pre-death grief, should be used in a situation specific manner. This alludes to the interpretation that research should be construed in a limited and specific population that is culturally and contextually embedded (Lindauer & Harvardt, 2014). This has implications for the range of the possible interpretations that can be made with regards to caregiving research. These implications can extend to cultural, temporal/historical and socioeconomic settings, which are likely to vary across time and place. Thus since the current thesis involves danish caregivers in the year 2020 extending the interpretations, made in this paper, to different cultures and timelines should only be made with caution. With regard to the term of pre-death grief experience, and how it affects the current thesis, can be elaborated that in terms of the caregivers' feelings of the negative aspects of caregiving, the thesis will focus on pre-death grief, and to some extend caregiver burden, which will be elaborated in the next sections. The rationale for this, is that the pre-death grief experience seems to better capture the unique experience that is associated with being a caregiver of a person with dementia, with respect to psychological phenomena. This is not to exclude neither anticipatory grief nor chronic sorrow as concepts and experiences that may occur as part of the caregiving experience. Lindauer and Harvadt (2014) proposed the Marwit and Meuser (2002) caregiver grief index as a possible tool for investigating the pre-death grief experience. This will be explored further in the methodology section. The concepts of anticipatory grief and chronic sorrow will be explored, should they occur naturally in the open ended section of the data gathering.

2.2 Caregiver burden, caregiver fatigue and caregiver grief.

In the sections above was described the definition of some of the experiences that caregivers have, during the course of their relative’s disease. As mentioned earlier, the experience of caregiving will supposedly vary with regard to a number of different factors. First could be mentioned whether or not dementia has been a prevalent factor in the caregivers life at another point in time. Has it not been, the caregiver may rely on the image that dementia has been given by popular media, and what they might have heard from friends and associates. Another is the (syndrome)stage which the PwD presently is experiencing. This is important to consider while researching dementia, as both PwD and caregiver is presumably affected by the different stages. In the following sections will be investigated research that has previously been carried out, with regard to the caregiving experience of informal dementia-caregivers, with a focus on some of the consequences, such as caregiver burden; caregiver fatigue; grief etc. The next few sections of the literature review will be subdivided with regard to different types of research that has been conducted with caregivers of people with dementia. This is done in order to more easily distinguish between the different types of terminology that has been related to dementia caregiving, besides pre-death grief.

2.2.1 Caregiver burden

Caregiver burden is a multidimensional construct that is related to caregiver fatigue and caregiver grief. One of its original definitions with regards to dementia specifically was given by Zarit, Todd and Zarit (1986): " (Caregiver burden) defined as the extent to which caregivers perceived their emotional or physical health, social life and financial status as suffering as a result of caring for their relative." (Zarit et al. 1986, p. 261). As can be seen, Caregiver burden extends a bit beyond pre-death grief in caregivers, and its cause is also a bit different from pre-death grief, which is due to the perceived losses regarding the functioning of the PwD. Due to its relation to, and as mentioned earlier, partial overlap with other associated concepts there has been developed a plethora of different instruments to investigate caregiver burden and its related concepts. Zarit et al. (1986) arrived at the conclusion, that the phenomena that impacted burden the most was a combination of behavioral deficits of the PwD and the caregiver's low tolerance for such deficits. Caregiver burden has been found to be affected by many different factors such as dementia related neuropsychiatric symptoms; disorders of cognitive functioning; the need of assistance with activities of daily living; the caregivers loss of autonomy and perceived social capital of the caregiver (Van der Lee, Bakker, Duivenvoorden & Dröes, 2014; Papastavrou, Andreou, Middleton, Tsangari & Papacostas, 2015). Different aspects of the caregivers personality and characteristics may affect how well they deal with the challenge of caregiving. In a study related to caregivers of people with LewyBody dementia, using the *Zarit burden interview* (2011), caregiver burden and stress was found to be related to the caregivers role strain; personal strain and the caregivers worry about their performance (Leggett, Zarit, Taylor & Galvin, 2011). Van der Lee et al. (2014) has since systematically reviewed different determinants of caregiver burden. Through their systematic review, they identified caregiver role strains; physical and mental health; caregiver intrapsychic strains (sense of competence, self-efficacy, perceived caregiving adequacy) and coping/personality traits as determinants of caregiver burden. Of patient (PwD) determinants with regard to caregiver burden, the authors identified behavioral problems; lack of self-care/need of support, and disorders of cognitive function. With regard to caregiver determinants they found that caregiver role captivity; caregiver overload; and caregiver neuroticism was associated with higher levels of burden, while caregiver confidence was associated with decreased burden. - Other aspects have also been associated with caregiver burden prediction such as the caregivers social functioning; the caregivers health and the caregivers competence/self-efficacy. In studies that included coping and personality traits, emotion-based coping was associated with higher levels of burden, whereas problem-based coping was associated with lower levels of burden. Caregiver neuroticism was associated with increased burden, whilst caregiver extraversion and agreeableness was associated with less burden (Van der Lee et. al., 2014). Kim, Chang, Rose & Kim (2011) likewise found caregiver burden to be related to the disease related factors of the care recipient along with caregiver sociodemographics and caregiving related factors. Stress seems to be a concept that in the literature has been tightly related to burden. Allen et. al. (2017) made a systematic review of the cognitive and physical effects of burden as measured by biomarkers of chronic stress, they found that cortisol was increased in caregivers along with reduced attention and executive functioning. The authors also found implications that interventions had an effect on cognitive function but did not exclusively improve cortisol levels. Epinephrine, Norepinephrine and cardiovascular biomarkers were implicated with mixed results (Allen et. al., 2017). Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch and López-Pousa (2010) investigated burden with regard to the debate of, what group of caregivers (spouses versus adult children) suffered the greatest burden, as other studies overall had been inconclusive. Some showing that the first mentioned had greater burden, others showing that the last mentioned had greater burden, and other studies again showing no differences. Conde-Sala et als.' (2010) results showed that adult-child caregivers experienced higher levels of burden, especially when they lived with the PwD, whereas those who didn't live with the PwD experienced the highest levels of guilt. In both adult-child caregivers and spouses, burden was associated with behavioral and psychological symptoms. Higher levels of burden was correlated with worse levels of mental health. The correlation being strongest in daughters of the care receivers. The authors also emphasize that in their study, differences between spouse and adult-child caregivers were not attributable to respondents age or physical health but rather due to the structure of the family relationship (Conde-Sala et al., 2010).

2.2.2 Caregiver fatigue

Some caregivers might become so challenged by the caregiver-role, that they end up with what is described as compassion fatigue. Compassion fatigue has been described by Day, Anderson and Davis (2014) as a combination of helplessness, hopelessness, inability to be empathic and a feeling of isolation from prolonged exposure to perceived suffering. Compassion fatigue starts as a form of empathy (or compassion) for the person that is suffering. The feeling can over time then evolve into compassion stress, with continuous exposure to suffering, until it becomes compassion fatigue, due to an inability to detach from the situation and also due to experiences of life related demands and hardships. Expanding on previous research that primarily focused on caregiver fatigue in professional healthcare providers, the authors investigated caregiver fatigue in adult children, who cared for a parent with dementia. Through content analysis of semi structured-interviews, they found 4 themes to be associated with the risk of developing caregiver fatigue: uncertainty; doubt; attachment and strain (Day, Anderson & Davis, 2014; Day & Anderson, 2011).

2.2.3 Studies on other types of Caregiver grief

As mentioned earlier, caregiver pre-death grief is somewhat differentiated from the type of grief that occurs in bereavement. Meuser and Marwit (2001) concluded in their study, that the (anticipatory) grief experienced in relation to caregiving was comparable to bereavement related grief, with regards to intensity and breadth. In their definition of grief, anticipatory grief is a type of grief that somewhat seems to prepare the caregiver for the loss, that will come with certain types of progressive diseases, such as Alzheimer's disease. They also emphasize that earlier studies have shown that the pre-death experience of the caregiving quality could mediate the bereavement related grief process and adjustment. Marwit and Meuser (2001) did their initial investigation in form of semi structured interviews with the aim of making a model that could describe the grief response for caregivers of patients with Alzheimer's disease. Their study showed differences between spousal and adult child caregivers, such as spouses having a greater focus on the loss of emotional (loneliness) and sexual intimacy, whereas the adult child caregivers put greater emphasis on their jealousy of others, negativity, loss of interest in hobbies and questioning the meaning of life. The differences seem attributed to differences in life stage and social groups. The subsequent qualitative analysis revealed that the grief experience for child caregivers of patients with mild dementia was characterized by approaching and simultaneously avoiding conflict. The experience of caregivers of patients with moderate dementia was characterised by recognition of personal loss and the inevitability of decline. The experience of adult child caregivers of patients with severe dementia was characterized by a deep sadness which replaced the anger that was representative of the previous stages. In contrast the spousal grief experience was characterised by determination, togetherness and adjustment in the mild stages; Compassion, frustration, a focus on "the now" and a loving redefinition of the relationship in the moderate stages, and a sense of being stuck and unsure about life in the severe stages. This was exemplified in the caregivers becoming alone in relation to placement of the PwD in a healthcare facility. In this situation the caregivers became nervous about living alone, and struggled with how to continue/develop social relationships. With regard to post death grief, the experience seemed comparable between the caregivers. Both adult-child- and spousal caregivers felt worn down and either had a general or temporary (grief resurfacing) relief from their grief over that their loved one had "gotten peace." The authors argue that their study, as is probably also evident from the above mentioned differences, supports an approach in which caregiver grief is explored in a stage and caregiver(type) sensitive manner (Marwit & Meuser, 2001). Others have investigated in depth, the caregiving experience post death. Corey and McCurry (2018) investigated the grief related experiences of family caregivers after the death of the PwD. Through this the authors found 3 overarching themes: sleep disturbances; (negative) changes in health status and learning to live again. The sleep disturbances persisted for up to ten years (Corey & McCurry, 2018). As such there are also a number of grief related consequences and more importantly, as can be seen from the Marwit and Meuser study, these consequences might differ from caregiver to caregiver. An interesting prospect, would be to carry out a similar study like the one of Marwit & Meuser (2001), but longitudinally, in order to see if this is a consecutive order that caregivers go through or if there might be differences or middle stages. However, such a study is beyond the scope of this thesis. Lindstrøm et al. (2010) also investigated the grief experience of caregivers, this time with regard to its ambiguousness. They emphasize the physical presence of the PwD, who becomes increasingly psychologically absent. This is not much different from the emphasis on the asynchronous death by Lindauer and Harvadt (2014). In Lindstrøm et al.'s (2010) study, adult child caregivers went through different patterns of grieving. Initially, the grief was characterized by being related more to the caregivers themselves, with emphasis on their personal loss. The level of grief started as low, but began increasing as the PwD's condition deteriorated and the adult-child caregiver assumed a greater amount of responsibility. The grief response gradually shifted towards more anger, guilt and resentment, until finally culminating with feelings of loss of the relationship with the parent (Lindstrøm et al. 2010).

From the implications of the literature thus far, the term caregiver grief seems somewhat muddled between different forms of grief. As also mentioned by (Lindauer & Harvadt, 2014), it would therefore be interesting to investigate, if this is just due to too vague terminology of grief in caregiving, and/or if the plethora of grief related concepts are actually an expression of the complex and highly diverse experience that is caregiver related grief. However this project will, as previously mentioned, adapt the grief approach by Lindauer and Harvadt (2014), while not specifically excluding other interpretations, should they occur organically through the investigation. The concept of pre-death grief and its related concepts are, however, also likely to change, as part of social and/or scientific discourse. This may be yet another possible reason why the concept is so disorganized. While including the term in studies may help with specification, it might be as likely to contribute to further disarray of the terminology, perhaps leading to a discussion of, whether or not static definitions of terminology is idealistic. Regardless, it is probably desirable within scientific communities to attempt somewhat static and clearly defined definitions contemporary as they may be. In this section we have explored some of the negative consequences or experiences related to being a caregiver of a person with dementia. However, as will be explored in the next section, not all caregiving related experiences need have a negative outlook.

2.2.4 Caregiver reliefs

Many studies have reported an element of personal growth in the aftermath of the caregiving experience (Corey & McCurry, 2018). In other situations the act of caregiving itself could be seen as something satisfactory, usually in combination with positive appraisal of the prior and current relationship, and accepting things for what they are (Shim, Barroso & Davis, 2012). A recent review by Quinn and Toms (2019) identified several pieces of literature and even scales (E.g. *Positive aspects of caregiving scale,* Tarlov et al., 2004) that can be utilized in measuring the positive experiences. Through the review it became evident for the authors that most of the caregiving literature has focused on the negative aspects of caregiving. The review resulted in the identification of several constructs of positive aspects of caregiving (e.g. finding meaning; satisfaction; gains; uplifts; rewards; esteem; gratification and coping) and found that high amounts of these were associated with better wellbeing in the form of fewer symptoms of depression; lower burden; higher psychological well being, psychological health, mental health and positive affect (Quinn & Toms, 2019). Another study by Yu, Cheng and Wang (2017) also explored the research on positive aspects of caregiving and found that the positive aspects of caregiving formed a "multidimensional construct" including domains such as a sense of personal accomplishment and gratification; feelings of mutuality in a dyadic relationship; increase in family cohesion and functionality, and a sense of personal growth and purpose in life. These aspects were predicted by personal and social affirmation of role fulfilment; effective cognitive emotional regulation, and contexts which promote finding meaning in the caregiving role (Yu et al., 2017). The positive aspects of caregiving have likewise been shown to differ across cultures. A study by

Roth, Dilworth-Anderson, Huang, Gross and Gitlin (2015) showed that hispanics and african american people experienced higher amounts of the positive aspects of caregiving, than “white” americans. Life appreciation due to caregiving was also significantly higher in african americans compared to both white americans and hispanics (Roth et al., 2015).

Therefore it is important not to exclude or ignore the possibility of positive aspects of caregiving.

2.3 Individual and cultural factors affecting the caregiving experience.

2.3.1 Differences with respect to the caregiver dyad

In the previous sections of this thesis we have explored some different aspects of the caregiving experience, however it would be wrong to assume that differences might not be found across individual and cultural spans. Therefore in this section, we will explore some of the factors that might diversify the caregiving experience, first with regard to individual differences, then with regard to cultural differences.

As should already be evident, differences in the caregiving experience can be found between different types of caregivers, however, intra-caregiver type differences have also been found. A study by Shim, Barroso and Davis (2012) showed that spousal caregivers can have different appraisal and focus points of their experience. The study consisted of data from interviews of spousal caregivers who followed a longitudinal skill training program for caregivers of people with degenerative diseases. The study found that caregivers could be subdivided into people who had majorly negative experiences; majorly ambivalent experiences or majorly positive experiences. The negative group expressed only negative aspects of their prior, and present, relationship with their spouse and mainly focused on their own unmet needs rather than that of their spouse and reported a significant caregiving burden. The ambivalent group was characterised with loss of their relationship with their spouse, yet found some positive aspects regarding them being able to care for their spouse. The positive group was characterized by a loving approach to the caregiving experience with a focus on “what still is” contrary to “what is lost” (Shim, Barroso & Davis, 2012).

Pinquart & Sörensen (2003) emphasized that studies that investigate different factors affecting caregiver burden and depression tend to focus on factors that are unique to the caregiving context, and factors that are more generalized. In their meta-analysis, they focussed mainly on factors that were unique to the caregiving context (i.e. the care receivers impairment, the caregivers involvement and uplifts for the caregiver). With regard to care receiver impairments three aspects were related to caregiver outcomes: physical impairment, cognitive impairment and behavioral problems associated with dementia. With regard to caregiver involvement, specifically the duration of caregiving, Pinquart and Sörensen emphasize that there has been inconclusive evidence regarding its effect on caregiver burden. However, they mention three different hypotheses regarding the effect that caregiving duration exacts on caregiver burden: the *wear-and-tear* hypothesis (longer duration causes greater burden); the *adaptation hypothesis* (caregiver adapts over time causing a reduction in burden), and the *trait hypothesis* (caregivers pre existing resources mediate the caregiver outcome). The Authors conclude that caregiver burden and depression had the strongest association with the care receivers behavioral symptoms, followed by positive aspects of caregiving and then the amount of time provided. They also concluded that the strength of those associations were mediated by the relationship of caregiver and care receiver (i.e. spouse vs. adult child). Furthermore they speculate that behavioral problems might be less tolerated than physical problems (Pinquart & Sörensen, 2003).

Other studies have found that attachment style might mediate negative feelings associated with caregiving. Attachment theory builds on the early works of Bowlby (1969) and Ainsworth (1985) (Ainsworth, 1985 In Cicirelli, 1993; Bowlby 1969 In Cicirelli 1993). Attachment, and subsequently attachment behavior stems from the attachment between the infant and its primary caregiver. From the perspective of attachment theory, the bonds made between caregivers (parents) and infant in the early years of life create scripts and expectations from which the individual interprets and models their relationships the rest of their life (Crispi, Schiaffino & Borman,1997; Schneider, 1991). Chen et al. (2013) found that adults use their attachment experiences as a script (base script) they can access in caregiving and that secure base scripts were associated with lower levels of criticism, hostility and emotional over-involvement in “adult-child”-parent caregiver dyads. The authors also found that these scripts exert a stronger effect on the more difficult tasks of caregiving. In the article, it was proposed that adult-child caregivers make a mental shift, about their relationship to the parent and their role in the given relationship (Chen et al. 2013). This relationship is particularly interesting with regard to caregivers, who are adult children of a parent with dementia with regard to the potential of role reversal. Likewise, it would be interesting to investigate, if differences in childhood attachment to a parent potentially is able to mediate the caregiving experience, especially in regard to the caregiving-relations between a child and parent. It would also be interesting to explore whether this potential mediation can account for different experiences in all caregiver dyads or if it has a higher impact on adult-child-parent relations. Browne and Shlosberg (2005) emphasized that the attachment system is activated in times of danger, distress and novelty. Which could be said to characterize the caregiving experience. Referencing the YouGov study mentioned in the introduction, if the danish population has limited knowledge about dementia, the situation of becoming a caregiver can be characterized as novel. With respect to the point made by Browne and Shlosberg it could then be assumed, that the caregiving situation may activate attachment behavior. Therefore the findings of Chen et al. (2013) seem reasonable. Cicirelli (1993) also investigated attachment and filial obligation in relation to caregiver motivation and burden. Cicirelli found that attachment and filial obligation was related to the amount of caregiving that the respondents provided. However, only the obligation aspect was positively related to burden, while attachment was negatively related to burden. Cicirelli emphasizes that the individual’s attachment to a parental attachment figure is continued in a symbolic manner throughout life (Cicirelli, 1993). The caregivers ability to perceive pain in the care receiver is also likely to be subject to some variation depending on different caregiver variables. Pain perception has been shown to be dependent on perceiver gender (with males tending to underestimate pain to a greater extent than women); previous experiences with pain perception; personal characteristics (e.g. empathy); how to pain is expressed;

characteristics of the one in pain; relational and contextual factors (such as the cultural context, illness, etc) and the relationship between the pain perceiver and person in pain,. In this regard, closer relationships tend to increase the pain rating. It has also been shown that perceiving others' pain while experiencing pain in oneself can decrease the evaluation of others' pain (Coll, Grégoire, Latimer, Eugene & Jackson, 2011).

2.3.2 Cultural differences

As such the previous section investigated some potential differences, within the caregiving dyad, that may affect the caregiving experience. However, as it has been emphasized earlier, the caregiving experience is also likely to be subject to some cross-cultural variation depending on a number of different factors relating to different cultures and countries, such as economy, cultural norms etc. Therefore it seems relevant to illuminate potential discoveries about caregiver experiences in different cultures, in order to address potential cross-cultural differences and similarities.

Ali and Bokharey (2016) investigated a Pakistani dementia caregiving setting, through semistructured interviews with subsequent interpretative phenomenological analysis.They argue that in Pakistan, informal caregiving is an integral part of the culture, as there is a large cultural emphasis on the family as an institution. At the same time, they regard the caregiving systems as being relatively sparse. This is one way, in which the caregiving setting might differ culturally and systematically. Both in regard to the societal mindset/orientation (i.e. individualistic vs. collectivist societies) but also with regard to the healthcare available in different countries. In the Pakistani setting, the caregiving duties often befall young women, i.e. daughters-in-law, who experience the negative impact of caregiving on their mental health. This is often further aggravated due to criticism and lack of support from their peers. This contrasts with the danish caregiving setting, which can be interpreted to have a potentially differently organized welfare system and where the caregivers are mainly spouses. Ali and Bokharey also describe a cultural setting, in which the elderly population is often underdiagnosed, with regard to dementia. The elderly are cared for at home, and the families are described as fearful of the stigmatization that follows a dementia diagnosis. It is not unthinkable that some form of stigmatization potentially can occur in the danish caregiving setting, especially referencing the low level public knowledge mentioned in the introduction. However, it seems likely to expect that it won't prompt the caregivers to, what could almost be interpreted as, hiding their elderly in fear of stigmatization. Ali and Bokharey (2016) found certain themes to be emergent in the daily lives of the caregivers and their coping with the duty of being a caregiver to a person with dementia. The themes encompassed mal-adaptive behaviors, such as reactivity and self neglect, and maladaptive emotions such as worry, low frustration and an inability to cope with the situation. These seem to correspond well to the experiences previously described. All of these behaviors were proposed to interact in the total caregiving experience. Conclusively the authors emphasize that it is important to remember that different caregivers have vastly different experiences but that some similarities could be found in their study (Ali & Bokharay, 2016).

Another group of researchers likewise investigated the caregiving experience via a similar approach but in relation to caregivers from India. The indian healthcare system is likewise described as sparse. The focus of the study was with an emphasis on the caregivers' experience and their view of the use of coercion. The respondents of this study also felt emotional and physical effects in the form of burnout. This was partially due to a lack of respite care; absence of shared caregiving limited knowledge of dementia and a lack of community support services, which also seems comparable to previously mentioned experiences. In response to these feelings, the caregivers commonly used coercive methods such as sedatives; seclusion; environmental restraint; restricted dietary intake, restricted access to finances and participation in social events - in order to safeguard the PwD and manage the physical health and behavioral problems of the person with dementia. The cultural setting, that is described in the article, in this case, encompassed that dementia is seen as a part of normal aging, and therefore not seen as anything pathological. On the other hand, the behaviors that might be exhibited by the elderly population was described as stigmatized and could therefore lead to neglect and abuse (Stokes, Combes & Stokes, 2014).

But what happens in a setting, where public healthcare is not as sparse, where hospital or nursing home placement is a possibility?

McCormack, Tillock & Walmsley (2017) investigated just this. Their focus was on the experience of transitioning from having a PwD, that is being taken care of in the family home setting, to relinquishing those to a residential care facility. These authors also followed a similar analysis. The caregiving setting was Australian caregiver dyads, and the analysis represented one overarching theme that was described as “navigation system control,” which had three underlying themes including: connecting/disconnecting; Windows closing and capacity for sensations. The first of the themes focused on the interaction between the caregiver and the residential caregiving facility. Where inconsistent quality of caregiving; ambiguous responsibility and unclear guidance options were associated with increased worries, whereas the care facility becoming recognized as the patient’s home and rapport between patient, caregiving facility and informal caregivers was related to diminished levels of worry.

The theme of windows closing was related to the caregivers’ experiences of stress related to the behaviors they experienced that the patient had; stress over the transition and feelings of guilt and loss over the abdication and the loss of hope, purpose, and connectedness as the disease-course progressed.

The last sub-theme, *Finding the capacity for sensations*, largely regarded finding new ways of communication with the person with dementia. These largely included communication through movements such as dancing and tactile communication. The relative with dementia, who had largely lost their verbal communication was still able to convey their feelings through tactile sensations.

The respondents of this survey were often in an emotional conflict between their own needs and the needs of the PwD.

The authors put emphasis on that the dementia caregiving setting includes both the caregivers and the PwD’s, as such the dyad follows a double bio-psychosocial model that includes both the patient AND the caregivers. The authors also emphasized that some of the respondents viewed the medical system as an “opposing force” especially when it came to the medication aspect of caregiving. Situations in which the caregivers felt powerless and felt that the professional caregivers were disrespectful made the caregivers feel stressed and defensive (McCormack, Tillock & Walmsley, 2017).

Likewise, a study of greek caregivers found themes of role-reversal, in which the child became the parent and the parent become the child; finding meaning in the caregiving experience; impact of caregiving; issues related to changes in the person with dementia and seeking support, and also some of the positive aspects relating to dementia. Conversely, most of the caregivers were also found to have a feeling of growing stronger, through the experience (Issari, Philia, Tsaliki & Christina, 2017). As such, it seems that there are some disconnections between the caregiving family system and the public healthcare system. Whether this relates to the lack of a proper healthcare system and education or whether this relates to some miscommunications between the health care facilities and the family caregivers as with McCormack, Tillock & Walmsley is not clear. It seems that the caregiving experience is generally impacted by the PwD's behavioral symptoms, which is subject to different degrees of stigmatization across cultures. Nonetheless, the notion of whether dementia is pathological or not seemed to differ across different cultures. In the next section we will explore some models that can be used for the interpretation of the caregiving experience.

2.4 Models for interpreting the caregiver experience

2.4.1 The stress process model

In their study, Conde-sala et al. (2010) study utilized a model based on the work of Pearlin et al. (1990) and Schulz and Martire (2004) (Pearlin et al., 1990 In Conde-sala et al., 2010; Schulz & Martire, 2004, In Conde-Sala et al., 2010). They made an adaption of the model to fit their framework of the caregiving experience, with a focus on the multidimensionality of the caregiving experience, including stressors and interventions. With the caregiver symptoms as the centre of the model, it emphasizes different stress-inducing variables such as contextual variables (i.e. family relationship; relationship history; living with the patient; gender of the caregiver/patient; time spent caring); Primary stressors (i.e. behavioral disorders; functional deficits; cognitive deficits; severity and time since onset); and secondary stressors (i.e. family conflicts; difficulties at work and psychotherapy). The model also emphasizes different interventions such as Social support; Social resources and treatments (both pharmacological and psychological) (Conde -Sala et al. 2010).

2.4.2 Constructivist Self-Development theory

Proposed as a framework for understanding the experience of dementia caregivers (McCormack, Tillock, Walmsley 2017), the *Constructivist Self-Development theory* of trauma was first proposed by McCann & Pearlman (1992). The theory lends ideas from object-relations theory, self-psychology and social cognition theories. The core idea of the theory is that an individual's unique history shapes their experience of traumatic events and defines their adaptation to the trauma. The theory can (if. McCann & Pearlin, 1992) be used as a guiding framework in the assessment and treatment of three aspects of the self that is related to trauma (self-capacities; cognitive schemas, inclusive trauma memories and related affect). The theory’s practical implications in the non acute state focuses on challenging disruptive cognitive schemas in relation to six domains (safety; trust; independence; esteem; power; intimacy) (McCann & Pearlin, 1992). While this project will not focus much on interventions for dementia caregiving, the core idea that the individual’s history shapes their experience of events is promising, and in line with some of the research described earlier with regard to individual differences. By suggesting this as a framework, I would interpret that McCormack, Tillock and Walmsley (2017) either sees the caregiving experience as somewhat traumatic or sees the core idea of the theory as something that can easily be adapted from trauma theory to other experiences. It does not seem counter-logical to assume that an individual’s history could generally shape how they experience life and hence their caregiving experience.

2.4.3 Stress-coping model

According to Quinn, Toms and Heyn's (2019) review the majority of the included literature (in their study) references some version of coping theory, like the Lazarus and Folkman (1984) approach. This approach was originally described by Lazarus and Folkman (1984) who emphasizes that people appraise their interactions with the environment. When the interactions are appraised as stressful the individual can use a range of coping mechanisms to manage their distress from the interactions. These can either be emotion based or problem-based. If the outcome of the coping process is positive, not only will the individual be more likely to repeat given behavior in another situation that is akin to the one just experienced, but the individual will also stop searching for coping mechanisms in the current situation (Lazarus & Folkman 1984 in Folkman 1997). The coping theory was since revised, by Folkman (1997) to include positive psychological states as a result of their research regarding caregiver-spouses of people with acquired immune deficiency syndrome (AIDS). The positive states were included in three stages. The first stage involved including positive states as a result of *meaning-based* coping processes in response to the stressor itself (e.g. positive reappraisal; revision of goals and planning goal directed problem-based coping; activating spiritual beliefs and experiences). The second stage is coping as a response to the emotions of distress that are elicited by the stressor. And the third stage of inclusion relates to that generated positive psychological states affect the reappraisal of the situation that occurs after the coping process and this helps with the sustaining the coping process that is needed, in the chronic situation of being a caregiver, or if the coping strategy has led to an unfavorable outcome (Folkman 1997). Piiparinen & Whitlach (2011) also include notions of coping-theory in their model but emphasize that way too often, the coping is based on problem-focused coping whilst almost ignoring emotion-focused coping. This, they describe, can lead to micro-managing of the daily care in an attempt to push away the painful thoughts and feelings. This could perhaps be compared to the earlier referenced study of Indian caregivers and the use of coercive methods. It is also interesting in relation to earlier studies, in which caregivers focusing more on emotion-based coping were associated with higher levels of burden. It seems plausible that some level of balance might be needed between the two concepts.

2.4.4 The existential loss model of Dementia caregiving

Piiparinen and Whitlach (2011) set out to compile a model of the dementia caregivers experience based on the caregiver's confrontation with loss in caring for a person with dementia. The model includes 11 stages, the first, begins with the caregiver (and receiver) being confronted with the dementia diagnosis, that indicates that the relationship will change. In the second part a "back-drop" of loss is brought to the forefront of the caregivers' cognition. This is a backdrop of the things that we all are aware eventually will occur (existential problems such as death), but which are pushed to "the back of the mind". This elicits existential threats related to isolation, meaninglessness and vulnerability. In this part emphasis is put on how the caregiver is able to deal with the loss (relating to attachment theory among other things) and how it may affect the course of the caregiving. The paths of the model diverge into Avoidance based caregiving, which is followed by very taxing control-based coping, and in turn may negatively affect the caregiving relationship with authoritarian decision-making styles leads to the diminished well-being of the care-receiver. Alternatively the caregiver can work with a framework of acceptance, and can appraise the situation. This is possible, since emotion-based coping is not neglected, with an over-focus on control-based coping and emotional denial. The inner emotions of the caregiver will not take up as much energy to neglect, and therefore the caregiver has more energy to observe and be mindful of the care-receivers needs. This according to the authors encourages empathic coping and promotes an adaptive relationship in the dyad based on communication, negotiated decision making and a positive affect bond for both parts of the dyad.

The model implements interventions that are aimed at interrupting the negative cycle in the first mentioned scenario (Piiparinen & Whitlach 2011).

2.4.5 Biopsychosocial model

In his critique of the biomedical model as *dogmatic*, Engel (1977) put an emphasis on culture and psychological phenomena, and distanced himself in part from some of the psychiatric community that wished to “come back to medicine” by adapting the biomedical model. This he emphasized would lead to either a reductionist view (i.e. psychological phenomena are only a sum of physicochemical principles) or an exclusionist view (in which phenomena that cannot be explained physicochemical principles are excluded) of behavioral disease phenomena. He accentuated that the physician's professional skills had to include both social, psychological and biological knowledge in order to address the whole picture (Engel, 1977). Henningsen (2015) emphasizes that the model has since been criticized for being too eclectic and not specific enough with regard to priorities in research and therapeutic interventions. The author however argues that we should not view the model as static, with regard to how it was defined at its conception, but as a concept in development and as a concept that still needs further research and development. Henningsen proposes three clarifications to the model: 1) to release the model from being a “blueprint” of holistic or humanistic healthcare, viewing it rather as a conceptual framework 2) the social part of the model should not only be seen as “psychosocial” but as sociocultural, 3) the dynamic, rather than static nature of the model (Henningsen, 2015). As such, with regard to the aforementioned double bio-psychosocial model an ideal study would address the biopsychosocial conditions of both the caregiver and the recipient.

2.4.6 Differences and commonalities between the models:

As such the above mentioned models have provided ample justification for including different variables in the investigation and discussion that looks beyond simply just caregiver and PwD, such as the social and cultural context in which they are both embedded. The cultural context is unlikely to vary much from caregiver to care-receiver, but the social context may vary. Most of the models emphasize the need to look beyond the individual. However, both the existential loss model and the stress-coping model emphasize more on how the caregiver may cope with the current situation and approach the topic of caregiving. With the existential loss model emphasising how the caregivers approach to caregiving can turn into a negative cycle which affects both parts of the caregiving dyad, if interventions with regard to emotions are ignored. Although this is expected to be influenced by different factors that are also culturally and socially embedded.

2.5 How does the accumulated knowledge affect the investigation?

The section above has reviewed some of the literature that has already been composed with regard to caregiving and dementia. Comparing this to our research question: *What is the caregiving experience for relatives who are caregivers of people with dementia in Denmark*, we can already now make some specifications as to what will be investigated, what can be hypothesized and how the circumstances play a role. As previously mentioned, this project will focus on the term of pre-death grief as it seems adequate to describe some of the caregiver experience, along with caregiver burden. With regard to hypotheses' it can be proposed we have seen that: A) different caregiver types (e.g. spouses vs. adult child caregivers) can have an effect on the caregiving experience. This could be exemplified with adult child caregivers focusing more on their personal sacrifice, while spouses focus more on the relationship. B) The caregivers appraisal or perception of the caregiving relationship will vary and affect caregiver grief. Such an investigation however, is beyond the scope of this thesis. C) different aspects of personality such as Attachment bond and style can affect the caregiving relationship and perception of burden.With more anxious caregivers exhibiting greater levels of burden and/or grief. D) The caregivers' experience of burden and pre-death grief will be affected by the severity of the PwD's disease. E) The caregivers can be able to find positive experiences in caregiving, but this will likely be dependent on a number of different factors including culture and the caregivers' approach to the caregiving situation. As such the literature review has been concluded, with a short review of its implications for the progression of the thesis. The next section will explore the methodology utilized in the thesis' investigation.

3.0 Methodology and method

3.1 Items included in the investigation and the reasoning behind their inclusion

With respect to the knowledge accumulation thus far, it seems favorable to include measures of Caregiver pre-death grief as a measure of the caregiving experience. As has been previously mentioned, disease severity is one of the factors that might affect this pre-death grief experience, thus it seems reasonable to include measures of such in the investigation along with demographics and caregiver independent variables. Regarding independent variables it seems interesting to further elaborate the individual's attachment to the PwD. Therefore in the following investigation will be included measures of demographics (age, biological sex, education level, occupation etc) in order to assess the representativeness of the respondents to the danish population; a measure of the caregiving grief experience; A measure of the Caregivers' attachment styles, and a measure of disease progression in the PwD. However, since these scales have been developed with regard to other historical and cultural settings, a number of open ended questions will also be included to address whether the "caregiver experience scales" are actually representative of the experience of Danish Caregivers. In the following sections will be described the tools that have been chosen to investigate the above-mentioned phenomena of interest, along with the reasoning behind the selection of each tool.

3.2 Marwit-Meuser caregiver grief scale

Lindauer and Harvadt (2014) recommend the usage of the Marwit & Meuser (2002;2005) Caregiver grief scales as a measure of the pre-death grief in caregivers. The Marwit and Meuser scales were also chosen due to their good psychometric values (Cronbach's alpha = .90-96 for the original version, α = .80-.83 for the short form version) and their inclusion of a measure of caregiver burden, along with the recommendation from Lindauer and Harvadt. The scales thus not only fulfills the inclusion of pre-death grief in caregivers, but also the inclusion of a measure of burden within the same scales. This was seen as favorable, since including too many scales might fatigue the respondents. The original scale was developed on the foundation of the Marwit and Mauser (2001) study, (see section 2.2.3). The first version of the scale was the Marwit & Meuser (2002) version *the Marwit and Meuser Caregiver Grief Index* (MM-CGI). The original scale consisted of 50-items spanning over 3 caregiver grief subscales: *Personal sacrifice burden*; *Heartfelt sadness and longing*, and *Worry and felt isolation*. The scale has since been condensed into a short-form inventory, the Marwit and Meuser (2005) Caregiver Grief Index - Short-form (MM-CGI-SF). The short form of the scale consists of 18 items, spanning over the general score and previously mentioned three subscales. On all the versions of the scale, informants respond to statements about their caregiving experience, that are placed on a 5-point likert scale (*Strongly disagree; Disagree; Somewhat agree; Agree; Strongly agree*). Since the current project was already including a lot of different measures, the short-form of the scale was chosen in order to avoid the respondents answering the items less vigorously due to fatigue over the many items.

Permission for translation and usage was obtained by contacting Thomas Meuser, via mail. Requirements for the permission to use the scale included transparency in the translation-process, that a copy of the finalized scale would be sent to Thomas Meuser and that the final translation and process could be reviewed by Thomas Meuser pre-distribution of the entire questionnaire.

3.3 The Experiences in Close Relationships-Revised Questionnaire

The *Experiences in Close Relationships-Revised questionnaire* (ECR-R) was developed from an Item-response Theory measure of different adult attachment style questionnaires. This was done with the intention of investigating and creating a scale with a “high and evenly distributed degree of measurement precision” (Fraley, Waller & Brennan, 2000). It was developed by Fraley and colleagues using item response theory of the *Experiences in Close Relationships questionnaire*; *Adult Attachment Scales*; *Relationship styles questionnaire*, and the (*unnamed) attachment scales questionnaire by Simpsons* (Brennan et al., 1998, In Fraley, Waller, Brennan, 2000; Collins & Read, 1990, In Fraley, Waller, Brennan, 2000; Griffin & Bartholomew, 1994, In Fraley, Waller, Brennan, 2000; Simpson, 1990, In Fraley, Waller, Brennan, 2000). The result consisted of two scales (anxiety & avoidance) with 18 items belonging to each scale, resulting in a 36-item questionnaire. Respondents are required to respond to the items in the form of statements that are placed on a 7-point Likert Scale (*strongly disagree; disagree; slightly disagree; either/Or; slightly agree; agree; strongly agree)*. The two scales have generally shown good reliability (α= .90) and the questionnaire is within the public domain (Fraley, 2012). The questionnaires have also been tested on nordic populations (Esbjørn et al., 2015; Olssøn, Sørebø & Dahl, 2010 In Esbjørn et al., 2015), however the results suggested that a two factor structure of attachment would not be sufficient for nordic cultures. Instead Esbjørn et al. (2015) suggested a five factor structure consisting of the factors: *Independent avoidance; Anxious;counterdependent avoidance; angry preoccupation,* and *anxious low self-regard factors* (Esbjørn et al., 2015). This structure might be reflective of the original multitude of scales utilized in the generation of the ECR-R scales, or it may be that nordic cultures simply don't conform to a binary structure of attachment. Neither is definitively disclosed, as the reason for the five-factor structure, in the litterature. However, since a five-factor structure seems more applicable to nordic cultures the standards derived from these nordic studies will be utilized in this given thesis.

3.4 The Global Deterioration Scale (1983) Copyright © by Barry Reisberg, M.D.

The global deterioration scale, is a scale developed by M.D. Barry Reisberg and colleagues (1982), as a tool for the assessment of cognitive decline secondary to primary degenerative dementia. It has been validated against behavioral, neuroanatomic and neurophysiologic measures of primary progressive dementia

(Reisberg, Ferris, De Leon & Crook, 1982). The scale consists of 7 stages, representative of the cognitive decline that is associated with progressive dementia. (Stage 1*, No cognitive decline;* Stage 2, *Very mild Cognitive decline/age associated memory impairment;* Stage 3, *Mild cognitive decline/mild cognitive impairment;* Stage 4*, Moderate Cognitive Decline/mild dementia;* Stage 5*, Moderately Severe cognitive decline/moderate dementia;* Stage 6*, Severe Cognitive Decline/moderately severe dementia;* Stage 7*, Very Severe Cognitive decline/severe dementia*) (Reisberg et al., 1982). The scale will be used for the current thesis, in a modified (adapted) form, with the aim of giving the caregivers a surface level description/indication of disease severity to investigate whether or not the dementia progression affects the caregiving experience. The respondents were asked to choose the statement that seemed to best describe their PwD. Permission for the adaptation of this scale was obtained from the Scale's developer and copyright holder © Barry Reisberg via email communication. requirements for the permission included proper citation of the copyright along with transparency in the translation process. The adaptation of the Scale consisted of 1) a translation of the scale into danish and 2) the transformation of the scale into statements about the PwD, from which the caregiver could choose a severity degree. It has to be noted that this is an adaptation and transformation of a scale, beyond its intended use, which therefore places somewhat cautions on the interpretations, which can be made from it.The caregivers were likewise informed, that this was not the original scale's intended utilization along with a caution that the disease progression of dementia is highly heterogeneous and therefore, the scale might not be fully representative of their PwD's current or future states.

3.5 Open ended questions

In line with the culture-sensitivity of the caregiving experience (as also emphasized in several of the studies mentioned in the introduction), and since only a few of the questionnaires have been used and previously validated to the experience of danish caregivers of people with dementia, a few open ended questions were included such as 1) "*How has dementia changed your relationship to the person with dementia?,* *please consider your relationship before the diagnosis compared to your current relationship."* 2) "*What is the biggest challenge of being a caregiver to a person with dementia?"* 3) "*Does dementia caregiving make any positive contribution to your relationship and/or your daily life? Please do provide examples."* 4) "*What area of PWD caregiving is in the most need of being provided with support for the caregivers?"*, to ensure that the caregiving experience had been covered at least to some degree, despite the aforementioned tools not being validated with regard to the target group. These questions will be analysed through thematic analysis and will also be compared with the items and subscales of the Marwit-Meuser (2005) Caregiver grief Scale -Short form, in order to asses, the appropriateness (adequacy) of the scales to the current caregiver experience, beyond the pilot study, along with a focus on the actual content.

3.6 Initial assembly and procedure of the questionnaire

The questionnaire was originally assembled with first the consensus form, then the more general and demographic questions; the Reisberg © Global deterioration scale; the Experiences in Close relationship questionnaire - Revised, followed by the Marwit-Meuser (2005) Caregiver Grief Scale, and then the open ended questions. However, as shall be explained in the next section, the layout was revised due to feedback from the pilot test.

3.7 Translation and pilot testing of the questionnaires

The Questionnaires were translated with a modified version of the World Health Organization's (2020) guidelines for the *Process of Translation and adaptation of instruments.* The procedure had to be modified due to the limitations imposed on the danish government in relation to the outbreak of the Covid-19 virus.

The general principles of the WHO process is described as 1) Forward translation, 2) Expert panel Backward translation, 3) Pre-testing and Cognitive interviewing, 4)

Final version (For a more in-depth description see World Health Organization, WHO, 2020 in the reference list). Prior to their usage and translation, permission was obtained to use all Questionnaire scales and items that required such.
The final translation-procedure was as follows: 1) Forward translation of the questionnaires. This was done with one “expert” translator, who had knowledge of the subject, was proficient in english and had danish as a native language, and one naive translator who was also proficient in english (international university master's degree) and who had danish as their native language. Two translations were produced independently from one another and afterwards the two translators discussed both translations with the aim of achieving consensus about the translated items. The goal of the consensus discussion was to keep the sentences as conceptually close to the original as possible. 2) The translations were then sent to an expert back translator who was proficient in both english and danish. 3) After the back-translation was received, the two initial translators discussed, whether the back-translated sentences were still representative of the initial sentences, and if any changes had to be made to the forward-translated sentences. With regard to the MM-CGI-SF scale a specific requirement was made by its original inventors, that the translations be sent back to them for review, before any distribution could be made. Therefore the entire translation process document was forwarded to Thomas Meuser. 4) After all corrections had been made, the entire questionnaire was assembled for Piloting.
Piloting was done on 4 respondents (2 males, mean age 24, grandchildren of PwD, and 2 females, mean age 57,5, children of PwD) who were representative of the target group. Two of the PwD-relatives were, however, not directly in a caregiver position, but were still deemed representative of the target group, as they were related to a person with dementia. The respondents occupation was also notified along with an estimate of how much time the pilot-respondents spent on filling out the questionnaire (Mean time 19,97 minutes). After the respondents had filled out the questionnaire, they were interviewed with regard to the appropriateness of the translations, both with regard to comprehension and appropriateness of the sentences and overall questionnaire. Initially, 6 questions were asked to each item in the questionnaire, however as the questionnaire contained a large amount of items

(n=66). This process was very time consuming and the first pilot-participant found that they were losing interest and becoming irritated with the entire procedure (this could be interpreted as dome form of task related fatigue). Therefore the procedure was revised so the respondents re-read sections of the questionnaire (e.g. MM-CGI-SF), and afterwards that section was discussed with regard to the comprehension- and appropriateness-questions to identify any irregularities.

5) After the piloting several things became evident: a) Some of the items needed to be corrected with regards to grammar, b) The attachment-related questionnaire was moved to the front of the questionnaire, after consent-form and demographics. This was due to the fact that most of the respondents found it confusing to first answer some dementia related questions, and then some attachment related questions, only to afterwards be asked some further questions about their experience as caregivers of a relative with dementia. c) The statements of the Reisberg scale, which was initially randomised, were changed to be non-randomised, as the respondents found it confusing with regards to estimating the severity of dementia for their PwD. It was also further emphasized that the respondent should choose the statement that best fitted their relative with PwD.

3.8 Participants

Due to the current situation with the global outbreak of SARS-CoV-II (Covid-19), the participants were sampled through convenience sampling via social media.

A picture was posted with the project topic and requirements for participants of the study. With the picture was attached a link to the survey, which started with a consent form. The Danish GDPR-Authority (Datatilsynet) was informed of the study prior to participant recruitment and data collection. However, as a response was not given prior to the data gathering it was not possible to have a discussion about collecting digital data in the form of email for the purpose of providing the participants with compensation. Datatilsynet has since responded that no permission was required for the gathering of data in relation to a master's thesis.

With regard to the requirements for the participants, respondents were required to be non-formal caregivers (e.g. no nurses) of a relative with dementia, and to have a personal (i.e. non-formal) relation to this relative. The caregivers were required to be older than eighteen years of age, and have some sort of caregiving role with regard to their relative with dementia. The participants were required to have had this role for at least 6 months, and to have contact with a living care-receiver, at least once a week. The social media post and data collection was active for three and a half weeks from April 7th to April 24th. After two and a half weeks the requirements were redefined so that the respondents no longer needed to be caregivers of a living person with dementia. Therefore the respondents could also include former caregivers of deceased PwD's. Likewise, the requirement that the respondents had to have been in the caregiving role for at least 6 months was also removed. And a copy of the questionnaire was sent out in the hopes of gathering more respondents. This was done due to the low number of respondents, which will be discussed further, in some of the sections that relate to analysis and discussion.

3.9 Procedure and equipment

The questionnaire was assembled in SurveyXact which operates in accordance with the GDPR rules for data-gathering. The pilot study was carried out with informal contact with the respondents and interviews over skype when the circumstances allowed it, in accordance with the Government directions during Covid-19. The final questionnaire was distributed via social media (i.e. Facebook) with the University of Aalborgs research recruitment page (*AAU: søg, find og bliv testperson*) and by distribution from the author's personal facebook page. Several dementia related institutions and care-facilities were contacted with the aim of distributing the questionnaire, however due to the circumstances (CoVid-19) it was not possible for them to participate in the study.

Both questionnaires were initiated with the first page being a consent form, and then followed by the questionnaire items in the above described sequences. The surveys could be filled out both via a personal computer, a tablet or a mobile telephone device. This allowed for a range of different equipment to be utilized in the filling out of the questionnaires.

4.0 Analysis

4.1 Target group Participants

3 participants responded to the target (non-pilot) Questionnaire, 2 males and 1 female. The age-interval of the participants ranged from (18-34 to 50-64 years). Of the 10 different possible types of caregivers (*spouse; sibling; child of PwD; grandchild of PwD; child in law of PwD; friend; neighbour; nephew/cousin; cohabitant; other)*, only 2 categories were represented: The Adult child category (2 participants) and the grandchild category (1 participant). All of the caregivers were part of the working sector, and represented different degrees of education (one university student; one with 9-10 years of education and one with 11-13 years of education). All caregivers spent on average an estimated 0-8 hours per week with their PwD, doing caregiving activities. Two of the respondents were non-primary caregivers, while one respondent was a primary caregiver. Due to the low rate of respondents, it was decided to include some of the participants from the pilot study, who were representative of the target group, and who met participant requirements.

4.2 Included pilot participants

The two participants included from the pilot study were females, in the age interval of 50-64. Both caregivers were children of their respective PwDs, with one being the primary caregiver in their family and the other being in a situation with shared caregiving. The primary caregiver spent an average of 9-20 hours of caregiving pr. week, while the other pilot-caregiver answered the “other” category with regards to the caregiving situation. Both participants had an average of 11-13 years of education, with one describing their working situation as “other” and one being retired.

4.3 Summative group of participants

The term “Summative Group” will be used as a reference to analyses’ that include both pilot and project data. Data that is only representative of the non-pilot group will be termed “Target Group” and data representative of the pilot study only will be termed “Pilot Group”. Due to the low participant number, most analyses’ will be conducted on the Summative group, however the initial scoring of the included scales (ie. MM-CGI-SF; ECR-R; GDS) will be demonstrated for both the target group and the summative group, to demonstrate any possible intergroup differences. 5 participants that met the participation-requirements have completed the questionnaires of the study. A total of 2 males and 3 females, age interval being divided from 18-34 years (1 male participant) and 50-64 years (1 male and 3 females). The participants represent two categories of caregivers, the adult children category (4 participants, 1 male and 3 females), and the grandchildren category (1 male). The participants represent a wide range of educational and occupational types ranging from 9-10 years of education all the way through to university education, with work ranging from other, to retired, to working. The amount of care given to the respective PwD’s ranged from an average of 0-8 hours pr. week to 9-20 hours pr. week, to “other”. Already now can be seen some differences in the respondent group compared to the general demographics of Danish dementia caregivers, which have been mentioned earlier (see section 1.2). As mentioned previously, the demographic majority of such caregivers are spouses that spent roughly five to seven hours pr. day on caregiving. Implications of these differences from the target demographic will be discussed later.

4.1 Scoring of the individual scales and results

4.1.1 The Experiences in Close relationship scales

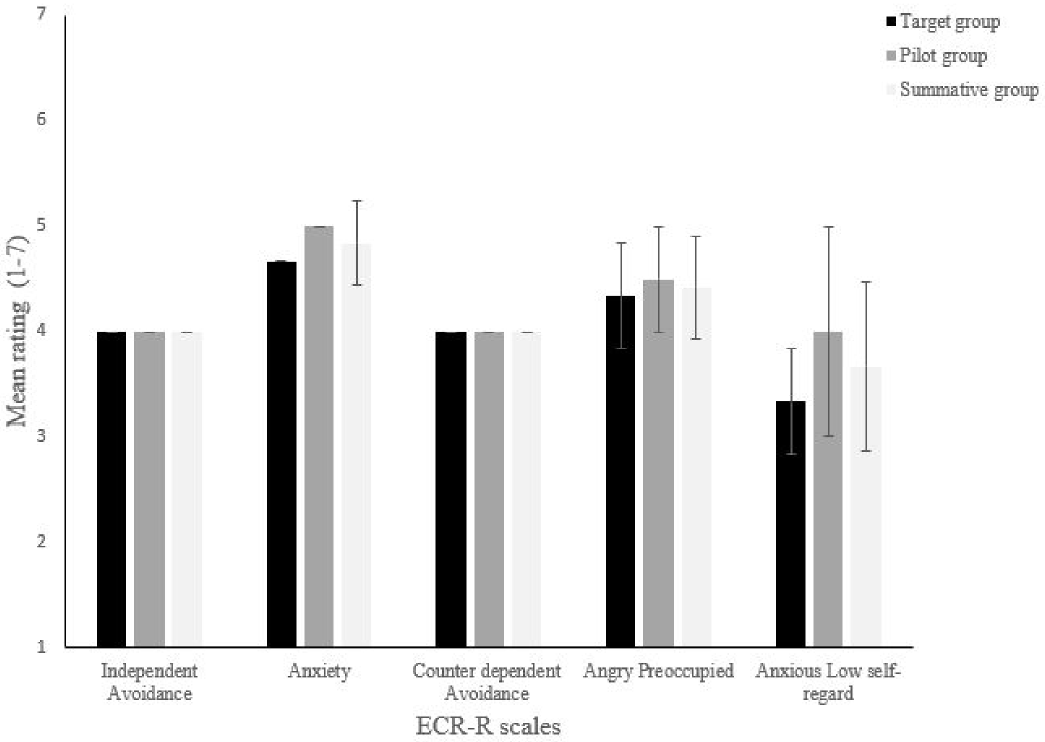

Figure 1. A graph of the *Mean* ECR-R scale ratings (5 different scales, based on Esbjørn et al.2015) with SD's for all representative groups (Target-; Pilot-; and Summative group). Where the SD bars are almost invisible, the SD is equal to zero.

The *Experiences in Close relationship scales* were scored with the standards of Esbjørn et al. (2015) and Fraley (2012). This means that the scores were averaged based on the five factor structure presented by Esbjørn et al. (2015). This was done in Microsoft Excel with the *AVERAGE* function (*MIDDEL* in danish). The scoring was based on the participants answers on the ECR-R scale, which is a 7 point likert scale ranging from (1)*meget uenig; (2)uenig; (3)delvist uenig; (4)hverken/eller; (5) delvist enig; (6)enig, (7)meget enig* (english translation: *(1)strongly disagree; (2)disagree; (3)slightly disagree; (4)either/or; (5)slightly agree; (6)agree; (7)strongly agree)*. A high score on one of the scales indicates that the participant highly identifies with the type of attachment related feelings, that the sub-scales represent (E.g. An average score of 7 on the Anxiety-scale items indicates a high presence of Anxious attachment related feelings). Some of the scores had to be reversed, this was done by subtracting the score from 8 (8-ItemscoreR), as described by Fraley (2012). This is done since the scale does not have an absolute zero, but ranges from 1 to 7. The scoring gave the following values, represented as mean pr. group, in order to keep as much anonymity of the limited number of participants as possible.

Scales	ECR-R1 (independent avoidance)	ECR-R2 (anxious)	ECR-R3 (Counterdependent avoidance)	ECR-R4 (Angry preoccupied)	ECR-R5 (Anxious Low self-regardt)
Mean Summative	4.00	4.80	4.00	4.40	3.60
SD Summative	0.00	0.40	0.00	0.48	.80
Mean Target Group	4.00	4.66	4.00	4.33	3.33
SD Target Group	0.00	0.00	0.00	0.50	1.00
Mean Pilot Group	4.00	5.00	4.00	4.50	4.00
SD Pilot Group	0.00	0.00	0.00	0.50	1.00

Table no. 1 Mean and standard deviation of ECR-R scores for the summative group, the study and pilot study.

As can be seen the participants scored an average of 4 (respondent answers: *Mean = 4;4;4;4;4*) on the first factor (*Independent avoidance*). This score represents the value description “Hverken/Eller” (translation: Either/OR), which is a neutral descriptor. The participants therefore neither agreed or disagreed with the statements that belonged to factor 1. The scores are somewhat higher than the scores obtained by Esbjørn et al. (2015). Whether this reflects Caregivers generally being more Independent-Avoidant than the respondents of the Esbjørn et al. study (2015) or reflects some of the answering qualities of these statements, or the translations is unclear. What can already be said now is that given that there is no variance in this factor, no analysis of potential differences in regard to this factor can be made.

With regard to the second factor, the *Anxious* scale, the respondents answered an average of 4.8 (respondent answers: Participant *Mean = 4;5;5,5,5*). Since 4.8 is not representative of an actual answer category, the median value was calculated (*Median* = 5), this represented the answer category (5) *delvist enig* (translation: somewhat agree). This value is also somewhat greater than the "standards" of Esbjørn et al. (2015), implications hereof will be further discussed in section 5. The factor was likewise subject to some variance between the respondents and between the two groups. The intra-group variance was 0 for both groups. Implications of this will likewise be discussed in section 5.

With regard to the third factor (*Counterdependent Avoidance*), the participants scored similarly to factor 1 (*Independent Avoidance*). Therefore some of the same points of discussion applies to this factor, since the variance is also 0. As with factor 1, the group generally scored higher than the Esbjørn et al. (2015) standards.

Factor 4 (*Angry Preoccupied*) was generally represented by a score of 4.4 (respondent answers: *4;4;4;5;5*), hence the median score was calculated (*Median = 4*), which like factor 1 and 3 represents a neutral score. However, with regard to this factor there was some variance with this factor. The intra-group variances were the same (*SD = 0.50)* for both groups however the summative variance was lower (*SD = 0.48*).

The 5th factor *Anxious Low Self-regard* represents the overall lowest mean summative score for the two groups. With a value of 3.6 (respondent answers: *Mean = 3;3;3;4;5*). The median value was calculated (*Median = 3*) as a means to display the closest possible answer, *delvist uenig* (translation: somewhat disagree). This factor represented the highest summative variance (*SD = .80*), with both groups having an intra-group standard deviation of (*SD = 1*), and with the pilot group also scoring higher than the target group. Implications of this will be discussed in section 5.

4.1.2 The Marwit Meuser Caregiver grief index

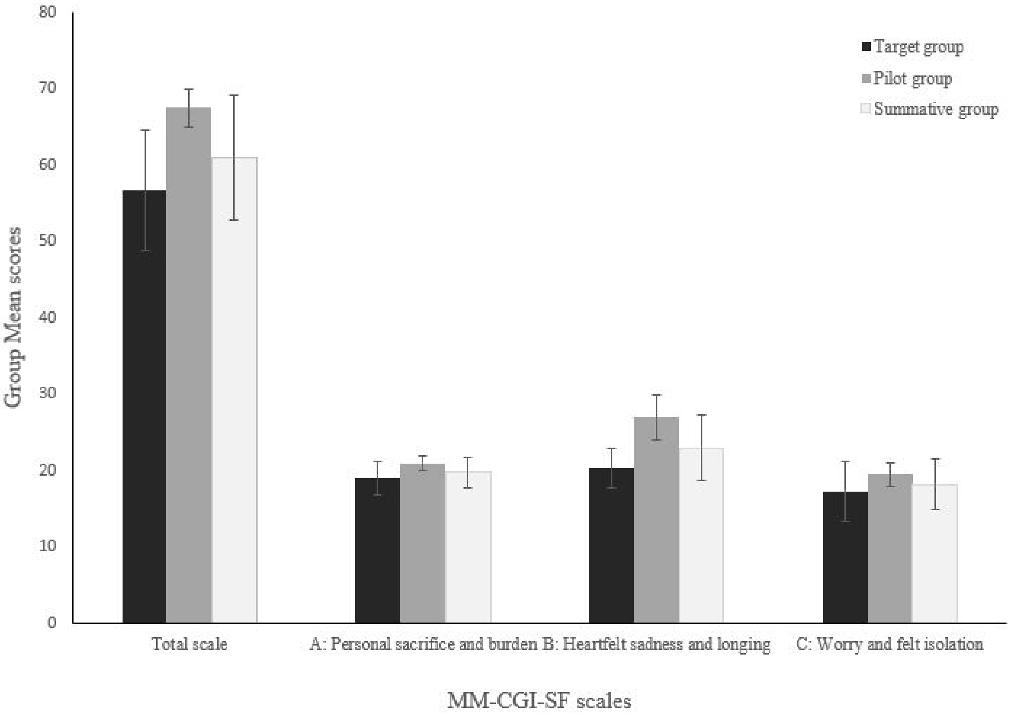

Figure 2, graph of group mean scores with SD, on the four scales (1 full scale and 3 subscales) of the Marwit Meuser (2005) caregiver grief index - short form.

The Marwit Meuser (2005) *caregiver grief index - short form* scores were scored accordingly with the Marwit and Meuser (2005) study. In this regard, the scores were scored summatively for each participant on 4 different scales. One total scale and three subscales. The *Total grief* scale score, consists of a summation of all the item-scores in the questionnaire. The A-scale representing *Personal Sacrifice Burden;* the B-scale representing *Heartfelt sadness and Longing,* and the C-scale representing *Worry and felt isolation.* All of these are scored on the basis of a summation of the individual items belonging to each subscales. A score on any of the subscales of 6-12 points represents a low score. A score of around 20 represents an Average score and a score of 30 represents a high score on the scale. Since the Total scale is scored by the summation of all questionnaire items, the *total* scale has somewhat different norms for low; average and high grief (Low = 18-36; Medium = 60; High = 90). The scale is made with the intent of creating an individual grief profile. However the average and low and high scores will be utilized in this study. For comparative purposes.

Scale	Total grief	A-scale: *Personal Sacrifice Burden*	B-Scale: *Heartfelt sadness and Longing*	C-Scale: *Worry and felt isolation*
Mean Summative	61	19.80	23.00	18.20
SD Summative	8.27	2.04	4.29	3.31
Mean Target Group	56.66	19.00	20.33	17.33
SD Target Group	2.50	1.00	3.00	1.50
Mean Pilot Group	67.50	21.00	27.00	19.50
SD Pilot Group	2.50	1.00	3.00	1.50

Table 2: Mean and Standard deviation for scores on the MM-CGI-SF scales for the Summative group, the Pilot group and the respondent group.

Starting with the total grief score, it is evident from table 2, that the caregivers averagely score within the normal range of total grief. However, the measure is subject to a relatively large degree of variance (*SD*), with the Pilot-group having a higher total score than the target group. Implications of this will be discussed in section 5.

Generally both of the groups score around average on most of the scales, however the score of the pilot group for B-scale: *Heartfelt sadness and longing* is a bit higher than the target group score. It is also the score, besides the total score with the highest variance. The other subscales (*Personal Sacrifice Burden; Worry and felt isolation*) are not subject to as much variance, but generally it can be seen that the pilot group scores higher than the Target group, implications of this will be elaborated later.

4.1.3 The Reisberg © Global deterioration scale

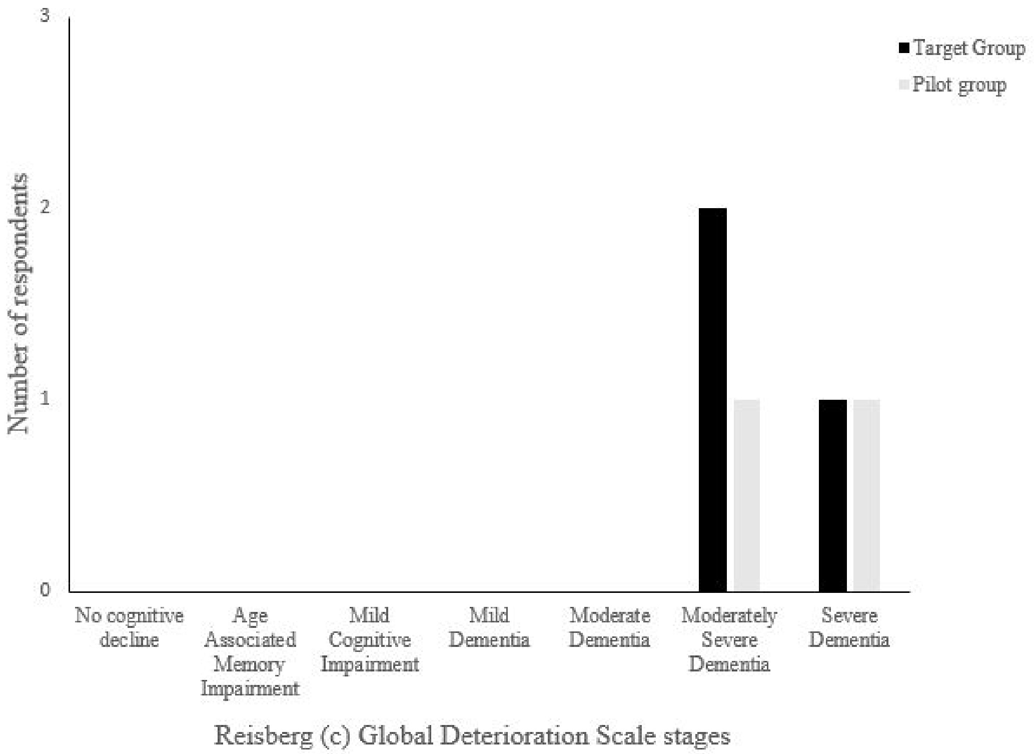

Figure 3, Graph of the number of respondents choosing each GDS category.

The adaptation of the Reisberg (1982) Global Deterioration scale needed little scoring as the respondents just chose one out of the seven statements which were deemed, by the caregiver, to best fit their relative with dementia.

Group/Scale	Global deterioration scale score
Mean (summative)	6.40
SD (Summative)	0.49
Target group Mean	6.33
Target group SD	0.50
Pilot Mean	6.5
Pilot SD	0.5

Table 3: Mean and Standard deviation for scores on the Reisberg © Global deterioration scale for the Summative group, the Pilot group and the target group.

As can be seen from the above, the caregivers generally scored their PwD's between 6 and 7 on the Reisberg Global deterioration scale. In order to investigate which score was most representative of the group the median value was calculated (*Median = 6, SD = .49*). In short this meant that the PwD's of the study were generally scored as exhibiting behavior correlating with moderately severe dementia to severe dementia. As the variance is quite low, and the caregivers seemed to be somewhat at the same stage of their PwD's journey with dementia, it is likely that any interpretations that can be made from comparing the severity scores are limited.

4.2 Hypothesis testing

The hypothesis testing subsection will be divided into two parts for each hypothesis that is tested. The first part of a section will describe what the hypothesis testing would have looked like, if sufficient amounts of data had been reached. Next a simplified form of analysis will be proposed and carried out, with emphasis on what tests can be done with the type of data that has been accumulated, and with the aim of demonstrating any relevant potential differences in the data. Different tests may be utilized and they may be more or less adequate to the hypotheses', however this should provide us with a means to conduct a G*Power analysis in order to infer what number of respondents would be required in order to show any type of effect, should this study be continued or re-attempted.

4.2.1 Grief as a function of Disease progression

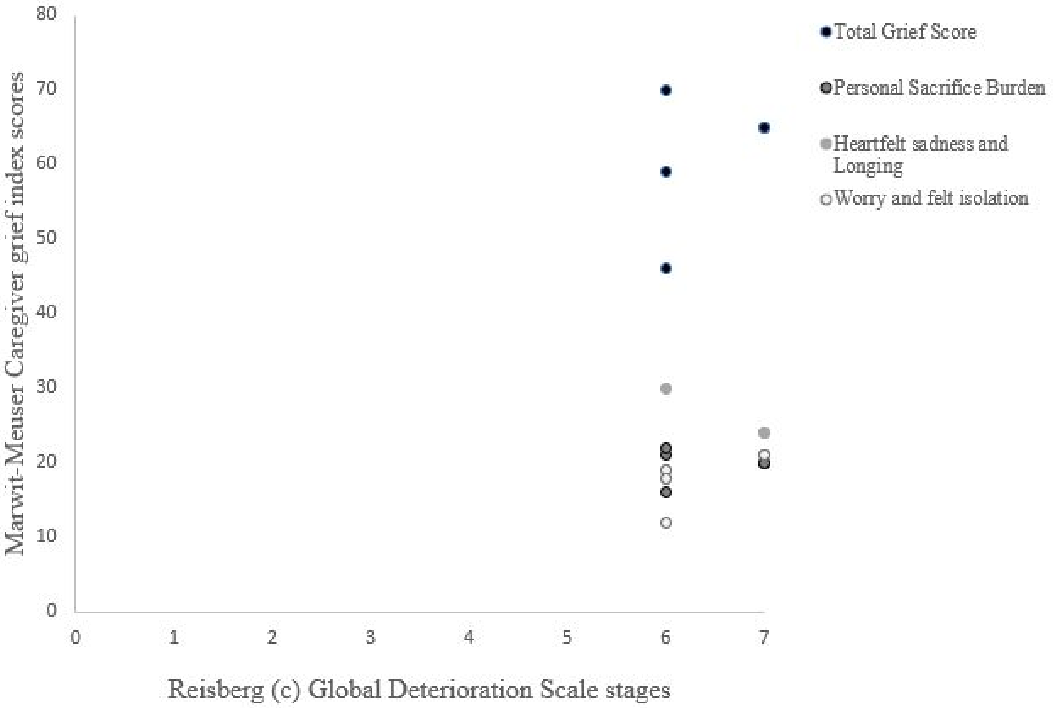

Figure 4, individual Grief-scale scores displayed as a function of GDS scale rating.

This section has the aim of testing hypothesis D) *The caregivers' experience of Grief and burden will be affected by the severity of the PwD's disease.* I hypothesize that, since burden is affected by disease progression, the other items of the MM-CGI-SF are also likely to be affected by disease progression. Therefore the hypothesis can be further specified as: D1)*The caregivers' MM-CGI-SF score will likely be greater in correspondence with disease severity.*

Normally, in the case of an adequate number of respondents, the disease progression would be seen as the independent variable, whereas the Grief score(s) would be seen as the dependent variable. Both the GDS score and the MM-CGI-SF score would be treated as continuous variables. Therefore, the best fitting type of analysis for this type of data set up would be a correlational analysis like Pearson's R.

However, looking at the raw data, or figure 4 for a visualization, the resulting values are split between two "categories", which doesn't make for a great data-model from which a linear regression can be inferred. Instead, since the data essentially forms two groups of either a GDS score of 7 (n=2) or a GDS score 6 (n = 3) we can use a

Mann-Whitney U test, to analyze if there are any differences between the “two groups” and compute a G*Power analysis to estimate the required number of required participants. However implications of such an analysis will be limited due to the sample size and therefore no inferences can be made about the potential covariance of disease progression with other hypothesis-tests. This will be the case for all tests of the different Grief-scales as a function of disease progression. It should be emphasized that normally the data should not be looked upon to determine what test is used, generally it is recommended to consider these before carrying out research. However, with this low sample-size the predetermined tests would not yield any applicable results. Therefore the independent variables are looked upon in order to discern between different types of statistics. The dependent data is not taken into consideration.

4.2.1.1 MM-CGI-SF grief scores depending on disease progression

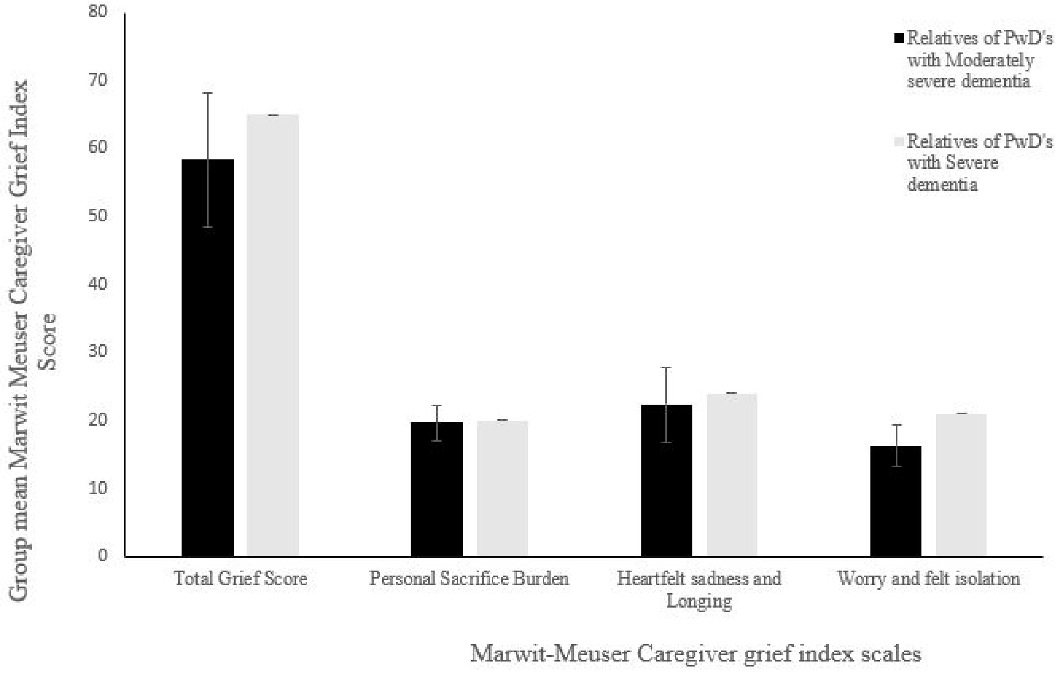

Figure 5. Group mean MM-CGI-SF grief scores compared on the basis of different Reisberg © GDS score grouping-variables.

As can be seen from figure 5, there seems to be some difference between the two groups (Relatives of PwD’s with moderately severe dementia and relatives of PwD’s with severe dementia). Therefore A Mann-Whitney U test was conducted to investigate this difference. The test indicated that the total grief score of the MM-CGI-SF was not significantly greater for relatives of PwD's with a GDS score of 7 (*Mdn* = 65, *SD*= 0) compared to relatives of PwD's with a GDS score of 6 (*Mdn* = 59*, SD*= 9.81), U = 2, p = .80, r = -.26. Thus we see no significant difference between the two groups. It would be interesting to see, if this will also be the case, with a larger group of participants. The small effect-size could indicate that the study would need a larger sample-size to demonstrate any effect. However, it is unclear if the effect size is due to a small effect, or the appropriateness of the statistical analysis. A G*Power analysis showed a power of .08 and suggested that if the effect-size calculation can be trusted, a sample of 758 people would be necessary to demonstrate an effect if a power of around .95 was desired. With such a low power, it is difficult to rule out any potential effects as there is a large probability of committing a type II error.

4.2.1.2 Feelings of Personal Sacrifice Burden (MM-CGI-SF: A) as a function of Disease progression

As can be seen from figure 5, not much difference is evident between the two groups. However, a Mann-Whitney U test was carried out to investigate potential differences. The test indicated that the *Personal Sacrifice Burden* score of the MM-CGI-SF was not significantly greater for relatives of PwD's with a GDS score of 7 (*Mdn* = 20) compared to relatives of PwD's with a GDS score of 6 (*Mdn* = 21) , U = 2, p = .80, r = -.26. As such, akin to the first analysis, no difference could be demonstrated between the two groups. As the effect-size is the same as for the total score, a G*power analysis would likely yield the same results as for the total grief scale score. Therefore this and the further analyses are liable to the same speculations as the first analysis.

4.2.1.3 Feelings of Heartfelt sadness and Longing (MM-CGI-SF: B) as a function of Disease progression

As can be seen from figure 5, the caregivers that scored their PwD's on the severe end of the GDS scale had somewhat higher feelings of *Heartfelt sadness and Longing* than the group of caregivers that indicated their PwD's as moderately severe dementia, on the GDS scale. A Mann-Whitney U test was conducted to analyze this difference. However, it indicated that the *Heartfelt sadness and Longing* score of the MM-CGI-SF was not significantly greater for relatives of PwD's with a GDS score of 7 (*Mdn* = 24) compared to relatives of PwD's with a GDS score of 6 (*Mdn* = 19), U = 2, p = .80, r = -.26. Neither with this analysis could a significant effect be demonstrated. It is subject to the same speculations as the above mentioned analyses, with regard to power and required participants due to the comparable effect-size.

4.2.1.4 Feelings of Worry and felt isolation (MM-CGI-SF: C) as a function of Disease progression

As can be seen from figure 5, the last subscale the Worry and felt isolation has the largest difference between the two groups. A Mann-Whitney U test was conducted to investigate this difference. It indicated that the Worry and felt isolation score of the MM-CGI-SF was not significantly greater for relatives of PwD's with a GDS score of 7 (Mdn = 21) compared to relatives of PwD's with a GDS score of 6 (Mdn = 18), U = 0, p = .2, r = -.76. However a larger effect-size of .76,was computed for this scale, in comparison to the previously investigated scales of this section. A G*Power analysis showed a power of .14 and suggested that any effect would be demonstrable with a sample size of 58 participants, if a power level of .95 was desired.

4.1.2.5 Summary of the analysis of hypothesis D, whether there is a relationship between caregiver grief/burden and disease progression

As can be seen from the above, no significant relationship could be demonstrated between disease progression and caregiver pre-death grief and burden. Overall can be derived from the analyses, that the sample size was not adequate to demonstrate any of the generally small and one somewhat large effect-sizes. As the G*Power analyses revealed a necessary sample-size of 58-758 participants, in order to demonstrate any effects. Thus the sample was simply not large and representative enough of the target group to extract any firm conclusions. More research, with a larger and more representative sample is therefore recommended. It is therefore also unclear if any differences that can be demonstrated are due to any group differences, or simply interindividual differences. The potential implications for the large gap in required respondents will be discussed in section 5.

4.2.2 Is the caregivers' Grief-related experience different, depending on different caregiver-type categories?

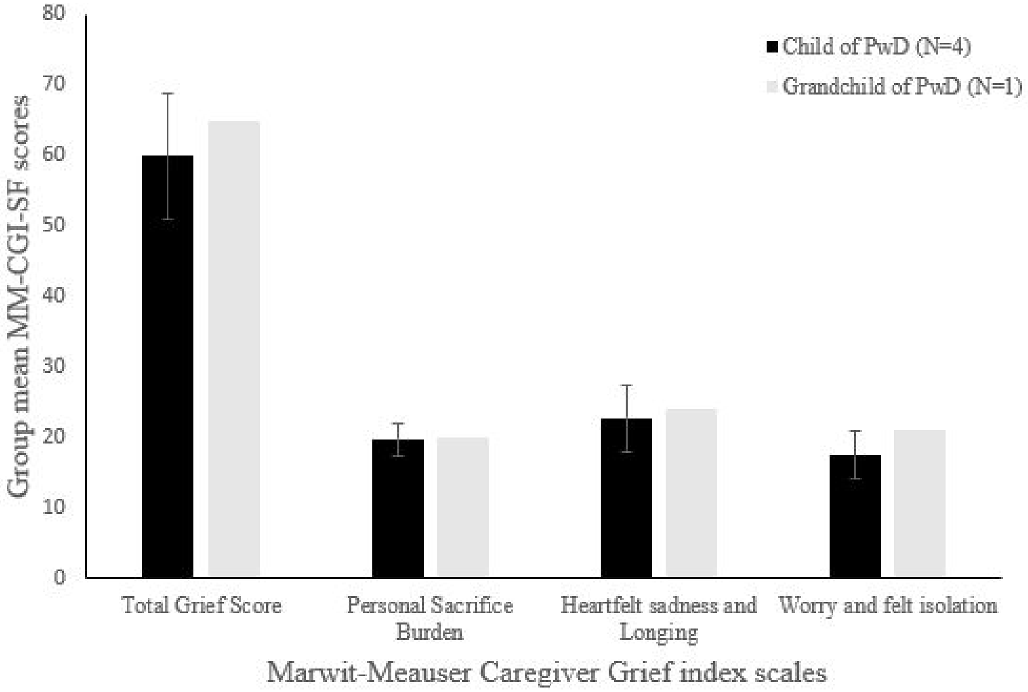

Figure 6. Scores on the MM-CGI-SF scales depending on grouping variables Child of PwD and Grandchild of PwD. Scores are indicated as the Grandchild's score and the mean of the Adult children group. SD's are only presented for the Adult children group, as the Grandchild has no variance in scores for the individual scales.

This Analysis sub-section has the aim of testing hypothesis A) *Different caregiver relation-types can have an effect on the caregiving experience.* In accordance with the literature, this could be elaborated further such that A1) *children will experience higher degrees of burden than spouses.* However, given the nature of our data (respondents being distributed between adult children and grandchildren of their respective PwD's) such expansions could not be tested, as we only have data representative of children and grandchildren. It is also unclear if this relationship (children scoring higher on burden than spouses) would expand to the other facets of the MM-CGI-SF (total grief; longing and heartfelt sadness; worry and felt isolation). Since we have no theoretical foundation from which to make an a priori prediction of the direction of any relationship, the hypothesis test would need to take the form of a two-tailed analysis.

With an adequate amount of respondents, this type of data would have several independent non-continuous grouping-variables in the form of different caregiver types. This makes the data suitable for a one-way ANOVA, assuming the data would be normally distributed, or a Kruskal-Wallis test if the normality assumptions were violated. Alternatively could be used a two-way anova in order to include disease progression (GDS-score) if GDS scores were suspected to covary with other different measures that are related to caregiver pre-death grief. These are the considerations that would have been further explored and elaborated, had an adequate amount of data been gathered. Instead the data is considered, with regards to the independent variables. As has already been explained, we have two groups of caregiver types, the children of PwD's (n = 4) and the grandchildren of PwD's (n=1). This means we could compare the two groups with a t-test or non-parametric equivalent. However, as parametric t-tests and their nonparametric counterparts are not reliable to group sizes of one, instead we shall consider using single-case statistics. In this case, Crawford statistics for single cases can be used (Crawford & Howell, 1998; Crawford 2020a/2020b). In this a single case is compared with a control group on a modified t-test (Case-control design). Though this is not the ideal comparison, however, the Adult child group could serve as a control group, through which differences between the case (grandchild) and the control group (Adult children) can be compared.

4.2.2.1 Total Grief score depending on different caregiver types

As can be seen from figure 6, the grandchild seems to score higher on the total grief score of the Caregiver grief index, than the mean value of the Adult child group. A two-tailed Case-control t-test was carried out in order to investigate this relationship. The test indicated that the total score of MM-CGI-SF score was not significantly different for the adult child group (M = 60, SD = 8.97) compared to the score of the grandchild (Score = 65), t(4) = 0.499 p = .65, d = 0.557. The effect size is medium, and a G*Power analysis revealed a power of .16, which suggested that for a single case design, the control group would need to have a size of 44 people if a power-level .95 was desired. In the case that it was desired to compare two samples, the two samples would have to include a total of 264 participants.

4.2.2.2 Feelings of Personal Sacrifice Burden (MM-CGI-SF: A) depending on caregiver type

As is evident from figure 6, there seems to be little difference between the “case” and the Adult child group. However, any differences were investigated with a Case-control t-test, which indicated that the feelings of personal sacrifice and burden were not significantly different for the Adult Child group (M = 19.75, SD = 2.28) compared to the score of the grandchild (Score = 20), t(4) = 0.1, p=0.92, d = 0.11. As can be seen the effect size was small and a G*Power analysis revealed a power of .05 and suggested that for a single case design the control group would need to have a size of 1076 people. In the case that it was desired to compare two samples, the two samples would have to have been a total of 6716 participants. The small effect size seems reasonable considering figure 6.

4.2.2.3 Feelings of Heartfelt sadness and Longing (MM-CGI-SF: B) depending on caregiver type

As can be seen from figure 6, the grandchild case scored slightly higher on the MM-CGI-SF scale for Heartfelt sadness and longing. Therefore, a Case-control t-test design was carried out to investigate this difference. The test indicated that the feelings of heartfelt sadness and longing-score were not significantly different for the Adult Children (M = 22.75, SD = 4.76) compared to the grandchild (Score = 24), t(4) = 0.24, p=0.82, d = 0.26. The effect size was small, and a G*Power analysis revealed an actual power of .07 and suggested that for a single case design the control group would need to have a size of 195 people with a desired power of .95. In the case that it was desired to compare two samples, the two samples would have to include a total of 6716 participants.

4.2.2.4 Feelings of Worry and felt isolation depending on caregiver type

As can be seen once again, the grandchild seems to score higher than the Adult children group, this time on feelings of worry and felt isolation. This relationship was investigated with a Case-control design, which indicated that the feelings of worry and felt isolation were not significantly different for the Adult Children (M = 17.5, SD = 3.35) than for the grandchild (Score = 21), t(4) = 0.93, p = 0.41, d = 1.05. The effect size was in the spectrum between large and very large (.80-1.20), and a G*Power analysis revealed a power of .43 and suggested that for a single case design the control group would need to have a size of 14 people in order to demonstrate any effect. In the case that it was desired to compare two samples, the two samples would have to include a total of 76 participants.

4.2.2.5 Summary of hypothesis A: Caregiver grief and burden dependency on caregiver type

As can be seen from the above analysis of different caregiver grief measures, depending on caregiver types, any significant relationships between the different variables could not be demonstrated. This could be in part due to the highly fluctuating number of potentially required participants (14-1076 participants for case control designs; 76-6716 participants for two group comparisons) or the low power levels, with the highest suggesting that there is a 57 percent risk of inferring a type II error. Implications of these considerations will be investigated further in the discussion. A further interesting point is that generally the grandchild seemed to be impacted more with regards to grief items compared to the adult child caregivers. This is likewise a topic which will be revisited in the discussion.

4.2.3 MM-CGI-SF Caregiver grief experiences as a function of ECR-R Attachment scores

In regards to the hypothesis C)d*ifferent aspects of caregiver personality such as attachment style will affect the caregiver experience*, a further elaboration can be made, with regard to the ECR-R, such that C1) *the caregiving experience will be dependent on the caregivers attachment score.* This, with regard to the literature, can be further specified in that C2) *Higher degrees of anxious attachment behavior will be correlated with higher caregiver burden*. Therefore it would be interesting to analyze, if this is also true with regard to the other parts of the Marwit-Meuser Caregiver Grief index. With regard to the term Attachment style, one might think that an individual's score could lead to the categorization, that a person is generally anxiously attached or Avoidantly attached. However, such categorizations and dichotomization are generally advised against (Fraley, 2012). Therefore the individual's score should be seen as part of their scores on the, in this case, on five continuous scales. As such the individual is not an anxiously attached or avoidantly attached person, but a person that scores high or low on certain items of the ECR-R. Seeing that the scales should be taken as continuous and not categorical, the most logical way to analyze the correlation between ECR-R scores and MM-CGI-SF scores would either be in the form of a Pearson correlation or by splitting the respondents into groups of high, medium and low scoring respondents and then compare their scores on the MM-CGI-SF. However, this could be seen as a way of categorizing the individuals. These types of divisions would normally result in a high number of necessary analyses, with five subscales of the ECR-R, and with one overall (total) scale and three subscales of the MM-CGI-SF. This would result in a total of 20 different analyses. However, looking at the data displayed in table 1, we see that two of the ECR-R scales in this data set displays a variance of 0 (*Independent avoidance* and *Counterdependent Avoidance*), which essentially leaves any analyses of these impossible or redundant. This leaves us with 3x4 analyses, for a total of twelve analyses, spread over the three ECR-R scales that shows variation. However, as the sample size is low and the variation is low, it is unlikely that the data will be able to demonstrate any significant effects. Nonetheless, in order to estimate any possible differences in the data, and in order to provide an estimate of participants needed for potential further studies, a few investigations will be carried out. Differences relating to two of the ECR-R scales (*anxious attachment* and *angry preoccupation*) can, based on the respondent data, be analyzed by division of the participants into two groups (with the caution otherwise to not categorize based on scores). The analyses will be based on their mean scores of 4 or 5 (*neutral* and *somewhat agree*) on items relating to the given ECR-R scales. Therefore, a Case-control design and/or Mann-Whitney U significance test can probably provide some limited insight into any differences in this group, compared to a correlational analysis. With regard to the last ECR-R variable (*anxious low self-regard*), a correlational analysis may still be possible, due to the presence of 3 different data value types. However, any assumptions extracted from the data should be made with specific caution regarding the very low sample size and alternative implementation of analyses.

4.2.3.1 MM-CGI-SF Grief scale items as a function of ECR-R: Anxiety

As it turns out, looking at the data revealed that the participant that scored differently from the total group on the anxiety scale, was the same person that scored differently on the caregiver-type variable. Hence, the measures are essentially the same as MMCGI-scales depending on caregiver-type. Thus any novel examination of these, with utilization of the same methods would be redundant, as the scores would essentially be the same. For any interest in potential differences readers are thus referred to section 4.2.1.

4.2.4 MM-CGI-SF Grief scale items as a function of ECR-R: Angry preoccupation scores

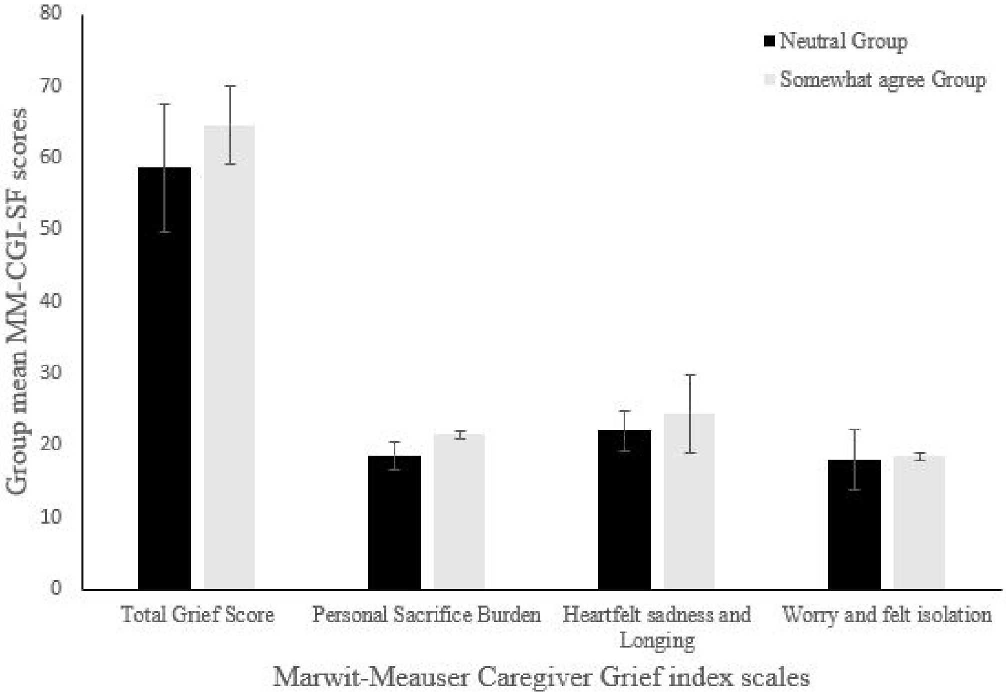

Figure 7. Caregiver grief scale scores depending on participant scores of the ECR-R scale Angry preoccupation.

The different scales were investigated with respect to the participants' different scores on the ECR-R scales of angry preoccupation. Since the groups were split into two groups with different scores on the given scale "*Neutral*" scores (n= 3) and one with "*somewhat agree*" scores (n=2), a Mann-Whitney U analysis was carried out in order to investigate potential differences between the two groups. As it was not possible to make any a priori assumptions with regards to the direction of any potential relationships, any tests on the ECR-R angry preoccupied scale with regards to caregiver grief were two-tailed.

4.2.4.1 Total grief scale as as a function of Angry preoccupancy

As can be seen from figure 7, the higher (*somewhat agree*) scoring on the ECR-R angry preoccupation scale seems to result in a higher total grief. However as explained above, no a priori assumptions about the hypothesis direction could be made, therefore a two-tailed Mann-Whitney U test of the MM-CGI-SF Total grief scale score was carried out. The test indicated that the Total score of the MM-CGI-SF was not significantly different for people scoring *neutral* (4) on the ECR-R Angry preoccupation scale (Mdn =65) compared to people scoring *somewhat agree* (5) on the ECR-R Angry preoccupation scale (Mdn = 65) , U = 2, p = .8, r = -.26. The effect sizes demonstrated a small effect. G*Power analysis revealed a power of .05 and suggested that 758 participants would be needed to demonstrate any effect, if a power of .95 was desired.

4.2.4.2 Feelings of personal sacrifice and burden as a function of angry preoccupancy

This measure likewise, referring to figure 7, seems to only differ slightly depending on scores of the ECR-R angry preoccupation scale. A Mann-Whitney U test indicated that no significant difference could be found between with regard to Personal sacrifice and burden, for the participants scoring *neutral* (4) on the ECR-R Angry preoccupation scale (Mdn =20) compared to people scoring *somewhat agree* (5) on the ECR-R Angry preoccupation scale (Mdn =22) , U = 0, p = .2, r =-.76. The effect sizes demonstrate a large effect. G*Power analysis revealed a power of .09 and suggested that 92 participants would be needed to demonstrate any effect with a desired power of .95

4.2.4.3 Feelings of longing and heartfelt sadness as a function of angry preoccupancy

From figure 7, a difference between people scoring *neutral* on the ECR-R angry preoccupation scale compared to people scoring *somewhat agree* on the ECR-R angry preoccupation scale can be inferred. A Mann-Whitney U test was conducted to investigate this difference. However, the test indicated that the scores on the feelings of longing and heartfelt sadness scale of the MM-CGI-SF was not significantly different for people scoring *neutral* (4) on the ECR-R angry preoccupation scale (Mdn =24) compared to people scoring *somewhat agree* (5) on the ECR-R Angry preoccupation scale (Mdn =25) , U = 2, p = .8, r =-.26. The effect size demonstrates a small effect, and a G*Power analysis revealed a power of .05. This suggested that

758 participants would be needed to demonstrate any effect with a desired power of .95.

4.2.4.4 Feelings of Worry and felt isolation as a function of angry preoccupancy

As can be seen from figure 7, a small difference can be seen between the two groups. Therefore a two-tailed Mann-Whitney U test was conducted in order to investigate this difference. The test indicated that the feelings of worry and felt isolation were not significantly different for people scoring *neutral* (4) on the ECR-R angry preoccupation scale (Mdn =21) compared to people scoring *somewhat agree* (5) on the ECR-R angry preoccupation scale (Mdn =19) , U = 2, p = .8, r =-.26. The effect size demonstrates a small effect. A G*Power analysis revealed a power of .05 and suggested that 758 participants would be needed to demonstrate any effect with a desired power level of .95

4.2.5 Grief scale items as a function of Anxious Low self-regard Scores.

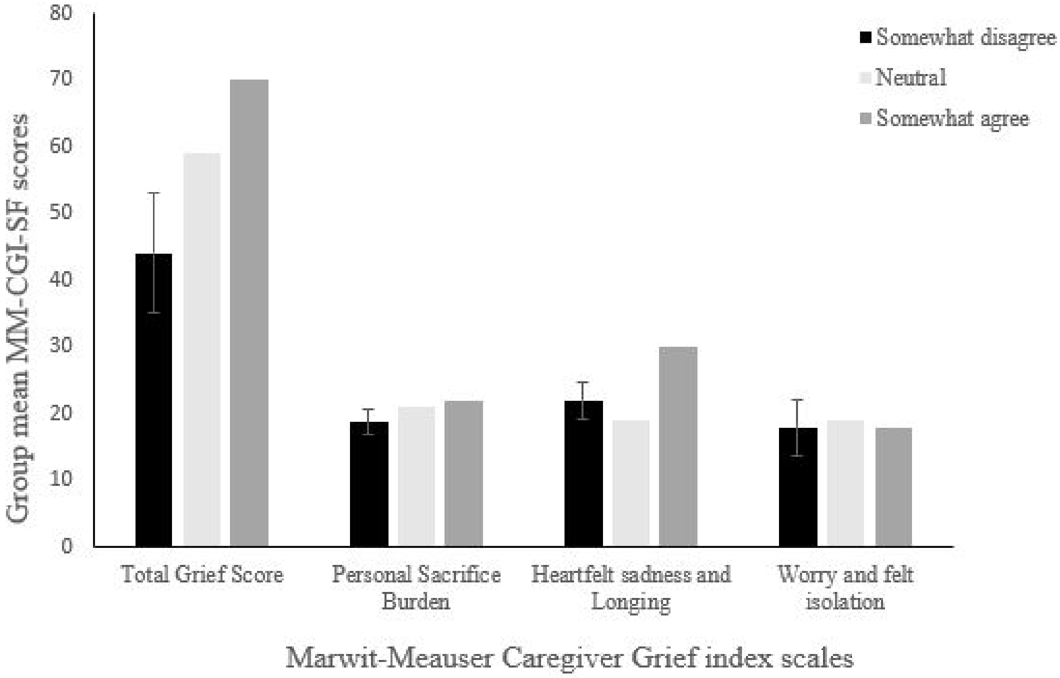

Figure 8. Differences on the MM-CGI-SF grief scale items depending on scores of the ECR-R: Anxious Low self-regard scale as the grouping variable. Scores are presented as group means with standard deviations. However, two groups only contained 1 participant per group. Hence no variation (SD) on the individual scales was present for the Neutral and somewhat-agree groups.

4.2.5.1 The relation between MM-CGI-SF: Total grief score and ECR-R: Anxious low self-regard scores

As can be seen from figure 8, the total grief score seemed to generally increase in correlation with the participants' mean scores on the ECR-R Anxious Low self-regard items. This relationship was investigated by conducting a Pearson correlational analysis. The analysis showed that scores on the MM-CGI-SF total scale and scores on ECR-R scale 5 (Anxious Low-self regard) were not positively correlated, Pearson’s r(5) = .48, p =.2. A G*power analysis revealed a power of .06 and indicated that 283 participants would be needed to demonstrate any effect with a desired power level of .95.

4.2.5.2 The relation between MM-CGI-SF: Personal sacrifice and Burden and ECR-R: Anxious low self-regard scores

From figure 8, it is evident that the participants scores on the personal sacrifice and burden scale seemed to increase in correspondence with the participants scores on the anxious low self regard scale of the ECR-R. This relationship was investigated with a pearson correlation, which showed that the scores on the MM-CGI-SF personal sacrifice and burden scale and the scores on ECR-R scale anxious low-self regard scale were not positively correlated, Pearson's r(5) = .69, p =.1. A subsequent G*power analysis showed a power of .06 that the number of participants necessary to demonstrate an effect would be 170 with the desired power level of .95.

4.2.5.3 The relation between MM-CGI-SF: Heartfelt sadness and longing and ECR-R: Anxious low self-regard scores

Scores on the MM-CGI-SF heartfelt sadness and longing-scale and scores on ECR-R scale 5 (Anxious Low-self regard) were compared by a Pearson correlation. The analysis showed that scores on the scales were not positively correlated, Pearson's r(5) = .58, p =.15. Thus there was no indication of a positive relationship between the scales. A subsequent G*Power analysis revealed a power of .06 and suggested that 229 participants would be needed to demonstrate any effect, given the desired power level of .95.

4.2.5.4 The relationship between MM-CGI-SF: Worry and felt isolation and ECR-R: Anxious low self-regard scores

Correlation between scores on the MM-CGI-SF: worry and felt isolation-scale and scores on ECR-R: anxious low-self regard scale were analysed by a Pearson correlation analysis with regard to whether there was any positive correlation between the two scores. The test indicated that the scores on the scales were not positively correlated, Pearson's r(5) = .03, p= .48. A subsequent G*Power analysis revealed a power of .05 and indicated that 525 participants would be needed in the study, in order to demonstrate any effect, with a desired power of .95

4.2.5.5 Summary of hypothesis C, the relation between attachment styles and caregiver grief

As can be seen, there are very limited indications of whether the scores on the different ECR-R scales can be correlated with the participants' experience of pre-death grief and burden. Whether this lack of correlation between the scores on the two instruments are either due to the inadequacy of the tests; the low sample size, - with G*Power analyses generally suggest a needed number of participants ranging from 92 to 758 participants depending on the individual correlational analyses (e.g. MM-CGI-SF worry and felt isolation x Anxious Low self regard scores vis a vis MM-CHI-SF total score x Anxious low self regard), in order to demonstrate any effects - or if the results are a genuine expression of a lack correlation between the phenomena of attachment and grief is unclear. However the implications of these analyses will be investigated in the discussion.

4.2.6 G*Power analysis of the results

The G*Power analyses have already been reported under each individual analysis. The measures of G*Power analyses were included in order to provide an estimate of risks related to concluding type II errors, and to provide an estimate of how many people would be needed to demonstrate any effects, with the utilized tests. However, some emphasis must be put on, that there cannot be certainty about whether these results are purely representative of the actual numbers needed, with the tests that were initially intended for these studies (given an adequate amount of data). Therefore, any inferences which can be made from these results are limited. However, the G*Power analyses do serve a purpose in relation to the emphasis that the interpretations of the analysis will be limited due to the low sample size. The analyses were made using the computer program G*Power (version 3.1.9.4). The program uses Cohen's d, for t-tests of parametric and non-parametric form. However, Cohen's d was not calculated for the Mann-Whitney U tests. Therefore a conversion was made from the effect size r to Cohen's d, by the general principle mentioned in Coolican (2009, p. 394). The principle states that the effect-sizes of nonparametric tests generally have 95.5% of the power of a parametric test. Thus the r-effect sizes were multiplied by 0.955 in order to carry out the G*power analysis.

The other G*Power analyses followed the standard procedures emphasized by the program. For the calculations of participants needed, a desired power level of .95 was used, instead of the actual powers found through the post hoc analyses. This was to indicate the amount of people needed, if it was desired to have a fair chance at discriminating, whether there would be a possibility of an actual effect, or if any differences and correlations found were mainly due to pure chance.

The generally very low power levels for all analyses indicated that it would be very difficult to discern the presence of any effects, and that there would be a high risk of making a type II error (false negative), if the results of the analysis were accepted as true.

4.3 Qualitative analysis of the open ended questions

The analysis of the open ended questions relied on the method of Thematic analysis. This was to ensure that the mixing, and perhaps slight bit of eclecticism with regard to method and analysis, would not be invalidated by a mixture of scientific ideologies (Coolican, 2009). The approach was data-driven, or inductive, with regard to the previously made arguments of the historical and cultural situatedness of the caregiver experience. Thus a Theoretical approach was used with regard to the Marwit and Meuser (2001) and other previous investigations, when possible. However, since the aim was to compare the appropriateness of such knowledge to a novel situatedness, it seemed more appropriate to utilize an inductive approach. This section has the aim of testing hypothesis E) *The caregivers can be able to find positives in caregiving* and more inductive insights into the culturally situated caregiving experience. Since the current report only emphasizes danish caregiving culture, however, any cultural differences will only become evident from the subsequent discussion. This part of the thesis also serves as a way to compare the respondents' experience to other cultures, the appropriateness of some of the scales and the support offered to caregivers by the danish healthcare system. However, these will also be elaborated in section 5.

4.3.2 Overall themes

In this section, the caregiver responses on the open-ended questions, were analysed with a thematic procedure.

4.3.2.1 "How has dementia changed your relationship to the person with dementia? Please consider your relationship before the diagnosis compared to your current relationship"

The first question, relating to how the relationship in the caregiver dyad had changed, was primarily dominated by a theme of changes in the personality of the PwD. This theme generally regarded externalized reactions; the PwD withdrawing from communications; the relationship gaining characteristics of the caregiver becoming the "mother of a child", and of course the memory problems that usually accompany dementia. - One caregiver also found something positive in the changing relationship by becoming closer to their PwD. In contrast, another caregiver found that they had feelings of having lost some closeness in their relationship, because the PwD had trouble remembering them.

As such. it seems probable that the changes in the caregiver relationship is characterized by a multitude of different changes, in the norms surrounding the relationships, and in the feelings of connectedness. From the last example it is also evident, that the experience of these changes is also subject to some individual differences in perception, either due to the nature of the relationship in the caregiver dyad, or intraindividual differences.Whether it is the case of the first or last mentioned possible cause, or something entirely else is not evident from the answers, but a topic that will be revisited in the discussion.

4.3.2.2 "What is the biggest challenge of being a caregiver to a person with dementia?"

The second theme was dominated by a theme of communication and disease progression. The latter being emphasized in a pattern of sub-themes relating to one of the caregivers wishing for the PwD to have insight into their illness; the general progression of the disease seen as deterioration, with a few bright moments. These themes generally seem very reasonable given the nature of dementia and the underlying diseases. It also seems reasonable to wish that the PwD would be aware of their illness. Implications of this relating to the caregivers experience of burden and grief will be emphasized in the discussion. The theme of Communication was exemplified by one caregiver being unsure about how much their PwD was actually aware of. For another caregiver it was related to having conversations and not being able to explain different topics, potentially relating to some of the semantic deficits that are seen in some types of dementia. The challenges will likely also vary to some degree depending on the different types of dementia. However, difficulties with communication seems likely, especially when considering that the respondents of this investigation generally scored their PwD's a 6 or 7 on the GDS scale. Implications of this will be discussed in section 5.

4.3.2.3 "Does dementia caregiving make any positive contribution to your relationship and/or your daily life? Please do provide examples"

The third theme was generally emphasized by an appreciation of the PwD's gratitude and some of the moments of heightened awareness that were sometimes displayed by the PwDs. One caregiver also emphasized the activities that the dyad were doing together as a positive, in this case singing. While another caregiver found no positive aspects in the process. This theme was characterized by a division for the caregivers, while the majority seemed to be able to find some positive aspects in the caregiving situation it also seems interesting that one of the caregivers found no positive aspects in caregiving. It would be interesting to investigate further, whether this relation would be due to either conditions surrounding the PwD; the caregiver or the caregiving dyad in general, and whether or not this would correspond with higher levels of caregiver pre-death grief and burden. Implications of this will be discussed in section 5.

4.3.2.4 “What area of PWD caregiving is in the most need of being provided with aid/ help solutions for the caregivers?”

With regard to the last question, relating to the adequacy of the possibilities for support, the themes were actually dominated by a lack of support. One caregiver felt that they could not get help anywhere, where another caregiver wanted more constructive support. One of the caregivers described that the support groups, provided by their local municipality, to them seemed as more of a coffee-club, where they would go to hear others complain about “how bad it is going to get”. This seemed, from the description to actually have a negative impact on the caregiver, instigating more worry than calm. The general type of help that was sought for was help with “making it work”, in regard to both daily life, but also to help the PwD cope with their condition, and with how the caregivers themselves could cope with the situation. These implications are interesting as they suggest a discrepancy with the support that is provided by the danish healthcare system, and the help that the caregivers need.

4.3.2.5 Summary of thematic analysis of the open ended questionnaires

In the section above has been thematically analysed the respondents answers, to the included open ended questions, as part of the investigation. A likely interpretation of the above analyses is that the problems of caregiver dyads bear a larger emphasis on the inter-psychological space between PwD and caregiver, in the caregiving dyad, contrasted with more practical problems. It is interesting that the caregivers generally seem to feel that no adequate support has been offered. Whether this is due to an actual insufficiency in the danish healthcare system or a lack of appropriate communication is not apparent.

4.4 Summary of Results and analysis

As such has been analysed the data from the survey of caregiver experiences in danish caregivers. Implications for discussion have been provided to some extent under the individual analyses. As is evident, a lot of the statistical analyses did not provide any significant differences, with some of the results possibly being explained by the low number of participants. Implications of these compared with effect sizes, power and needed number of participants will be discussed in the next sections. With regard to the analyses of the open ended questions it seemed likely that the problems etc. with being a caregiver was largely related to psychological phenomena contrasted with physical/practical problems.

5.0 Discussion

Some discussion based on the analysis of the data; limitations of the study, and the literature review, will be presented in this section. For the sake of keeping anonymity all data that has been analysed and will be discussed in the current sections will be based on group means as there, due to the limited range of participant recruitment, is a slight possibility that the author might know, and thus be able to recognise something from the data. Therefore all data has been treated as means in order to preserve the anonymity of the respondents. Likewise, some of the demographic data has been unspecific, and age-ranges have been in intervals with the aim of limiting the range of recognisability of this study.

5.1 Limitations of the study

5.1.1 Low respondent value

As previously mentioned, the questionnaire was distributed through social media (i.e. Facebook). Only 3 people completed the questionnaire, however it was seen by 111 people. The low number of respondents could be interpreted as a valuable point with regard to the temporal situatedness of caregiving and research. The current investigation was carried out under the global pandemic that has since become known as COVID-19/Sars-CoV-II. The current pandemic has not only made it an interesting time to develop and implement research but perhaps more importantly has had a great impact on the Danish caregivers. Due to danish legislations, caregivers were not allowed to visit relatives in caregiving facilities, and those who were caregiving at home might have trouble tackling the caregiving duties with all the other restrictions etc., imposed by the danish government and society, under the pandemic. This might further be compared to the term caregiver fatigue, which has been mentioned in the literature review, in a more concrete way in which the caregivers might not physically be able to obtain some respite from the caregiving duty, thus not leaving many resources to participate in research. As such the lack of responses might reflect some sort of fatigue over the current process for home-caregiving relatives, or it might be too painful for caregivers to think about a relative that needs visitation, but who cannot be visited at current times, due to the potential risk of spreading the infection to elderly people, or people in the “at risk” groups.

In the immediate situation it would have been interesting to further explore the caregiving experience of different types of caregivers under the COVID-19 pandemic, with regard to how it has affected caregivers on different aspects of daily living. However, as the current investigation already was composed with a long list of different items, it was decided not to further expand the investigation. Nonetheless, the current situation is not to be used as a shortcut, to excuse the lack of respondents and further plausible causes will be discussed. Another way in which COVID-19 has affected the data gathering process, is by imposing limitations as to where and how data could be collected. With social distancing and lock-down/isolation of many public elder-care facilities, from other than their users/inhabitants and working personnel, it was not possible to go out to such locations, to actively seek out caregivers of people with dementia. As such the recruitment of respondents were limited to social media (authors personal social media page and Aalborg university’s group for finding test participants), and an attempt to contact several institutions related to dementia patients and their relatives. However due to the occuring events, a lot of given institutions were unable to provide support with regard to the distribution of the questionnaire.

Another possible reason for the low number of respondents, would be that respondents simply were unable to spend the time filling out the questionnaire, as it was rather long. Earlier has been described how one of the Pilot-respondents was somewhat fatigued by the questions, related to the pilot evaluation, due to the large amount of different items. The questionnaire was rather long, with most respondents taking 15-30 minutes to complete the questionnaire. As was described earlier, a total of 111 possible respondents saw the questionnaire, but did not continue, thus the expected time may have been one factor that influenced the low number of respondents.

One further possible explanation could be that the potential respondents simply did not agree with the consent form, or did not want to read it. The consent form itself amounted to roughly half a graphical A4 page, which may have been a lot to read through. Another possibility is that no compensation could be given for the participation. Due to longer response times with the danish GDPR authority (Datatilsynet), it was not possible at the time of the data collection to offer any sort of compensation to the participants, since the participants could neither be met in person nor provide their email. The GDPR authority has since answered that no "permissions" are necessary for a study at this scale. However, it was not possible to provide incentive for participation to potential respondents.

One further possible reason, for the difference in the amount of people seeing the questionnaire, compared with the number of people actually filling out the questionnaire, could be that the questionnaire was shared on the Author's personal social media page, from which curious friends, family etc. could have clicked on the link, thus artificially inflating the number of "interested respondents".

5.1.2 Representativeness of the target group

As has been previously mentioned, the group of participants are not necessarily representative of the demographics of Danish caregivers for people with dementia. Since the sample size was so low, it is unlikely to expect that this is an expression of a shift in the demographics of danish caregivers for dementia. However, there are some potential biases related to the method of finding respondents. Since the caregiver demographic of danish informal dementia caregivers according to (Jakobsen, Poulsen, Reiche, Nissen & Gundgaard, 2011, see section 1.2) was composed of spouses, it could be assumed that a large part of the target demographic might be subjected to, what could be interpreted as a form of technological bias. It is uncertain whether the large part of the target demographic are actually represented on the social-media (facebook), which was utilized for the distribution of the questionnaire. A recent report on the global age and gender of social media users suggested that only around 2% of the collective mass of Facebook users are 65 years old or older (Clement, 2020). Thus since the questionnaire was distributed on Facebook and especially the author's personal page, and the participant recruitment site of Aalborg university, it is likely that a large part of the target demographic might have been missed or underrepresented, under the assumption that the majority of PwD-spouses would be 65 years old or older.

5.1.3 Implications with the usage of alternative methods of analysis and methodological eclecticism.

As has been described earlier, some alternative methods of analysis have been employed in this project, compared to the initially intended methodology of what analysis. This was due to not only due to the limited sample size, but also to the fact that much of the data was relatively homogenous in nature. This was evident on some of the scores on the GDS scale, the ECR-R scale and the MM-CGI-SF. Thus, due to the relative homogeneity of the data, some of the analyses were not possible to conduct, whilst others became somewhat redundant.

As some of the methods utilized were not the ones intended, this affects the width and strength of the conclusions, which can be made. Since only a small amount of participants had filled out the questionnaire, the alternative methods were used to see if any form of difference in the data could be found. As has been described previously, this was not the case. However, the novel methods of analysis are of course also subject to potential errors as a result of the low sample size. Nonetheless, the analysis section can be used to confirm some assumptions which have been made. First of all, it can be confirmed that a larger sample size would be necessary in order to demonstrate any of the effects. That being said, some of the analyses demonstrated somewhat large effect sizes, indicating that at least some, however not statistically significant, differences were present between the groups. However as we could see, even for the large effect sizes, the sample size was still not sufficient to demonstrate any effects. Therefore no conclusions can be made regarding the significance of the tests. In this regard, further research with larger sample sizes is recommended. However, before one can rely much on interpretations based on measures of power, it is important to remember that power is also dependent on the effect size, sample size etc. which are all subject to some level of scrutiny. Therefore, the power calculations may also only be subject to cautious interpretations.

5.2 Implications relating to the group mean scores of the individual tools.

As the statistical analyses yielded few constructive insights, some emphasis will be put on the scores of the individual tools.

5.2.1 Implications of the ECR-R scores

Looking at the mean scores of the ECR-R, it becomes evident that generally most of the scores fluctuate around the “hverken/eller” category which, as have been discussed earlier, is a somewhat neutral term. The attachment scales are an interesting phenomenon, in which low scores on the original scale generally meant secure attachment. So what does a “neutral” score mean? Generally the scores are somewhat higher for the participants in this study compared the “norms” developed by Esbjørn et al. (2015). Does this mean that the participants are both more anxiously attached, and avoidantly attached etc. than the participants of the Esbjørn et al.’s study? - Not necessarily. The results could also be an effect of the participants not knowing what to answer, and then answering the neutral position as it seemed to neither agree nor disagree with the statement. A potential problem with “neutral” statements in these kinds of scales is that one can never know what the respondent thought when they chose the neutral answer. Another possibility may be social desirability bias. It seems likely that sometimes there could exist certain discourses in different types of cultures or subcultures, especially in regard to how one interacts with others. Denmark is generally known for having a social discourse of

independence, in which it is seen as undesirable to be “needy”, which could lead respondents to answer the ECR-R from the terms of social desirability.
Another implication of the study is that the respondents scored the same on some of the ECR-R scales, whilst answering almost the same on others. Therefore, this limits the conclusions about both the ECR-R and attachment, which can be made from the study. Whether this is due to the target population just having a tendency to answer in a certain kind of way, or if it is due to the low sample size or coincidence is unclear. However, since the sample size is so low, the latter is more likely. Another important point to make is that the possibilities for comparing the results of this study to the Esbjørn et al.’s study are limited. Not only are the target groups not the same (parents vis a vis caregivers) neither is the possibility that the translations are exactly the same. The Esbjørn et al. (2015) article did not include their translations in the appendix, therefore a novel translation of the questionnaire was made (Esbjørn et al., 2015).

5.2.2 Implications of the GDS scores

As we saw in the analysis, this measure was also affected by a low variation in data scores. Whether this was due to the translations, the low sample sizes, the scale or other is unclear. Once again the most likely culprit is the sample size. However, it is interesting that answers are mostly distributed over the two last stages of the Reisberg © Global deterioration scale. This could be due to pure coincidence, or perhaps it could be an effect of, whether people who are caregivers of PwD’ that are further in the disease progression have a larger drive for participating in research, or they may have a greater need, for an outlet for their grief and burden. Regardless, this type of data of course limits the conclusions which can be drawn from the data set, but it also affects the interpretations which can be made from this study. Likewise, the data from the study is unlikely to be comparable to the original scale as it is an adaptation. However, this should not discourage interpretations made in the given study. The main limiting factor is the low sample size.

5.2.3 Implications of the MM-CGI scores

As we saw in the analysis, the participants generally scored within an average level of grief on the different MM-CGI-SF scales. This was perhaps one of the measures that was subject to the most variation across both the summative group and between the pilot and target group, with the standard deviation ranging from 2.5 to 8.27 on the total grief scale and with the standard deviation ranging from 1 to 4.29 on the different subscales. This may reflect different aspects of the respondents' situation, as we have concluded in at least some of the demographic measures, the respondents are a somewhat diverse group. There is a possibility that the differences could be explained by differences in the GDS ratings, and while it is true that the pilot group had a higher mean GDS score than the target group, this difference is rather small, and therefore it seems unlikely that the differences is explained by differences in GDS scores. Another possible explanation is the differences in the relationship and inclusion criteria for both groups. Not only did the target group include a grandchild but the pilot group also included the possibility of the PwD being deceased, which diversifies the different mindset or reasoning from which the MM-CGI-SF was answered. This is especially interesting with regard to the pilot group scoring higher than the target group on the heartfelt sadness and longing subscale where the pilot group actually lands in the area of the norms that indicate a high level of grief on this scale. This could be an expression of the caregivers' possibility to participate, despite the death of their PwD. However such suggestions are purely speculative.

5.2.4 Implications of the Thematic analyses

Comparing the themes and analysis with the GDS score we see that the caregivers are relatively far in the process which may reflect in the types of answers that were given. As implicated by the thematic analysis the caregivers seemed to have a need for more support in caring for their PwD. Many of the caregivers were able to experience positive aspects in caregiving. However, they seemed to have problems with the psychological aspects of the caregiving. As we saw, even though some common themes occured in the caregiving aspect, the different themes were subject to some levels of variation. Due to the low and relatively homogenous sample size it is unclear whether the commonalities in the themes relate to general commonalities between the caregivers or whether the sample size simply wasn't diverse enough to show potential differences in the themes that characterise the diverse experiences of caregivers. Regardless, these implications are still valid insights into what being a danish caregiver for a person with dementia is like.

Upon comparing the themes from the analyses with the Marwit Meuser (2005) Caregiver grief index, it becomes evident that different themes characterised the caregiver experience of the participants. Where the MM-CGI-SF emphasizes feelings of personal- and disease related loss, and isolation the respondents generally put a larger emphasis on communication with the PwD and how to provide adequate care for the PwD. This could be indicative of some mismatch between the danish caregiver experience and the MM-CGI-SF, or perhaps the participants did not answer the questions from a pre-death grief related mindset, but perhaps one that is more related to burden, worry and caregiving related efficacy. Another difference is the positive aspects, but it seems reasonable that a questionnaire relating to grief would not provide much content relating to the positive sides of caregiving. The conclusion that there are differences between the MM-CGI-SF and the themes evident from the open ended questions, however, can be explained by a difference in the methodology. The MM-CGI-SF questionnaire was as mentioned earlier made on the basis of interviews with several caregivers. Thus the MM-CGI-SF can be interpreted as having a more deductive than inductive nature. Whereas the open ended questions have some inductive qualities. While the questions themselves are formed, to a degree, by the literature and preconceptions of the author, they are still open ended. Despite the focus on certain themes. The questions can be interpreted as somewhat leading or close ended, especially the question about whether or not the caregivers experienced any positive aspects of caregiving is leading the respondent in a certain direction. This also means that, since the questions had some different focus points than the MM-CGI-SF, this is also one of the causes from which differences can be found between the two specific tools. It is thereby not excluded that some interesting implications can be found, on the basis of the open ended questions. However, it would be interesting to elaborate these by conducting an interview similar to the

Marwit & Meuser (2001) study in order to further investigate, if these differences have appeared organically or due to differences in the methodology.

5.3 Hypothesis testing and research questions

In this subsection will be explored some of the implications which became evident from the hypothesis testing and research questions.

5.3.1 What is the experience and consequences of being a caregiver to a person with dementia?

As we saw from the literature review, caregivers are affected in a number of different aspects regarding the act of being a caregiver.

From the open ended questions the likely assumption can be drawn, that when a relative is affected by dementia, the relationship with that relative changes. The caregiver now has to provide care for a person, that may be their spouse; parent or grandparent. The participants in this study could be interpreted as being relatively conscientious as many of the caregivers focused more on the aspects of how they could communicate better with, and provide good care for their PwD. This is what the responses to the open ended questions seemed to indicate. On the other hand, the participants also scored somewhat averagely on the MM-CGI-SF scales, which suggests that the feelings of *Personal sacrifice and burden; Heartfelt sadness and longing*; and *Worry and felt isolation* is not alien to them. However, this is also reasonable and might even be expected from the life-circumstances that the caregivers probably find themselves amidst.

However, not all consequences of being a caregiver for a PwD were in the form of negative associations. One of the caregivers reported becoming closer with their relative through being a caregiver, and the others also found positive aspects in the PwDs gratitude and special moments that the caregivers shared with their respective PwD. That being said, it is my humble opinion and guesstimate that most caregivers would rather have been spared the experience of their relative having dementia.

5.3.2 How does different individual characteristics affect the caregiving experience?

5.3.2.1 Different caregiver types can have an effect on the caregiving experience.

From the literature, it became evident that spouses and adult child caregivers were affected by, and approached the act of caregiving in dissimilar ways. While the adult child caregivers seemed to have higher degrees of burden, their focus from the disclosed literature was more on the personal sacrifice that they had made compared with the spouses. As previously discussed the participants in this study were more focused on how to provide adequate care. This seemed closer to the spouses of the Marwit and Meuser (2001) study. Where the spouses had a loving approach to the caregiving activities. The hypothesis with specific focus on spouse vs. adult child was not something that could be investigated in this study, neither many of the other differences in types of caregiver relations. The one relationship that could be investigated, was the difference between adult children and grandchildren. Although the test did not provide significance, it could be seen that the grandchild group generally scored higher, than the Adult children group on measures of grief. Specifically with regard to Worry and felt isolation, which also had one of the largest effect sizes in this entire study (*d = 1.05*). One possible explanation for this difference could be (referencing the implications of the Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch and López-Pousa 2010 study) that caregivers that are more distanced from their PwD seems to have higher levels of guilt. It is possible that this feeling of guilt could translate into feelings of worry and felt isolation. Another possible explanation for the differences is simply that it is an effect of the low sample size. With one group only being represented by one individual, and the other group being relatively small, it is possible that the non significant differences that are viewed are mainly due to change and or individual differences. This might especially be true regarding the other subscales, which only had small to medium effect sizes (*d= .11; .26; .56*).

5.3.2.2 Different aspects of personality such as Attachment bond and style can affect the caregiving relationship and perception of burden.With more anxious caregivers exhibiting greater levels of burden and/or grief

As is evident from the analysis, the different hypotheses for attachment related measures did not yield any significant differences with regard to caregiver burden. As it was explained in the analysis section, the analysis of ECR-R anxiety was essentially the same for caregiver type and caregiver grief. Therefore, even though no significant differences were found, the testing of anxious attachment depending on Worry and felt isolation is likely to have a large effect size. This also means that the hypothesis could be tested further with around 14 participants in the control group of a case control design, and is something that would benefit from further investigation, as it seems likely that feelings of anxious attachment could be related to measures of worry and felt isolation. There is a large variation in the necessary sample size depending on which items were tested. This is reflected by the effect sizes. A possible explanation for the large gap in values is reflected in the literature, where measures of avoidance, on its own, generally were not significantly associated as much with measures of caregiver burden (Lee et al., 2018). Therefore this is one plausible explanation for the large differences in the study. It could also be related to the method, or the appropriateness of the different measures of analysis. So why even investigate the measures that are associated with avoidance etc., and not only focus on measures related to the original anxiety scales? - Simply because the five factor structure of attachment is relatively novel and has only, to my knowledge, been researched sparingly. Therefore, since the five factors are not necessarily equivalent to the two factor scales mentioned earlier, it seemed reasonable to also include all measures in this investigation. This also means that even though some of the five factors might sound like, or include items from the avoidance scale, this is not necessarily the same as them being equivalent to the avoidance scale. Looking at the three scales that could be investigated *Anxiety; Angry preoccupation,* and *Anxious low self regard,* the anxious subscale is perhaps the one scale of the ECR-R that, compared with measures of the MM-CGI-SF, had the highest variation in effect sizes ranging from quite small (d= .11) to large/very large (d= 1.05). There are several plausible explanations for this. First of all, it could be that the different scales of MM-CGI-SF are explained to different degrees by the measure of anxious attachment. Another different interpretation could be that the score generally could be affected by the fact that the more anxious individual was the grandchild category caregiver. Thus, if the grandchild is not a primary caregiver they could be less affected on some of the scales, such as personal sacrifice and burden. Whereas measures such as felt isolation and worry might likewise be affected, since grandchild caregivers can be assumed to not be as involved as an adult child primary caregiver. However, like with the measures of personal sacrifice and burden, it could also be representative of an actual non significant difference between the two groups. Future studies could benefit from either a much larger sample size or a uniform caregiver type group in order to distinguish between, whether these types of data are due to differences between caregiver types or caregiver attachment styles.

With regard to the measure of angry preoccupations effect on measures of caregiver grief, effect sizes are generally small, with the exception of measures on personal sacrifice and burden. This could suggest that generally, angry preoccupied attachment is not related to grief, with the exception of feelings of personal sacrifice and burden. Though no significant relationship between these measures were found, it seems reasonable that feelings of being angry-preoccupied could be related to feelings of personal sacrifice and burden. However, as with most of the other measures of this thesis, investigations could benefit from a larger and more diverse sample size.

With regard to the last analysis, the correlation between anxious low self regard and grief, only moderate associations were found in the correlational analysis, with the largest associations being made between Anxious low self regard and personal sacrifice and burden, and longing and heartfelt sadness. Whereas the total grief score was only weakly associated with anxious low self-regard attachment. Once again this could be suggestive of the result only being low to moderately associated. - Or it could be indicative of the low and relatively homogenous sample size. Generally, the low power levels suggest that discerning any effects will be difficult.

5.3.2.3 The caregivers' experience of burden will be affected by the severity of the PwD's disease.

As explained in the literature section, disease progression has generally been linked to higher levels of burden. This was further extended to the hypothesis that disease progression would affect the different aspects of caregiver grief, as indicated by scores on the MM-CGI-SF. However, the analysis of such differences did not yield any significant results, with the "best" p-value reaching .2. Generally the effect sizes for this measure were small (.26) to somewhat large (.76). However, the null hypothesis could not be rejected. The power estimates for the given analyses were around .8 to .14, indicating a probability of conducting a type II error of about 80 percent. So even though the tests indicated non-significance, there is a slight possibility that at least a potential analysis with a larger sample size, of one of the comparisons that showed a larger effect size could yield a significant result, in the case that a larger sample size was available. However, such a conclusion cannot necessarily be extended to the smaller effect sizes. Different factors affect the conclusions, which can be made from these analyses. Like with many of the analyses of the given thesis, the results are likely to be affected by the low sample size. Another further limitation to the conclusions is the usage of an unintended method of analysis, in order to see if there was any sort of difference in the data. However, due to the low power; low sample size and relative homogeneity in the data, any conclusions that can be extracted are highly limited, especially since the results are conflicting with results from current literature. Nonetheless, it must be emphasized that not all studies did find a correlation between disease progression and burden (E.g. Lee et al., 2018). As mentioned earlier factors such as cultural and historical embeddedness are also likely to affect the caregivers experiences also with regard to the grieving experience, which potentially could explain any differences. Another possible factor that could affect the results would be the translation and adaptation of the different scales which also affects any possible conclusions such that they should be made with some level of caution. Perhaps the results are just indicative that there is not much difference to be found in caregiver related grief and burden in the later stages of dementia. Generally it can be recommended that more research into this topic is conducted.

5.3.2.4 The caregivers can be able to find positive experiences in caregiving, but this will likely be dependent on a number of different factors including culture.

As was indicated by the thematic analysis, most of the caregivers generally seemed to be able to find some degree of positive aspects in the act of being a caregiver. However, one caregiver said that there were no positives to be found. For the sake of keeping with anonymity, the data from the open ended questionnaire will not be directly compared with other individual scores from the questionnaires in regard to the aforementioned possible anonymity problems that potentially could arise from the distribution of the questionnaires from the author’s personal social media page. However, some possible explanations will be discussed.

One possible explanation for these differences could be the due to differences in the caregiving dyad. It is possible that the nature of the relationship, or factors within either the PwD, the caregiver or both could affect how the caregiving situation is perceived or approached. Another possible explanation is that it is simply due to natural variation in the experience of caregivers, or the support that the caregiver was able to obtain, either from social resources or the healthcare system.

Referencing the Shim, Barroso & Davies (2012) study, emphasized in the literature review, it is possible that such differences occur naturally within different caregivers. As emphasized by the Shim et al. study, caregivers were found, who primarily had positive; ambivalent or negative experiences related to caregiving. Whether the positive respondents of this thesis primarily experience positivity or ambivalence related to the caregiving experience is unclear, however, considering all other analysis and data, the ambivalence condition seems more likely.

In future studies, it would be interesting to have a larger sample size in order to distinguish if this is indicative of an actual difference in caregivers, or if this difference in one caregiver is an isolated example. Regardless, the experience is still interpreted as a valid representation of the caregiving situation.

5.3.3 Is the experience similar or different to what is experienced in other non scandinavian cultures?

As has already been described in the literature review, the danish caregiving welfare system and culture differs from the caregiving setting in Pakistan and India. It is however interesting, that despite the differences in the caregiver settings, danish caregivers also seem to find themselves wanting for more support in relation to being a caregiver.

An interesting prospect would be to investigate these differences and commonalities especially with regard to, whether the healthcare systems seems to be equally lacking in providing support to caregivers with regard to the more psychological aspects of caregiving, or if this feeling of what could be interpreted as some form of caregiving related insecurity is just inherent in being a caregiver for a treasured relative. It would further be interesting to investigate these thoughts compared to formal caregivers, in order to further elaborate if this is just something inherent to caregiving in itself. - Or if the act of being an informal caregiver brings further insecurity, stress and perhaps a form of performance anxiety related to caring well for the PwD. Culturally there seems to be a difference regarding, who is a caregiver and stigmatization. Where stigmatization was a relatively prevalent phenomenon in the pakistani and indian investigations. The australian and greek caregivers, along with the participants in this study, were more concerned with how to navigate the situation of being a caregiver, and the navigation within the different countries' healthcare systems. The themes of finding capacity for sensations; new ways of communication and finding in the caregiving role was well represented within the respondent group (see section 2.3.2). An example of this could be one caregivers appreciation of the PwDs gratitude and the singing, as a new way of communicating in the caregiver dyad. In the future it would be interesting to further investigate the differences and similarities between cultures, especially with emphasis on, what characterizes the caregiving experience and what motivates caregivers across different cultures. However, as emphasized earlier, it is not only the culture but also differences within the individual and the caregiver dyad that may affect the caregiving experience and relationship.

5.4 Implications for future research

A lot of different proposals for future research has already been mentioned throughout the thesis. Mainly the focus has been on establishing a larger sample and higher power for the study. Another interesting prospect would be to perhaps isolate the study's sample to one type of caregiver, i.e. either spouses, or children or others, or one type of underlying disease, such as Alzheimers. Likewise it could also be interesting to approach the topic of the danish caregiver experience in a more qualitative manner. The more open ended questions in this questionnaire would have benefitted from the possibility of elaborating some of the answers to further specify, wherein the troubles for caregivers appear. One solution for this would be to conduct a semi-structured interview, instead of the open ended questionnaire questions, which should provide rich opportunities to further elaborate any interesting revelations which might appear from the questions. Another further possibility would be to include an option for the participants to participate in a follow up interview, wherein the participants would have the opportunity to further elaborate the different answers that they provided to the questionnaires.

As has already been mentioned, the current thesis was carried out during the Covid-19 pandemic, therefore it would also have been interesting to investigate and further elaborate on the caregiving experience of different caregivers, in different situations, with respect to caregivers that are “cut off” from their relative with dementia, contrasted to caregivers who provide at-home care to their relative with dementia.

Another prospect could be to perhaps separate part of the project into smaller sub-studies, which could be provided with more time and specificity, such as including more than one measure of phenomena specific tools e.g. tools for assessing caregiver burden. - Or perhaps conducting a more longitudinal study in order to elaborate, how the experience of being a caregiver might change over a longer period of time, or perhaps an entire disease course. Such studies are, however, very elaborate and are perhaps ill suited to be a semester project. One further interesting prospect would be to ask the caregivers, if they have experienced any of the support options mentioned in the introduction under cultural settings of Denmark, such as annual/bi-annual doctoral visits, dementia coordinators etc. in order to further address the possibility, of the perceived lack of support stemming from issues of communication, or an actual deficit in the danish healthcare system. - Or perhaps in a further expansion of the emphasis on role captivity by Van der lee et al. (2014) it would be interesting to investigate differences between sole primary caregivers and caregivers with a shared responsibility. Another theory driven prospect for future studies could relate to caregiver role strain and worry about performance/perceived caregiving adequacy was related to caregiver burden. This could warrant interest, as it seems from the open ended questions, that role strain and worry about performance generally was a theme that was well represented within the respondent group. However, due to the relatively high homogeneity of the group, this was not something that could be investigated further (Leggett, Zarit, Taylor & Galvin, 2011). In some of the literature (Corey & McCurry, 2018) it was emphasized that caregiving itself could be seen as something satisfactory in combination with the prior relationship. This could also be interesting to further elaborate or investigate with regard to coping theory and its emphasis on positive appraisals throughout the entire process (Folkman, 1997).

6.0 Conclusion

In the current thesis, an attempt has been made at investigating the danish caregiving experience in the cultural and historical situatedness of Denmark by the year 2020. Though most of the study and statistical analysis provided low power and non-significance, partially due to the low sample size, some of the effect sizes indicate interesting prospects for further investigations. Generally no statistically significant results could be provided. However, the qualitative analysis provided some interesting insights with regard to the potential adequacy of the danish healthcare system. Unfortunately the current thesis was unable to investigate differences between spouses and adult child caregivers, therefore the implications of the current study cannot be compared to the vast majority of the current literature in that aspect. It generally seems that further research into the topic is warranted and recommended, in order to further elaborate, how caregivers can be supported in the overall emotionally, physically and economically challenging task of providing care for a relative with dementia. Implications for further studies have been provided including qualitative studies, larger sample sizes, longitudinal studies and cross cultural studies. The cross cultural studies were recommended as there through the literature review were revealed some interesting similarities and differences that warrant further investigation. However, ultimately, the different caregiving experiences seem likely to be subject to large variations across cultural and historical situatedness, and inter- and intra individual differences both with respect to the caregiver, the PwD and the dyad itself.

Acknowledgements

A special thank you to Professor Thomas M. Meuser and Professor Barry Reisberg M.D. for permission to translate and adapt their respective tools (Marwit-Meuser Caregiver Grief index - short form & Reisberg © Global deterioration scale) for this current thesis. And a special thank you to R. Chris Fraley for allowing the ECR-R (Experiences in close relationships - Revised) to reside within the public domain.

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