

Graduate thesis

NTNU
Norwegian University of Science and Technology
Faculty of Social and Educational Sciences
Department of Psychology

Daniel Sjøvik

Grief reactions in young adults following the loss of a parent to cancer - a mixed methods study

Graduate thesis in Clinical Psychology Program

Supervisor: Trude Reinfjell

June 2020



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Science and Technology

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Trondheim, June 2020

Supervisor: Trude Reinfjell

Co-supervisor: Beate André

"...Every time you talk about the grief you make new reflections in light of what has been, but surely, it will affect me for the rest of my life..."

- Interviewee

Preface

This study was motivated by the personal experience of losing my own mother to cancer in 2010. The study focus, planning, data collection, analysis and writing were all a result of my own work. After REK gave permission to conduct this study in May 2019, the data collections were finished in September, and analysis finished by December.

Completion of the study has however not been possible without the guidance from my supervisors Trude Reinfjell and Beate Andrè and additional help from Kyrre Svarva and Odin Hjemdal. Trude has with her knowledge and experience with grief research motivated and guided me through the writing process. She has patiently helped me to develop the research -aim and -questions, and regularly read through my work, continuously improving it with important feedback and ideas. Beate gave me valuable thoughts and perspectives in the making of the interview guide and qualitative result layout. She has contributed with enlightening reflections which I believe enriched this study. Kyrre did a phenomenal job helping me with designing the online survey and afterwards creating a statistical dataset to be analyzed. Odin has been very helpful sharing his knowledge and perspectives regarding resilience and coping strategies which have been an important part in my work.

Thank you to all who chose to participate in my study, either through the interviews or answering the survey. I am very grateful and humble to have been given insight into some of your life experiences which you shared with me. I think you are courageous, and I wish you all the best in the future.

Trondheim, 20.06.20

Daniel Sjøvik

Abstract

The Norwegian Cancer Society states that cancer prevalence in the population will increase in the upcoming decade. This leaves many young adults (YA) with grief reactions after parental death during their adolescence. Despite the increase in incidence and loss of a close relative to cancer in young age, few studies have focused on the specific group of YA in the age-span 18-25 regarding parental loss to cancer, and complicated forms of grief. The study aim was to explore normal and possible complicated grief (CG) reactions in Norwegian YA, after a parental loss to cancer, also if there are associations between indication of CG, ability to integrate stressful life events, degree of resilience, health related quality of life (HRQOL), and psychological distress.

Participants were 19 individuals (18-25 years old), who answered a self-report internet-based survey. This consisted of the Pediatric Quality of Life Inventory (PedsQL™) 4.0, to measure HRQOL, Hopkins Symptom Checklist-10 (HSCL-10), to measure psychological distress, Inventory of Complicated Grief (ICG), to measure indication of CG, Inventory of Stressful Life Events (ISLE), to measure integration of stressful life events, and Resilience Scale for Adults (RSA), to measure indication of resilience. Six individuals (18-25 years old), participated in a semi-structured interview about their loss experience after a parental death to get in depth knowledge regarding their grief reactions. All participants had lost a parent to cancer within the last seven years, coming from Sør-Trøndelag, Oslo, Tønsberg and Bergen.

The qualitative results indicated that being overwhelmed by emotions, an unpredictable situation, a changed family system with altered roles, and responsibilities and needs were experiences most often mentioned as something probably complicating their grief process. The quantitative results indicated that there is a strong negative correlation between indication of CG and total score of resilience, furthermore a strong positive correlation between total score of resilience and ability to integrate meaning from the loss experience. The subscale of perception of self (PS), was most negatively correlated with indication of CG.

Potential CG reactions among the YA in this preset study could be associated with reduced degree of resilience factors, inability to integrate meaning of the loss experience, increased psychological distress and lack of social support. Early preparation could potentially increase ability to integrate meaning and increase resilience during the terminal phase and after the parental loss. Future grief research should have longitudinal designs with much larger study samples and an equal gender balance to increase representativity and generalization.

Table of contents

<i>Preface</i>	S. IV
<i>Abstract</i>	S. V

1.0 Introduction

1.1 <i>Topic of interest</i>	S. 1
1.2 <i>Normal grief reactions</i>	S. 2
1.3 <i>Bowen`s family system theory</i>	S. 8
1.4 <i>Secondary losses</i>	S. 9
1.5 <i>Social support</i>	S. 10
1.6 <i>Resilience as a protective factor</i>	S. 11
1.7 <i>Research on vulnerability and protective factors related to grief</i>	S. 12
1.8 <i>Domains of resilience</i>	S. 12
1.9 <i>Study aim and research questions</i>	S. 15
1.9.1 <i>Qualitative research question</i>	S. 15
1.9.2 <i>Quantitative research question</i>	S. 15

2.0 Methods

2.1 <i>Study design</i>	S. 16
2.2 <i>Increased validity through triangulation</i>	S. 16
2.3 <i>Study subjects and inclusion criteria</i>	S. 18
2.4 <i>Recruitment procedures</i>	S. 18
2.5 <i>Psychological assessment</i>	S. 19
2.6 <i>Qualitative analysis</i>	S. 22
2.7 <i>Quantitative analysis</i>	S. 23
2.8 <i>Ethical aspects of the study</i>	S. 24

3.0 Results

3.1 <i>Qualitative results</i>	S. 25
3.2 <i>Quantitative results</i>	S. 34

4.0 Discussion

4.1 <i>Grief longevity and conversation with the dying parent</i>	S. 37
4.2 <i>Complicated grief, meaning integration, resilience, HRQOL and psychological Distress</i>	S. 38
4.3 <i>Complicated grief might affect the perception of self</i>	S. 40
4.4 <i>Maladaptive coping strategies</i>	S. 41
4.5 <i>Vulnerability and young age</i>	S. 44
4.6 <i>Grief, attachment bonds and gender differences</i>	S. 46
4.7 <i>A grieving family</i>	S. 47
4.8 <i>Secondary losses</i>	S. 50
4.9 <i>Social support</i>	S. 50
4.10 <i>Strengths and limitations</i>	S. 53

5.0 Conclusion

5.1 <i>Conclusion and further recommendations</i>	S. 57
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6.0 References.....S. 58

7.0 Attachment 1: Online survey.....S. 78

8.0 Attachment 2: Interview guide.....S. 87

9.0 Attachment 3: Information letters.....S. 90

10.0 Attachment 4: REK Approval.....S. 94

Overview tables and figures

Figure 1:	Main- and -subthemes conversation and grief process.....	S. 25
Figure 2:	Main- and – subthemes social support and grief process.....	S. 30
Figure 3:	Hypothetical grief trajectories.....	S. 43
Table 1:	Characteristics of survey participants.....	S. 35
Table 2:	Means, standard deviations, correlations ICG, ISLE, RSA, HRQOL and HCL.S.	36
Table 3:	Correlations RSA subscales.....	S. 36

Abbreviations

NTNU:	Norwegian University of Science and Technology
REK:	Regional committees for medical and health research ethics
YA:	Young adults
CG:	Complicated grief
ICG:	Inventory of Complicated Grief
ISLE:	Inventory of Stressful Life Events
RSA:	Resilience Scale Adults
PedsQL:	Pediatric Quality of Life Inventory
HRQOL:	Health related Quality of Life
CGT:	Classical Grounded Theory
PS:	Perception of self
PF:	Planned future
SC:	Social competence
FC:	Family cohesion
SR:	Social resources
SR:	Structured style

Introduction

1.1 - Topic of interest

Every year about 30.000 people die due to a cancer disease in Norway (Larsen, Ursin, & Weiderpass, 2018). As a consequence, many individuals will experience a loss followed by grief reactions being left behind. According to Syse (2019), there are currently about 31.000 YA in the age between 18 and 25 years olds, who have or had a parent with a cancer disease. About 2300 YA will annually experience that one of their parents get a new cancer disease, while about 800 YA experience that one of their parents die from cancer every year (Syse, 2019). In the years to come the cancer incidence is sadly increasing in the general population (Larsen, 2019). The cancer incidence is foreseen to increase with 42% for males and 27% for females approaching 2030, and eight of ten new occurrences will happen to individuals over 55 years old (Johannesen, 2020). Despite the increase in incidence and loss of a close relative to cancer in young age, few studies have focused on YA in the age-span 18-25 regarding parental loss to cancer, and complicated forms of grief. Individuals in this age group are dependent on their parents to create an autonomous identity, socialize with others, and ability to develop emotional regulation (D'Agostino, Penny, & Zebrack, 2011; Young, Sandman, & Craske, 2019). Further, due to inner challenging emotional states it can be difficult for this age group to communicate the intensity of their feelings, thoughts, and needs (Choudhury, Blakemore, & Charman, 2006; Steinberg, 2005). A parent should this way be seen as an important prerequisite for healthy development as the YA develop from receiving care from parents, to be self-regulated and themselves becoming caregivers (Allen, 2008; Allen, & Miga, 2010). Loss of a parent in this age might thus make the YA vulnerable if these natural processes are interrupted.

1.2 - Normal grief reactions

Grief is something most individuals will experience once or several times during their lifetime. Although the process of grieving is seen as something natural, the phenomenon of grief might be challenging to operationalize. A definition of grief is the emotional, cognitive, and social processes and reactions following the loss of a loved one (Aarseth, 2019; Bonnano & Kaltman, 2001). Grief has traditionally been thought as emotions emerging due to someone's death but is today also associated with a loss experience in general (Dyregrov, Dyregrov, & Kristensen, 2017; Røkholt, Bugge, Sandvik, & Sandanger, 2018). Every individual has their own subjective way to react to a loss, and the phenomenon is also seen differently in different cultures (Smid, Groen, De la rie, Kooper, & Boelen, 2018). Studies have found that denial, longing for the deceased, anger and depression are typical reactions the first year after the death of a loved one (Aarseth, 2019). Emotional and cognitive symptoms are expected to peak during the first months after the loss, and then gradually diminish (Aarseth, 2019). Finding acceptance for, and creating meaning of the loss is something often happening during the first year after the loss (Maciejewski, Zhang, Block, & Prigerson, 2007). Grief reactions can be seen as appearing on a continuum, thus also having an end (Kristensen, 2013). Grief can hence probably be understood as a process until the individual regains a subjective feeling of control, meaning, and achieves adaptation to the changed environment (Dyregrov, 2006; Stroebe & Schut, 1999; Wortman & Silver, 2001). It is thus expected that individuals following a normal grief trajectory after a loss, experience an increased amount of psychological distress before these struggles reduce over time (Aarseth, 2019).

Grief and attachment to caregivers

Regarding grief, Bowlby (1980), states that there is a big difference in experiencing grief after a loss of close caregivers being young, compared to experiencing the same as an adult, although many of the grief symptoms might be similar. In developmental theory, attachment refers to an emotional bond created between a child and its closest caregivers. This can be seen as an interactional process where both the child and the caregiver contribute create an emotional bond between them (Bowlby, 1982; Reinfjell, Vikan, & Diseth, 2014). According to Balk

(2014), young individuals in grief are dependent on adults to adapt to a changed life situation without the loved one, while adults are expected to manage the grief better themselves. Thus YA need to be taught techniques and strategies which can help them cope with the grief in a more adaptive way. A good quality attachment between the adolescent and the parent prior to the death, has been found as an important factor in compensating against stressful life events (Ainsworth, 1979).

Grief after the death of a loved one might be understood as an attachment bond being broken. Research has found a close association between grief expression and quality of the attachment to the deceased (Field, 2006). Quality of the attachment and feeling of safety is likely to affect how a young individual grieve after a parental loss (Ainsworth, 1979; Bowlby & Bowlby, 1998). Individuals who grew up with a safe attachment are thus probably more able to master loss of caregivers, compared to individuals who grew up with an insecure attachment. Hence it looks like a secure attachment to primary caregivers provide self-confidence and increased chance of search for social support in times of stressful life events. According to Bowlby and Bowlby (1998), satisfaction with life is increased knowing that people individuals trust, are available with support and care when they need it. If the attachment is characterized by emotions like anger, ambivalence, guilt, or dependence to a caregiver, a loss of this individual might be perceived as extra challenging. This might be due to the remaining YA not being able to address these feelings related to the deceased, and the emotions thus continue to affect overall life quality. Anger towards the deceased might lead to guilt, and these unresolved emotional states are considered to affect the grief process (Dyregrov, 2006; Li, Tendeiro, & Stroebe, 2019; Shear, 2012). The reason why someone cope with the grief process, and some do not, might thus be characterized by several factors and are difficult to understand (Dyregrov et al., 2017; Shear, 2012).

Attachment between YA and caregivers changes considerably compared to the attachment between infants and caregivers. During adolescence individuals try to detach from the parents to become more autonomous. This age is according to Erikson's stage theory (1994), a vulnerable stage in life due to physical, emotional, and cognitive development, and parallel to growing social expectations and norms from others. Furthermore, this is a process where the individual starts to structure their self-identity, as they go through a transition towards adulthood

(Tetzchner, 2008). Many individuals might experience this time challenging, as the bond to the parents sometimes becomes more complicated and weakened compared prior to puberty, something which can be extra challenging given a loss at this age. According to Allen (2008), the attachment bond to the parents during adolescence, still is of most importance regarding the creation of attachment to new individuals after a loss experience. Attachment the adolescent create to others throughout life, can be associated with how their parents perceived their attachment to caregivers in their own upbringing (Bowlby, 1988; Winston, & Chicot, 2016). Two types of attachment patterns have been identified as contributing to two types of reactions after an experienced loss. Dependent attachment might lead to chronic grief, and ambivalent attachment might lead to conflicted grief, both types of CG (Kemp, 2014; Parkes, 2013). Bowlby's work revealed that individuals with an attachment according to the two previously mentioned, increase the chance of developing CG when losing close loved ones (Bowlby, 1980). According to Erikson's stage theory (1994), individuals who go through identity structuration while experiencing support, care and motivation from parents or other caregivers, have an increased sense of self, self-belief, and autonomy (Erikson, 1994). Thus, individuals who do not get the necessary encouragement and opportunity to develop an identity, assumably remain confused regarding the self and the future. Erikson (1994), labels this missed opportunity as "role confusion", which is characterized by the individual being undetermined in life choices, and not really knowing what is desired. This might further influence life goals, affect social relationships, and result in a lack of personal fulfillment, disappointment, and insecurity about their role in life (Tetzchner, 2008).

Psychological distress and grief

The majority of those who lose a loved one, manage to cope with the changed life circumstances. If grief reactions endure past six months and daily functioning still is affected, this points to a postponed grief reaction (Killikelly & Maercker, 2018). In such cases the individual might be subject to overwhelming psychological distress such as depression and anxiety (Dyregrov et al., 2017). Depression following grief might be characterized by fatigue, loss of interest in activities, hopelessness, but also sadness and longing for the deceased

(Kristensen, Dyregrov & Dyregrov, 2017). Depression might cause extra psychological distress due to reduced sleep and eating, difficulties in ability to concentrate, self-medication with alcohol or drugs, suicidal tendencies and reduced social functioning (Miller & Reynolds, 2012).

Furthermore, studies have shown that previous psychological distress and psychopathology are known predictors to later psychological distress and psychopathology (Aarseth, 2019). This also applies to individuals in grief, and psychological distress early in life after the death of a parent might worsen overall life quality later in life (Marks, Jun & Song, 2007; Zisook, & Shear, 2009). Psychological distress before the death of a loved one could also be related to what many individuals describe as constantly waiting for something negative to happen, and can be understood as anticipatory grief (Toyama & Honda, 2016). Anticipatory grief can be associated with increased discomfort, depression, anxiety, guilt, functional impairment, spiritual crisis, and difficulties making sense of the loss experience (Burke et al., 2015; Fowler, Hansen, Barnato, & Garand, 2013; Theut, Jordan, Ross, & Deutsch, 1991; Toyama & Honda, 2016). A study found that parents of children with cancer experienced psychological distress long before the death of the child, which made them vulnerable to experience psychological distress also after the loss (Aarseth, 2019).

The grief process

Grief should be perceived as unique to the individual, however also composed of individual, systemic, and relational factors which in different ways influence how the grief is expressed and develops (Røkholt et al. 2018). A modern dynamic understanding of the grief process is influenced by the Dual Processing Model of Grief, which states that the individual fluctuate between confronting and denying the loss (Stroebe & Schut, 1999). In this manner the individual might both address painful emotions, parallel to adjusting to living without the loved one. How the individual manages this process is thought to give rise to individualistic grief processes (Aarseth, 2019).

Grieving individuals may develop severe health issues after the loss of a loved one (Dyregrov et al., 2017). Many individuals with grief have complex symptom pictures characterized with signs of a traumatic experience related to the disease development, and

death of the caregiver (Dyregrov, 2006). Grief development and expression has been found to be related to previous experiences with loss, personality, attachments bonds, resilience, and ability to integrate meaning, making grief unique yet complex (Lichtenthal & Breitbart, 2015; Prosser-Dodds, 2013; Shear et al., 2007). Psychological distress and health issues as a result of the loss might thus appear simultaneously to another co-existing psychopathology. For example, prolonged grief disorder and depressive disorder resulted by grief, might be comorbid, but two different states (Kristensen et al., 2017; Li et al., 2019). Studies show that prolonged grief disorder and depression share some similarities, but also have certain differences (Kristensen et al., 2017). If thoughts and emotions continuously concern the deceased, this is typical for prolonged grief, while depression is characterized by general depressed thoughts and emotions, and negativistic rumination (Kristensen et al., 2017). Prolonged grief is associated with an intense continuous longing for the loved one, which is not necessarily found in depression (Shear, Ghesquiere, & Glickman, 2013). In depression the individual normally might have a reduced interest to engage in daily activities, while with prolonged grief the individual might be preoccupied with objects reminding of the loved one (Shear et al., 2013). Characteristic for depressed individuals might be feelings of guilt, reduced self-worth, or self-hate in general, while individuals with prolonged grief might experience guilt or having bad conscience related to behaviors towards the loved one before the death (Kristensen et al., 2017; Shear, 2012). In depression, avoidance-behavior is normally associated with avoiding social situations, while in prolonged grief, items belonging to the loved one might be avoided (Kristensen et al., 2017).

Loss of a parent in the age span 13-16 has been seen as a predictor of increased health problems throughout life, and children who lost a parent has shown increased suicidal intentions (Bylund-Grenklo, Fürst, Nyberg, Steineck, & Kreichbergs, 2016), depression in adulthood (Saler & Skolnick, 1992), and shorter life expectancy (Li et al., 2015).

Complicated grief reactions

If the grief's length extends six months, overall life quality might be severely reduced by accompanying psychological distress, and symptoms are complex and diverge from what is expected symptoms of "normal" grieving, CG is used to describe such grief reactions (Killikelly

& Maercker, 2018). CG in adults was first in 2018 internationally acknowledged as a diagnosis by World Health Organization. Individuals falling into this category of grief are often trapped in rumination about the death and circumstances related to the death, such as avoidance of what reminds them of the deceased (Shear, 2012). These individuals seem to struggle with intense emotions, also struggling to grasp the fact and finality surrounding the death and thus lack ability to adapt to the new life without the loved one (Shear, 2012). Grief research has shown that 7% of all individuals in the general population who go through a grief process, can be placed in the category of CG (Simon, 2013). Melhem, Porta, Shamseddeen, Payne and Brent (2011), found in a group of 182 children and adolescence aged 7-18, that 10,4% showed high and sustained symptoms of CG three years after the parental death. A study done by Bylund-Grenklo et al. (2016), showed that 49% of a sample of 622 teens still presented prolonged grief symptoms six to nine years after a parental death to cancer. However similar findings in the group of 18-25 years old are still few (Mash, Fullerton, Shear, & Ursano, 2014).

A recent Canadian mixed methods study concluded that in the aftermath of CG becoming a diagnosis, the operationalization contains certain flaws (Thompson, Whiteman, Loucks, & Daudt, 2017). Several researchers have argued that despite the need for a diagnostical operationalization of more serious grief variations, it might be too early to put CG as a diagnostic entity, fearing to pathologize normal grief symptoms due to a lack of empirical research (Wagner & Maercker, 2010). A main criticism is the lack of a clear operationalization of CG since the current literature provides several different operationalizations with somewhat different symptoms, which in some cases overlap (Kristensen, 2013). Moreover, some researchers focus on different subgroups of CG, while others focus on contrasting CG symptoms to other psychological diagnosis` (Wagner & Maercker, 2010). Very little research has been made on the distinction between normal and CG reactions in different cultures, making it harder to distinguish normal and complicated forms (Wagner & Maercker, 2010).

In the operationalization of CG, a specific narrow subgroup of individuals who had not experienced traumatic bereavement was used as a foundation (Prigerson, et al, 2009). Thus, to further validate CG as an entity, comparisons between other subgroups such as grieving parents, normally grieving individuals, traumatically grieving individuals is needed regarding their

symptom expressions (Wagner & Maercker, 2010). Finally, the new diagnosis does not define unique criteria to distinguish between children, adolescents and adults who have CG, meaning that children and adults are evaluated on the same diagnostic criteria (Dyregrov & Dyregrov, 2013; Dyregrov et al, 2017; Wagner & Maercker, 2010). This can be seen as problematic since children nor adults have one specific way to grieve, and children might have a different grief expression than adults (Dyregrov & Raundalen, 1996). Children and adolescents compared to adults, assumably are at two very different stages in life regarding development, understanding and emotional needs, and should hence be seen as unique to culture and context. There is limited research on CG in young people, and an understanding on which services and support these individuals and families are offered from the surrounding society is needed (Benkel, Wijk, & Molander, 2008; Melhem et al., 2011).

1.3 - Bowen`s family system theory

This theoretical perspective views the loss as something impacting the whole family as a functional unit. This perspective means that the individual`s ability to adapt and develop is intertwined with the other family members, thus when one family member dies, the rest of the family members are immediately affected, and emotional consequences follow the family network (Brown, 2013). According to Bowen (2018), every family would perceive death to a family member as a major threat and will react with some level of avoidance.

Four factors were identified which influenced the grief response and ability to adapt after a familial loss: expected or acute disease development, degree of social support in the family, functional position of the diseased and family cohesion (FC) (Bowen, 2018; Brown, 2013). Whether the disease development is acute or expected, it potentially could send emotional shockwaves throughout the family, potentially lasting for years after the loss (Brown, 2013; Stroebe, Schut, & Stroebe, 2011). In addition, to what degree the grieving family has a functionally supportive network in the larger family, was associated with more intense grief in cases of low support (Brown, 2013; Delalibera, Presa, Coelho, Barbosa, & Franco, 2015). According to Bowen (2018), social support and cohesion within the family and community is important for the grieving family. A family which does not have a broad connection to the larger

family or community, might result in every family member carrying a bigger emotional load than if they shared these with others outside the primary family (Bowen, 2018). FC and emotional flexibility in contrast to a family with internal conflicts or a lack of openness regarding emotions, heightens the tolerance and capacity to cope with the emotional states, and such can lead to a faster recovery (Bowen, 2018; Vegsund et al., 2019).

The functional role of the diseased and the reminding gap after the death is assumably also of importance. This role can be educational, financial, or organizational, which results in the remaining family becoming dysfunctional, struggling to continue their lives due to inability to fill this gap (Delalibera et al., 2015; Shapiro, 1994). An individual who had an important position in the family balancing it, might thus leave much more vulnerability in the family after the death than an individual the family was not as dependent on. Bowen (2018), considers this as an explanation to why some families manage to recover faster than others. Thus, a death of a family member might yield different consequences for the family unit.

1.4 - Secondary losses

While the death of a loved one can be understood as the primary reason for grief, the remaining individuals could also experience secondary losses. Examples of secondary losses can be changes in the economic situation, recreation, and activities as well as loss of future dreams and hopes. The loss process should hence be seen as a series of happenings also emerging after the loss which continues to impact those left behind (Mahon, 1999). Haine, Ayers, Sandler and Wolchik (2008), found that persisting alterations in daily life activities after the loss of a parent, had a strong influence on overall life quality to the remaining children. Loosing friends might be experienced as a secondary loss, related to the primary loss (Mahon, 1999). Furthermore, Kranzler, Shaffer, Wasserman, and Davies (1990), found that children who experienced economic challenges after a loss, experience bigger struggles afterwards compared to remaining children who had not experienced such a secondary loss.

The loss of a working parent can for example in many cases mean a change in family economy and might thus influence the ability for children and adolescence to continue with their prior sports, activities, or recreational hobbies. Moving to a new location, parental divorce prior

to the loss, and the remaining parent grieving, are also thought factors which might influence the remaining children. Secondary losses can thus be seen as traumatic in an already challenging time because what reminded of the family living together as a whole, now might be gone or dissociated.

1.5 - Social support

Social support and care must be seen as an important factor in influencing which type of trajectory the grief follows (Logan, Thornton, Kane & Breen, 2018; Wågø, Byrkjedal, Sinnes, Hystad & Dyregrov, 2017). To be part of a social network with close relationship to family and friends is thought to help satisfy important emotional needs for the individual. Love, appreciation, a feeling of belonging, validation, care, comforting, equality, and safety are needs important to perceive as fulfilled to experience a good quality of life (Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, 2014). When these elements are within reach and fulfilled, it is presumably easier for the individual to direct energy and behavior towards stressful life events. Social networks might however also play an important part in the ability to feel safe and self-confident knowing that you have someone to return to in times of adversities. This is in consensus with the theory of circle of security (Bowlby, 1980), where the individual has the certainty that it can return to someone for social support. Research has found that increased level social support works as a buffer against life adversities (Hostinar & Gunnar, 2015; Sippel, Pietrzak, Charney, Mayes, & Southwick, 2015).

Regarding grief development it can thus be thought crucial to be a part of a social network and to receive social support. In cases of depression, isolation or avoidance towards friends or family, this can be seen as a secondary loss due to of loss of care (Mahon, 1999; Southwick et al. 2014). Another reason can be that other people do not want to involve themselves with the individual in struggle because of fear of emotional consequences regarding caring for him/ her. As a consequence, a person in grief might experience multiple social losses in an already difficult situation which can be a complicating factor (Mercer & Evans, 2006). Social support or lack of this, can hence be seen as something both positive and important, but

also in cases where this is not available as something potentially worsening the situation (Hostinar & Gunnar, 2015).

1.6 - Resilience as a protective factor

According to Aburn, Gott and Hoare (2016), resilience must be seen as an important protective factor regarding psychological distress and overall life quality. Although resilience is difficult to operationalize (Aburn et al. 2016), there are several characteristics of resilient individuals: a) the ability to maintain a good quality of life despite a major stressful life events (Aarseth, 2019; Sheerin et al., 2018), b) the ability to stand up against life adversities (Aarseth, 2019), c). managing to adjust oneself and regulate emotions during a major stressful life events (Anyan & Hjemdal, 2016; Fletcher & Sarkar, 2013), d). reduced prevalence of psychological distress and health issues (Kermott, Johnson, Sood, Jenkins, & Sood, 2019), e), the ability to recover after a major stressful life event (Southwick et al., 2014), f), resilience being a trait all individuals possess in a varying degree (Anyan & Hjemdal, 2016; Friborg et al. 2006; Sippel et al., 2015). Importantly, the trait of resilience does not protect the individual from experiencing stressful life events, although when this is present, it looks like the individual adjust in a more flexible and adaptive way to preserve overall life quality (Aarseth, 2019). In fact, research show that resilient individuals recover faster after a parental death (Purandare & Sathiyaseelan, 2018).

In this current study, resilience will be defined as thoughts, feelings, and behavior the individual use to maintain development, overall life quality, recovery, or adaptation despite challenging life experiences with the help of intra- and interpersonal coping strategies and resources (Fletcher & Sarkar, 2013; Vegsund et al. 2019). This might increase the individual adaptation to new circumstances, increased endurance, and usage of strategies for adaptation which increase overall life quality (Southwick et al., 2014). There is however consensus that individual psychological traits, affectional bonds within the family, and support from the society are among the most important factors (Vegsund et al. 2019).

1.7 - Research on vulnerability and protective factors related to grief

The process of grief development can be quite unpredictable, and it is not easy to predict grief outcome due to the complex interplay between risk- and protective factors and psychological distress. Current grief research has in general focused on factors increasing the probability to develop psychological distress such as accompanying anxiety and depression, however less on factors which decrease the probability developing psychological distress (Jaaniste, Coombs, Donnelly, Kelk, & Beston, 2017; Myklestad, Røysam, & Tambs, 2012). There is a great demand for research on resilience factors related to psychological distress (Harms et al., 2019; Kennedy, et al 2018). Both risk- and resilience factors are of great importance regarding YAs grief since they could influence how the individuals react after the parental death (Jaaniste et al., 2017). A better understanding on this interplay might reveal who is most vulnerable to developing psychological distress and other health issues (Jaaniste et al., 2017).

Regarding resilience, grief and their relationship, there are some studies today focusing on resilience development in grieving individuals after the loss of a parent or a child. These studies have their focus on children in the age group 6-17 who lost a parent for unspecific reasons (Kennedy et al., 2018), coping ability in the family after a parental loss (Greeff & Human, 2004), parental grief after loss of a child (Jaaniste et al., 2017; Vegsund et al., 2019), and resilience in individuals who lost loved ones in terror attacks (Mancini & Bonanno, 2009).

1.8 - Domains of resilience

Since there is little empirical research on resilience and psychological distress regarding grief outcome, it is challenging to say which resilience factors are most related to a good psychological health during grief (Aarseth, 2019). Resilience could be understood as a wide term and divided into six domains, measured by the RSA instrument: Perception of self (PS), Planned Future (PF), Social Competence (SC), Family Cohesion (FC), Social Resources (SR), and Structured Style (SS) (Morote, Hjemdal, Martinez Uribe, & Corveleyn, 2017). PS refers to the individual's perception on their own strengths and limitations, and belief in capabilities to

withstand life adversities. A high score would represent an individual who has self-belief and intra-personal strength against life adversities (Morote et al, 2017). PF measure the individual attitude towards their future, and if they perceive it as achievable and realistic. A high score indicate that the individual has a future with goals and plans and has faith that these goals can be accomplished (Capanna, Stratta, Hjemdal, Collazzoni, & Rossi, 2015). SC is the individual ability to adjust to social environments, ability to communicate to others, and curiosity towards social stimuli. A high score indicates that the individual has good SC (Capanna et al. 2015). SS measures the individual ability to plan, structure, and organize daily life, and a high score indicate that the individual has a structured way of living (Morote et al. 2017). FC refers to degree of family conflicts, ability to cooperate, give support, and internal stability. A high score indicates that the family unity is high, and that family members are a source of support, help, care, and comfort (Delalibera et al. 2015). SR indicates that the individual has available support and comfort from friends, relatives, and family members. It also measures the individual's ability to give support to others. A high score indicates that the individual has available SR, as well as being able to give support when necessary (Delalibera et al. 2015; Friberg, Hjemdal, Rosenvinge, & Martinussen, 2003; Morote et al, 2017).

Several studies have focused on risk- and protective factors within these resilience domains in relation to psychological distress and mental health. Eilertsen, Hjemdal, Le, Diseth and Reinfjell (2016), found that a PF, a positive PS, and satisfactory FC could be associated with lower degree of psychological distress in mothers with children having cancer. In another study, psychological distress was measured in caretakers of individuals with cancer. Research found that a positive PS and a good FC are resilience factors associated with lower degree of psychological distress and accompanying symptoms (Çuhadar, Tanriverdi, Pehlivan, Kurnaz, & Alkan, 2016). A positive PS and a PF were found as resilience factors most associated with low levels of depression and anxiety symptoms in a Norwegian sample (Aarseth, 2019). Finally, Hjemdal, Friberg, Stiles, Rosenvinge, and Martinussen (2006), found that PF, and a positive PS, functioned as protective factors against psychological distress. Kennedy et al. (2018), state that upon today there are few studies which specifically look at resilience development in adolescence who has experienced loss of a parent to cancer in young age. Little research exists specifically on resilience, personality, attachment to caregivers, relation to the deceased, familial

conflicts, and how an interplay among these might affect influence CG development in YA (Kennedy et al., 2018; Mash et al., 2014).

To summarize, few studies have investigated relationships between death of a close caregiver to cancer in young age, grief development, and individual resilience in adolescence, and vulnerability factors in relation to CG reactions (Mash et al., 2014; Neimeyer & Burke, 2012; Sawyer, 2019). To better understand how YA adjust to parental loss, it is important to do research on grief reactions and available vulnerability and protective factors that might influence the YAs` grief process.

1.9 - Study aim and research questions

Despite the increase in incidence and loss of close loved ones to cancer in young age, few studies have focused on the specific group of YA in the age-span 18-25 regarding parental loss to cancer, and complicated forms of grief. This has led to the creation of the following research aim and research questions:

The overall aim with this explorative mixed-methods study is to get more knowledge and insight in Norwegian YAs normal and possible CG reactions. Of interest are associations which might exist between indication of CG, ability to integrate meaning of the loss experience, resilience factors, and how this impacts HRQOL and psychological distress before and after a parental loss to cancer.

1.9.1 - Qualitative research question 1: *“Which experiences are mentioned by Norwegian 18-25-year olds, which potentially complicated their grief process, and such challenged meaning integration of the loss, protective factors such as resilience, and HRQOL? In addition, which factors were experienced as protective in the grief process prior to and after the death of a parent”.*

1.9.2 - Quantitative research question 2: *“Which associations exist between indication of CG, meaning integration of the loss, protective factors such as resilience, HRQOL, and psychological distress in Norwegian 18-25-year olds?”*

Methods

2.1 - Study design

The use of a mixed method design in grief research can be justified as it offers a more comprehensive approach when exploring complex phenomena such as a loss experience, and where neither quantitative nor qualitative approaches are seen individually sufficient to cover the chosen topic (Johnsen, 2016; Kroll, & Neri, 2009; Neimeyer, & Hogan, 2001; Östlund, Kidd, Wengstrø, & Rowa-Dewar, 2011).

Since this present study aims to explore potential grief reactions and personal experiences in YA who lost a parent to cancer, a mixed method design was thought to be an appropriate approach. Kroll and Neri (2009), states that mixed method studies are characterized by the integration of qualitative and quantitative data in the research process, either at the stage of data collection, analysis, or discussion. The qualitative and quantitative data in this present study were collected in parallel, but were first integrated and seen together in the discussion to highlight and answer the research questions. The quantitative element of the study was a self-report online survey which focused on occurrence of CG symptoms, HRQOL, ability to integrate meaning of the loss, and occurrence of resilience factors among the participants. The qualitative element of the study, a semi-structured interview was created to explore which factors complicated and helped the YA in the grief process before and after the loss. The qualitative interview also focused on social support from a familial and public perspective, if social support was available for the YA related to their grief process, and in what way social support possibly had an impact on HRQOL.

Qualitative methods can be seen advantageous being used to survey topics like grief processes and loss, to get a better understanding on the individual subjective perception and narrative which is thought to be unique (Costa, Hall, & Stewart, 2007; Stroebe, Stroebe, & Schut, 2003). This way the individual creation of meaning, understanding, feelings and thoughts about mental struggles and other life experiences better could be identified and conceptualized (Johnsen, 2016). A qualitative approach was thus thought to be a good choice to gain insight into the emotional bond between the YA and the dying parent, and how this possibly influenced the

grief process. Another advantage with the use of qualitative research methods, is that the participant gets the opportunity to formulate feelings and thoughts as close to reality as they were experienced (Neimeyer & Hogan, 2001).

A quantitative approach was seen advantageous due to the interest of identifying potential correlations, specifically whether there are associations between indication of CG, resilience, meaning creation and HRQOL. Although it was assumed that CG would lead to reduced HRQOL, it was more unsure what relationship resilience and meaning creation had in an assumed complex interplay. Quantitative research methods are suitable to produce such findings (Neimeyer & Hogan, 2001).

2.2 - Increased validity through triangulation

According to Curry, Nembhard and Bradley (2009), when making research on complicated phenomena such as grief and loss experiences, it can be seen advantageous to use both qualitative and quantitative research methods, as they complement each other and help to produce results which are closer to reality. Triangulation refers to the use of both quantitative and qualitative research methods in the same study, and where strengths from both approaches compensate limitations and such increase the validation of research findings (Moon, 2019). Standardized quantitative instruments and surveys such as self-report scales can give important information about grief patterns and reactions in different populations (Stroebe et al., 2003). Qualitative methods on the other hand might give a valuable depth view of the grief experience and meaning creation (Stroebe et al., 2003). This means that if a mixed method design produce similar results, this might reflect a more trustworthy picture of a phenomena (Curry et al., 2009). This research design is also especially recommended where the aim is to get new knowledge about complex social phenomena such as interpersonal relations (Leung, 2015). According to Neimeyer and Hogan (2001), the use of both quantitative and qualitative methods is an example of “methodical pluralism” which is favorable to produce a comprehensive understanding as well as generating new theory.

2.3 - Study subjects and inclusion criteria

The criteria for study inclusion were the same for the interview participants, as for the survey participants. The inclusion criteria were: The participant must be living in the region of Midt-Norge, Oslo, Bergen or Tønsberg, and have experienced a parental loss to cancer, and be in the age-range from 18-25 years old at the time of the study. These criteria were communicated in information letters sent to the leaders of Ung Pårørende -Trondheim, -Oslo, -Bergen and -Tønsberg, Øya Helsehus, Vardesenteret and The Norwegian Cancer Society in Trondheim. The locations of Oslo, Bergen and Tønsberg were chosen specifically after advice from The Norwegian Cancer Society, and due to an increased chance of recruitment from Ung Pårørende. The interviewees consisted of three men and three women, who were aged 18, 19, 20, 23, 24 and 21. Four of them came from a city and two came from rural populated areas in Midt-Norge. The time since the death of their parent ranged from 1-4 years for four of the participants, and for two, from 8-10 years. Respondents to the survey came from Midt-Norge, Oslo, Bergen and Tønsberg, aged 18-25.

2.4 - Recruitment procedures

Semi-structured interview

The leader of Ung Pårørende -Trondheim was asked to look for individuals who might be interested to participate in the interview. For the study's purpose, a number of 5-10 individuals would be satisfactory to reach topic saturation. This was evaluated as a realistic number of participants given the topic and potential emotional challenging experiences and memories, and that the criteria of inclusion realistically would narrow down potential participants.

The information letter given to Ung Pårørende included contact information to the researcher of the project, and informed the participant about the necessity for audio recording during the interview, and its length of 45-60 minutes. The participant could choose between a face-to-face interview, or a telephone interview. Four individuals chose telephone, and two face-to-face. The participants were also informed that they without any consequences could stop the interview at any time, and their recording would then be deleted.

The internet survey

To recruit participants to the online survey, Ung pårørende -Trondheim, -Tønsberg, -Bergen, and -Oslo were contacted. The leaders of each location were informed about the purpose of the study, the criteria for inclusion, participation was based on voluntarism, and that it would take 30-40 minutes to complete through Select Survey. The leaders then published a direct link to the online survey and brief information about the study through an information letter. In addition, Øya Helsehus in Trondheim was important in the process of recruiting participants since co-supervisor Beate Andre had her work there with the relevant group of YA. In the latter case flyers were hung up at Øya Helsehus/ Vardesenteret, and individuals who were thought as potential participants were asked if they were interested to participate. The participants were informed that the completed responses at all times would be secured through encrypted web servers in the NTNU computer system. These are only available through a password, and only the author and the main supervisor had access. Furthermore, information was also given that the collected data would be used for statistical analyzes, and that the data would be stored in five years after completion of the study in 2020 for safety reasons in accordance with Regional Etisk komitè`s demands.

2.5 - Psychological assessment

The semi - structured interview

The semi - interview was made up of three self-made categories with questions:

Category 1. The questions in this category were aimed to get more information about the conversation between the YA and the sick parent about the disease and future. This was to discover what purpose conversation had, and if it was perceived as having a positive or negative impact on the grief process before and after the loss.

Category 2. These questions investigated if the YA were offered and received attention and public health offers and support before the death of the parent, and how this potentially influenced HRQOL and the grief process. The purpose was to get a better understanding about receiving public healthcare, and how the YA felt about this.

Category 3. In this category the questions investigated if, and what kind of follow-up the YA received from close family and friends, and what effect this might have had on the grief process before and after loss.

The internet survey

Sociodemographic measures

Among the sociodemographic data considered to be relevant to this study were gender, years of education, household economic situation and years since parental death. These data were self-reported. All questions were used in their original layout, and there has not been made any changes to the question order or meaning.

Inventories

Pediatric Quality of Life Inventory™. This inventory consists of 23 questions across the sub-categories physical functioning, social functioning, academic functioning, and emotional functioning (Halvorsen et al., 2018). PedsQL™ items can be through reverse-scoring and linear transformation made to a number on a scale from 0-100, in which higher scores indicate better HRQOL (Halvorsen et al., 2018). HRQOL is a measure on how individuals or a group perceive their physical or emotional health, and how this affects quality of life over time. The PedsQL™ is translated and validated for Norwegian conditions (Reinfjell, Diseth, Veenstra, & Vikan, 2006). In this present study a YA version (18-25 years), translated and linguistically validated in 2011, was used. The validation of the adolescent version, practically identical to the YA version, showed good psychometric properties (Reinfjell et al., 2006). Varni and Limbers (2009), tested the PedsQL™ YA version on students aged 18-25 and found excellent reliability for the total scale score, and acceptable reliability for subscale scores. A Chronbach`s alpha of 0.77 was found for the Norwegian translation of the PedsQL™ (Reinfjell, 2007). The instrument uses a five-point likert scale ranging from “never” to “almost always”.

Hopkins checklist-10. The instrument is a short version of the HSCL-25 and is seen as effective in measuring psychological distress, depressive and anxiety symptoms among adolescence and adults (Halvorsen et al., 2018). The instrument has a likert scale ranging from

1 (not at all) to 4 (extremely). The instrument has good psychometric properties such as validity and reliability (Kleppang & Hagquist, 2016). Higher mean values on the HCL-10 indicates higher levels of psychological distress, and a mean cutoff above 1,85 will indicate that the psychological distress in the individual is significant (Halvorsen et al., 2018; Strand, Dalgard, Tambs, & Rognerud, 2003).

Inventory of Complicated Grief. The instrument measures indication of CG with a five-point likert scale ranging from “never” to “always” when scores are above 25 points. Studies where the instrument has been used shows satisfactory internal consistency, reliability, and validity, although there is not consensus in the international literature about diagnostic criteria for CG (Bui et al., 2015; Dyregrov et al., 2017; Wagner & Maercker, 2010). The instrument is the most preferred inventory to measure CG symptoms (Thimm, Davidsen, Elsness, & Vara, 2019).

Inventory of Stressful Life Events. The instrument measures integration and creation of meaning of a stressful life situation, for example a loss of a family member. Respondents answer on a five-point likert scale ranging from “completely agree” to “completely disagree”. The use of ISLE in grieving populations has shown strong internal validity and reliability (Holland, 2016). The ability to integrate a loss or stressful happening into the life narrative after a loss has been seen in relation to psychological and physical health (Holland, Currier, & Neimeyer, 2006). The use of ISLE has also contributed in giving insight in meaning construction as a crucial factor in the individuals attempt to adapt after a loss (Holland et al., 2006). A total score above 52 points show good ability of meaning integration.

Resilience Scale for Adults. This instrument consists of 33 questions and measure the indication of individual resilience and gives a picture of the ability to withstand stressful life events. For every question, the respondent get two statements and had to check a box relative to how much he/she agrees with the on a 7-point scale. The instrument was developed and validated in the Norwegian population, but also shows validity, reliability, and consistency in cross-cultural populations, (Hjemdal et al., 2011; Morote et al., 2017). Six protective dimensions are evaluated with the instrument: PS, PF, SC, FC, SR, and SS (Morote et al., 2017). A higher score than 140 points reveal a higher level of protection through resilience (Morote et al., 2017).

2.6 - Qualitative analysis

In the analysis of the recordings and following transcriptions, Classical Grounded Theory (CGT), was the chosen approach. A straightforward transformation was conducted from the spoken word to text in its identical form without adding symbols or extra material. CGT is recommended due to a parallel data sampling and analysis from the very start of the process (Glaser & Strauss, 2009). Next to other approaches to thematic analysis, CGT also aims to discover new theory using empirical data, which helps to explain phenomena in their social context (Mediani, 2017). Thematic analysis embraces several approaches, including CGT, working with texted data material, and is characterized through six steps of information processing (Braun & Clarke, 2006). CGT starts with the researcher before the data collection starts, decides from where the data is collected (Kolb, 2012), hence selecting and framing the focus. CGT is a dynamic process where the researcher constantly evaluates and chose information is focused on (Glaser & Strauss, 2009).

The first step was to read several times through the transcript to get a general knowledge about it. Immediate thoughts and ideas while reading through were written down. The second step is theoretical coding where categories are created and relations between these are found (Singh & Estefan, 2018). Certain moments or elements which emerge throughout the text are clustered together with a specific code. This code is a tag of meaning for that specific part of text. The codes will then help to group and organize traits in the text which seems relevant and interesting relevant to the hypothesis. There are two different types of coding, respectively semantic and latent coding (Terry, Hayfield, Clarke, & Braun, 2017). In semantic coding what is directly said by the respondent is important, while with latent coding, also underlying meaning, ideas and interpretations also is important to discover (Braun & Clarke, 2006). The process of coding might create new insight as new understanding and meaning are added to the codes. However, if there are new elements and meanings identified which can relate to the exiting codes, the codes can be changed so they fit better with the new information as a whole (Braun & Clarke, 2006). It thus required by the scientist to have an open mind while coding, and not work in a static manner, but being guided by intuitive understanding as the codes are being created and re-fitted. A list should be made with all codes from the transcript which can be associated with relevant information from the respondent's narrative (Javadi & Zarea, 2016).

In the third step of the process the goal is to re-group the codes to bigger units of knowledge and meaning, and they are then called categories (Braun & Clarke, 2006). Few guidelines exist to how this category creation is made, but it was done seeing what was relevant regarding the context and hypothesis. In this way the codes are summarized into bigger chunks of meaning related to the questions needed to be answered. This means that some of the codes found in the previous step can be discarded or merged to fit better. The scientist also here must be aware not to get too attached to the codes and original mindset but be able to see new underlying connections and contexts as they emerge. It is also possible to make sub-ordinate codes and categories (Javadi & Zarea, 2016). In the fourth step the categories again are reviewed and possibly changed and refitted or discarded. Here it is important to see a connection throughout the process from the original codes, and the rest of the text material (Hallberg, 2006).

The fifth step is to nuance the categories into topics, trends, or definitions, which can be used in the continuing interpretation (Hallberg, 2006). Thematic analysis and hence CGT is about being deductive when starting with much information and throughout several steps build up relevant chunks of information which reflects the respondent's personal narrative. These constructs of meaning are then usually being put into models where the relations between codes, categories and trends/topics are seen how they emerge, influence, or co-operate together (Glaser & Strauss, 2009), which represents the sixth and final step of the process. In CGT, the final trends and categories might be used to help create a new theory which can help explain the scientific hypothesis. These categories and topics can also be used with already existing theories to see if there is consensus and confirmation, or if the findings violate exciting theories on the field.

2.7 - Quantitative analysis

Analysis of the quantitative data from the survey was conducted by using descriptive statistics and percentages of responses. Due to a small sample size, (n=19), non-normal distributions, and an uneven distribution in gender among the participants, a non-parametric test was chosen. Spearman's rho could find potential correlations in the dataset, and see if these were significant. Test of normality showed that a Spearman's rho correlation was still possible to use despite some of the limitations (Aggarwal & Ranganathan, 2016; Mukaka, 2012). Spearman's

rho correlation have been used in several bereavement studies (Tomarken et al., 2008; Machale, Mcevoy, & Tierney, 2009), and is in accordance with the aim of this study to look at associations related to grief expression and reactions. Thus, further use of inferential analysis in this present study was not recommended or thought to be valid due to the small sample size (Faber & Fonseca, 2014; Mishra et al., 2019). The statistical software IBM SPSS 26.0 was used to analyze the dataset.

2.8 - Ethical aspects on the study

This study was made possible through the permission from Regional Etisk Komitè-Midt. Reference: 2019/512/REK Midt.

Information letters were sent to every leader at Ung Pårørende, and the study purpose was explained to potential participants. All participants in this study were made anonymous for extra protection. All information was transcribed, de-identified and anonymized. Each interviewee were given a number which connected them to their citation in-text. The survey participants were not asked demographical questions which altogether could reveal their identity. All responses were also in SelectSurvey given an id-number, not revealing location of origin.

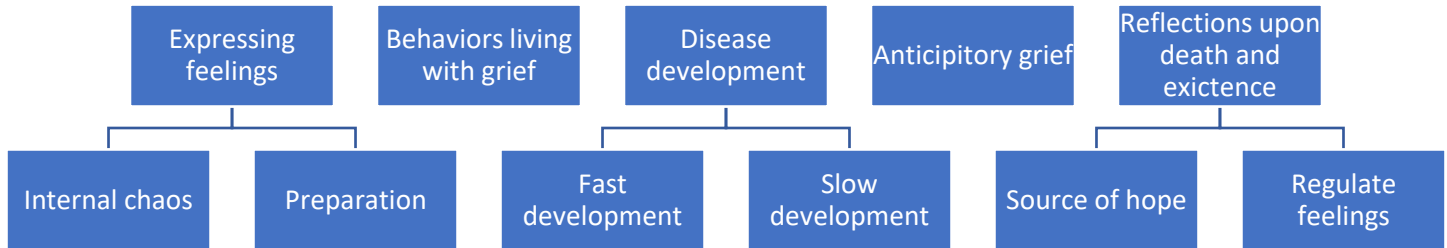
Making a study with individuals who lost a parent to cancer led to ethical considerations, and could also influence the study itself. An ethical dilemma in this study was the participants` young age. For some individuals it could be difficult to express thoughts and feelings if they not fully had come to terms with their grief. It is a possibility that participation in this study to some degree could have retraumatized the YA. Participation could potentially make some individuals start reflecting upon their own grief process and consider its validity.

It was thus thought unethical to study this vulnerable group without offering some kind of emotional support if this should be needed. Unique to this study was that the main supervisor`s offer to give a support meeting to the participants if they felt the need for some extra emotional support after the interview. This was decided as an offer to better take care of the participant given that the interview would be challenging. Importantly, participation in this study was voluntarily. The participants were also given the choice to abort the interview if necessary without any consequences.

Results

3.1 - Qualitative results

Table 1. Main themes and subthemes asking about conversation with the dying parent and grief process



CGT used on the interviewees responses (n=6), revealed five main themes related to the conversation with the sick parent: Expressing feelings, Behaviors living with grief, Disease development, Anticipatory grief, and Reflections upon death and existence.

Expressing feelings

The need for conversation with the dying parent, and the desire to express emotional states was mentioned by several interviewees as something important for them. It also seemed desirable to engage in such an emotional conversation as early as possible. Two subthemes were found regarding expressing feelings: Internal chaos and Preparation (Table 1).

Internal chaos. Mentioned by all interviewees, internal emotional struggle was a major finding. There was internal consistency as well as a consensus across the interviews that emotional chaos was present during the grief process, and for some also after the parental loss. Anger, confusion, sadness, fear, and feeling of emptiness were mentioned as related to the grief process.

“...I spoke with the school nurse who said that I’ve got a postponed grief reaction, because I hadn’t reacted right after the death...” (2).

“...I was left with a lot of feelings which I kept to myself. I was seriously afraid to show others that I was deeply sad...” (3).

“...Many dark thoughts, and if you are alone, you surely fall into a hole of grief...” (4).

Preparation. Conversation and expressing feelings seemed also to serve an important purpose as it potentially prepared the YA against upcoming adversities.

“...Early conversation with her would absolutely have been a difference. I think it could have helped me to not be afraid of the feelings I had. I wanted to be completely normal, I didn't want to have the thoughts I had, so I pushed them away...” (3).

Lack of preparation was described as a potential stressor. In some cases, the interviewee saw that not being prepared for what was coming was traumatic, as well as finding it problematic to express different feelings with the sick parent. This apparently worsened the grief reactions, due to suppressing emotional states instead of sharing them.

Behaviors living with grief

Several of the interviewees explained that living with a sick parent over time resulted in changes in their normal behavior. Specifically, it looked like there was one way of behavior when the YA was physically with the sick parent, for example visiting them at the hospital, and one behavior when they were away from the sick parent.

“...The grief process while he was sick became two folded, where one situation was to be with him and have a good time, while the other situation was sadness when I where apart from him...” (4).

Several interviewees described what looks like putting up an emotional facade related to the decease and the sick parent, and that appearing without emotional struggle seemed important, as well as being perceived as normal as possible. This was described as making it possible to have a positive attitude and behaviors being with the sick parent. A pivotal point across the interviews was to appear in a way which would not be of an extra load or stress to the sick parent. Being

close to him/her was also associated with a fear of upsetting the parent unnecessarily, also contributing to the previous mentioned emotional facade. Some YA seemed also to be influenced by certain emotions: a feeling of duty to stay close to the sick parent as long as possible, and guilt or self-blame if this was not possible.

“...I was very afraid of doing things which could upset her, and me being depressed was in a way, unacceptable, no I was not depressed. Later it became clear that I actually was depressed, and the fact that I never got to talk about it with my family may have influenced how I feel today...” (3).

The grief process was by several also associated with another type of behavior. This was characterized by withdrawal from the social environment and daily activities, loss of energy and fatigue, and sadness being apart from the sick parent. Paradoxically to the mentioned emotionally struggle and the need to express this, in some cases it looked like the YA acted evasive to the sick parent for self-protection. The need for a pause and distance to the disease was by some described as important.

“...I felt I had to appear strong and without sadness in front of my dad, he wasn't supposed worry about me. But home I could stay in bed and cry...” (6).

Disease development

When asking how the parental disease developed and how this might have had an influence on the ongoing grief process, a consensus among the interviewees was found regarding this. Specifically, there was an attribution of more severe grief symptoms and postponed or -prolonged grief given that the parental disease had developed in one of two described patterns which are the subthemes Fast- and Slow - disease development (Table 1).

Fast disease development. The first pattern was characterized by the YA and family accumulating hope during early stages of the parental cancer disease, for example due to the parent's first recovery, and then the sudden shock and reactions in the case of relapse or fast development later:

“...The first time she had a tumor everything went well, so we got a hope that everything would turn out good. The last time it took eleven days, and we understood that there wasn’t any hope...” (2).

Slow disease development. The second pattern was characterized by the family getting an expectation of the disease development as fast and acute resulting in death by the doctor giving a bad and short prognosis. When the dying parent however continued to live, and these expectations were violated, the grief process was described as a long and painful “waiting period” and especially unpredictable. This pattern was also described as very stressful:

“...There was a constant feeling that he lived overdue. That it could happen any time. It was a big source of stress...” (4).

“...Her prognosis was six months, but she lived for five years. The nightmare started after six months as we then didn’t know when or what things could start to happen...” (5).

Both patterns were by the interviewees associated with reactions exceeding what can be thought as “normal grieving” in that the grief process could be characterized by a disruption in daily functioning. Also, the interviewees who were exposed to the second pattern, described exposure to more graphic experiences as they witnessed their parent slowly deteriorating by the disease over time, and this was not expected.

Anticipatory grief

All the interviewees described what they felt was a waiting period after they received the message that their parent was going to die. This period was associated with unpredictability and such extra stressful in not knowing how and when the disease would escalate into the parental death. Several respondents also described that they felt this waiting period as an emotional challenging and difficult situation forced upon them, and wish from they wished to escape but could not until the death of the parent. Some respondents felt however that after the loss, although the grief continued, it was now «acceptable» to start looking forward again.

“...I sat and waited for my mom to die. I hoped she would die so we could be done with it all...” (1).

“...Throughout the period he was sick it became a limbo situation where you only waited, and you couldn't continue until he was actually dead...” (4).

Reflections upon death and existence

Upon the question if the YA had religious or spiritual thoughts during the grief process, several responded that they did not develop a new religious identity specifically due to the parental disease. However, several mentioned that they became more reflecting about existence. Two subthemes were found related to this topic: Source of hope and Regulate feelings (Table 1).

Source of hope. In some cases, it looked like the YA in grief were more likely to be drawn to these types of thoughts to gain hope and serving as a calming effect.

“...There was a time I wanted to die so I could meet her again, we were very closely attached, but I don't want to die, I want to live for my family, and then I can meet her again when I get older. It may even be a greater reunion then...” (1).

“...To believe in life after death gives hope, then I can meet him again later...” (6).

Regulate feelings. In other cases, these types of reflections could be related to the assumed need to direct guilt and anger, or in general regulate emotions.

“...Directing guilt against God gave me a confirmation that there could not be a God, because if he existed, he had to be evil. At least this made me feel calmer ...” (3).

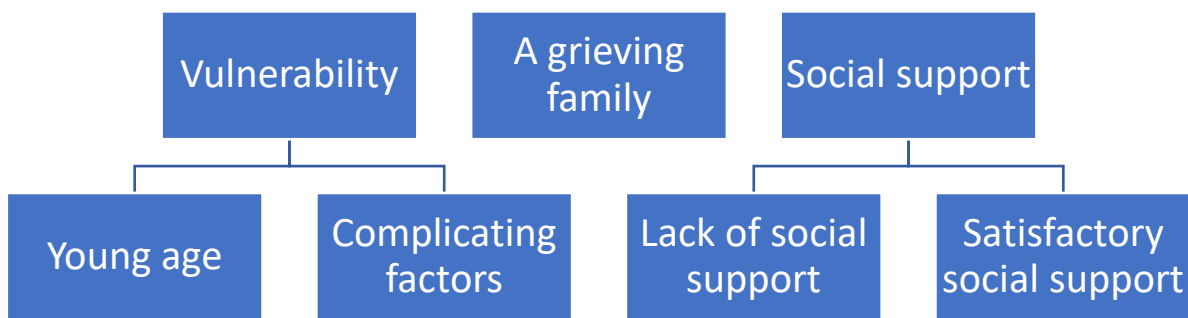
Reflection about death and existence was also associated with finding acceptance for the loss by putting the death in a bigger perspective. Also mentioned by several was the consciousness about the individuals own mortality and focus on death. This was described as a “reality check” which could be very frightening, a contrast between before and after the message about the disease was

delivered. Before the disease, the interviewees had lived rich and explorational lives, thinking about everything but death. While after the message, death became a focus which was difficult to grasp the operationalization of.

“...It is quite a unique situation where you look death into the eye, and suddenly you have to take a stand whether there is a life after death, and such questions...” (4).

Social support and grief process

Table 2. Main themes and subthemes asking about social support and grief process



Regarding the questions in the interview related to the grief process and social support the YA and their families received, three main themes were identified: Vulnerability, A grieving family and Social support.

Vulnerability

A topic which was found in most interviews was the consensus that the YA perceived themselves as extra vulnerable to the loss of a parent due to young age, and such, extra susceptible for emotional struggles and grief. Most YA were clear that social support was something helpful to compensate for this. Underlying the fact that YA can be seen as going through a chaotic phase in life in this age-range with puberty, identity exploration, and creating new relations, life can be understood as difficult also in a normal developmental perspective.

Two subthemes were identified: Young age and Complicating factors (Table 2).

Young age. Lack of knowledge about the disease and lack of self-insight, were two factors mentioned by several participants as something that influenced their emotional state during the grief. Also, several respondents drew a line between the experience of a parental loss in young age, and the development of more severe grief symptoms, due to lack of social support in the future from the lost parent.

“...I felt that what my mom told be about the future, that things would be okay, that I would be successful and such. It felt a bit abstracted, or that it was difficult to take seriously. Afterall I was young, and this concerned my future far ahead...” (3).

“...It was a process of maturation, it became an important part of my adolescence, and I believe I’ve become a more reflected individual being thrown into such an experience. These are very big and difficult reflections for an adolescent...” (4).

Complicating factors. Several other life circumstances were mentioned that if they emerged simultaneously to the loss, these were likely to further complicate the emotional state, and such the grief development. Lack of openness and willingness to talk about feelings in the family, parental divorce prior to the disease and familial conflict were some of these factors.

“...No, he hasn’t been very good to talk about feelings. Whether then or now. The loss hasn’t really been a topic in the family...” (2).

“...My parents had their divorce when I was quite young, this was just before the disease came...” (6).

“...The conflict between my mom’s side and my fathers’ side of the family still affects me...” (2).

Naturally, it is very subjective how every individual cope with added life struggles and challenges, but it is also interesting how grief symptoms develop, when additional life stressors are accumulating in an already assumed difficult situation for the YA.

A grieving family

The family as a unit was by several of the interviewees described as being heavily affected and such the ability to function was disrupted. This was mentioned as also complicating the grief process because the YA in many cases lost an important source of support, as well as witnessing family member`s grief process next to their own. Daily functioning was also mentioned as being affected because family members now cannot offer practical help such as transportation to activities.

“...My brother started to struggle right afterwards and left school...” (2).

“...Next to taking care of me, everyone else also had their grief to process...” (4).

The grief process could such be felt as very overwhelming due to it also affecting the household, which prior to the disease was seen as an arena of safety and comfort. However, after the disease the home was in some cases associated with discomfort due to objects and smells which reminded of the sick parent. Although some respondents felt that they got the necessary support from the remaining family, some of the respondents expressed a wish that they were able to talk to family members more about their feelings and felt that lack if this contributed to prolonged grief.

Social support

Friends has been agreed upon among the interviewees as a very important source of social support in times of grief. Friends also seemed to fulfill needs which parents could not, for example talking to someone who is not affected by grief. As this citation points to, perceived social support and togetherness seem to be of great importance during the grief process. Two subthemes were found: Lack of social support and Satisfactory social support (Table 2).

“...To meet others with the same experience was important. You get the opportunity to see that it goes well with them and may then think that it might also go well for me. I think that if I didn't have a social network surrounding me, everything would have felt much darker...” (4).

Lack of social support. Worrisome findings were identified regarding the question if local health services were offered and given to the YA and if so, did this help on the grief process. Some of the interviewees reported that they did not get any attention at all from teachers, the school nurse, their primary physician, priest, psychologist, or others.

“...As a teenager, I was not old enough to understand, but I needed help from others, there is no doubt. I did not have enough self-insight to understand that I needed help and being so young. It is an adult’s responsibility to help me nonetheless, which I felt nobody did...” (3)

“...The school didn’t take initiative to find out how I felt, and I think it has contributed to prolong the grief...” (6).

Satisfactory social support. However, there were also examples of satisfaction with the support the YA received, and friends were mentioned several times as very important. Satisfaction with social support where however more often related specifically to living in a place with bigger population, due to even more specified public health offers. In cases where the support was not given by the public health care and systems, there were examples that private initiatives were taken to receive help and this was much appreciated, but apparently in places with a bigger population.

“...My friend came to get me, and we spoke about other things, it felt good to be able to talk, and not to talk in a way. Think about other things. We used to take walks and talk about everything...” (2).

“...My friends have been very important when I felt bad...” (5).

Some of the interviewees also mentioned elements which they describe as helping them in the grief period, maybe making it somewhat easier. These factors were the importance of getting necessary space, the need to be seen by others as someone who is especially vulnerable, time, but also flexibility in expressing their thoughts and feelings.

3.2 - Quantitative results

Descriptive statistics

Table 1 gives an overview of the characteristics regarding the survey participants. A majority of these were women. Moreover, more than half of the participants had a relatively high educational level with several years in university. Household economic situation revealed that 52.6% found themselves in an average economic situation. Among the survey participants, 38.9% experienced the parental death within the two last years. Among the interviewees 66.7% experienced the parental death within the 7-8 last years.

Means, standard deviations, correlations, and Cronbach's alphas

Table 2 shows Spearman's rho correlations between indication of CG, RSA, ISLE, HRQOL and HCL-10, among the survey participants. Means, standard deviations and Cronbach's alphas are also included. The results revealed a negatively moderate/high correlation between indication of CG and total score of resilience. A strong positive correlation was found between ability to integrate meaning after the loss, and degree of resilience. The presence of CG seemed to influence both HRQOL, and ability to integrate the loss negatively. Psychological distress was found to be negatively correlated with HRQOL and indication of resilience. A positive correlation was found between indication of CG and psychological distress, while a positive correlation was found between HRQOL and indication of resilience. The results also revealed that the mean score of RSA indicated a moderate level of resilience.

RSA correlations of subscales

Table 3 shows Spearman's rho correlations analysis between total score indication of CG and the resilience subscales, among the survey participants. As CG was present, PS, PF and SS were most significantly negatively correlated with indication of CG. This points out that complicated types of grief greatly alter the way individuals feel and think about themselves, plan about the future, and structure their lives. Although not significantly, FC, SR

and SC were also found to be negatively correlated with indication of CG. Altogether this might explain why the total resilience score was highly negatively related with the indication of CG score.

Table 1. Characteristics of survey participants

	n	%
Gender		
Male	1	5.3
Female	18	94.7
Years of education		
Primary school 1-10 years	1	5.3
High school 10/11-12/years	8	42.1
University < 4 years	8	42.1
University > 4 years	2	10.5
Household economic situation		
High above average	1	5.3
Above average	5	26.3
Average	10	52.6
Below average	3	15.8
Years since parental death survey participants		
< 1 year	2	11.1
1-2 years	5	27.8
3-4 years	4	22.2
5-6 years	2	11.1
7-8 years	5	27.8
Years since parental death interviewee participants (n=6)		
< 1 year	-	-
1-2 years	-	-
3-4 years	1	16.7
5-6 years	1	16.7
7-8 years	4	66.7

Note. Years since parental death for the interview participants has also been added.

Table 2. Means, standard deviations, Cronbach's alphas, Spearman's correlations ICG, ISLE, RSA, HRQOL and HCL-10

	Cutoff	Mean	SD	α	ICG	ISLE	RSA	HRQOL	HCL-10
ICG	25	34.3	11	0.87	-				
ISLE	52	49.8	9.5	0.84	-0.55*	-			
RSA	-	158.8	27.9	0.76	-0.69**	0.73**	-		
HRQOL	-	65.1	14.4	0.81	-0.71**	0.47	0.58**	-	
HCL-10	mean \geq 1.85	2.09	5.6	0.79	0.62**	-0.46	-0.51*	-0.71**	-

Notes. ICG= Total score Inventory complicated grief. ISLE= Total score Inventory of stressful life events.

RSA= Total score Resilience scale adults. HRQOL= Total score Health related quality of life.

HCL-10= Total score Hopkins Checklist-10.

* p = < 0.05

** p = < 0.01

Table 3. Spearman's correlations for the RSA subscales with indication of CG

	PS	PF	SC	FC	SR	SS
ICG	-0.81**	-0.49*	-0.25	-0.36	-0.36	-0.56*

Notes. ICG = Total score indication of complicated grief.

PS = "Perception of self"; PF = "Planned future"; SC = "Social competence"

FC = "Family cohesion"; SR = "Social resources"; SS = "Structured style".

*p = < 0.05

**p = < 0.01

Discussion

4.1 - Grief longevity and conversation with the dying parent

Both the qualitative and quantitative results indicated that the YA in grief were highly impacted by the parental loss experiences. A major quantitative finding in this present study was that 15 out of 19 (78.9%) of the survey participants had an indication of CG as measured by the ICG. It is interesting that this high number was found in this small study sample as they came from four different geographical locations. Psychological distress seems to be the reality for several of the survey participants as the measured total score of HCL-10 was above cutoff (Table 2). The interviewees mentioned among other things longing for the deceased parent, depressed mood, and difficulties focusing on the future as contributing to reduce HRQOL.

The results revealed that there was a big discrepancy in time since the parental death; 1-7 years after the loss for the survey participants, and 3-7 years for the interviewee participants (Table 1). Being conscious about how much time has passed since the loss experience when grief reactions are investigated, is assumed important as time probably is crucial to create a complete grief narrative, and this way might influence research results. A study found that the longer time which passed after the death of a loved one, the higher adolescents and YA rated the perceived intensity of their immediate grief to have been (Servaty-Seib & Pistole, 2006). A study on CG in friends of victims of the Utøya-terrorist attacks found that grief intensity in several cases were maintained over time because the grief reactions had been delayed (Dyregrov, Dyregrov, & Kristensen, 2015). Indeed, the qualitative results in this present study found that while some YA felt that their grief became attenuated as years passed by, some scored the grief as still being overwhelming 7 years after the loss. Specifically, it was still leading to depressive rumination, anxiety, and reduced daily functioning.

Contributing to the longevity of grief are feelings of worthlessness, rumination, less adaptive coping such as avoidance, and loss related memories such as unrealness (Eisma, de Lang, & Boelen, 2020; Smith & Ehlers, 2020). Also of importance are relational factors and level of vulnerability in the individual (Stroebe, Folkman, Hansson, & Schut, 2006). Another

explanation for grief longevity might be that YA in grief with emotional maturation develop more knowledge and understanding about the grief process. If ability of emotional handling were not available as the parent died, this could result in the past grief being appraised more overwhelming compared to present grief. Holland et al. (2006), found that sense making of the loss experience was a more robust predictor of grief relief, than how much time which had passed after the loss.

Finding acceptance decrease grief-related psychological distress (Johnsen, 2016; Prigerson & Maciejewski, 2008). Conversation with the sick parent could in this manner seem to serve the purpose of helping the YA to find acceptance and create meaning of the unpredictable situation. A qualitative finding in this present study revealed that most participants had a big desire to be able to talk more to their dying parent about their emotional state and the future. However, factors such as sudden disease development, and a wish not to trouble the sick parent hindered this desire in the terminal phase. Several of the interviewees mentioned that being able to talk to the sick parent in an earlier stage of the disease, better could have prepared them and given them more information about what was happening. Specifically, the interviewees in this present study wished to know more about cancer in general, and what would happen in the terminal phase. This is in consensus with international grief research that familial members request more, and earlier preparation and information (Tarberg et al., 2019).

4.2 - Complicated grief, meaning integration, resilience, HRQOL and psychological distress

Among the survey participants, a moderate positive correlation between HRQOL and ability to integrate stressful life events, together with a strong positive association between resilience and ability to create meaning of stressful life events were found (Table 2). Holland et al. (2006), argue that when the individual lack ability to make sense of a loss experience, this is critical for developing CG. These positive correlations point out that meaning integration might be an important element in resilience, and something increasing HRQOL. Indeed, the quantitative results in this present study revealed a moderate negative correlation between indication of CG and the ability to integrate stressful life events (Table 2). This is in accordance with research which found that degree of resilience was inversely correlated with degree of grief

symptoms (Clements, 2014). Thus, given that the individual gets help to better integrate the loss, the degree of CG symptoms probably might be reduced. A study found that the ability to integrate meaning related to the loss of a parental death, was an important element of the individual resilience in YA (Purandare & Ssthiyaseelan, 2018). This leads to the assumption that individuals who have an indication of CG, actively rationalize, comprehend, and try to integrate the loss experiences into their life narratives. Being mentally prepared towards the loss, degree of trauma, degree of suffering of the dying individual, and perception of the death process as being distressing, has been found to be important when looking at risk factors for developing CG (Boerner & Schulz, 2009; Johnsen, 2016; Schulz, Boerner, Klinger, & Rosen, 2015). The quantitative results further revealed that the lower degree of meaning integration, lower degree of resilience, and lower degree of HRQOL, the higher degree of CG symptoms (Table 2). These findings overall are in agreement with current grief research showing that the individual in grief has a lower HRQOL and struggles to find and integrate meaning of the loss (Dyregrov et al., 2017; Peri, Hasson-Ohayon, Garber, Tuval-Mashiach, & Boelen, 2016; Wågø et al, 2017).

The quantitative results in this present study also showed that indication of CG was highly negatively correlated with HRQOL (Table 2). Given that grief has been understood as very overwhelming, and specially complicated trajectories of grief (Simon, 2013; Trevino et al., 2018), this finding might not be surprising. This finding is confirmed by the interviewees in this present study who described how living next to a sick parent changed their ways of living with sadness, unpredictability and waiting for something to happen. A metastudy found that familial caregivers to individuals with cancer experienced a burden of care, restrictions on daily activities, anxiety, insecurity, loneliness, a bad prognosis, and lack of emotional, practical and informative support as crucial factors making them more vulnerable to fatigue and burnout during the terminal phase (Tarberg, et al. 2019). Moreover, the quantitative results in this present study revealed that sleeping difficulties and fatigue were among the most common symptoms among the survey participants and both group mean scores were above cutoff, indicating a clinical level (HCL-10). As many as 42.1% (n=11) reported moderate or extreme sleeping difficulties, while as many as 84.2% (n= 16) reported minor, moderate, or extreme fatigue related to daily activities 1-7 years after the loss. This is in consensus with some of the interviewees

reporting that they had an altered sleeping pattern, for example sleeping for hours after school, or felt the need to isolate themselves from social activities or the family to preserve energy. It is therefore likely that low energy levels might make the individual more vulnerable to psychological distress and fatigue, and simultaneously making it harder for the individual to mobilize protective resources.

The quantitative results in this present study revealed a strong negative correlation between total score of resilience and totalscore of CG (Table 2). The survey participants had a mean score of 158.8 points out of 231 in total, indicating a moderate resilience level (Table 2). The correlation analysis on an individual level also showed that resilience score was reduced as indication of CG increased. Looking at the individual survey responses in this present study also indicated that the less degree of resilience in the individual's life, the more indication of CG symptoms. It is however unknown whether an individual low degree of resilience emerged before the grief, then led to a higher degree of CG, a high degree of CG led to lower degree of resilience, or both circumstances interacted simultaneously. Research shows that the higher individual level of resilience, the more intra- and inter- personal protective factors the individual possess, giving better psychological health, and the individual becoming better at coping with stressful life events (Kermott et al., 2019, Southwick, 2016).

4.3 - Complicated grief might affect the perception of self

According to the quantitative results, among the six sub domains of resilience, PS was found to be most negatively correlated with indication of CG among the survey participants (Table 3). This is in consensus with other grief studies showing that the self-perception is changed after a loss of a close loved one (Balk, 1983; Boelen, 2017). One reason a parental loss may alter the PS in the YA, is that witnessing the disease development and later death, might be felt quite overwhelming. Indeed, several of the interviewees described the situation with a dying parent as uncontrollable, unpredictable, and a situation that felt forced upon them from which they could not escape or hardly control. Given this experienced state, this reminds of the phenomenon of learned helplessness where the individual is more prone to develop resignation, anxiety, and depression due to the situation being perceived as uncontrollable and unescapable.

In fact, individuals who perceive a situation as extreme and difficult to accept, difficult to comprehend or escape from, has been found to enable more energy consuming coping strategies and emotions which reduce overall life quality (Gacek, Smolèn, & Pileca, 2017; Mohanty, Pradhad, & Jena, 2015; Sprang & McNeal, 1995). Learned helplessness has been found as a plausible explanatory factor for differentiated behaviors and symptoms in grieving individuals such as reduced self - esteem, self - efficacy, future life goals, and reduced ability to plan and trust in own ability to act upon life adversities (Balk, 2014; Lemoine, 2016; Stroebe & Stroebe, 1987). Although there is little research on learned helplessness and grief reactions, the feeling of hopelessness has been associated with prolonged grief reactions (Stroebe & Stroebe, 1987).

Interestingly, similar findings were found in both the survey- and interview group in this present study. Among the survey participants the results revealed that hopelessness, doubt regarding the future, and tendencies of self-blame were common symptoms. As many as 36.8% (n=7) reported quite a bit or extreme hopelessness and doubt regarding the future, while 47.4 % (n=9) reported quite a bit or extreme tendencies of self-blame. The interview participants in this present study agreed upon that HRQOL was drastically changed, routines and daily activities were in many cases changed or paused, and depressive thoughts were more present with self - doubt and reduced self - esteem. The qualitative findings in this present study confirmed preoccupation with thoughts of sadness, death, and existence relative to before, gives a clue that the view on the self-concept probably was altered by the magnitude of the disease and loss experience.

4.4 - Maladaptive coping strategies

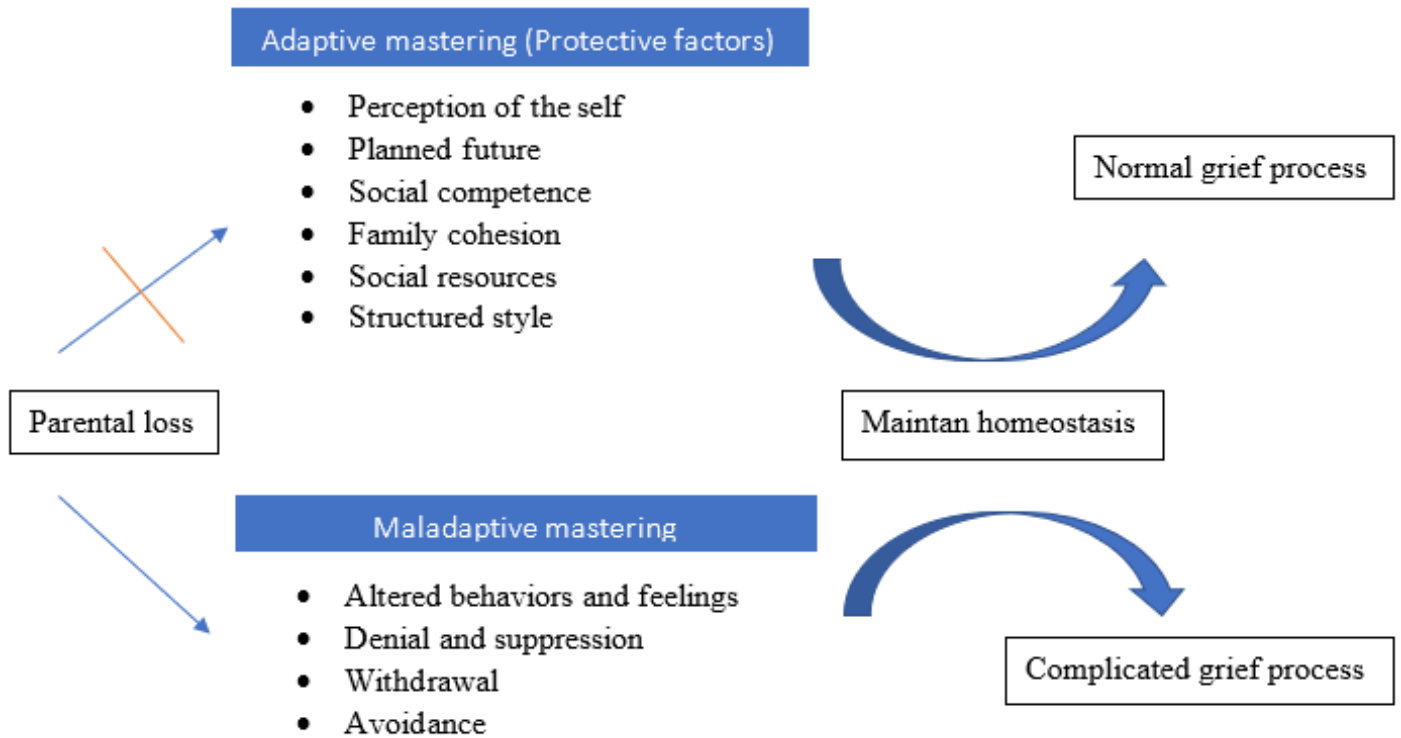
Taking advantage of resilience factors when CG is present thus seems challenging. Grief research is in consensus that a loss of a parent in young age, is one of the most stressing happenings one can experience (Shear, 2012). If YA in grief instead use other types of coping mechanisms and strategies which not necessarily are adaptive or helpful, this could potentially complicate the grief process (Figure 3). Several of the interviewees mentioned one specific type of behavior being around the sick parent, and one being apart from the parent. Specifically, some of the interviewees were clear that it was important for them, not to act in a way that might upset

or stress the dying parent, and it was rather important to be perceived normal and without any struggles by others. This is something the YA described as changing their normal behavior to something they thought or expected was socially favorable or required in the difficult situation. In other words, it looks like the YA placed self-restrictions on emotions and normal behavior which both differed from their desires and needs in the current situation. Whether this should be understood as self-protection, or protection of the sick parent is unknown, but it might complicate the process due to putting up energy consuming behaviors, thoughts, and feelings. Familial caregivers were found to tend to neglect their own personal needs in favor of the dying person in the terminal phase (Tarberg et al., 2019). Coping strategies being used should be seen as something very understandable and necessary to obtain some sort of homeostasis when this type of life crisis occurs (Figure 3). If assuming that the YA use coping strategies such as suppression, denial, avoidance, and withdrawal, these have been found to reduce the intensity of grief and to conserve energy in context of loss experiences (Baker et al., 2016; Eisma, et al., 2013; Rahimian & Talepasand, 2015).

If the YA have difficulties facing, confronting, or accepting the loss, or avoiding thinking about the loss by counterfactual thinking or distracting oneself from emotional challenging topics, this might be a form of avoidance found in depressive rumination (Stroebe et al., 2007). Shear (2010), states that for individuals who engage in depressive rumination and this becomes rigid and overwhelming, such maladaptive avoidant thinking and behaviors might increase the risk of developing CG. Interestingly, some of the interviewees in this present study mentioned behaviors and thoughts compatible with suppression and denial, while others said they became more isolated and avoided things which reminded them of the sick parent in the terminal phase. Thus, the grieving individual could manage to temporarily regulate their emotional states, however, altered behaviors, feelings and thoughts might be seen as a discrepancy between a crucial need and actual behavior, hence leading to a cognitive dissonance. Cognitive dissonance may this way contribute to lower general HRQOL, increase psychological distress, and increase CG symptoms as a result of striving to maintain homeostasis (Figure 3). Cognitive dissonance has been found to induce feelings like shame, guilt, anger, and denial (Breslavs, 2013) These are feelings and states also mentioned by some of the interviewees in this present study. This may

also make sense given that PS was found to be altered among the survey participants. Research shows that after a loss in a family, the familial system changes due to the gap after the deceased, and family members trying to return to some sort of homeostasis (Bowlby-West, 1983).

Figure 3. Hypothetical grief trajectories



Note. This chart is a hypothetic model of how adaptive and less adaptive coping strategies might create two different trajectories in a grief process. It is assumed that the individual strives to maintain internal homeostasis after the loss. The red line is symbolizing the hindered utilization of resilience factors.

From the interviews, several participants described what they felt was a waiting period for something to happen and not knowing what was coming. This might be understood as anticipatory grief, and is characterized by impairment on several domains in life (Burke et al., 2015). In fact, those interviewees who experienced this waiting period, also described witnessing graphic situations with the dying parent such as their parent's bodily deformation like loss of hair, swelling due to medicines, dementia, or the parent being unconscious. Research has found that unreality, surrealism and drama surrounding deaths can be problematic in order to create meaning and find acceptance, which has led to greater psychological distress, poorer coping skills, and risk of developing CG (Holland et al. 2006; Kaltman & Bonanno, 2003;

Miyajima et al., 2004). This was described by some of the interviewees as shocking, which increased depressed mood, and a wish to keep distance to the parent. It thus seems that the longer the YA had to live with unpredictability, and if using less adaptive coping mechanisms, the more this could reduce HRQOL and potentially complicate the grief process.

4.5 - Vulnerability and young age

The loss of close significant relationships is considered to have a great negative impact on overall life quality in adolescence and young adulthood (Alm, Brodin, & Bohman, 2019; Keenan, 2014). As the parental loss for the majority of the survey participants and the interviewees in this present study happened in the age-range 11-16, this was a crucial time in their upbringing as they still were dependent on their parents. The interviewees pointed out that they were very young when they experienced that their parent became sick and died. According to them, the young age during their parental disease was related to lack of self-insight, lack of knowledge and a difficulty to understand the situation, characterized by a feeling of emptiness, unreality, and hopelessness. The grief process was also described as a process of maturation in some cases, and lack of self-insight was seen as a difficulty in judging what was best regarding physical and emotional self-care, and such worsening HRQOL.

It is interesting to see a parallel between these experiences described by the interviewees and what Erikson (1994), calls role confusion. An assumption is that experiencing the loss of a parent who is an important caregiver in this age, leads to the disruption in natural development according to Erikson's theory. If the YA does not have the supporting environment needed to develop sufficient self-belief and autonomy, indeed it may be expressed as the confusion described by Erikson (1994). A relevant protective factor for YA who had a parental loss was found to be the remaining parent exhibiting reality-orienting behavior, facilitation for continuation in life, regaining structure in the home, and being a good role model (Bergman, Axberg, & Hanson, 2017; Ellis, Dowrick, & Lloyd-Williams, 2013; Hilgard, Newman, & Fisk, 1960). An assumption is that lack of self-belief and insecurity might make the individual less resilient in times of adversities, thus HRQOL in general and degree of grief symptoms should also be understood in a developmental perspective.

Due to the above-mentioned factors one can assume that YA are more vulnerable and less resilient compared to older adults. A lifetime study sought to compare psychological resilience in older adults > 64 years old with younger adults < 26-years old (Gooding, Hurst, Johnson, & Tarrier, 2012). Interestingly, the older adults were found to be more resilient regarding emotional regulation and problem-solving skills, while YA had more resilience through social support (Gooding et al., 2012). Low scores of hopelessness predicted greater resilience in both groups, but only for the < 26-year olds social support compensated for the negative effect depression had on resilience (Gooding et al., 2012). From the first finding one can assume that YA are more dependent on external sources such as social support and problem-solving skills from parents, family members and friends during life adversities. This points back to the importance of care from close caregivers in this age, as the YA develop autonomy, described by Bowlby (1982). Research suggests that intrapersonal resilience such as ability to regulate emotions increase with age (Livingstone & Isaacowitz, 2018). Ability to regulate emotions may this way be less available for YA since it is less developed than in older adults.

Mentioned by several of the interviewees was that living with a sick parent throughout the disease development, new and difficult reflections emerged, and some of these were related to existential questions and roles in the family. It is maybe understandable that the YA seek an understanding in the chaotic situation in which they live but are also in some cases more prone to find this through focus on religious or existential thoughts. According to Erikson's stage theory (1994), individuals in this age group who experience life adversities and do not receive support from caregivers, will develop insecurity, making them more vulnerable. Interestingly, the quantitative results in this present study revealed a moderate negative correlation between the resilience subscales PF, SS, and indication of CG (Table 3). It might seem like when the grief becomes profound, ability to focus on the future as well as ability to structure the life and goals become influenced, which is in consensus with Eriksson's theory. The quantitative finding that meaning integration also is reduced leads to the assumption that the YA becomes trapped in a focus narrowed towards death and unpredictability experiencing parental disease and loss.

4.6 - Grief , attachment bonds and gender differences

Regarding normative development stages in adolescents and YA lives, attachment and certain attachment figures might have different and important functions (Johnsen, 2016). As previously mentioned, the age between 18-25 can be seen as turbulent due to natural development regarding social, emotional, and cognitive domains in life. Going through this age span, the individual needs to become autonomous, and establish new relationships with adults and peers. Further, develop intimate relationships, cognitive capacities, and orientate oneself regarding ethical questions and values. It is normal for this age group to experience conflicting feelings, thoughts, and behavior as chaotic, also towards their parents. In the interviewee group there were examples of less optimal attachment bonds to the remaining parent after the loss, which could be a vulnerability for the YA to develop CG (Bowlby, 1982). The perceived level of trauma and grief after a parental death have been found to depend largely on relationships within the home prior to the death, but also to the ability to reinstate order in the home after the loss (Ellis et al., 2013; Osterweis, Solomon, & Green, 1984). Several participants of the interview were clear that if there had been more openness to feelings after the loss in the family, this might have made the grief process easier. Research has found that attachment between parents and the YA still is important also in the continuous development becoming an adult (Field, 2006). In other words, the theory of circle of security based on Bowlby's work, is still valid, where the individual comes back to the parent's safety in times of struggles or stressful life events.

Losing a parent in this age thus means that the young individual might lack necessary and important social support from an attachment figure. Research shows that the quality of attachment to the parents, are important in creating new relationships with other individuals later in life (Høeg et al, 2018). Research has also found that YA expect support from their parents as they are grieving (Sawyer, 2019). The same study also states the importance of the remaining parent offering emotional support and nurturance to be able to cope after a parental death (Sawyer, 2019). A Danish study with 70.000 YAs who lost a parent showed that the remaining parent's attempt to help the grieving individual overcome the grief was crucial to what degree the individual managed to cope with the loss and whether later psychopathology was developed (Høeg et al, 2018).

Research suggest that culture and gender role socialization must be accounted for in understanding gender grief reactions (Doka, 2011). Males compared to females are to a bigger degree socialized to keep emotions to themselves, while it is more accepted for females to express grief (Doka, 2011). Research has found that females are more likely to have ruminative symptoms compared to males experiencing stressful life events (Lawrence, Jeglic, Matthews, & Pepper, 2006). Male students in grief have been found more likely to exhibit behavioral disturbances after a parental loss, while females were more prone to express grief and sadness (Kraatz Keiley, Bates, Dodge, & Pettit, 2000). While the interviewees in this present study were more equally balanced regarding gender, the survey participants consisted of one male and 18 females. Further research should thus emphasize including equal numbers of males and females in grief studies to get more representative results.

4.7 - A grieving family

In a grief perspective one can argue that the family has at least four very important functions for the YA. Firstly, given that the bond of attachment has been strong, the family will be important in helping the YA to master adaptation to new environments and regulation of emotions (Svendsen & Jacobsen, 2013). This might in turn boost individual resilience and hence increase HRQOL. Secondly the family still functions as an important source of social support in times of adversities, meaning that the YA should be certain to get this support when needed. Thirdly, the family creates an important logistical important system which makes it possible to continue daily life activities, which again serves to promote HRQOL and resilience. Finally, the family is thought to serve the important function of helping to frame the loss, making it more concrete instead of abstract and such easier to understand. This process of meaning creation is thought to help creating more adaptive perspectives around the loss and can such be seen as an important element of individual resilience.

From the interview group one participant mentioned that the grief was especially overwhelming due to a strong relational bond to the dying parent, while the attachment to the remaining parent in periods was not perceived as close and safe. The quantitative results revealed that as many as 10.5% (n=2), reported that they were unhappy in their family, 5.3%

(n=1) experienced that family members disagreed in what was important in life, while as many as 21.1% (n=4), reported their family was divided due to conflicts 1-7 years after the loss. One can from these findings assume that many individuals who experienced CG symptoms also experienced familial attachment bonds which were not of an optimal quality. Research recommend for YA to increase their ability to take advantage of resilience resources and the attachment bond to the remaining parent to help the individual move forward after the loss (Bowlby, 1980; Høeg et al, 2018; Masten 2001; Svendsen & Jacobsen, 2013). The familial support and closeness should thus be central during the grief process and in the aftermath of the loss.

YA grief reaction should be seen in the context of the whole family as the family system is changing due to the loss (Delalibera et al., 2015; Dyregrov & Raundalen, 1996). It is very likely that the rest of the family also has their own grief process, hence limiting how much support and comfort they might share with other family members. Grieving individuals often have difficulties coping to the new situation with other family members grieving simultaneously, something that could alter familial relations (Bowlby-West, 1983). This is in consensus with what some of the interviewees reported saying that they were witnessing other family members grief, resulting in the YA withdrawal from expressing own emotional states due to giving space to the others. Also, mentioned by some of the interviewees, that changes in work, school, and daily activities and routines happened due to familial incapacitation due to grief. A study found that families having a higher degree of psychological distress symptoms, worse social functioning, difficulty taking advantage of community resources after a loss, could be seen as more dysfunctional and hence had a more complex grief process (Delalibera et al. 2015). The same study also found that family conflicts complicated the grief reactions, while FC, openness to feelings and expressing these reduced grief symptoms (Delalibera et al. 2015). Familial conflicts and a tradition of not expressing feelings were mentioned by several participants in the interview group, arguing that familial conflicts drew the attention away from the grief process, also consuming time which could have been spent together. Interestingly, although not significant, a low negative correlation between FC and indication of CG in the survey group was found in this present study (Table 3).

Not being able to express emotional states in the family might be due to cultural traditions but might also be understood in accordance to Bowen's family system theory. This theoretical perspective sees the loss of a family member as a threat to familial unity and must such be avoided (Bowen, 2018), making avoidance of talking about feelings more understandable. However, one very important consequence of not addressing the obvious loss in the family is according to Bowen that the emotional distress after the loss will be kept in few relational bonds, not changing or reducing the strength or intensity, and such continuously stressing the individual (Brown, 2013). The quality of attachment to the lost and remaining parent, familial openness to feelings, witnessing others grief, and familial conflicts emerge as mentioned reasons in both the survey and the interview group as potentially complicating their grief processes. Furthermore, a metastudy looking at caregivers to patients suffering from terminal cancer found that close caregivers strived to maintain normality at home, and the availability of support and stressors influenced how they adapted to new and changed roles within the family (Tarberg, et al. 2019). It was also found a connection between trying to maintain these new familial roles and reduction in overall life quality due to the fact that these new roles felt unnatural and alien (Tarberg, et al. 2019). These findings with role alienation and fatigue give sense from the theoretical perspective of Bowen. According to Brown (2013), the dying parent might leave behind a social, educational, or economical vacuum, and also care and attachment which the rest of the family members try to fill due to them striving to maintain normality.

There are probably limitations to what degree the remaining family members achieve this. For example, it will be harder for a non-educated parent to take an educated role, or a YA to start taking care of a sibling next to themselves when this prior to the loss never had been the case. An assumption is that while the remaining family members struggle to fit into the new family dynamics, self-blame, anxiety, insecurity, low motivation, and depression is easier to occur next to the grief in cases where the individuals do not feel they succeed with their self-placed roles and responsibilities. Tarberg et al. (2019), found that familial caregivers experienced that they often took a role as assistant instead of a family member towards the dying individual. This is assumable also a source of cognitive dissonance due to the fact that the family undertakes roles and responsibilities they do not really are capable to fill during grief and

fatigue. This is confirmed through the interviewees as they point out that they changed behaviors and roles to satisfy the dying parent, but it often happened on the expense of their own HRQOL.

4.8 - Secondary losses

A parental loss might however also influence the overall life quality to a considerable extent through secondary losses. In the interviews, some participants who already experienced a parental loss, also mentioned several other stressors in their lives which existed simultaneously, and which were described as complicating their grief process even further. These were divorce, a worse economic situation prior and after the parental death, lost friendships due to isolation and less time in school. The descriptive characteristics revealed that, 15.8% (n=3) among the survey participants rated their current familial economic situation as below average (Table 1). Some of the interviewees explained that in cases of a worse economic situation, this could mean quitting expensive recreational activities, and in one case, a participant felt that acquiring a job was necessary to help with money to the family. Regarding spending less time in school due to grief reactions, some interviewees said that this meant less time with friends as well as less time receiving care from teachers and the school nurse. Masten (2001), states that there is a worse prognosis related to overall life quality when adverse life events accumulate. When factors like these occur simultaneously as losing a parent, one can assume that HRQOL and ability to create meaning in a chaotic situation are affected even further, and such probably complicating the grief process.

4.9 - Social support

According to Sandler, Wolchik and Ayers (2008), individuals in grief will benefit greatly from information and social support to better discover their strengths and weaknesses to help the person through life stressors. Emotional and social support has been found to contribute to increased PS, which in turn strengthen intra-personal resilience traits like optimism, self-efficacy, and general coping skills (Vegsund et al., 2019). The quantitative result in this present study revealed that PS was most negatively correlated with the total score of CG symptoms (Table 3). Thus, social support can be assumed very important during and in the aftermath of a

loss experience to increase feeling of self. The qualitative results revealed that those interviewees who did not receive social support outside the family were in consensus that lack of this, potentially could have complicated their grief process. One interviewee said, “it was of great value to meet others to see that they were prosperous after a loss experience”. This is in consensus with Iacoviello and Charney (2014), who recommend the togetherness of individuals who had similar experiences to increase resilience in the YA.

Qualitative findings from this present study reveal that those interviewees who did not receive social support from others or the public health care system at all during the disease development or after the parental death, wished they had gotten more. In a study looking at public health services offered to families in grief, several of the caregivers expressed that they would have consulted primary health services much earlier, using it even more often, or that they received this support much too late due to not knowing what type of help they actually needed (Tarberg et al, 2019). Those interviewees who both received social support or lacked this, emphasized teachers and the school nurse as important, and they had wished to be seen by these personnel. The school system next to close friends and family, might be the most important arena to find the necessary support because of the closeness and availability in the YAs lives. Participation and engagement in school and education could be very relevant for grieving YA, as it is a big part of their lives (Gooding et al., 2012). Social support and education according to Gooding et al. (2012), were highlighted as factors increasing resilience in YA. The quantitative results in this present study revealed that more than half of the participants had either up to 4, or more than 4 years in university (Table 1). Research has found that academic performance is positively associated with being more conscientious, structured, self-disciplined and goal directed (Arnesen, Elstad, & Christophersen, 2017; Wang et al., 2019). Being in the educational system must thus be assumed of great advantage to promote resilience, both being a source of social support but also helping to increase sub-categories in resilience such as PS, SS and PF. This is somewhat confirmed by the qualitative results in this present study, as some participants mentioned that taking education helped them focus on something else than the grief, becoming more reflected, elevated mood, as well as this being an arena to meet friends.

Probably, social support serves to give attention and care from others that are not biased with grief. Social support also helps to lift the attention from the grief perspective onto new reference points in life to which the grieving individual can focus on. Interestingly, familial caregivers have been found to experience more daily stress than the dying person, and receiving less public health services compared to the dying person who in most cases were hospitalized and a part of the healthcare system (Tarberg et al, 2019). This leads to the other finding from the interviewees, that being seen by others while being vulnerable, getting time and space, and flexibility when expressing feelings and thoughts was especially important in the grief process. As another respondent said, “there is a certain responsibility for adults to approach the grieving YA, however in the right time and way because the grief sometimes prevents the YA from being receptive to support”. This responsibility is thought to be especially important in situations the YA might show behavior like disinterest or avoidance.

One factor which could help explain why it might be difficult to take initiative to receive help prior to the death is that grieving young individuals might refuse this because in seeking help, they subconsciously accept that the loss is imminent. As previously discussed, and given that the grieving YA in several cases subconsciously has thoughts and behavior which goal is to strive for normality and obtain daily function in a crisis, it seems logical that approaching a point where you accept the death of the parent is something to be prevented as long as possible. Seeking help from others, talking about the death, or organizing/ initiate preparations before the death is a fact, might hence feel irrational, or a feeling of abandoning hope. Furthermore, shifting the perspective from “keeping things as it is” to “focus on the future” might be difficult due to young age and reflections about the future as abstract and far ahead.

A study found that psychological support given by health care professionals to parents in the terminal phase of children with cancer, had a positive effect on the grief process (Kreichbergs, Lannen, Onelov, & Wolfe, 2007). This would substantiate the need for social support from health care professionals for YA, not only in early phases of a parental cancer disease, but also in late phases. A qualitative finding from this present study was a discrepancy between living location and to what degree there were satisfactory social support. Participants living in less populated areas expressed lacking social support either through the school system or close friends, while individuals living in urban populated places to a bigger extent were

overall satisfied with the school system but wished for more. It is worrisome that this present study revealed that some left behind after the parental death felt they lacked social support. Social support is associated with a shorter grief process, while lack of information and preparation is found to be a substantial stressor and increase the probability to develop CG (Bergman et al., 2017; Thimm et al., 2019).

4.10 - Strengths and limitations

Strengths

This present study is thought to have several strengths and can potentially contemplate the field of grief research. Firstly, few studies have focused on the specific group of YA in the age-span 18-25 years regarding loss of a parent to cancer, and complicated forms of grief. Secondly, there are limited research on this particular age group and the above-mentioned factors in the Norwegian population. Furthermore, this study considers indication of CG, resilience factors, HRQOL and ability to create meaning of the loss experience, giving the option to see potential associations between these. An advantage with using standardized instruments is that one can compare results with populations in other studies. One can however argue that these instruments only captures grief in the moment of distribution, but maybe not grief as a process. Moreover, important aspects of the grief process might be ignored depending on which instruments are included in the survey. Lastly, the mixed method design in this study gives the opportunity to combine quantitative and qualitative results to have an explorative focus which might give a rare and valuable insight into YA narratives and their grief reactions. Both groups of participants together increase overall validity in that they complement each other.

Regarding the recruitment process, a satisfactory number of participants for the interview were recruited (n=6). An equal number of males and females in the sample, and the age requirement was satisfactory distributed within the age criteria. However, these participants were only recruited from Midt-Norge hence not fulfilling geographical representativity. Recruitment for the online survey was a challenge, first trying to recruit only from Midt-Norge. Few volunteers qualifying according to the inclusion criteria led to including Oslo, Bergen and

Tønsberg due to also having the offer Ung Pårørende, and a somewhat greater geographical representativity was thought to be fulfilled.

Limitations

A major limitation to this study is that the overall low response rate. N=19 regarding the online survey, is not a big enough study sample to use parametric analytical tests such as regressions or t-tests, thus limiting other types of potential data to be explored and found. Skewness in normality distribution also made the use of a variety of non-parametric tests challenging. The sample size must such be credited as an error source. Furthermore, in cases of extreme values, the statistics might easily be influenced, making them less valid. The chosen statistical test of correlations does only state that there is a relationship between factors, but nothing about causality. It is hence not possible to conclude with certainty, only that there is a positive or negative relationship between the factors, and that something is responsible for this.

In total 106 individuals opened the survey, but only 19 responses qualified to be used in the analysis. A nonresponse trend was found in this study, and might lead to a sample bias, and make calculation of effect size problematic. A consequence might be that the study does not manage to capture the individuals with most grief symptoms. Although a high level among the survey participants was found to have CG, in theory this group could have been individuals with a better daily functioning and capacity compared to the nonresponse individuals. Furthermore, the majority of the survey participants were approached by their Ung pårørende leader, informing about the study, and the participants might have been motivated by feeling of duty or social desirability. It is also possible that those who chose to participate have advanced in their grief process, having a somewhat better overall functioning than those who did not choose to participate.

Another big limitation is the skewness between the genders since one male and 18 females completed the survey. Naturally, interpreting the results should thus be done by great caution, and concluding about the grief reactions in males from this study cannot be done. A Norwegian study found that gender was significantly correlated with CG, suggesting that being female was associated with higher levels of CG (Wågø et al., 2017). Why so many females

contra males chose to answer the survey is unknown. From a cultural perspective, one can find gender differences in assumptions and self-perception on how to grieve. Traditionally males might be seen as more reserved emotionally due to a thought of being perceived as strong and not showing emotions revealing assumed weakness. Due to this study's explorative design, gender and cultural differences have not been compensated for. This might influence the results, making them biased.

For many individuals, the topic of parental death assumable is potentially emotional challenging. As a result, many YA might avoid participating in a study reminding them of this life experience. In an attempt to gather as much information as possible, several instruments were put together, and the length of the survey might be another reason why so many did not complete the survey. Also, if the individual's view on their own grief process was different than how the survey questions were operationalized, this might be a reason for low participation. The creation of the survey might exclude certain aspects of a grief process as certain instruments were included specifically regarding the study aim.

Furthermore, the quantitative findings revealed that there is a big discrepancy in time since the parental death (Table 1). Because of this, one can expect that for the individuals who had the loss experience closer in time, the grief process could have been felt more overwhelming than by others. Naturally for these individuals, psychological distress and grief could have been felt more potent and such produced higher scores. Also, in the interviewee group there was such a discrepancy in time since the parental death.

Finally, the participants were recruited from an association which is intended for individuals who have lost someone to cancer in young age. The degree of grief symptoms can therefore be expected to be higher relative to the general population, and is such somewhat biased if assumed that individuals with greater degree of grief approach this offer. The finding of 79% indication of CG symptoms divided on four geographical locations among the survey participant, show that there might be unmapped numbers and patters regarding grief. Afterall, there is no criteria regarding degree of grief to participate in Ung Pårørende.

Something which can be seen as both a strength and a limitation to this study is the author's own personal experience with a parental loss. A strength might be the general

interest and curiosity in the topic, moreover, being updated on where to recruit participants from. A limitation is however that study design, focus, and interest in the topic potentially could have been influenced in a certain direction. Research objectivity is naturally harder to keep due to personal experiences. Moreover, this could have led to inclusions or exclusions of certain perspectives and thoughts, something a neutral researcher to the topic might have considered. Furthermore, there is a chance of a confirmation bias happening, when the authors prior knowledge and experiences, assumptions and beliefs serve as a guide to confirm new information according to these. Although awareness of this has been prioritized, this is something which potentially could influenced the overall validity on the study.

Due to these reasons' representability and such generalization from this study to other populations is greatly influenced, and if so, should be done with great caution. However, this study in its design, aims to be explorative and might contribute in giving insight where this already is limited, and thus the chosen design was thought to be satisfactory. Since most findings in this study in general are in consensus with similar research, it is not impossible that processes and mechanisms mentioned in this study, also could appear in other similar grief situations. Naturally, these must be observed from that given context. This study could also serve as an inspiration and creation of new research hypothesis and questions in further grief research.

5.1 - Conclusion and further recommendations

Potential CG reactions among the YA participating in this present study could be associated with reduced degree of resilience factors, inability to integrate meaning of the loss experience, increased psychological distress and lack of social support, indicating that CG is a complex process. Presence of CG could further impact the overall ability to direct energy towards activities, thoughts and feelings which promote resilience and HRQOL. This could in turn reduce self-worth, goal-directedness, and induce psychological distress. One relevant recommendation based on a previous study could be for the primary health services to early identify low degree of resilience factors in YA, focusing on PS and increase intra-personal factors such as optimism, self-efficacy, belief in oneself and the future (Vegsund et al., 2019).

The qualitative results in this present study revealed that conversation with the sick parent about the disease, seems to be an important way the YA can get help to create meaning and acceptance of the chaotic circumstances. Thus, meaning integration seems to be an important element in protective factors such as resilience for the YA. Being seen by others and having the opportunity to talk to others outside the family like friends, teachers and school nurse was by the YA experienced as important. Moreover, the qualitative results revealed that the parental loss affected the family as a whole. Witnessing family members grieve, losing support from them, self-placed roles, and responsibilities, and feeling of a vacuum after the deceased, were related to self-blame, anxiety, insecurity, and low motivation. These factors happening separately or together with little openness to feelings within the family, and familial conflicts, were mentioned as complicating the grief process. Another recommendation based on a previous study, is to increase FC through family therapy to address and improve potential challenges and needs (Vegsund et al., 2019). This could be of great value increasing openness about feelings, roles, responsibilities and avoiding conflicts. Further, in resolving stressors occurring simultaneously to the loss, it is thought that the YA can save energy and focus more on self-care with help from the family.

Future research should prioritize longitudinal studies with larger study samples and equal gender balance. Such studies could provide important information about CG development, resilience, and coping mechanisms and how these change over time.

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«SORG HOS UNGE VOKSNE ETTER TAP AV FORELDER I UNG ALDER»

Bakgrunnsinformasjon

1. Ditt kjønn:
 - Kvinne
 - Mann
 - Annen oppfatning av kjønn

2. For hvor lenge siden døde din forelder?
 - Under ett år siden
 - 1 - 2 år siden
 - 3 - 4 år siden
 - 5 - 7 år siden
 - Over 7 år siden

3. **Hvem bor du sammen med nå?**
 - Mor og far
 - Enten mor eller far
 - Jeg bor alene
 - Sammen med kjæreste/ ektefelle
 - Sammen med kjæreste/ ektefelle og barn
 - Alene, sammen med dine barn

4. **Hva er din høyeste utdanning i dag?**
 - Har ikke fullført grunnskole
 - Grunnskole (1-9/10 år)
 - Videregående opplæring (10/11-12/13 år)
 - Høyskole/universitet mindre enn 4 år
 - Høyskole/universitet mer enn 4 år

5. **Dersom du planlegger å ta mer utdanning? Hvilken?**
 - Grunnskole (1-9/10 år)
 - Videregående opplæring (10/11-12/13 år)
 - Høyskole/universitet mindre enn 4 år
 - Høyskole/universitet mer enn 4 år

6. **Hvordan vil du vurdere din /husholdningens økonomiske situasjon i dag?**
 - Svært mye over det som er gjennomsnittet
 - Over det som er gjennomsnittet
 - Omtrent som gjennomsnittet
 - Under det som er gjennomsnittet
 - Svært mye under det som er gjennomsnittet

«**SORG HOS UNGE VOKSNE ETTER TAP AV FORELDER I UNG ALDER**»

Livskvalitet og sosiale forhold

7. **Under finner du en liste over ulike plager. Har du opplevd noe av dette de siste to ukene?**

	Ikke plaget	Litt plaget	Ganske mye plaget	Veldig mye plaget
Plutselig frykt uten grunn	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Føler deg redd eller engstelig	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Matthet eller svimmelhet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Føler deg anspent eller oppjaget	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lett for å klandre deg selv	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Søvnproblemer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nedtrykt, tungsindig (trist)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Følelse av å være unyttig, lite verd	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Følelse av at alt er et slit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Følelse av håpløshet mht. framtida	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

8. **Hvor stort problem har dette vært for deg i løpet av SISTE måneden?**

Helse og aktiviteter

Sett ett kryss per linje

	Aldri	Nesten aldri	Noen ganger	Ofte	Nesten alltid
Det er vanskelig for meg å gå en tur	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Det er vanskelig for meg å løpe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Det er vanskelig for meg å delta i idrettsaktiviteter eller trening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Det er vanskelig for meg å løfte noe tungt	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Det er vanskelig for meg å bade eller dusje alene	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Det er vanskelig for meg å gjøre husarbeid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg har vondt eller smerter.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg har lite overskudd og energi	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

9. **Følelsene mine**

	Aldri	Nesten aldri	Noen ganger	Ofte	Nesten alltid
Jeg føler meg redd eller skremt	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg føler meg nedfor og trist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg føler meg sint	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg har problemer med å sove	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Jeg bekymrer meg over hva som vil skje med meg

«SORG HOS UNGE VOKSNE ETTER TAP AV FORELDER I UNG ALDER»

10. Hvordan jeg kommer overens med andre

	Aldri	Nesten aldri	Noen ganger	Ofte	Nesten alltid
Jeg har problemer med å komme overens med andre unge voksne	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Andre voksne vil ikke være venner med meg	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Andre unge voksne erter meg	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg kan ikke gjøre ting som andre unge voksne på min alder kan	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Det er vanskelig å holde følge med vennene mine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

11. Arbeid og Skole

	Aldri	Nesten aldri	Noen ganger	Ofte	Nesten alltid
Det er vanskelig for meg å følge med i arbeid/ skole	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg glemmer ting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg har problemer med å gjøre mitt arbeid/ skole	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg er borte fra arbeid/ skole fordi jeg ikke føler meg i form	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg er borte fra arbeid/ skole fordi jeg skal til lege/ sykehus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

12. Spørsmålene under omhandler alvorlige livshendelser siste 12 måneder

Sett ett kryss per linje

	Ja	Nei
Har det vært dødsfall i nær familie?	<input type="radio"/>	<input type="radio"/>
Har det vært alvorlig sykdom i nær familie?	<input type="radio"/>	<input type="radio"/>
Har du selv hatt en alvorlig sykdom?	<input type="radio"/>	<input type="radio"/>
Har du vært i overhengende livsfare pga. alvorlig ulykke, katastrofe, voldssituasjon eller krig?	<input type="radio"/>	<input type="radio"/>
Har du hatt samlivsbrudd i ekteskap eller i (lengre) samboerforhold?	<input type="radio"/>	<input type="radio"/>
Har du opplevd samlivsbrudd hos dine foreldre?	<input type="radio"/>	<input type="radio"/>

«SORG HOS UNGE VOKSNE ETTER TAP AV FORELDER I UNG ALDER»

Sorg

13. Nedenfor følger en rekke utsagn som handler om det å miste en som har stått en nær. Vennligst velg det svaret som passer best med hvordan du har hatt det i løpet av de siste to ukene.

	Aldri	Sjelden	Av og til	Ofte	Alltid
Jeg tenker så mye på han/hun/dem (som døde) at det er vanskelig for meg å gjøre ting som jeg vanligvis gjør	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Minner om han/hun/dem gjør meg urolig	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg føler at jeg ikke kan godta at han/hun/dem døde	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg lengter etter han/hun/dem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg trekkes mot steder og ting jeg assosierer med han/hun/dem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg kan ikke hjelpe for at jeg føler meg sint over hans/hennes/deres død	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg føler vantro over det som hendte	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg føler meg ør og forvirret over det som hendte	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helt siden han/hun/dem døde har jeg hatt vanskeligheter med å stole på andre	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helt siden han/hun/dem døde har jeg følt at jeg har mistet evnen til å føle omsorg for andre mennesker eller jeg føler avstand til mennesker jeg er glad i	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- 14.

	Aldri	Sjelden	Av og til	Ofte	Alltid
Jeg har smerter i kroppen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg tar omveier for å unngå minner omkring han/hun/dem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg føler at livet er tomt uten han/hun/dem som døde	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg «hører» stemmen til han/hun/dem snakke til meg	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg «ser» han/hun/dem foran meg	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg føler at det er urettferdig at jeg lever når han/hun/dem døde	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg føler meg bitter over hans/hennes/deres død	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg misunner dem som ikke har mistet noen så nær	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg føler meg ensom store deler av tiden etter at han/hun/dem døde	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

«SORG HOS UNGE VOKSNE ETTER TAP AV FORELDER I UNG ALDER»

Opplevelsen av tapet

15. Hvor enig eller uenig er du i hver av disse utsagnene med hensyn til tapet du har opplevd?
NB: Vær obs på at et enig- eller uenig-svar ikke nødvendigvis betyr det samme i alle utsagnene.

	Helt enig	Enig	Verken / eller	Uenig	Helt uenig
Etter tapet fremstår verden som et forvirrende og skremmende sted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg har forstått hva tapet betyr	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hvis eller når jeg snakker om tapet, tror jeg at folk ser annerledes på meg	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg synes det er vanskelig å få tapet til å passe inn i min forståelse av verden	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Etter tapet føler jeg at jeg er havnet i en troskrise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tapet er ubegripelig for meg	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Etter tapet gir målene og forhåpningene jeg tidligere hadde for fremtiden, ingen mening lenger	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Det som hendte, har gjort meg rådvill	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16.					
	Helt enig	Enig	Verken / eller	Uenig	Helt uenig
Etter at tapet inntraff, vet jeg ikke hvor veien min videre i livet skal gå	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Det ville være lettere å snakke om livet mitt hvis jeg utelot tapet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Etter tapet står det mindre klart for meg hva jeg tror på, og hvilke verdier jeg har	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg forstår ikke meg selv lenger etter tapet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Etter tapet synes jeg det er vanskeligere å føle at jeg er en del av noe som er større enn meg	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tapet har gjort at jeg føler meg mindre målbevisst	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg har ikke klart å stable livet mitt på beina igjen etter tapet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Livet fremstår som mer tilfeldig etter tapet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

«SORG HOS UNGE VOKSNE ETTER TAP AV FORELDER I UNG ALDER»

Robusthet

Vennligst angi hvordan du i løpet av den siste måneden har tenkt og følt om deg selv, og om betydningsfulle mennesker omkring deg. Vennligst kryss av i boksen som er nærmest det utsagnet som best beskriver deg.

17. Når noe uforutsett skjer

føler jeg meg ofte rådvill finner jeg alltid en løsning

18. Planene mine for fremtiden er

vanskelige å gjennomføre gjennomførbare

19. Jeg trives best

sammen med andre mennesker for meg selv

20. I familien min er forståelsen av hva som er viktig i livet

ganske forskjellig lik

21. Personlige tema kan jeg

ikke ta opp med noen ta opp med venner/familiemedlemmer

22. Jeg fungerer best når jeg

sammen med andre mennesker får ta en dag av gangen

23. Mine personlige problemer

vet jeg hvordan jeg kan løse finner jeg ingen løsning på

24. Jeg føler at fremtiden min

ser lovede ut er usikker

25. Å kunne være fleksibel i sosiale sammenhenger

er jeg mindre opptatt av er viktig for meg

26. Jeg trives

svært godt i familien min dårlig i familien min

27. De som er flinke til å oppmuntre meg

er noen nære venner/familiemedlemmer finnes ikke

28. Når jeg skal gjøre noe

planlegger jeg sjelden og hopper bare i det foretrekker jeg å ha en plan

29. Mine vurderinger og avgjørelser

tviler jeg ofte på stoler jeg fullt ut på



Kunnskap for en bedre verden

«SORG HOS UNGE VOKSNE ETTER TAP AV FORELDER I UNG ALDER»

30. Målene mine

vet jeg hvordan jeg skal nå er jeg usikker på hvordan jeg skal nå

31. Nye vennskap

knytter jeg lett har jeg vansker med å knytte

32. Familien min preges av

splittelser godt samhold

33. Samholdet mellom vennene mine

er dårlig er godt

34. Jeg er flink til å

organisere tiden min rote bort tiden min

35. Troen på meg selv

får meg gjennom vanskelige perioder hjelper meg lite i vanskelige perioder

36. Målene mine for fremtiden er

uklare godt gjennomtenkte

37. Å komme i kontakt med nye folk

er vanskelig for meg er jeg flink til

38. I vanskelige perioder

beholder familien min et positivt syn på fremtiden ser familien min mørkt på fremtiden

39. Når noen familiemedlemmer kommer i en krise

får jeg raskt beskjed får jeg sent beskjed



Kunnskap for en bedre verden

«SORG HOS UNGE VOKSNE ETTER TAP AV FORELDER I UNG ALDER»

40. Regler og faste rutiner

mangler i hverdagen min er en del av hverdagen min

41. I motgang har jeg en tendens til

å se mørkt på tingene finne noe bra jeg kan vokse på

42. Når jeg er sammen med andre

sitter latteren min løst sitter latteren langt inne

43. Overfor andre mennesker, er vi i vår familie

lite støttende overfor hverandre lojale overfor hverandre

44. Jeg får støtte fra

venner/familiemedlemmer ingen

45. Hendelser i livet som jeg vanskelig kan gjøre noe med

klarer jeg å innfinne meg med er en stadig kilde til bekymring

46. Å komme på gode samtaleemner

synes jeg er

vanskelig enkelt

47. I familien min liker vi å

finne på fellesaktiviteter gjøre ting hver for oss

48. Når det trengs, har jeg

aldri noen som kan hjelpe meg alltid noen som kan hjelpe meg

49. Mine nære venner/familiemedlemmer

verdsetter egenskapene mine misliker egenskapene mine

Intervjuguide

Åpningsspørsmål

- Hva gjorde at du hadde lyst å delta på dette intervjuet?
- Er det noe du gruer deg til å snakke om? / Ser frem til å snakke om?
- Alder, hva gjør du i hverdagen? Sivilstatus/ hvem bor du med?

Kategori 1: Samtale mellom deg og din syke forelder og sorgprosessen.

1. Hvem fortalte deg om din forelders sykdom?
 - Evt. Hvem skulle du ønske fortalte deg om den?
2. Hva visste rundt du på forhånd før du ble fortalt om din forelders sykdom?
3. Hvordan reagerte du da du fikk beskjed om din forelders sykdom?
 - Personlig
 - Sosialt
 - Spirituelt
 - Ang. aktiviteter/ jobb/skole
4. Hvordan reagerte din familie da dere fikk beskjed om din forelders sykdom?
 - Personlig
 - Sosialt
 - Spirituelt
 - Ang. aktiviteter/ jobb/skole
5. På hvilken måte ble du forberedt på din forelders død?
6. Hva ble det snakket om i samtaler mellom din syke forelder og deg?
 - Var det noe du skulle ønske ble fortalt?
7. Hvordan skulle du ønske at ting ble fortalt (evt. annerledes)?

8. På hvilken måte gjorde samtale mellom deg og din syke forelder at du fikk forståelse av hva som skulle skje videre?

- Personlig
- Sosialt
- Spirituelt
- Ang. aktiviteter/ jobb/skole

9. Har det å snakke om den alvorlige sykdommen med din syke forelder før tapet vært viktig for deg med tanke på hvordan du har hatt det etter tapet?

- Evt. Hvorfor?

10. Ble det i din familie snakket om håp rundt den alvorlige sykdommen?

Kategori 2: Kommunal oppfølging og sorgprosessen.

1. På hvilken måte ble du og eventuelt din familie oppfulgt av noen fra kommunen før tapet?

- Fastlege
- Prest
- Helsesøster
- Psykolog

2. Hvis du ikke fikk oppfølging av noen fra kommunen, hvem skulle du ønske du hadde fått støtte/ hjelp fra? (Hvorfor denne?).

3. Har det vært viktig for deg bli oppfulgt av noen fra kommunen før tapet med tanke på hvordan du har hatt det etterpå?

- Hva tror du hadde (har) vært viktig?

4. På hvilken måte følte du at dine følelsesmessige behov og ønsker ble tatt hensyn til før tapet gjennom kommunal oppfølging?

5. Hva opplevde du som positivt med kommunal oppfølging?

- Hva var eventuelt negativt?

6. Ble det fortalt i klassen din om din forelders sykdom?
 - Evt. Skulle du ønske det ble gjort? Evt. Hvorfor?

7. Ble det av noen fra kommunen sagt/gjort noe som gjorde det lettere å se fremover?
 - Evt. Hva skulle du ønske ble sagt/gjort?

Kategori 3: Sosial støtte og sorgprosessen.

1. Hvordan følte du deg tatt vare på av dine venner etter tapet av din forelder?
 - Evt. Hvordan skulle du ønske det ble gjort?

2. Hvordan følte du deg ivaretatt av resten av din familie etter tapet av din forelder?
 - Hvem ble din nærmeste du kunne snakke med?
 - Hvem skulle du ønske du kunne snakket med?

3. På hvilken måte føler du dine behov og ønsker etter tapet best kunne blitt ivaretatt av venner og familie?

4. Har måten du ble tatt vare på av venner og familie etter tapet påvirket hvordan du har hatt det senere?

Avsluttende spørsmål

- Hvordan har det vært for deg å snakke om dette temaet?
- Hva var det vanskeligste å snakke om?
- Er det noe du vil tilføye?
- Har du noen spørsmål?

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

«SORG HOS UNGE VOKSNE ETTER TAP AV FORELDER I UNG ALDER»

Dette er en invitasjon til deg om å delta i et forskningsprosjekt hvor vi ønsker å få mer kunnskap om sorg etter at du har opplevd å miste en forelder i ung alder. Vi ønsker å undersøke hva som er vanlige reaksjoner hos unge voksne som er i sorg, og hva som kan hjelpe slik at det blir lettere å leve med sorgen. Vi ønsker også å finne ut mer om hvilke faktorer som kan gjøre det vanskelig å leve med sorgen etter tapet.

I denne studien er NTNU ansvarlig institusjon.

HVA INNEBÆRER PROSJEKTET?

Hvis du ønsker å delta, innebærer din deltakelse å besvare spørreundersøkelsen. Det tar ca. 20-30 minutter å besvare spørsmålene. Du vil bli spurt om din Hvordan du har hatt det siden tapet, hvordan du opplevde tapet, og faktorer som gjorde det lettere å håndtere tapet.

MULIGE FORDELER OG ULEMPER

Vi vil alle reagere ulikt når vi påminnes om det som kan være vanskelig å snakke om. Noen kan kjenne på nedstemthet eller på andre følelser. Du står fritt til å avbryte spørreundersøkelsen dersom du kjenner at belastningen blir for stor.

Deltakelse i studien bidrar til at vi får mer kunnskap om sorgreaksjoner, og hvordan de som har mistet noen bedre kan ivaretas.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Å delta i denne studien er frivillig. Du kan avslutte undersøkelsen når du måtte ønske. Besvarelsen og alle dine personlige opplysninger er anonymiserte, slik at du ikke kan på noe tidspunkt gjenkjennes av andre.

Vennligst besvar alle spørsmålene i én økt. Bryter du av underveis, må du starte på nytt. Du samtykker i å delta i undersøkelsen ved å svare på spørsmålene og sende dem inn ved å klikke på «Ferdig» på siste side.

For å melde din deltakelse, eller dersom du har spørsmål til prosjektet, kan du kontakte Daniel Sjøvik, tlf: 95 94 58 31, daniesja@stud.ntnu.no eller psykologspesialist og veileder Trude Reinfjell, 90 54 13 97, trude.reinfjell@ntnu.no

HVA SKJER MED OPPLYSNINGENE OM DEG?

Opplysningene som registreres om deg skal kun brukes slik som beskrevet i hensikten med prosjektet. Når du har fullført spørreundersøkelsen vil besvarelsen lagres på passordbelagte og krypterte servere ved NTNU. Det er kun Daniel Sjøvik som skribent og prosjektleder Trude Reinfjell som har tilgang til informasjonen. Prosjektleder vil være ansvarlig for den daglige driften av forskningsprosjektet og at dine opplysninger behandles på en sikker måte.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjenne opplysninger.

FORSIKRING

Du som deltaker er forsikret gjennom norsk pasientskadeerstatning (NPE).

GODKJENNING

Regional komité for medisinsk og helsefaglig forskningsetikk har vurdert prosjektet, og har gitt forhåndsgodkjenning saksnr. hos REK (2019/512).

Etter ny personopplysningslov har behandlingsansvarlig NTNU, v/ instituttleder Ute Gabriel, og prosjektleder Trude Reinfjell, begge fra Institutt for Psykologi, et selvstendig ansvar for å sikre at behandlingen av dine opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning artikkel 6a og artikkel 9 nr. 2.

Du har rett til å klage på behandlingen av dine opplysninger til Datatilsynet

JEG SAMTYKKER TIL Å DELTA I PROSJEKTET OG AT INFORMASJON FRA INTERVJUET BRUKES SLIK DET ER BESKREVET

Samtykke gjelder også for bruk av lydopptak av intervjuet.

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

«SORG HOS UNGE VOSKNE ETTER TAP AV FORELDER I UNG ALDER»

Dette er en invitasjon til deg om å delta i et forskningsprosjekt hvor vi ønsker å få mer kunnskap om sorg etter at du har opplevd å miste en forelder i ung alder. Vi ønsker å undersøke hva som er vanlige reaksjoner hos unge voksne som er i sorg, og hva som kan hjelpe slik at det blir lettere å leve med sorgen. Vi ønsker også å finne ut mer om hvilke faktorer som kan gjøre det vanskelig å leve med sorgen etter tapet.

NTNU er ansvarlig institusjon i denne studien.

HVA INNEBÆRER PROSJEKTET?

Din deltakelse innebærer å bli intervjuet vedrørende din opplevelse av din forelders bortgang. Vi vil gjerne spørre deg om dine reaksjoner etter at din forelder døde, hva du opplevde hjalp deg i denne fasen, og hva som eventuelt gjorde sorgen vanskelig å leve med. Det vil også bli spurt rundt om du opplevde oppfølging av kommunale tjenester i forkant av tapet, og hvordan dette eventuelt har påvirket din sorgprosess i etterkant. Intervjuet tenkes å vare ca. 45-60 min.

Det vil bli gjort lydopptak av intervjuet for å forenkle bearbeidelse av informasjonen i etterkant. Ditt samtykke og underskrift vil også gjelde for tillatelse for lydopptak av intervjuet.

MULIGE FORDELER OG ULEMPER

Vi vil alle reagere ulikt når vi påminnes om det som kan være belastende å snakke om. Noen kan kjenne på nedstemthet eller på andre følelser. Hvis nødvendig vil det tas pauser underveis i intervjuet.

Hvis du ønsker det, vil min veileder som er psykologspesialist og som har jobbet lenge med sorg, være tilgjengelig for deg for en støttesamtale når du velger å avslutte intervjuet. Du står også fritt til å avbryte intervjuet dersom du kjenner at belastningen blir for stor.

I intervjuet er jeg interessert i din opplevelse, og det er derfor ingen fasit på spørsmålene eller gale svar.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke.

Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede opplysninger og lydopptak.

For å melde din deltakelse, trekke din deltakelse, eller har spørsmål til prosjektet, kan du kontakte Daniel Sjøvik, tlf: 95 94 58 31, daniesja@stud.ntnu.no eller psykologspesialist og veileder Trude Reinfjell, 90 54 13 97, trude.reinfjell@ntnu.no

HVA SKJER MED OPPLYSNINGENE OM DEG?

Opplysningene som registreres om deg skal kun brukes slik som beskrevet i hensikten med prosjektet. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert. Du har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjenne opplysninger. En kode knytter deg til dine opplysninger. Det er kun Daniel Sjøvik som skribent og prosjektleder Trude Reinfjell som har tilgang til informasjonen. Prosjektleder vil være ansvarlig for den daglige driften av forskningsprosjektet og at dine opplysninger behandlet på en sikker måte.

Opplysningene om deg vil bli slettet senest fem år etter prosjektslutt desember 2020.

FORSIKRING

Du som deltaker er forsikret gjennom norsk pasientskadeerstatning (NPE).

GODKJENNING

Regional komité for medisinsk og helsefaglig forskningsetikk har vurdert prosjektet, og har gitt forhåndsgodkjenning saksnr. Hos REK (2019/512).

Etter ny personopplysningslov har behandlingsansvarlig NTNU, v/ instituttleder Ute Gabriel, og prosjektleder Trude Reinfjell, begge fra Institutt for Psykologi, et selvstendig ansvar for å sikre at behandlingen av dine opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning artikkel 6a og artikkel 9 nr. 2.

Du har rett til å klage på behandlingen av dine opplysninger til Datatilsynet.

KONTAKTOPPLYSNINGER

Dersom du har spørsmål til prosjektet kan du ta kontakt med prosjektleder og veileder Trude Reinfjell, 90 54 13 97, trude.reinfjell@ntnu.no

Hvis du har spørsmål om behandlingen av dine personopplysninger i prosjektet, kan du kontakte institusjonens personvernombud. Thomas Helgesen, tlf.: 93079038, e-mail: thomas.helgesen@ntnu.no

JEG SAMTYKKER TIL Å DELTA I PROSJEKTET OG AT INFORMASJON FRA INTERVJUET BRUKES SLIK DET ER BESKREVET

Samtykke gjelder også for bruk av lydopptak av intervjuet.

Sted og dato

.....
Deltakers signatur

.....
Deltakers navn med trykte bokstaver

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK midt	Hilde Eikemo	99572363	10.05.2019	2019/512/REK midt
			Deres dato:	Deres referanse:
			19.03.2019	

Vår referanse må oppgis ved alle henvendelser

Trude Reinfjell
Psykologisk institutt

2019/512 Sorg hos unge voksne med tap av en forelder i kreft

Forskningsansvarlig: Norges teknisk-naturvitenskapelige universitet
Prosjektleder: Trude Reinfjell

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK midt) i møtet 24.04.2019. Vurderingen er gjort med hjemmel i helseforskningsloven § 10.

Komiteens prosjektsammendrag

I dette prosjektet skal man samle kunnskap om komplisert sorg hos unge mennesker (18-25 år) bosatt i Midt-Norge, som har mistet en forelder i kreft. Man skal undersøke andelen som viser indikasjon på komplisert sorg, og hvordan dette påvirker deres livskvalitet, normale reaksjoner og sorgprosess. Data skal samles inn ved hjelp av spørreskjema (n=70-100) og intervjuer (n=5-10). Studien er samtykkebasert. Prosjektet skal være en hovedoppgave i psykologi.

Forsvarlighet

Komiteen har vurdert søknad, forskningsprotokoll, målsetting og plan for gjennomføring. Komiteen ber om endringer i rekrutteringsprosedyren og informasjonsskrivet, men har ellers ingen forskningsetiske innvendinger til prosjektet. Under forutsetning av at vilkårene nedenfor tas til følge vurderer REK at prosjektet er forsvarlig, og at hensynet til deltakernes velferd og integritet er ivaretatt.

Informasjonsskrivene

Komiteen ber om at informasjonsskrivene revideres noe. I informasjonsskrivet til intervjudelen må du

- fjerne avsnitt 2 og 3
- endre avsnitt 4 (trenger bare si at NTNU er ansvarlig institusjon)
- endre fra privat hotmailadresse til ansatt- eller studentadresse
- under «forsikring» endre til norsk pasientskadeerstatning (NPE)

I informasjonsskrivet til spørreskjemadelen må du

- fjerne avsnitt 2, 3 og 4, og erstatte med en setning om at NTNU er ansvarlig institusjon
- endre fra privat hotmailadresse til ansatt- eller studentadresse
- under «forsikring» endre til norsk pasientskadeerstatning (NPE)
- fylle ut under "fordeler og ulemper".

Rekrutteringsprosedyren

Besøksadresse:
Fakultet for medisin og
helsevitenskap Mauritz
Hansens gate 2, Øya helsehus

E-post: rek-midt@mh.ntnu.no
Web: <http://helseforskning.etikkom.no/>

All post og e-post som inngår i
saksbehandlingen, bes adressert til REK
midt og ikke til enkelte personer

Kindly address all mail and e-mails to
the Regional Ethics Committee, REK
midt, not to individual staff

I rekrutteringen til spørreskjemadelen av prosjektet er det planlagt at Dødsårsaksregisteret skal identifisere mulige deltakere vha. inklusjonskriteriene, og deretter sende en liste med kontaktinformasjon over aktuelle deltakere til studenten i prosjektet. Komiteen mener deltakerne ikke kan rekrutteres på denne måten av personvern hensyn. Studenten bør altså ikke få tilgang til navnelister fra et helseregister før man vet om de registrerte ønsker å være forskningsdeltakere. I stedet kan deltakere rekrutteres gjennom at dere informerer om studien gjennom foreninger og interesseorganisasjoner for målgruppen. På den måten kan aktuelle deltakere selv ta kontakt med dere som forskere. Vi ber altså om at rekrutteringen til spørreskjemadelen endres til å bli mer i tråd med den planlagte rekrutteringen til intervjudelen.

Beredskap

Du har i punkt 4.3 i søknaden beskrevet at deltakerne skal tilbys en støttesamtale med deg hvis ønskelig etter at intervjuet er gjennomført. Komiteen ber i tillegg om at dersom dere avdekker at en deltaker antakelig har diagnosen komplisert sorg, så skal ordinær klinisk prosedyre med henvisning utføres.

Vilkår for godkjenning

1. Du må sende inn reviderte informasjonsskriv. Vennligst benytt e-postadressen post@helseforskning.etikk.no og «REK midt 2019/512» i emnefeltet. Du kan ikke ta skrivenes bruk før vi har bekreftet at de er endret i tråd med våre merknader.
2. Komiteen ber om en beskrivelse av revidert rekrutteringsprosedyre til spørreskjemadelen. Beskrivelsen sendes sammen med revidert informasjonsskriv.
3. Komiteen forutsetter at ingen personidentifiserbare opplysninger kan framkomme ved publisering eller annen offentliggjøring.
4. Komiteen forutsetter at du og alle prosjektmedarbeiderne følger institusjonens bestemmelser for å ivareta informasjonssikkerhet og personvern ved innsamling, bruk, oppbevaring, deling og utlevering av personopplysninger.
5. Av dokumentasjonshensyn skal opplysningene oppbevares i 5 år etter prosjektslutt. Du og forskningsansvarlig institusjon er ansvarlig for at opplysningene oppbevares avidentifisert, dvs. atskilt i en nøkkel- og en datafil. Opplysningene skal deretter slettes eller anonymiseres.
6. Du skal sende sluttmelding på eget skjema, jf. helseforskningsloven § 12, senest et halvt år etter prosjektslutt.
7. Dersom du vil gjøre endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må du sende endringsmelding til REK, jf. helseforskningsloven § 11.

Vedtak

Regional komité for medisinsk og helsefaglig forskningsetikk Midt-Norge har gjort en helhetlig forskningsetisk vurdering av alle prosjektets sider og godkjenner det med hjemmel i helseforskningsloven § 10, på de vilkår som er gitt.

Komiteens beslutning var enstemmig.

Klageadgang

Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK midt. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK midt, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Vibeke Videm
Professor dr.med. / Overlege
Leder, REK Midt

Hilde Eikemo
Sekretariatsleder

Kopi til: postmottak@su.ntnu.no; postmottak@ntnu.no

