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Psychosocial well-being in bereavement among family members with a special focus on young adults who have lost a parent to cancer

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Psychosocial well-being in bereavement among family members with a special focus on young adults who have lost a parent to cancer

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ABSTRACT

Introduction: The loss of a loved one is a distressing life event for family members which often affects psychosocial well-being. Young adults who have lost a parent may be a particularly vulnerable group of bereaved individuals. This age group is often characterized by a certain instability, as the individual has left childhood but has not yet established an adult life, which could further compromise psychosocial well-being after the death of a parent. Young adults who have lost a parent to cancer comprise a sparsely studied group, and increased knowledge about their needs is called for.

Aim: The general aim of this thesis was to explore the psychosocial well-being of family members in bereavement, with a special focus on young adults who have lost a parent to cancer.

Methods: Two different study populations were used to examine the overall aim of this thesis. In Study I, 25 family members who lost a loved one within a palliative care service were interviewed about their supportive interactions with health care staff and their emotional experiences associated with these interactions. The interviews were analyzed with qualitative content analysis. Studies II–IV involved 77 young adults, aged 16–28 years, who had lost a parent to cancer and who participated in a support group within the palliative care context. They responded to a comprehensive questionnaire at three time-points within the first 18 months after their parent's death. In Study II, loss- and restoration-oriented bereavement stressors, as well as psychosocial well-being, were analyzed with descriptive statistics. Study III investigated longitudinal variations in psychosocial well-being and Study IV examined the relationship between self-esteem and symptoms of anxiety and depression. In both of these studies, descriptive and analytical statistics were used.

Results: Study I showed that: clear information presented in an honest dialogue fosters certainty and security; empathetic and flexible encounters with health care staff promote feelings of warmth and comfort; patient- and family-oriented health care staff gave a sense of value; the atmosphere and physical environment contributed to dignity and harmony; and bereavement support provided feelings of strength. Support groups for parentally bereaved young adults were mentioned as being especially important. Studies II–IV revealed an overall poor psychosocial well-being, for example, many young adults reported symptoms of anxiety and low life satisfaction. However, normal levels of self-esteem and a strong belief in a meaningful future might indicate resilience in grief. Minor improvements in psychosocial well-being were found within the first 18 months after the loss. Higher self-esteem was shown to be associated with less symptoms of anxiety and depression.

Conclusion: The results support the suggestion that young adults who have lost a parent to cancer constitute a specific group in bereavement. The indicated resilience may protect the young adults from long-term problems despite their poor psychosocial well-being. Furthermore, supportive interactions that are perceived as helpful may contribute to the development of good psychosocial well-being.

LIST OF SCIENTIFIC PAPERS

- I. Lundberg T, Fürst CJ, Olsson M.
The perspectives of bereaved family members on their experiences of support in palliative care.
International Journal of Palliative Nursing, 2013, 19:282-288
- II. Lundberg T, Forinder U, Olsson M, Fürst CJ, Årestedt K, Alvariza A.
Bereavement stressors and psychosocial wellbeing of young adults following the loss of a parent – a cross-sectional survey.
European Journal of Oncology Nursing, 2018, 35:33-38
- III. Lundberg T, Forinder U, Olsson M, Fürst CJ, Årestedt K, Alvariza A.
Poor psychosocial well-being in the first year-and-a-half after losing a parent to cancer – a longitudinal study among young adults participating in support groups.
Submitted
- IV. Lundberg T, Årestedt K, Forinder U, Olsson M, Fürst CJ, Alvariza A.
Associations between self-esteem and anxiety and depression among young adults after the loss of a parent to cancer.
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LIST OF ABBREVIATIONS

HADS Hospital Anxiety and Depression Scale

LiSat Life Satisfaction Checklist

RSE Rosenberg Self-Esteem Scale

1 PREFACE

A few years after my graduation from the Department of Social Work at Stockholm University in 1998, I began working as a medical social worker. During my years at the hospital I mainly worked with lung cancer patients and their families and it became obvious to me that the family members had a difficult task in simultaneously supporting their sick relative while at the same time managing their own needs and despair. Sometimes the families wanted their adolescent children to talk to me, which often was a difficult task as the children themselves were mostly of a different opinion than their parents about their need to talk to a medical social worker. To meet the needs of family members of lung cancer patients, a medical social worker colleague and I started support groups for spouses of lung cancer patients with the purpose of addressing their needs as family members: a difficult but very rewarding task. During this period, I began my master's studies in clinical medical sciences at Karolinska Institutet, from which I graduated in 2008. I performed the research for my master's degree with family members, exploring their experiences of support in palliative care at a specialist palliative care service. By now my interest in knowing more about the life situation of family members and especially bereaved young adults had been evoked and, by January 2011, I was accepted as a PhD student at the Department of Neurobiology, Care Sciences and Society at Karolinska Institutet. During my first maternity leave at the beginning of my PhD studies, I applied for and was granted a PhD position at the Palliative Research Centre at Ersta Sköndal Bräcke University College, which gave me the opportunity to perform my PhD studies among magnificent colleagues in a stimulating environment. Despite a second maternal leave having lengthened my PhD years further, I think the journey I have made during these years has made my work better through the personal and professional experiences I have gained. In retrospect, I can see that my interest for the life situation and well-being of family members has followed me throughout my career and I am proud that this thesis offers a voice to a vulnerable and often unheard group of family members – young adults who have lost a parent to cancer.

2 INTRODUCTION

The loss of someone loved is one of the most strenuous experiences in life. This thesis concerns the psychosocial well-being of bereaved family members, with a particular focus on young adults, who have lost a parent to cancer. The psychosocial well-being of bereaved adult family members is firstly explored by examining their perceived supportive interactions at the specialized palliative care unit where the patient had died, and the emotional consequences associated with these interactions. The results of the study indicated that support groups for parentally bereaved young adults were especially important and that young adults may be a group with special needs after the loss of a parent to cancer. Knowledge and research about this vulnerable group of parentally cancer-bereaved young adults are lacking. The need to explore the psychosocial well-being of these young adults emerged as being crucial and the importance of filling these gaps guided the focus of the forthcoming studies in this thesis. Accordingly, the thesis concerns the psychosocial well-being of bereaved family members, with a focus on the psychosocial well-being of young adults who lost a parent to cancer and who participated in a support group within the palliative care context. The studies involving the young adults examine factors of psychosocial well-being, such as symptoms of anxiety and depression, self-esteem, life satisfaction, feelings of loneliness and being understood, belief in a meaningful future, and the ability to concentrate as well as experiences related to the loss and restoration after the loss, including received support.

2.1 Psychosocial well-being

The term psychosocial is related to “the interrelation of social factors and individual thought and behavior”, which means that psychological factors affect the social sphere, and that the social world is influenced by psychological features.¹ In the domain of psychological features, cognitive development is also included.²

Because the psychosocial is described as being the interaction between psychological and social factors, the term well-being might be referred to as the “state of being comfortable, healthy, or happy”.¹ In behavioral research, well-being is related to an individual’s personal experience of satisfaction and happiness with, for example, their family or work. Two approaches have emerged in behavioral sciences; subjective well-being, and psychological well-being. Subjective well-being relates to the subjective evaluation of life, such as being happy, satisfied and having positive affections. Psychological well-being focuses on how well individuals are living their lives, such as their self-acceptance, personal growth and feelings of having purpose in life.³

The illness and decease of a loved one concerns psychological as well as social stressors of family members affecting areas such as the emotional state, cognitive functioning and interpersonal relations, which can diminish psychosocial well-being.⁴ In this thesis, the term psychosocial well-being is used to refer to psychological and social factors related to the subjective as well as the psychological well-being of the family members who lost a parent to cancer.

2.1.1 Bereavement and grief

Bereavement is related to being in a state of loss, while grief is related to the reactions in bereavement, such as sorrow after a loss, most often the death of someone close.⁵ Grief normally diminishes gradually without problems,⁶ ending in the loss being an integrated part of the bereaved one's life. However, the experience of an important loss will continue to impact the individual throughout life.⁷ Only a minority, 10–20%, of bereaved individuals will develop persisting problems with problematic grief.⁸⁻¹²

Although common expressions of grief can be described, they should not be expected to strictly occur among all bereaved, as bereavement is a highly individual process.⁷ Four different trajectories of grief have been suggested in an overview of grief trajectories; resilience, chronic grief, distress-improved, and chronic depression. The most common of these is characterized by resilience, which signifies an adequate coping style and a healthy adjustment. A minority of bereaved individuals experience chronic grief patterns with sudden painful emotions and yearning up to several years after the loss. Another minority of bereaved individuals follow the trajectory of distress improvement, where pre-loss distress is replaced by lessened distress, for example, enjoying positive memories, or if meaning was found with the loss. Lastly, there is a trajectory of chronic depression, where pre-depression remains or worsens after loss and remains for many years among individuals in grief.⁷

Stroebe, Schut and Stroebe⁶ have provided an overview of common reactions to loss, summarized into five areas: affective (such as depression, anxiety, loneliness, and yearning); cognitive (such as rumination, self-reproach, and sense of unreality); behavioral (such as agitation, crying, and social withdrawal); psychological-somatic (such as loss of appetite, sleep disturbance, and somatic complaints); and immunological and endocrine changes (such as a susceptibility to disease).

2.1.2 Psychosocial well-being related to loss

As shown, psychosocial well-being includes many factors at different levels. Anxiety and depression relates to cognitive and emotional aspects of an individual¹³ and is part of psychosocial well-being. Anxiety and depression are common

experiences among bereaved individuals that might have already occurred before the actual loss. According to the Swedish MeSH database, symptoms of anxiety include emotions of dread, apprehension and impending disaster without being as limiting as anxiety disorders, which are more persistent and disabling.¹⁴ Factors such as unexpected changes leading to, for example, a worsened prognosis and sudden death, themselves present a risk of psychosocial impairment, and may in addition evoke anxiety among the family members. An uncertain future, conflicts in the family, economic problems, and poor communication with health care staff are psychosocial issues that may complicate psychosocial well-being, including anxiety. Although symptoms of anxiety are normal among bereaved individuals, persistent anxiety may be an indicator of more severe anxiety problems that should be properly addressed.⁴ Symptoms of depression are characterized by despondency and dejection but are not as severe as neurotic and psychotic disorders.¹⁴ Symptoms of depression are common among bereaved individuals; however, in normal grieving, positive feelings can still be experienced and connections with important persons in their lives can still be appreciated, whereas, in depression disorders, no fluctuation in the state of mind appears, even after positive events.⁴

An important intrapersonal factor determining psychosocial well-being is self-esteem. Self-esteem refers to the way in which an individual feels about himself/herself in regards to their acceptance of their self and their feelings of self-worth.¹⁵ Self-esteem has been demonstrated to be correlated with depressive and anxiety symptoms among adolescents.¹⁶ Among adults, higher self-esteem has been found to be associated with fewer symptoms of anxiety and depression.¹⁷ Furthermore, one of the main components of subjective well-being is the cognitive evaluation of overall life satisfaction, as well as specific domains of life, such as satisfaction with work and partner. Bereaved individuals have demonstrated negatively impacted levels of life satisfaction in a meta-analysis on subjective well-being and adaption of life events.¹⁸ Other factors that have been identified as being important to psychosocial well-being among bereaved individuals are related to the circumstances surrounding the death, previous psychological problems, the quality of the relationship with the deceased, caregiver experiences, and the relationship with health care staff.⁴

2.2 Losing someone close

Family members in palliative care already begin to experience difficulties before the loss of their loved one. Caring for a loved one who is affected by cancer continuously subjects a family members to changes, such as living with uncertainty, as well as the balancing between dilemmas, such as conflicting needs and demands, or being simultaneously capable and vulnerable.¹⁹ Before the death, family

members may already experience feelings of loss, such as the loss of their loved one pre-death, as well as a loss of their own plans and possibilities. When one's own family and friends do not provide the support that family members need, feelings of isolation may arise.²⁰ On the other hand, a closer bond between the ill person and the family members may be experienced through an increased level of intimacy.¹⁹ Furthermore, the physical health of the family member may also be affected, for example, with feelings of fatigue,^{20,21} or a lack of opportunities for empowering social interactions with others besides their loved one, as well as a change in responsibility in having to perform new tasks.^{19,20} Family members in palliative care may perceive feelings of reward if they are prepared and if they experience high feelings of hope, however, high levels of anxiety or being a spouse may aggravate the family members' feelings of reward related to caregiving.²²

A systematic review involving family members before and after loss revealed that pre-loss grief and low preparedness were associated with poor bereavement outcomes, such as symptoms of depression or complicated grief.²³ Bereaved family members have been shown to have a lower quality of life, lower mental health and higher psychological distress compared to nonbereaved.²⁴⁻²⁶ Symptoms of anxiety and depression 2 to 6 months after the loss among family members have been widely recognized in the research.^{24,27,28} For example, a literature review of bereavement needs after cancer, covering the years 2003 to 2013, demonstrated high levels of complicated grief, anxiety and depression; however, it was also shown that there could be meaning in loss,²⁵ such as a rewarding feeling of having done everything for their relative.²⁹

Furthermore, a meta-summary involving family members in bereavement revealed that they may experience positive feelings related to serenity, that is to say, feeling acceptance and relief, in bereavement. Nonetheless, difficult feelings, such as sadness, guilt and regret (about how their caregiving affected the ill person), uncertainty (related to life change), trauma (related to chaotic feelings), escape (from painful feeling), and anger (toward oneself, the family or health care providers), dominated the individuals' experiences in bereavement.³⁰

2.3 Losing a parent in young adulthood

As described above, the loss of a loved one is a difficult experience for family members. However, one group of family members, young adults, seems to constitute a specific group with different prerequisites compared to younger and older children who lose a parent. This chapter will describe the specifics of the development from child to a young adult as well as the psychosocial well-being of bereaved young adults.

2.3.1 Being a young adult

Young adulthood can be referred to as the period between the late teens up to the late twenties.³¹ However, internationally, there are no guidelines regarding the age criteria that determine young adulthood, nor is there consensus in the research on the definitive age of young adults.³² Human development is an ongoing process and it can be assumed that the line between being an older adolescent and being a young adult is somewhat fluid. Furthermore, in developed countries, the time when adulthood is established has been extended over the last 50 years and it has been suggested that this period nowadays extends up to the age of 30.³¹ In this thesis, the age range 16–28 has been used to describe young adults.

What sets aside young adulthood is that it marks the transition from childhood to adulthood. Compared to adolescents, young adults are no longer in the puberty stage, and, by the age of 18, they become responsible, according to the law. Furthermore, at the young adult age, most have not yet established the stable structure that often characterizes adult life. What distinguishes young adulthood is that the individual explores their own identity and that the individual becomes less dependent on their parents.^{31,33} Relationships may be flighty and changeable. Finishing school and entering further studies or work can cause instability in life. This changeability makes the social network surrounding the young adult less reliable, leaving the young adult at risk of being placed in a vulnerable position,³¹ for instance, if support is needed due to parental bereavement. Sometimes adolescence is characterized by a strained relationship with parents, which is often repaired when the adolescent develops into a young adult. However, the death of a parent deprives the young adult of the possibility to reconcile.³⁴ Furthermore, events and failures in the young adult's development period may have repercussions in later life. At the same time, the demands placed on young adults today are higher than before, as the previously more predictable path to adulthood (i.e., finishing school, getting a job, moving away from parents, getting married and having children) has been altered in a more changeable world where there are more opportunities but also greater risk of failure.³⁵ In addition, in Sweden, the proportion of young adults who state that they are feeling well or very well has been decreasing, while at the same time, levels of mental ill-health and substance use have increased over the last 10 years.^{36,37}

What distinguishes bereavement in young adulthood compared to those of younger ages is that younger children have a less developed cognitive ability to understand the consequences of the disease, which places the young adults in a different position.³⁸ Young adults might have to take on additional responsibilities that younger children do not, such as being involved in planning the funeral or supporting other family members. Similarly, parental loss in young adulthood differs from parental loss at older ages. Young adults have demonstrated having less stable mental

health, which includes symptoms of anxiety and depression, over a 12-year period, compared to adults older than 29 years.³⁹ The loss of a parent may furthermore be more problematic in young adults compared with parental loss for those in the ages 50 to 65, most likely because parental loss is more expected at older ages.⁴⁰ Therefore, young adulthood may constitute a particularly vulnerable period in life to lose a parent.

2.3.2 Psychosocial well-being among young adults who lose a parent to cancer

Despite the characteristic vulnerability unique to young adults, few studies have focused on this age group in relation to a parent's death to cancer.^{25,41} In Sweden, about 1200 children under the age of 18 years lose a parent to cancer each year.⁴² A population-based study in Norway showed that, each year, 8.4% young adults, aged 19–24, have a parent who had received a diagnosis of cancer and 2.5% have been faced with parental death from cancer.⁴³

The extant research demonstrates that psychosocial well-being is negatively affected after parental loss. In the US, of a group of young adults, aged 17–29 years who lost a family member or a close friend during the last three years, 34% were found to suffer from mild to severe forms of depression.¹² In a nationwide Swedish study, a group of 13–16-year-olds who were followed 6–9 years after they had lost a parent to cancer disclosed that half had unresolved grief, which was distinctly associated with moderate to severe depression as well as an increased risk of insomnia and fatigue, compared to those with resolved grief.⁴⁴ Furthermore, among young adults aged 18–25 years, parental cancer experienced about 10 years previously has been found to predict higher anxiety levels.⁴⁵ A study comparing non-bereaved with parentally bereaved 11–21-year-olds revealed that levels of separation anxiety and depression were higher among the bereaved group of youths. This was preceded by higher stress pre-death, such as higher levels of life stress, depression, substance abuse, conduct disorder and generalized anxiety in the bereaved group compared to the non-bereaved.⁴⁶ Moreover, in a sample of 7–25-year-olds, comparing non-bereaved with those whose parents had natural, sudden causes of death, higher levels of a variety of mental disorders were found, including alcohol and substance disorders in the bereaved group.⁴⁷ Moreover, parental loss in younger ages (6–30) has been shown to increase the use of antidepressants.³³

Some gender differences among young adults have been demonstrated in the literature, however, the research is not entirely consistent. The loss of a mother has been shown to impact young adults in bereavement more negatively than the loss of a father, irrespective of whether the bereaved young adult is a woman or a man.⁴⁰ However, in another study on young adults, women were found to be more severely impacted by parental death, particularly if the mother was lost.⁴⁸

Furthermore, a sample involving bereaved children within a wide range of ages (10–59), who had lost a parent to natural causes, demonstrated that a mother’s death increased the mortality risk more than did a father’s death. The highest mortality risk was among 10–19-year-old daughters and sons, with daughters having a higher risk than sons. However, in the young adult ages, 20–29 years, sons had a higher mortality risk compared to daughters of the same age, regardless of whether the lost parent was a mother or a father. Among 20–29-year-olds, sons had the highest mortality risk if a mother was lost, while daughters had the highest mortality risk if a father was lost.⁴⁹

2.4 Support in bereavement

In this thesis, all participants were provided with supportive interactions by health care staff; either through *individual* supportive interactions during and after the palliative care, or through participation in *support groups*. The experience of loss and grief is unique for each family member; thus, a variation of support is needed in bereavement.³⁰

Support can be divided into serving four functions: emotional support (e.g., caring and empathy); informational support (e.g., information and advice); instrumental support (e.g., tangible help such as financial or practical assistance); and appraisal support (e.g., feedback on the individual’s approach and behavior to promote self-evaluation.⁵⁰⁻⁵² Who delivers the support might determine whether the interaction is appreciated as supportive, for example, advice received from health care staff could be perceived as being helpful, while the same advice received from a family member could be perceived as being provoking.⁵⁰

On account of the fact that most bereaved individuals overcome the loss naturally, there is no need for providing direct treatment interventions to all bereaved. Instead, interventions, such as grief therapy or psychotherapy, should be targeted to those in need.⁵³⁻⁵⁵

Three levels of supportive interventions in grief have been suggested in a review of efficacy of intervention programs.⁵⁶ In primary preventive interventions, support is offered to all bereaved, however, there is no clear evidence about the effectiveness of this approach. The secondary preventive interventions offer support to those assessed as being at risk for complications, for example, by having high levels of distress or difficulties related to the loss. The tertiary preventive intervention is provided to individuals with the purpose of alleviating severe grief reactions, such as complicated grief.⁵⁶ Another similar model within a public health approach has been developed and supported in the UK, the three-tiered model of bereavement care.⁵⁷ The model proposes that all bereaved with low level of need for support

should be offered universal support, such as information. Selective or targeted support, such as non-specialist support groups or community support, should be offered to those with medium levels of need for support, along with those at risk of complex levels of needs. Indicated support, such as professional specialist interventions, should be given to those with high and complex needs in bereavement.⁵⁷

Despite clear indication that support should be given to those with the most complex needs, it has been suggested that support can also have therapeutic factors for those who experience normal grief, in that it improves well-being, such as self-esteem, anxiety and depression.⁵⁸ Rice⁵⁸ has proposed that the most common therapeutic factors may be divided into three groups. The first group concerns support that contributes to cohesion by the interrelations in the group, promoting universality by sharing experiences with others in a similar situation and altruism by supporting others. The second group relates to interpersonal learning and attachment, such as developing their ways of interacting and forming bonds with others. The third group deals with meaning-making of the loss by building new ways of apprehending the world after the loss.

Almost half (46%) of the family members in palliative care units indicated, three to nine months after the loss, that they needed bereavement follow-up.⁵⁹ Among young persons in Australia (12–25 years) who lost a parent (88%) or a sibling (12%) to cancer within the previous five years, about half have reported their needs to be unmet. The most unmet needs regarded the possibility to receive support from peers, and having an opportunity to recreate and take time out from the strains of cancer.⁶⁰ In addition, Australian young adults (12–24 years) who had lost a parent to cancer reported a need for help in coping with difficult feelings, such as grief, anxiety and depression, and only half of the young adults felt that this need was met.⁶¹ Remaining needs for support may sometimes be a consequence of support not having been offered at all, or because the intervention was not perceived as support.^{62,63} On the contrary, sometimes the need for support is not acknowledged by the one in need.⁶⁴

The body of research describing support groups for young adults who have lost a parent is limited and only a few are described. In these studies, the young adults' own assessments of their support group participation were reported as being very satisfying and helpful,⁶⁵⁻⁶⁸ One of these studies, using a smaller part of the sample that was used in the present thesis and relating to young adults who had lost a parent to cancer, reported that support group participation had presented the young adults with a possibility to talk about their feelings without burdening anyone, thus enhancing the experience of not being alone and promoting a sense of fellowship with others in a similar situation.⁶⁸

2.5 Family perspective in the palliative care context

This thesis is performed within the palliative care context. Palliative care is defined by the World Health Organization as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”⁶⁹ Alongside the care provided to the patient, palliative care includes the offering of “a support system to help the family cope during the patients [*sic*] illness and in their own bereavement” and using “a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.”⁶⁹ Accordingly, the support needs of family members are of importance in palliative care.

Internationally, in Europe, 18% of palliative care services do not deliver any bereavement support, while 82% do. Among these, formal guidelines and risk assessment tools are only used by a minority, and the support offered is often universal, that is to say, it is offered to everyone.⁷⁰ In Australia, despite reports on the use of risk assessment tools and the provision of bereavement support,⁷¹ only a minority report that they received support after the loss or that they were asked questions about their emotional or psychological problems before the death.⁷² In Sweden, the national guidelines provided by the National Board of Health and Welfare does not include family members,⁷³ however, supplementary recommendations and clarifications include the importance of the role that the family members play and their need for support.^{74,75} Support to family members is offered in all specialist palliative care organizations in Sweden. Furthermore, 77% have procedures in place to support family members who are children or adolescents.⁷⁶

2.6 Theoretical framework

2.6.1 Grief theories

Theoretical frameworks can be of assistance in allowing an understanding of the bereavement process and a variety of theories have been formed for this purpose. Previously, stage theories were often used to describe how loss impacts an individual; however, these were criticized for their simplicity. Nowadays, process theories are more common, as they reflect the grieving individual’s bereavement experiences, thoughts and emotions as well as the process of dealing with loss.⁷⁷ The theory of psychosocial transition by Parkes^{78,79} theorizes that grief can lead to a psychosocial transition. This is achieved if the grief largely affects the assumptive world (i.e., the world as we know it); if the transition happens within a short period of time (i.e., with no time to prepare oneself); and if it has a long-lasting

effect due to feelings of unsafety and loss of control that obstructs adaption to a new assumption of the world. Individuals who experience helplessness and difficulties in the changes can be helped, by protection and emotional support, in the making of new world assumptions.^{78,79} Machin⁸⁰ has suggested the range of response to loss model to be applicable for understanding grief. The model suggests that loss either evokes core reactions of overwhelming distress, or reactions with the pursuit of attempting to remain in control. An individual's coping ability depends how well these reactions can be balanced; and, as these coping strategies range from resilient to vulnerable, they thus cover the diverse responses that loss may give rise to.⁸⁰ Furthermore, the dual process model⁸¹ and the integrative risk factor framework for the prediction of bereavement outcome have also been developed to understand grief.⁸² These two theories are used in this thesis and are described below. In addition, an overarching theory, the ecological systems theory, also used in this thesis, will be described in the last section of his chapter.

2.6.2 The dual process model of coping with bereavement

The dual process model of coping with bereavement was developed by Stroebe and Schut.⁸¹ This model consists of loss- and restoration-oriented bereavement stressors that the individual has to cope with (see Figure 1).

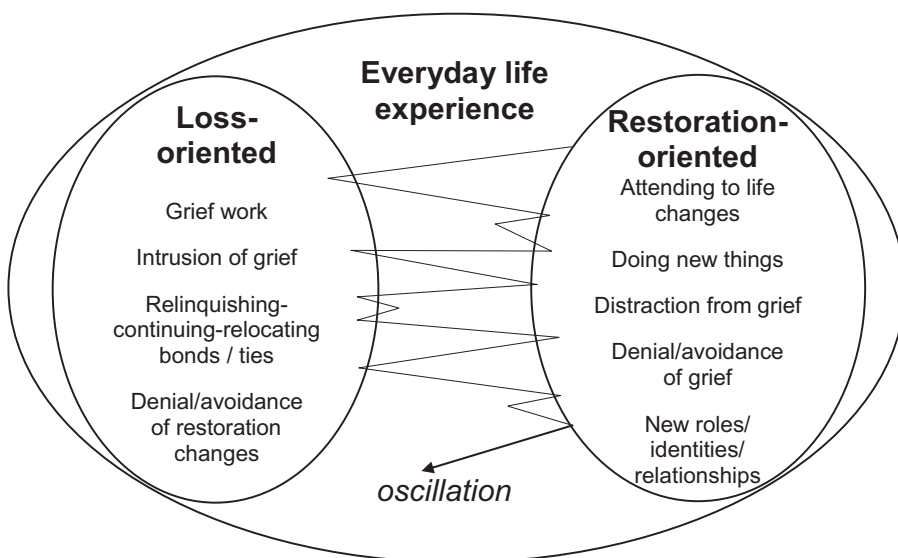


Figure 1. Stroebe et al. 's⁸¹ dual process model of coping with bereavement.

The loss-oriented stressor is distinguished by issues that are connected to the loss and the deceased person and how this is dealt with. This could be dwelling on the situation in which the person died or dwelling on the lost person. The feelings could be both a positive remembrance as well as painful yearning. The restoration-oriented stressor refers to the adjustment that must be made because of the loss and how this is performed. This may be dealing with a new life situation as a parentally bereaved person, or being bestowed with new duties within the family. The restoration-oriented coping adjustments could also be filled with positive experiences after succeeding with a task, as well as with negative emotions when the coping strategies fail to succeed.

An important part of the dual process model is the oscillation that takes place between the two bereavement stressors. In a dynamic evolution, the individual moves back and forth between loss-oriented issues and restoration-oriented focus. This process allows the individual to rest at times from the strenuous confrontation with the loss, which has been expressed as a need for taking time to recreate and to have time out from the grief by young persons in bereavement after parental loss.⁶⁰ In time, the oscillation process will be less loss-oriented and more restoration-oriented, allowing the individual to be relieved from the most painful memories or tasks, as habituation takes place.⁸¹ The psychosocial well-being among bereaved family members, such as a bereaved young adult, depends on factors that are related both to loss- and restoration-oriented stressors.

2.6.3 The integrative risk factor framework for the prediction of bereavement outcome

The integrative risk factor framework for the prediction of bereavement outcome was developed by Stroebe, Folkman, Hansson and Schut, with the purpose of providing a way of understanding how individuals differ in their adjustment to bereavement.⁸² The framework is built upon a combination of the dual process model,⁸¹ and the cognitive stress, appraisal and coping model.⁸³

The integrative risk factor framework offers a complexity of variables within five categories that all interact, as well as pathways of how this interaction may occur and the outcomes that they may lead to. Among these, some are variables that pose a risk, while others entail protective functions. Stroebe et al.⁸² define risk factors as variables that increases the probability of negative outcome, and protective factors as increasing probability of positive outcomes. It may be that the protective factors could help to build resilience and alleviate the effects of the risk factors, but it may also be the opposite, that long-term risk factors could dampen the protective factors. In addition, the framework offers variables in both the personal and external sphere that may influence the bereavement process. Interaction between

variables is highlighted in the framework, however, it may be too comprehensive to use as a whole; instead it could be used as guidance to researchers on which variables to examine.⁸²

The model consists of five interacting categories. *Category A* concerns the loss- and restoration-oriented bereavement stressors in the dual process model of coping with bereavement⁸¹ described above. In this thesis, factors such as awareness of death and quality of relationships with the still-living parent are examined. *Categories B and C* are related to the demands and resources related to the loss.⁸³ In *Category B*, the interpersonal, external sphere is involved, and it regards social and environmental factors in relation to loss, such as family dynamics or support group participation. *Category C* relates to intrapersonal factors related to the individual him/herself, such as personality, for example, self-esteem, or predisposed vulnerabilities, such as previous losses or mental health disorders. *Category D* concerns adjustment, appraisal and coping, which reflects the process of continuously managing internal and external demands that are perceived as difficult to cope with.⁸³ This category is also related to the oscillation process which helps adjustment to take place.⁸¹ In *Category E*, the outcomes of the processes involving categories A to D are placed, such as psychological (ill-)health, for example, anxiety or depression. A model of the factors of relevance for psychosocial well-being in bereavement, as it is applied in this thesis, is presented in Figure 2.

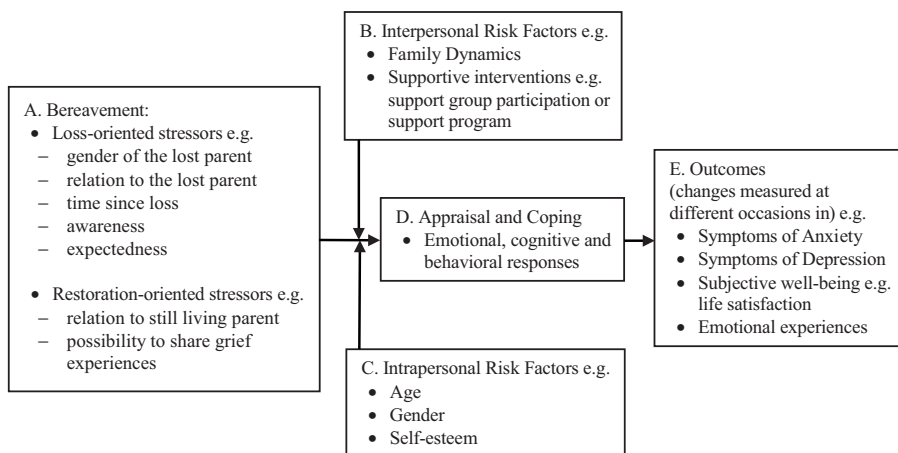


Figure 2. Factors of relevance for psychosocial well-being in bereavement that were examined in this thesis. Figure inspired by the integrative risk factor framework for the prediction of bereavement outcome.⁸²

2.6.4 The ecological systems theory

The ecological systems theory is particularly useful for understanding how illness and death affect young adults' life situations. Urie Bronfenbrenner, an American psychologist born in Russia, developed the ecological systems theory in which the "phenomenon of *development-in-context*" (page 12) is emphasized. The theory seeks to offer a scheme where interrelating structures and processes in both the close and the distant environment forms the development of humans through life. Throughout the life span, events and changes in roles, or "ecological transitions" (page 6), take place that affect the person's development and the development of other persons in his/her systems. Such events could include finding a job, moving home or losing a parent. How this development proceeds depends on the subjective perception of the environment, not the objective description of reality.⁸⁴

The theory consists of systems on different levels which all interact and affect each other. In the center is the individual, for example, the bereaved young adult, which is surrounded by multiple systems operating at different levels.⁸⁴

The microsystem is the environment closest to the individual and is signified by his/her interpersonal relations, roles and activities. It consists of at least one dyad of two individuals and there is an active interaction between the two. Changes and developments in one of them will also affect the other. If data about the two individuals are collected simultaneously, the dynamic between the two can be revealed.⁸⁴ This could be between the young adult and the sick parent, or between the young adult and a friend or a partner.

The mesosystem is a system of microsystems that changes as the individual develops and engages in new or altered microsystems. The mesosystem thus consists of two or more settings where there is ongoing activity. For young adults, this could be within the family, at school or work, or in their peer group.⁸⁴

The exosystem is the system outside the mesosystem in which the individual is not an active member, but where activities affect the individual or the individual affects the system.⁸⁴ For example, if a sick parent is moving from a hospital to a palliative care service, or if regulations about bereavement support to young adults are changed on an organizational level, the young adult is indirectly affected.

The macrosystem represents the social and cultural values in which the micro-, meso- and exosystems exist. These could differ in different countries as well as within countries, as socioeconomic status, ethnicity, religion and subculture will alter within each society. For instance, in a context where religion is dominant, faith may be a natural source of comfort among bereaved individuals, while religion in a secularized society will not play such an important role after a loss.⁸⁴

Therefore, the Swedish context has been described here, regarding young adults and regarding bereavement services.

The chronosystem refers to time. Changes over time in a person and in the environment can affect the development of an individual.⁸⁵ Individuals in the same time in history share experiences, but being of a certain age at a certain time in history may, in addition, alter the individual's development, as well as events and experiences in the past.⁸⁶ For example, the loss of a parent today is a different experience compared to 100 years ago. A non-normative life transition related to the chronosystem is the death of a parent, which not only immediately changes the role of the young adult, but also the dynamics of the whole family.⁸⁵

Accordingly, young adults, as individuals who have been bereaved of their parent, are affected by the family, and the family is affected by the young adult. No system stands alone; instead they are all inter-connected and all affect each other in complex ways.

2.7 Study rationale

The loss of a loved one is a difficult and strenuous experience for family members, one that often has repercussions on psychosocial well-being. Cancer is one of the most common causes of death in Sweden⁸⁷ and consequently impacts many family members. Psychosocial well-being in bereavement can be affected by a variety of factors, such as anxiety, depression, self-esteem and life satisfaction, as well as factors such as received support. Emotions associated with supportive interactions reflect the psychosocial well-being of family members. Understanding these emotional consequences of supportive interactions will provide important information on what and how to support family members in bereavement and this information is useful in the planning and performance of supportive interventions and interactions with family members.

One particularly vulnerable group of family members, often invisible in studies, is young adults who have lost a parent to cancer. They seem to be somewhere in-between children and adults. Although they are considered adults in many respects, there are factors related to their age, such as great life changes, that indicate that they differ from older as well as younger bereaved individuals. They are at a specific position in life, and knowledge is missing about what it means to lose a parent in young adult age. Knowledge is needed about how their psychosocial well-being evolves over time and whether factors known to be important for bereavement outcome, such as self-esteem, are associated with their psychosocial well-being, involving, for example, symptoms of anxiety and depression. The loss of a parent to death at young adult age may lead to short-term consequences for psychosocial

well-being, but there may also be long-term and far-reaching consequences; not only for the young adults themselves, but also to their families, in addition to society as a whole, as these young adults are part of the forming society at the present time and in the future. To be able to support young adults in bereavement, more knowledge about their specific situation is needed. Increased knowledge about psychosocial well-being and the needs of parentally cancer-bereaved young adults can therefore provide guidance to health care staff who encounter them in their daily work, guide future supportive interventions, and inform policy makers about how best to support these young adults.

3 GENERAL AIM

The general aim of the thesis was to explore the psychosocial well-being of family members in bereavement, with a special focus on young adults who have lost a parent to cancer.

3.1 Specific aims

Study I

To explore family members' supportive interactions in palliative care and the emotional experiences that they associate with these interactions.

Study II

To describe loss- and restoration-oriented bereavement stressors from the perspectives of young adults who have lost a parent to cancer. An additional aim was to describe psychosocial well-being among these young adults.

Study III

To investigate longitudinal variations in psychosocial well-being among young adults who have lost a parent to cancer.

Study IV

To examine the relationship between self-esteem and symptoms of anxiety and depression among young adults who have lost a parent to cancer.

4 METHODS

4.1 Design

The overall design of this thesis is built upon two different study populations in bereavement in a palliative care context; adult family members, and young adults who lost a parent to cancer. The psychosocial well-being of each group was examined. The findings of the study with adult family members led to the studies with young adults, as it was indicated in the earlier stages of the research that support groups for parentally bereaved young adults were of special importance and this evoked the question of whether young adults were a group with special needs in bereavement. Because of the lack of research on this special group, the three studies following the initial study in this thesis focused on young adults who had lost a parent to cancer and who participated in a support group.

This thesis uses a mixed method design with qualitative (Study I) and quantitative (Studies II–IV) methods, to answer the general aim of the thesis (see Table 1). Study I is an exploratory retrospective interview study, Study II a descriptive study using baseline data, Study III a prospective longitudinal study, and Study IV an association study. The aims of Studies II–IV were guided by the integrative risk factor framework for the prediction of bereavement outcome.⁸²

Table 1. Overview of the studies included in the thesis

	Participants	Data collection	Analyses
Study I	25 bereaved family members	Individual interviews	Qualitative content analysis
Study II	77 parentally bereaved young adults	Questionnaire data	Descriptive statistics
Study III	55 parentally bereaved young adults	Questionnaire data	Descriptive statistics and analytical statistics (Friedman's test and Wilcoxon signed-rank test)
Study IV	77 parentally bereaved young adults	Questionnaire data	Descriptive statistics and analytical statistics (Univariate and multiple linear regression)

4.2 Study I

4.2.1 Setting

Study I was performed in a specialist palliative care service in an urban area in Sweden with two inpatient wards and one home care unit. Within the service, a program aiming to identify and provide support to family members with special needs was ongoing. The purpose of the support program was to enhance the quality of life and mental health of family members. As routine practice, all families at the service were offered basic support, which included the establishment of a relationship between the care service and the family to be able to meet and have a dialogue about the patient's illness and prognosis as well as having meetings that focus on the family member's situation. This was accomplished by conducting enrollment meetings and family meetings, and by providing written and oral information and support at the time of death. In addition, a condolence letter was sent to the family three weeks after the death. The basic support involved the health care staff assessing the family member's needs for specialized support by using a checklist of risk factors for vulnerability. This assessment was repeated continuously throughout the whole period of care. Families considered to be at risk for vulnerability were those who had experienced a difficult time of illness, or a sudden or unexpected death; where there were psychological or social problems; or where there were children or young adults in the family (see Figure 3).

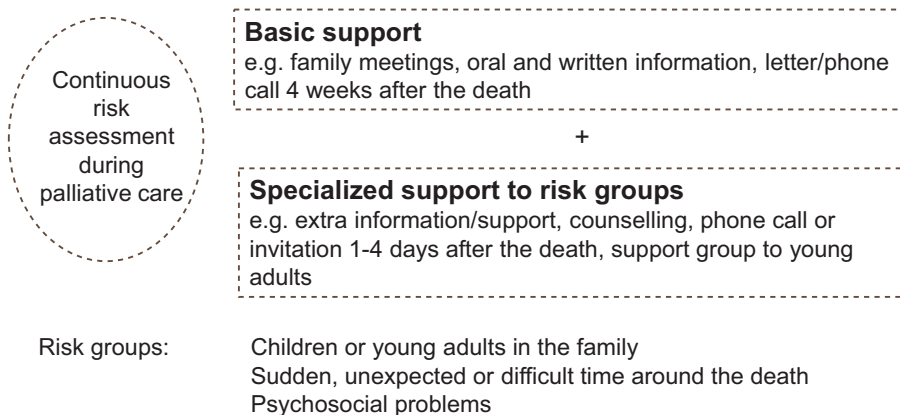


Figure 3. Program to identify and support family members with special needs.

There was an explicit routine about who was responsible for offering support, depending on risk factor. In families where there had been a difficult time of illness or death, a doctor was responsible for offering medical information and meeting the needs of the family in relation to the illness. In addition, a doctor was responsible for calling or inviting these families to a family meeting within four days after the death. In families where there were social problems or children/young adults, a medical social worker had the responsibility of supporting the family. In addition, young adults were invited to participate in a support group after the loss of their parent. The specialized support could also include support from a priest or a nurse, and sometimes a referral to external support sources.⁸⁸ The family members were not explicitly informed about the ongoing support program; instead, it was integrated with the usual care.

4.2.2 Participants

In Study I, family members of 60 patients who had died at the specialist palliative care service within a two-month period were selected for strategic sampling. The family member had to be over 18 years of age and was identified through medical records as the ‘key relative’, meaning the one who was considered to be most affected by the death, and, if such a relative was not identified in the records, the first family member noted was invited to participate. Accordingly, the family members could have different relationships to the deceased. To ensure inclusion of participants from different risk groups, the family members were divided into three groups: one where the family members were assessed as having no risk of complicated reactions, one where there were children or young adults in the family, and one where there were risk factors other than children or young adults in the family. A strategic sample of 10 was drawn from each group. Accordingly, 30 family members were invited via phone to participate in the study, after having received an information letter one week in advance. The participants gave their consent by phone and an interview was scheduled. The invitations were performed about six months after the death. Out of the 12 women and 13 men who agreed to participate in the study, 13 were partners, 8 were adult children, 2 were friends, 1 was a parent, and 1 a nephew. The five family members who declined participation specified one or more reasons, such as the pain of talking about their experiences ($n=3$), other traumatic events ($n=1$), disappointment with the palliative care ($n=2$), living abroad ($n=1$), and lack of time ($n=2$). The age range of the deceased patients at the time of death was 39–88, and the mean age was 65 years. All patients had died from cancer.

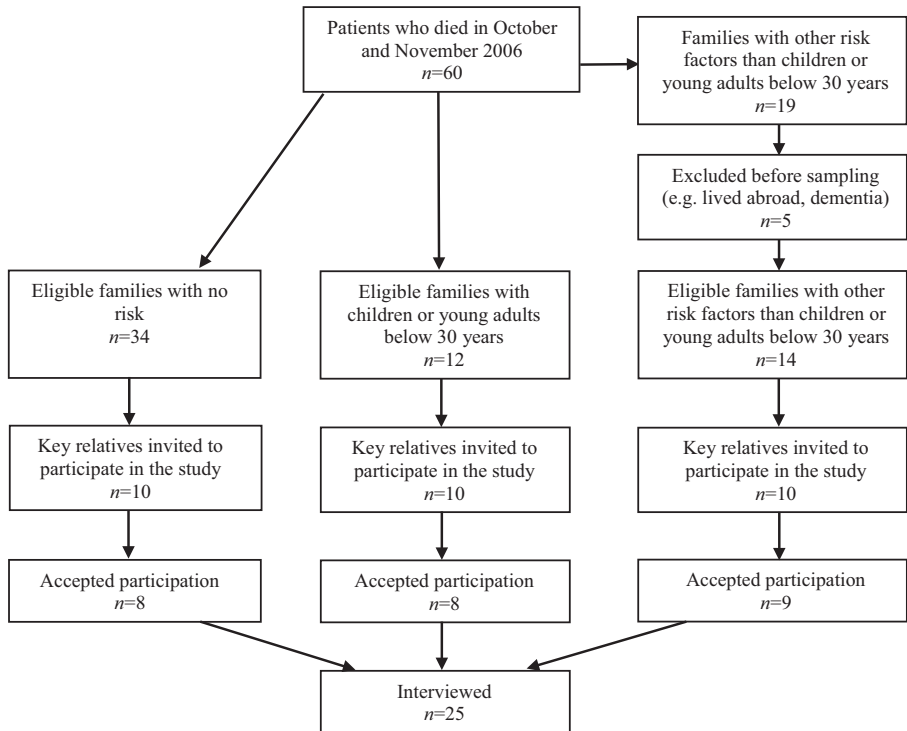


Figure 4. Flowchart depicting inclusion in Study I.

4.2.3 Data collection

Family members were interviewed, on average, 8 months (range 6–9 months) after the loss. The time since the loss was assessed so as not to coincide with any sensitive anniversary dates. Within the study, a semi-structured interview guide was developed by the researchers involved in the support program, which was piloted twice without finding any need for revision. The interview guide was designed to capture experiences of supportive interactions in the specialist palliative care service and the responses of the family members to these interactions. In accordance with Kvale,⁸⁹ the interview guide allowed changes in the form and order of the questions when needed. The family members were encouraged to talk freely about the questions and follow-up questions were asked. Examples of questions are: “Tell me about the encounters and the support you received from the health care staff?”; “What significance do you think this had for you?”; “How is your state of health?”, “Normally, and now?”; and “Are there any differences compared to before the loss?” The interviews were performed by a medical social worker

(myself) and an experienced nurse, neither of whom worked at the specialist palliative care service. The family member chose the place for the interview and 23 took place in the research unit close to the specialist palliative care service with one in the family member's home and on in their workplace. All interviews were audio-recorded. The interviews were performed in the spring and summer of 2007.

4.2.4 Analysis

In Study I, inductive qualitative content analysis, as described by Elo and Kyngäs,⁹⁰ was used. The 25 interviews were transcribed verbatim and then read repeatedly to obtain a sense of the whole. Thereafter, statements about supportive interactions and emotional experiences were excerpted. To condense the text, the statements were organized by using open coding, that is to say, notes and headings were written simultaneously as the text was read. To further reduce the text, codes and headings with conceptual relatedness were formed into categories and subcategories that described the phenomenon in the codes on a higher level. The abstraction into categories and subcategories was conducted to obtain a general description of the topic. During the analysis process, the researchers continuously went back and forth between the original interview text and the categories to validate the findings (see Figure 5). In the final analysis phase, the categories of emotional experiences were linked to the categories of support that the family member referred to. The initial analysis of condensing the text into statements was conducted by the first author (myself), however, the continuing analysis was performed jointly as well as individually by two of the researchers (myself and a supervisor) to be able to increase the trustworthiness of the analysis by reflecting and reaching agreement on the categorizations.⁹¹

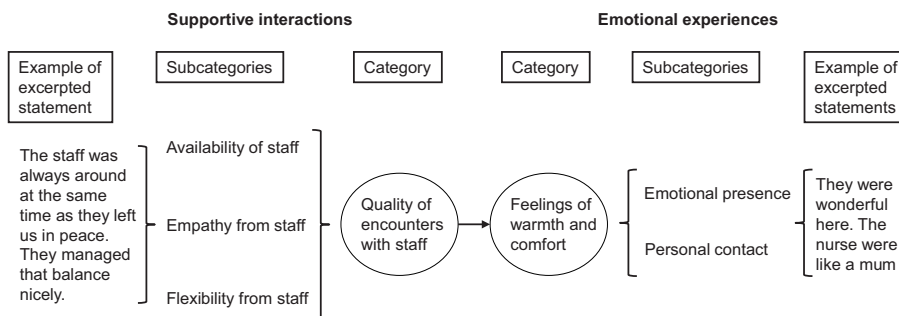


Figure 5. Examples of categories and subcategories of supportive interactions and connected categories and subcategories of emotional experiences.

4.3 Studies II–IV

4.3.1 Setting

Studies II–IV were conducted within three specialist palliative care services in different parts of Sweden where support groups for young adults who lose a parent to cancer were provided. At one of the services, the support groups were part of the support program in Study I of this thesis, offered as specialized support provided to young adult children of the deceased. In one of the other specialized palliative care services, support groups were directed to the whole family, however, young adults participated in support groups separate from the other family members. The support groups met for 2 hours. In two of the services, the support groups were held 10 times each week, and in one service, support groups were held 7 times every other week. All groups were led by group leaders with experience of working with bereavement and they were mentored by a psychotherapist. The purpose of the support groups was to give the participants a time and place where they could share their experiences of grief, lessen feelings of loneliness in bereavement, experience connection, as well as to give and receive support from peers in bereavement. The support groups had a similar structure. The themes that were discussed concerned who had died and how, the new life circumstances, the grief and existential thoughts, what they experienced as supportive, memories of the parent and continuing bonds, and moving on. Other studies based on the support groups drawn from two of the same specialist palliative care services have been published.^{67,68}

4.3.2 Participants

Young adults, aged 16–28 years, who had lost a parent to cancer at least two months earlier and who were about to participate in a support groups, were invited to participate in Studies II–IV. Before the support groups started, the young adults met with the group leaders to receive information about the groups as well as oral and written information about the study. If a young adult was assessed as having more complicated problems, he/she was referred to alternative forms of support. By responding to the first questionnaire in the study, the young adults gave their consent to participate in the studies. In total, 77 young adults, 64 women and 13 men, were included in the studies.

4.3.3 Data collection

Studies II–IV involved questionnaires distributed at three time-points during a period of about 10 months. The 77 young adults who agreed to participate in the study all completed the first questionnaire that they had been handed in the pre-meeting with the group leaders, on average, 5–8 months after the death of their parent. At the end of the final group meeting the group leaders provided the young

adults with the first follow-up questionnaire, on average, 8–12 months after the parent had died. About 6 months after the final group meeting the second follow-up questionnaire was sent to the young adults by the researcher, on average, 14–18 months after the parent’s death. Reminders were sent twice, after 3 and 6 weeks, if the young adult had not responded to a questionnaire.

The construction procedure of the questionnaire was guided by the integrative risk factor framework for the prediction of bereavement outcome⁸² and the dual process model of coping with bereavement.⁸¹ A comprehensive questionnaire was developed, which included a broad spectrum of variables that can affect bereavement, in accordance with the integrative risk factor framework,⁸² which underlines the importance of examining variables in conjunction. The questionnaires were composed of socio-demographic questions, which were related to: the young adults’ intrapersonal and non-personal characteristics; study-specific single items designed to measure loss- and restoration-oriented bereavement stressors, in accordance with the dual process model of coping with bereavement;⁸¹ single items related to psychosocial well-being; and validated instruments. Before the questionnaires were distributed to the young adults, they had been pilot tested without any need for revisions emerging. A total of 55 young adults responded to all three questionnaires (see Figure 6). The data collection was ongoing between October 2011 and July 2016.

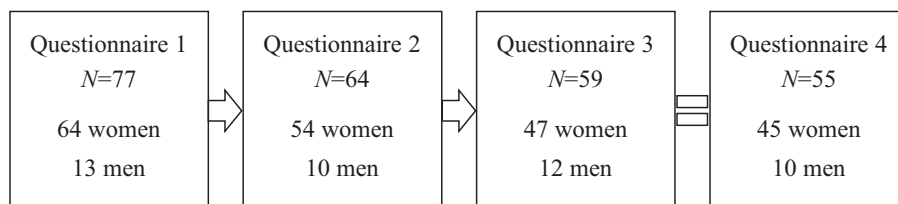


Figure 6. Number of respondents for each measurement point

4.3.3.1 The questionnaire

Single items measuring loss- and restoration-oriented bereavement stressors

The single items measuring loss- and restoration-oriented bereavement stressors were developed to measure items of value for the psychosocial well-being by using the dual process model of coping with bereavement.⁸¹ There were 10 single items related to loss-oriented stressors, which involved; gender of the deceased parent, what the relationship with the deceased parent was like before the death, the circumstances around the loss, how expected the death had been, and how aware the young adult had been about the impending death of their parent. There were

five single items measuring restoration-oriented stressors, which concerned; the relationship to the parent who was still living as well as to friends, the possibility to share grief and whether they had received support and from whom, and their alcohol and substance use. All response options were closed-ended.

According to the integrative risk factor framework, support belongs to interpersonal risk factors and alcohol and substance abuse to intrapersonal risk factors. However, in Study II, these two factors were assessed as restoration-oriented in as they could be of importance for the adjustment to loss in accordance with the dual process model.⁸¹

Single items related to psychosocial well-being

There were seven single items related to the psychosocial well-being of the young adult, each of which originated from an evaluation of support groups for young adults in Denmark.^{65,66} The items were answered on a seven-grade numeric rating scale, ranging from “high agreement” (1) to “low agreement” (7). Scores were reversed on one item. The items concerned to what degree the young adults felt; that their life in future would be meaningful, that they were understood by others, that they were different compared to peers, loneliness because they lost their parent, that they had someone to talk to about their feelings and thoughts, that they had high or low attendance at work or school, and that they could concentrate.

Validated instruments

The Rosenberg Self-Esteem scale (RSE) is designed to measure self-esteem and comprises 10 items answered on a four-point Likert scale.⁹² The scores range from 0 (strongly disagree) to 3 (strongly agree) with a total score ranging from 0 to 30. Higher scores suggest higher self-esteem. Before summarizing the total score, five positive statements must be reversed. There are no general cut-off scores recommended for the RSE, therefore, in this thesis, scores between 0 and 14 suggests low self-esteem, in accordance with Isomaa, Vaananen, Frojd, Kaltiala-Heino, and Marttunen.¹⁶ RSE is a frequently used tool which has previously been proven to have satisfactory measurement properties,⁹³ including for the Swedish translation of RSE.⁹⁴ Cronbach’s alpha was 0.87 in Studies II and IV, where all respondents to questionnaire I were included, and 0.85 in Study III, where young adults responding to all three questionnaires were included. Both values demonstrate good internal consistency reliability. RSE was used in order to consider intrapersonal risk factors.

The Hospital Anxiety and Depression Scale (HADS) consists of two subscales with seven items measuring symptoms of anxiety and seven items measuring symptoms of depression.⁹⁵ The scores range from 0 to 3 and the total score for each subscale ranges from 0–21. Higher scores indicate higher levels of anxiety

or depression. In total, eight items must be reverse-scored before summarizing the subscales. In consistency with Hansson, Chotai, Nordström, and Bodlund, this thesis considers scores 0–7 to be normal, 8–10 as indicating mild symptoms, and 11–21 as indicating moderate-to-severe symptoms of anxiety or depression.⁹⁶ HADS is widely used and has demonstrated satisfactory measurement properties,⁹⁷ including in the Swedish translation.¹³ Cronbach's alpha was 0.79 for anxiety and 0.73 for depression and in Studies II and IV, and 0.72 for anxiety and 0.74 for depression in Study III, all indicating satisfactory internal consistency reliability.

The Life Satisfaction Checklist (LiSat) measures life satisfaction and originally contained 11 single items (LiSat-11).⁹⁸ One item was removed from the questionnaire, with the authorization of the constructor, as it concerned the ability to cope with self-care, which was not relevant as the young adults were not patients themselves. The items are answered on a 6-point Likert scale, which ranges from 1 (very unsatisfying) to 6 (very satisfying). In conformity with the constructors' instructions, the answers were dichotomized; a score of 1–4 represents not satisfied, and a score of 5–6 represents satisfied. In Study III, the original ratings were used as well. The constructors do not recommend calculating a scale score, therefore the items in the checklist are treated as single items. The 10 items assess the satisfaction with life as a whole, work, economy, leisure, contacts with friends, sexual life, family, partner relation, physical health and psychological health. LiSat has previously shown satisfactory measurement properties.⁹⁸

4.3.4 Analysis

Studies II–IV applied descriptive and analytical statistics by using SPSS Statistics version 22 (IBM Corp., Armonk, NY, USA). If missing data did not exceed 20% for each scale, they were replaced, which was completed by using person mean scores.⁹⁹ Altogether, one missing value was replaced for RSE, one for HADS anxiety, and one for HADS depression. The statistical significance level was set at $p < 0.05$.

Study II was a cross-sectional study involving the 77 baseline questionnaires. Descriptive statistics were used to describe the characteristics, loss-oriented as well as restoration-oriented bereavement stressors, and the psychosocial well-being of the young adults, on average 5–8 months after the loss.

In Study III, questionnaires from the 55 young adults who responded to all three measurement points were used. Descriptive statistics were used for the participants' characteristics. To analyze the longitudinal variations in Study III, Friedman's test was used, due to the data not being strictly continuous. The analyses were performed on the seven single items related to psychosocial well-being, RSE, HADS anxiety, HADS depression and LiSat. The analyses were based on the original ratings, however, in the categorization of LiSat, the dichotomized scores were used. Wilcoxon

signed-rank test was used in the post hoc analyses to be able to detect differences between the different measurement points. Bonferroni corrections were not made for the post-hoc test as this would increase the risk of type II error.

In Study IV, the baseline questionnaires and the second follow-up questionnaires were included in order to investigate associations at baseline and 18 months after the death. The study used univariate and multiple linear regression models to examine associations between self-esteem and anxiety and depression. The association between self-esteem and symptoms of anxiety and depression (Q1) were examined by conducting linear regression analysis in two blocks. In the first block (Block I), HADS anxiety and HADS depression were used as the outcome variable and self-esteem as the explanatory variable. In the second block (Block II), the following covariates were entered: gender, the deceased parent's gender, whether the participant lived with the parent, whether the participant was in a relationship, and whether the participant had been aware of the impending death of the parent for a long or short period of time. To investigate whether self-esteem was associated with future symptoms of anxiety and depression (Q2), the regression analysis was repeated but the outcome variables were replaced with HADS anxiety and HADS depression from the second follow-up. Because a relatively strong correlation was detected between symptoms of anxiety ($r_s=0.52$) and symptoms of depression ($r_s=0.60$) at baseline and at follow-up, the regressor variable method¹⁰⁰ was used to investigate the association between self-esteem and changes in symptoms of anxiety and depression over time (Q3). In the first block (Block I), HADS anxiety and HADS depression from the follow-up assessment were used as outcome variables. Self-esteem, HADS anxiety and HADS depression from the baseline assessment were used as explanatory variables. In the second block (Block II), the same covariates as in the previous analyses were entered as adjusting covariates. There were no problems with multicollinearity in any of the regression models for the explanatory variables, using the criteria of variance of inflation factor (VIF) <2.

4.4 Ethical considerations

Studies involving individuals in bereavement entails a risk of evoking difficult feelings and responding to questions related to their particular situation of being bereaved can be demanding. At the same time, the attention given to the participants' experiences may be perceived as positive, and it can be a satisfying feeling to be able to contribute.¹⁰¹ This thesis was guided by the Declaration of Helsinki¹⁰² and the research ethics principles in humanistic-social sciences outlined by The Swedish Research Council.¹⁰³ According to The Swedish Research Council, it is necessary to perform research in order to be able to improve the health and life conditions of humans; however, this requirement must be weighed against the requirement of protecting the individual. The requirement to protect the individual

can be summarized into four main points; information, consent, confidentiality, and utilization.¹⁰³ The participants in each of the studies were informed that they could withdraw their participation at any time without any consequences. Potential participants approached in Studies II–IV were also ensured that they could participate in the support groups without participating in the study. All the participants were ensured of their anonymity and confidentiality in participating in the studies, and all working materials were coded and the original data identifying participants were stored in a locked and safe place to which only the researchers had access. The materials generated by the research have only been used for their intended purpose, of which the participants were informed.

In the interview study (Study I), the family members were informed about the study by letter and the participants gave their verbal consent over the phone one week later. They were furthermore informed that none of the interviewers worked at the specialist palliative care service in order to allow the family members to feel free to say whatever they wanted. The interviewers were accustomed to meeting patients and families in the end-of-life and after loss and had measures in place to guide the family member if they were assessed to be in need of further support. The family members were informed of who to contact after the interviews if they were in need.

In the studies involving young adults (Studies II–IV), the participants were informed about the confidentiality towards the group leaders and that the researchers were not involved in the support groups. They gave their written consent by responding to the questionnaires. The questionnaires were returned directly to the researchers. All questionnaires at follow-up II and III were screened for low satisfaction with the participants' own psychological health when they were received after completion. Scores of 1 (very dissatisfying) or 2 (dissatisfying) led to additional screening of HADS anxiety and depression. For 13 individuals who scored more than 10 on any of the scales in HADS (indicating moderate-to-severe symptoms of anxiety or depression), further contact was initiated to assess and offer supplementary support.

Ethical approval was obtained from The Regional Ethical Review Board in Stockholm (No. 2005/1355-31 and 2011/419-31/5).

5 RESULTS

The results of the four studies shed light on the psychosocial well-being in bereavement from different perspectives. In Study I, the results show that emotions experienced among bereaved individuals were affected by which and how supportive interactions were performed. Interactions that were experienced as positive were connected to positive emotions, thus affecting the psychosocial well-being in a positive direction, and vice versa if the interactions from staff were experienced as negative. Support group interventions for young adults were greatly appreciated. In Studies II–IV, the results demonstrate that the young adults who had participated in a support group had poor psychosocial well-being such as a high frequency of anxiety, low life satisfaction, feelings of loneliness and of being different. However, factors indicating resilience were having a normal/high self-esteem, as well as a strong belief in future meaning, and having support from the family. There were minor improvements in a few variables over the study period. Self-esteem was shown to be important for outcomes such as anxiety and depression in bereavement.

5.1 Study I

As intended, the family members in Study I had experienced basic support as well as specialized support and seven of the 17 participants who qualified for specialized support had received help from a medical social worker. When the inductive analysis was finalized, five categories of supportive interactions were connected to five categories of emotional experiences (see Table 2). Positive supportive interactions were characterized by information being delivered in a clear and honest dialogue, empathetic encounters from staff with a focus on the patient as well as the family member, a home-like environment, and bereavement support. These interactions were connected to positive feelings, such as having a sense of certainty and security, feeling comfort, value and dignity, as well as strength. These positive emotions promoted good psychosocial well-being. When the supportive interactions were experienced as negative, the emotions were characterized by anxiety and despair, uncertainty and guilt, thus fostering poor psychosocial well-being. The support groups for young adults were mentioned as a particularly positive experience. A prominent finding was that one of the specialized supportive interventions, support groups for a group identified at risk, young adults, were mentioned as being especially important. For some, these support groups were the most valuable experience for the family members and the young adults. A widower expressed this as: “Now afterwards, I’m most satisfied for the girls, actually. The fact that this support group was offered and that they experienced that they weren’t alone in this situation”.

Table 2. Categories of support and positive emotions connected to them

Supportive interactions	Emotional experiences connected to interactions
Kind of information (clarity, honest dialogue)	Sense of certainty and security
Quality of encounters with staff (empathy, availability, flexibility)	Warmth and comfort
Professional focus of staff (patient and family orientation)	Sense of value
Environmental aspects	Dignity and harmony
Bereavement support	Certainty and strength

5.2 Studies II–III

In total, 77 young adults participated in the study and this sample was included in Study II. In Study III the sample consisted of the 55 young adults who responded to all three questionnaires.

5.2.1 Participants' characteristics

The median age of the young adults was 24 years (range 16–28) ($n=76$) and 95% ($n=72$) were born in Sweden. Many, 91% ($n=70$) were working or studying, and 57% ($n=43$) had a partner. There were 43% ($n=32$) who did not live with the parent who died at the time of death (Study II).

5.2.2 Loss- and restoration-oriented bereavement stressors

The loss-oriented items revealed that most had lost their parent 5–8 months previously and slightly more than half, 58% ($n=44$), had lost their mother. The relationship with the deceased parent had been good for 92% ($n=69$) of the young adults. For 37% ($n=28$), awareness about the impending death occurred only a few days or less before the death, and 66% did not expect their parent to die when he/she did (Study II).

The restoration-oriented items revealed that the relationship with the parent who still lived were good for 61% ($n=45$). The young adults had shared their grief with their family of origin or relatives ($n=55$, 73%), but also with friends ($n=32$, 43%) or their partner ($n=27$, 36%). Many had received support from their family, friends ($n=60$, 80%) and/or a professional ($n=42$, 56%). Of the 15% ($n=11$) who did not receive support, 11% ($n=8$) reported that they would have wanted support (Study II).

5.2.3 Single items related to psychosocial well-being

There were 74 young adults who completed all of the seven single items related to psychosocial well-being at baseline (Study II). The results show that young adults were least troubled about finding meaning in the future (Mdn=6), talking to their next-of-kin (Mdn=5) or having low attendance at school or work (Mdn=5). They were most troubled by feelings of loneliness (Mdn=2) as well as feelings of being different than peers (Mdn=3). They neither rated high nor low agreement with having problems with being understood by others (Mdn=4) or having concentration problems (Mdn=4) (Study II). In Study III, only those who responded to all three questionnaires were included ($n=55$). The median score was the same at baseline when the sample only consisted of those young adults who responded to all three measurement points ($n=52$), except for the attendance at school or work, where the sample ($n=50$) showed less problems (Mdn=6) (Study III).

The longitudinal investigation revealed significant variations in the item about feelings of meaning in future life ($p=0.018$). The post-hoc analysis ($p=0.009$) showed significantly better outlook on future life in follow-up II compared to baseline (Study III). No other significant variation was found.

5.2.4 Validated instruments

At baseline, 76 young adults responded to the RSE questions, and the results disclosed that 80% had ($n=61$) had normal/high self-esteem (Study II). Among the 55 young adults who responded to all three measurement points, 85% ($n=47$) had normal/high self-esteem at baseline (see Table 3) with no significant variations discovered over time (Study III). In the original publication of Study II, the scores for the RSE had been incorrectly reversed, resulting in faulty results, which was corrected by a corrigendum to the publishing journal.

At baseline, 75 young adults responded to the HADS anxiety questions (Study II) and the results revealed that 27% ($n=20$) had no symptoms of anxiety, 31% ($n=23$) had mild symptoms, and 43% ($n=32$) had moderate-to-severe symptoms at baseline. The result including only those 54 young adults who responded to all three measurement points showed slightly less symptoms of anxiety: 28% ($n=15$) reported no symptoms, 35% ($n=19$) reported mild symptoms and 37% ($n=20$) reported moderate-to-severe symptoms at baseline (see Table 3), and no significant variations were found over time (Study III).

At baseline, 73 young adults responded to the HADS depression questions (Study II) and the results show that 68% ($n=50$) were free from symptoms of depression, 26% ($n=19$) reported mild symptoms, while 5% ($n=4$) reported moderate-to-severe symptoms (Study II). There were 52 young adults who responded to all three

measurement points, of which 69% ($n=36$) reported no symptoms of depression, 27% ($n=14$) reported mild symptoms and 4% ($n=2$) moderate-to-severe symptoms (see Table 3). The 52 young adults reported significantly less symptoms of depression over time ($p<0.001$). The post-hoc analysis demonstrated a significant decrease in symptoms between baseline and follow-up II ($p=0.002$) as well as between follow-up I and follow-up II ($p=0.002$) (Study III).

Table 3. Self-esteem, symptoms of anxiety and depression and satisfaction with life at baseline in Study II^a and Study III^b

	Study II (N=77)		Study III (N=55)	
	Valid	Total sample	Valid	Total sample
Self-esteem	76		55	
Mdn (q1–q3)		20 (16–23)		20 (16–23)
Low self-esteem (0-14), n (%)		15 (20)		8 (15)
Normal self-esteem (15-25), n (%)		61 (80)		47 (85)
Anxiety	75		54	
Mdn (q1–q3)		10 (7–13)		10 (7–12)
Normal (0-7), n (%)		20 (27)		15 (28)
Mild (8-10), n (%)		23 (31)		19 (35)
Moderate to severe (11-21), n (%)		32 (43)		20 (37)
Depression	73		52	
Mdn (q1–q3)		6 (3–8)		6 (3–8)
Normal (0-7), n (%)		50 (68)		36 (69)
Mild (8-10), n (%)		19 (26)		14 (27)
Moderate to severe (11-21), n (%)		4 (5)		2 (4)
Life Satisfaction, n (%)				
Life as a whole	76	27 (36)	55	21 (38)
Work	75	20 (27)	53	15 (28)
Economy	76	23 (30)	54	22 (41)
Leisure	77	28 (36)	55	22 (40)
Contact with friends	77	36 (47)	55	27 (49)
Sexual life	73	19 (26)	51	13 (26)
Family	75	28 (37)	55	23 (42)
Partner relation (those who had a partner)	42	25 (60)	23	16 (69)
Physical health	77	24 (31)	55	19 (35)
Psychological health	76	12 (16)	55	8 (15)

^a All of the participants in the study

^b The participants who responded to all three questionnaires

The LiSat component had a response rate ranging between 73 and 77 for the included items at baseline, except the item about partner relationship, which only included the 42 young adults who were in a partner relationship (Study II). When the sample included only those who responded to all three measurements, the response rate ranged between 51 and 55, except for the item directed only to those who were in a partner relationship, where 23 young adults responded. Analyses of the dichotomized scores show that the largest proportion was satisfied with partner relationship ($n=25$, 60%) and the smallest with psychological health ($n=12$, 16%) (see Table 3). To analyze the longitudinal variations of life satisfaction, the original scores were used. The analysis detected significant longitudinal variation in three of the areas of life; satisfaction with sexual life ($p=0.025$), and post-hoc analysis showed an increase in satisfaction between baseline and follow-up II ($p=0.036$). The satisfaction with partner relationship also demonstrated significant variations ($p=0.042$) and post-hoc analysis revealed that the satisfaction increased between baseline and follow-up I ($p=0.039$). The last item that showed significant variations was satisfaction with psychological health ($p=0.034$) and the post-hoc analysis found a significant increase in satisfaction between baseline and follow-up II ($p=0.049$) as well as between follow-up I and II ($p=0.047$).

5.3 Study IV

In Study IV, all of the 77 participating young adults were included and thus the participant characteristics were the same as in Study II.

5.3.1 Associations between self-esteem and symptoms of anxiety and depression (Q1)

The analysis showed associations between self-esteem and symptoms of anxiety and depression at baseline. Higher scores of self-esteem were associated with less symptoms of anxiety ($B=-0.28$, $p<0.001$) and the model explained 16% of the total variance of symptoms of anxiety. After adjustment to the covariates; gender, the deceased parents gender, whether the participant lived with the parent, whether the participant was in a relationship and, whether the participant had been aware about the impending death of the parent for a long or short time, the association remained significant ($B=-0.25$, $p=0.003$) and the model explained 23% of the total variance of the outcome variable.

Higher scores of self-esteem were associated with less symptoms of depression ($B=-0.26$, $p<0.001$) and the model explained 22% of the total variance of symptoms of depression. After adjustment to the covariates, the association remained significant ($B=-0.25$, $p<0.001$), the model explained 30% of the total variance in symptoms of depression.

5.3.2 Associations between self-esteem and future symptoms of anxiety and depression (Q2)

The analysis demonstrated associations between self-esteem at baseline and symptoms of anxiety and depression at follow-up. Higher scores of self-esteem at baseline were associated with less symptoms of anxiety at follow-up ($B=-0.30$, $p=0.001$) and the model explained 19% of the total variance in the outcome variable. After adjustment to the covariates; gender, the deceased parent's gender, whether the participant lived with the parent, whether the participant was in a relationship, and whether the participant had been aware about the impending death of the parent for a long or short period of time, the association remained significant ($B=-0.29$, $p=0.002$) and the model explained 26% of the total variance in symptoms of anxiety at follow-up.

Higher scores of self-esteem at baseline were associated with less symptoms of depression at follow-up ($B=-0.23$, $p=0.004$) and the model explained 15% of the total variance in symptoms of depression. After adjustment to the covariates, the association remained significant ($B=-0.23$, $p=0.004$) and the model explained 34% of the total variance in symptoms of depression. One covariate that was significantly associated with symptoms of depression was being male ($B=2.73$, $p=0.011$).

5.3.3 Associations between self-esteem at baseline and changes in symptoms of anxiety and depression over time (Q3)

The analysis revealed that self-esteem at baseline was significantly associated with changes in symptoms of anxiety over time, however, not with symptoms of depression. Higher scores of self-esteem at baseline were associated with reduction in symptoms of anxiety over time ($B=-0.18$, $p=0.035$) and the model explained 35% of the total variance in the changes of symptoms of anxiety. After adjustment to the covariates, this association remained significant ($B=-0.19$, $p=0.037$).

6 DISCUSSION

This thesis sheds light on psychosocial well-being in bereavement after the loss of a family member. Psychosocial well-being in bereavement was explored; among family members in relation to their emotional experiences of supportive interactions with health care staff, and among young adults participating in support groups through their reports on feelings and experiences after the loss in relation to their psychosocial well-being.

Study I showed that family members' emotions related to supportive interactions with health care staff are important aspects of psychosocial well-being. Although the family members were not explicitly informed about the ongoing support program, they shared which supportive interactions they had encountered or not, and described in the interviews how this was experienced emotionally. The results suggest that psychosocial well-being is enhanced when supportive interactions are experienced as positive and when they lead to feelings such as comfort and harmony. In contrary, it was implied that psychosocial well-being is negatively affected when supportive interactions are instead experienced as insufficient and feelings, such as uncertainty and discomfort, are demonstrated. Accordingly, supportive interactions between health care staff and family members can play an important role in the psychosocial well-being of bereaved individuals.

The indication of the results in Study I, that parentally bereaved young adults could be a special group in need after the loss, was explored further in Studies II–IV. Studies II–IV consequently examined the psychosocial well-being of young adults who had lost a parent to cancer by describing bereavement stressors and their psychosocial well-being and by investigating variations in psychosocial well-being over time, as well as examining the relationship between self-esteem and symptoms of anxiety and depression. Taken together, Studies II–IV demonstrated an overall poor well-being, with many young adults experiencing symptoms of anxiety and low life satisfaction and feelings of loneliness. Only minor improvements in a few variables during the first 18 months after the loss were experienced, despite support group participation. Higher ratings of self-esteem were associated with less symptoms of anxiety and depression.

6.1 Psychosocial well-being in bereavement – special focus on young adults

6.1.1 Awareness and being informed

The lack of awareness of the parent's impending death found among the young adults has previously been established among young adults who lost a parent to cancer 6 to 9 years previously.¹⁰⁴ As demonstrated in Study I, clear and honest

information is desired by family members and it has been found that information helps bereaved family members to mentally prepare themselves and to understand the situation.¹⁰⁵ Accordingly, a shortage of information could entail a risk of unawareness about the impending death. The importance of obtaining information to become aware and to enable psychosocial well-being has been confirmed in several previous studies.¹⁰⁶⁻¹⁰⁸ In Study I, information was found to be related to feelings of certainty and security, and a recent longitudinal study among bereaved family members has established the importance of security for psychosocial well-being and quality of life.¹⁰⁹ However, although young adults want information and have a need to be prepared,¹¹⁰ the pain of being confronted with their parent's illness,^{111,112} and their unwillingness to be a burden to their parents, leads them to avoid seeking support,^{106,111,113} which in turn can inhibit their possibility of becoming aware. In addition, sometimes parents want to protect their children by withholding information.^{38,114} A prerequisite that may facilitate the reception of information is experiencing empathetic, available and flexible encounters with health care staff, as they foster feelings of warmth and comfort, as demonstrated in Study I. Positive emotions have been found to be related to good relations with health care staff,³⁰ which is beneficial for the possibility to inform and prepare young adults for their parent's impending death.

Although an important minority of the young adults were unaware of and a majority did not expect the death, the young adults in this thesis were not exposed to sudden death, such as heart attack, or death by violent or accidental causes. Even though such deaths could have a more profound impact on the bereavement experiences compared to cancer deaths,^{40,47} the number affected by cancer loss is significantly greater.⁸⁷ This makes it critical from a societal and public health perspective to pay attention to and support family members, and especially young adults as an unattended group, who have lost someone to cancer.

6.1.2 Young adults' psychosocial well-being

The results demonstrated that a majority of the young adults had normal self-esteem levels (Study II). This coincides with previous research claiming that self-esteem is rather resistant to change and a stable trait that is inclined to remain throughout life.¹¹⁵ In addition, it has been suggested that self-esteem increases most in the ages between 15 and 30.¹⁵ Children develop their self-esteem to a great extent through their parents, who play an key role of the maintenance and development of the child's self-esteem.¹¹⁶ It has been argued that the death of a parent might compromise the self-esteem of children and adolescents.¹¹⁷ However, as the results revealed normal and unchanged self-esteem levels, it could be suggested that this does not apply to the young adults in this thesis.

Symptoms of anxiety were found to be more prominent compared to symptoms of depression (Study II). In addition, anxiety levels did not improve over the study period, while the symptoms of depression did (Study III). Nonetheless, the young adults experienced higher anxiety levels compared to normative data from Swedish young adults measured by HADS.¹¹⁸ Less symptoms of anxiety have, in addition, been demonstrated in several studies with bereaved adults.^{27,28,119,120} This indicates that the experience of losing a parent to cancer in young adulthood may constitute a particular vulnerability to anxiety. In addition, the young adults' depression levels were lower compared to samples of bereaved adults.^{27,28} It could be argued that this may be because young adults with more symptoms of depression might be less likely to attend support groups, however, in comparison with bereaved adults who participated in support groups, the depression levels in the young adults were also lower.¹²⁰ Although the depression levels were lower compared to the anxiety levels, the prevalence of depression was higher in comparison to normative scores of symptoms of depression among Swedish young adults.¹¹⁸ One way of understanding the fewer symptoms of depression compared to symptoms of anxiety may be that anxiety is naturally related to the loss of someone close, having to face mortality and the new demands that are imposed on an individual after an important loss.¹¹⁹ In addition, it could be that symptoms of depression occur later among young adults than during the 18 months that this thesis extends to, as has been shown in previous studies involving young adults in bereavement.^{12,44} However, during the study period, depression levels decreased (Study III), which coincides with reports of decreased depression levels among young adults participating in support groups after parental loss in Denmark.^{65,66} In contrast, a Swedish sample of bereaved adult family members who underwent support group participation showed no decrease in depression levels.¹²⁰ Furthermore, the finding that self-esteem affects the symptoms of anxiety and depression (Study IV) has been confirmed in another sample of bereaved adolescents and young adults,^{47,121} indicating the value of self-esteem for bereavement outcome. Self-esteem may furthermore have a buffering function against anxiety related to the awareness of one's own mortality, which may be evoked by a parent's death.¹²² Among widows, unawareness of impending death has further been found to increase the risk of anxiety,¹⁰⁷ however, no associations were found between awareness time and anxiety among the young adults in this thesis (Study IV).

Another protrusive finding was the low level of life satisfaction, which was lower in all domains compared to a representative national Swedish sample of 18 to 64-year-olds. The satisfaction with one's psychological health differed the most, with only 16% being satisfied among the young adults in this thesis (Study II) and 81% being satisfied in the representative sample.⁹⁸ Although it probably could be expected that young adults who recently lost a parent would experience lower life satisfaction than the general adult population, there is a noteworthy difference

between the samples. It is reasonable to assume that the low levels of life satisfaction are related to the parental loss, most likely because of the major effects that parental death has on psychological well-being,³³ as well as the effect that parental loss has on many areas of life, in accordance with the ecological systems theory.⁸⁴ In addition, the prominent feature of loneliness (Studies II and III) has been confirmed among other bereaved young adults and family members.^{34,59}

6.2 Application of theories on the results

6.2.1 The integrative risk factor framework for the prediction of bereavement outcome and the dual process model of coping with bereavement

The results could further be understood through the integrative risk factor framework for the prediction of bereavement outcome.⁸² In Study I, the family members' experiences of interpersonal risk factors, that is to say, interactions within the support program, and outcomes in the form of emotions and psychosocial well-being were examined. If an individual experienced information and bereavement support as reassuring, uncertainties related to the loss might be resolved, allowing the individual to move on in the coping process, and thus facilitating a more positive outcome, such as a positive emotional experience. This was exemplified by a widower who felt guilty about not having discovered his wife's cancer earlier who was relieved when the doctor reasoned that it was optimal the way it went because earlier identification would not have prolonged her life, only her suffering by knowing earlier. Furthermore, the same supportive factors could be experienced differently by different family members. One example is the experiences of the environment, as some individuals claimed that the nature in which the health care staff worked was helpful, while others felt that the system allowed only one way of grieving. This inequality could be understood through the complexity of factors that affect each individual. Factors described within the integrative risk factor framework, such as personality, predisposing vulnerabilities or differences in loss- or restoration-oriented stressors, differ between individuals and, accordingly, affect emotional experiences (i.e., outcome).⁸² These differences put health care staff under pressure to meet every individual where they are at that moment, taking their individual needs into account when supporting them. In Studies II–IV, a broad variety of variables were examined, in correspondence with the integrative risk factor framework, in order to obtain a comprehensive understanding of the bereavement outcome.

The integrative risk factor framework is partly based on the dual process model of coping with bereavement,⁸¹ which highlights the oscillation between loss- and restoration-oriented coping. This oscillation could be used to understand the results among the bereaved young adults, as factors related to good and poor psychosocial

well-being were simultaneously demonstrated. For example, the young adults had a belief that the future would be meaningful, while at the same time they reported low levels of satisfaction with their psychological health. Furthermore, the poor psychosocial well-being found among the young adults could be understood by the relatively short period of time that had passed since the loss. Loss-oriented issues may be salient and habituation to the new life situation may have not yet occurred. This oscillation process could also be applied to the family members, who at the time of the interview could be dealing with either loss- or restoration-oriented coping, thus reflecting the emotions as they were experienced then and there. This oscillation process supports the conclusion that all bereaved individuals must be met where they are at the moment, and that offers of support have to be repeatedly made, as the perceived need for support might differ depending where the individual is in the oscillation process.

6.2.2 The ecological systems theory

The ecological systems theory⁸⁴ overarches the thesis as it illustrates a complexity where all events affect each other. For family members, including young adults, it is not only the microsystem, consisting of a dyad of oneself and the sick person, or the mesosystem, where the whole family exists, that becomes altered by life-threatening disease or death, but also the exosystem. For the family members, events such as the admission to a palliative care service can have an impact on psychosocial well-being, as interactions within the exosystem immediately alter the micro- and mesosystems. The movement of the person who was ill from other care facilities to the palliative care service was often experienced as having a very positive effect on the family members' emotions. For example, the caring role often undertaken by a family member¹²³ (microsystem) may be changed if the family member felt that their relative were well cared for in the palliative care service (exosystem). Encounters such as these (dyads established between the patient or family member with health care staff in the exosystem) lead to comfort, which in turn enhances the psychosocial well-being of the family member. However, if the family member does not perceive that the palliative care service (exosystem) or the health care staff (mesosystem) is attending to the needs of the patient, negative feelings of lessened value could be experienced, as demonstrated in Study I, and no relief is obtained, thus affecting psychosocial well-being negatively. Furthermore, when a parent dies, the death does not only affect the dyad between the deceased parent and the young adult, but also the family system (mesosystem) is changed as every individual within the family system has an affected dyad in relation to the deceased. The young adults did, however, report that they had received support from family members despite them also being affected by the death, which could be beneficial for the young adult's psychosocial well-being.¹²⁴ Another mesosystem, the peer group relationships, were shown to be changed, as dyads with friends were modified, which was shown by 65% reporting better and/or worse

relationships to friends. In addition, the young adults showed dissatisfaction in all items measuring life satisfaction, indicating that the changed dyad with the deceased parent, in accordance with the ecological systems theory, could have affected the mesosystems, such as work, economy, leisure and partner relationship. However, all changes do not relate to psychosocial well-being. For example, a poorer economic situation after the loss of a parent may lead to material disadvantages, however, changes to the financial situation are only related to psychosocial mechanisms if it also evokes psychological responses, such as emotions and behaviors.¹²⁵

6.3 Risk and protective factors

As described in the integrative risk factor framework for the prediction of bereavement outcome proposed by Stroebe et al.,⁸² a vast variety of variables predicts bereavement outcome. Some variables pose a risk and some a protective function for outcomes, such as psychosocial well-being among bereaved individuals. The results highlight that the time within the first 18 months after an important loss is a vulnerable period, where psychosocial well-being could be poor and family members sensitive to lack of or insufficient interactions from health care staff, thus forming a risk to psychosocial well-being. On the other hand, interactions experienced as positive and factors in bereavement that indicate good psychosocial well-being can contribute to resilience in the coping process. Resilience refers to the ability to withhold negative psychological outcomes, despite external circumstances that entail a risk of negative consequences.¹²⁶ For example, the interpersonal risk factor of a support program in Study I could be referred to as a protective factor if the support was perceived as supportive and characterized by positive emotions, such as security and comfort, leading to a positive outcome such as good psychosocial well-being. On the other hand, support experienced as deficient raised negative emotions, such as uncertainty and insecurity, and thus entailed a risk factor for negative outcome, such as poor psychosocial well-being.

Furthermore, in Studies II–IV, the young adults simultaneously showed risk and protective factors. The loss itself and being in the vulnerable transition into adulthood composes a risk for poor psychosocial well-being. The young adults furthermore demonstrated a limited awareness about their parent's imminent deaths, leaving them unprepared, which composes a risk factor for poor psychosocial well-being such as anxiety and depression.²³ However, there were variables that indicated protective factors which could foster a good psychosocial well-being. Few young adults had low self-esteem and they had a high belief that their life in future would be full of meaning. Furthermore, they had good quality in their relationships with family and friends, where they could share their grief and receive support. A review including children whose parent had cancer showed that good family function is associated with better adjustment.¹²⁷ This could suggest that the good family

relationships demonstrated among the young adults in the thesis can be protective to them as well. Among a national sample of adolescents in Ireland, support from an available adult protected from severe symptoms of anxiety and depression.¹²⁸ In addition, the high levels of work and/or studies found among the young adults may serve as a protecting factor. In a public health cohort of 18–29-year-olds in Sweden, high levels of occupation, and especially employment, as well as emotional support, were associated with the development of stable mental health, including symptoms of anxiety and depression, over a 12-year period.³⁹ On the other hand, although many young adults reported receiving support from others, for example, family members, symptoms of anxiety were prominent. In the Irish sample, higher symptoms of anxiety were associated with lower levels of life satisfaction, which in turn entailed a risk of symptoms of depression,¹²⁸ which suggests that the low levels of life satisfaction may be a risk in the sample of young adults as well.

As argued earlier in this thesis, all individuals are unique,⁵³⁻⁵⁵ and, to understand how different factors affect the bereavement outcome for an individual, you must look at the conditions for that specific individual. It could be suggested that young adults may benefit from supportive interventions that are based on their risk and protective factors, which has previously been indicated as an appropriate approach for interventions to children with a seriously ill parent.¹²⁹ Seeing each individual with their special prerequisites is crucial to supportive interactions, as was also concluded in Study I, signifying that support should be tailored to the needs of the certain individual you meet, individually or in a group, and if this succeeds, support can contribute to building resilience.

6.4 Findings of importance for supportive interactions and interventions – implications for practice

This thesis offers knowledge about the psychosocial well-being of family members after the loss of a loved one. This knowledge is useful for health care staff who encounter these family members and it provides valuable information on which aspects to consider when forming future supportive interventions. In this chapter, findings from this thesis that are important to take into account when meeting and supporting bereaved family members are summarized.

- *Personalized support*

A prominent finding from Study I that indicates a universal implication, and thus is equally important for the young adult group of family members, is that it is not only the kind of support provided, but also how the support is delivered that determines the emotional experiences of the support. By using an exploratory approach using open-ended questions, health care staff can learn from the young adults what they want and need.⁴ It is of significance that individuals

are met where they are at the moment, as the bereavement experience differs between individuals and societies.¹³⁰ The family member's unique situation has to be recognized³⁰ and support from health care staff has to be tuned in to the family member's specific needs related to their coping strategies.¹³¹ In accordance with findings among young adults who were parentally bereaved in their teens, the bereaved should be acknowledged and support should be directed to the needs of the bereaved.¹¹⁰ This is an overarching aspect that is indicated to be embedded in all interactions aiming to support bereaved individuals. In bereavement follow-up, personal traits, such as an ability to listen, is of more value compared to, for example, type of profession.⁵⁹ The family member's relationship with the health care staff is vital, as they want to be seen and recognized. If family members have not been able to establish a relationship with the health care staff, they feel invisible, without appreciation, and with all the focus placed on the patient and no one asking them about their situation.¹²³

- *A need to be informed*

One additional lesson learned from Study I that is applicable to the specific group of bereaved young adults is that supportive interactions should entail honest and clear information. This may help to avoid uncertainty and to make the young adult more aware of and prepared for the parent's impending death, as unawareness was a prominent feature among the young adults. As described previously in this thesis, family members and young adults want repeated offers of information and support,¹⁰⁵⁻¹⁰⁸ which is indicated to be beneficial to young adults as they are a hard-to-reach group.

- *Addressing symptoms of anxiety and life satisfaction in young adult bereavement*

Another important finding was the many young adults demonstrating symptoms of anxiety, which adds valuable information to the scarce research on anxiety¹¹⁹ among young adults in parental bereavement. The results indicate that experiencing symptoms of anxiety is one aspect that is important to address when supporting bereaved young adults. Future supportive interventions should consider addressing how to cope with symptoms of anxiety specifically, as this was shown to be a prominent feature among the young adults in this thesis. It may be that the development from adolescence to being adult, with all the changes and uncertainties that may already be ongoing, reinforces the symptoms of anxiety evoked by the loss. This reasoning may, in addition, be linked to the dissatisfaction with life that was demonstrated in all items measuring life satisfaction. The common instability in work, finances, and contact with friends and family that young adulthood often entails may be more strenuous, causing dissatisfaction if a parent dies at this period in life.³⁴ Accordingly, issues related to life satisfaction should be taken into consideration when supporting these young adults.

- *Not feeling alone*

In Study I, the support groups for young adults were solely spoken of in good terms. Further, supportive interventions could have a substantial role in lessening feelings of loneliness and of being different than peers, which were prominent feelings among the young adults, as long as the support entails the meeting of others of the same age who share similar experiences. This function of supportive interventions has been confirmed in the previously mentioned study using a smaller part of the sample that was used in the studies among parentally bereaved young adults in the present thesis. There the young adults report that the benefits of support group participation are that it offers an opportunity to talk about feelings, discover that you are not alone and to experience companionship with peers in a similar situation.⁶⁸ Furthermore, family members want to talk about their loneliness.⁵⁹ By meeting others in a similar situation, normalization of the loneliness often experienced among young adults can be achieved,³⁴ and thus the therapeutic function of cohesion may be fulfilled by the support.⁵⁸

- *Opportunity for clarification in bereavement*

Psychosocial well-being in bereavement may be disrupted if no opportunity is given to have remaining questions answered. As shown in Study I, positive emotions are aroused by bereavement follow-up and when left out, despite promises, uncertainty and guilt darkened the participants' psychosocial well-being. Unfulfilled promises by health care staff could raise overwhelming feelings.¹²³ Bereavement support, which is also described within the definition of palliative care, is supported as being important to fulfill by the results of this thesis. It may also be that bereaved family members in other care contexts may benefit from bereavement follow up as well.

6.4.1 Application of results to other care contexts

The knowledge about psychosocial well-being in bereavement gained in this thesis may, in addition, be useful in other care contexts, although the context of this thesis is palliative care. The results and suggested implications of the result could be applicable in other care settings, such as hospitals, where many patients with palliative care needs still die.¹³² The palliative care approach that includes family members and that distinguishes palliative care services may not be apparent in hospitals despite the fact that it is needed.^{133,134} Families experience similar needs in hospital settings as those in palliative care services when a loved one is dying.¹³⁵

6.5 Methodological considerations

A great strength of this study is that it highlights family members' psychosocial well-being in bereavement from two different study populations. Together, the four studies represent family members with different relationships with the

deceased, however, the emphasis in this thesis is on young adults because of the vast knowledge gap about this group. In all, the use of these different populations allowed for a broader picture of psychosocial well-being to be comprehended.

6.5.1 Study I

6.5.1.1 Trustworthiness

To describe the trustworthiness in qualitative research, aspects of credibility, dependability and transferability are used.¹³⁶

The credibility of research refers to how the data and analysis examines what it intends to examine.¹³⁶ The choice of participants is of importance for promoting credibility. In the study involving bereaved family members, the strategic sampling method ensured that family members with different vulnerabilities were included. Furthermore, the participants included those of different ages, genders and relations to the deceased. The results hence offer a breadth and possibility to illuminate the experiences as richly and as soundly as possible.¹³⁶ Adopting an appropriate data collection method also enhanced the credibility of the research. Interviews were chosen as the method as this allows for great depth in the results. Interviews with 25 family members were considered adequate to achieve rich descriptions of support interactions and the participants' emotions connected to these. In the analysis process, two researchers worked closely to assess and form, for example, the categories and sub-categories. Together with the transparency of the analysis process and appropriate demonstrations of quotes, the assessment of credibility was also increased.¹³⁶

A study's dependability concerns how the researchers affect the data and the acknowledgement that data can change over time.¹³⁶ Any potential effects of the researchers' skills and abilities in the analysis process were addressed in the thoroughly performed analysis, in which two researchers with different credentials (a supervisor and myself) separately and conjointly performed the analysis. The interviews were performed within a limited time frame and a semi-structured interview guide was followed in order to obtain information on the experiences and emotions related to the supportive interactions. At the same time, the interviewees were free to talk openly about what they wanted in relation to the topic, in order to minimize the effect of the researchers' pre-understanding.

Transferability regards providing enough information for the reader to be able to assess whether the result could be transferred to other settings or groups.¹³⁷ In qualitative research, there is no right way of interpreting findings, only an interpretation of the most probable meaning. The detailed descriptions of the study design, context, population, data collection and analysis allow for assessment by

the reader of the transferability of the findings and any comparisons with other populations and contexts. The results concerning the bereaved family members are specific to the Swedish palliative care service setting, however, similarities with the findings of other studies involving bereaved family members in palliative care suggests that there may be transferability of the results to similar populations.¹³⁶

6.5.2 Studies II–IV

6.5.2.1 Sample reflections

This thesis does not offer any information on how the support group participation affected the results in Studies III and IV. However, parental loss at a young adult age is in itself regarded as a risk for complications and, as described in the introduction (Section 2.4), individuals at risk are suggested to benefit from support,^{56,57} which could be an indicator that the support may have affected the young adults. Furthermore, the support groups for the young adults included functions such as forming bonds with, sharing and supporting others in similar situation, which is likely to affect their psychosocial well-being.⁵⁸ This reasoning is furthermore consistent with the ecological systems theory,⁸⁴ which argues that all changes in systems, such as participating in support groups, affect the individual. The wider research on the effects of support are inconclusive. A review between 2003 and 2013 found that only a few interventions directed at families had an effect on bereavement outcomes,²⁵ however, a recent review of nursing interventions delivered to family members in end-of-life care at home demonstrated that interventions, especially those where different components were combined, such as peer support and psychoeducation, were beneficial for preparedness, competence, reward, and on reducing the burden of the family member.¹³⁸ Previous research on supportive interventions to bereaved children have shown varying effects on outcomes such as self-esteem and symptoms of anxiety and depression.^{129,139} In this thesis, only minor changes were reported in a few variables by the young adults, despite support group participation, however, without control or matched comparison groups it is not possible to assess how the support group participation has affected the results in this thesis. Accordingly, the result must be interpreted with caution, bearing in mind that the participating young adults also participated in support groups. However, as research is lacking on young adults who lost a parent to cancer, this thesis still presents valuable knowledge about an understudied group.

A further limitation of the young adult studies is that the statistical power was reduced by the small sample size. Conversely, a strength was that the material included very few missing data (two for HADS and one for RSE). In Study III, multiple tests were performed, which might heighten the risk of type I errors. However, considering the small sample size, no Bonferroni correction were used, as this instead could have heightened the risk of type II errors.

In general, the statistical analyses were guided by the distribution and type of data. Self-rated data on item level were treated as ordinal data, while scale scores were treated as continuous data. The scale scores were analyzed with non-parametric statistics when possible, as these variables are not strictly continuous (lacking equidistance) and/or were not normally distributed. However, to examine associations between self-rated variables, linear regression analyses were used. The rationale for this was that non-parametric alternatives such as logistic regression analyses require larger sample sizes compared with linear regression analyses, larger sample sizes than the young adult sample constituted here.

6.5.2.2 Validity and reliability

Validity refers to whether we believe that we have measured what we intended to measure,¹⁴⁰ and reliability refers to the accuracy of an instrument.¹⁴¹ The questionnaires were distributed on several occasions and were composed by a variety of variables in order to cover the topic, psychosocial well-being, as thoroughly as possible, which has strengthened the validity of the research. This approach is furthermore in agreement with the integrative risk factor framework for the prediction of bereavement outcome,⁸² as it advocates that variables should not be examined independently. The questionnaire was also piloted. The questionnaires did, in addition, include validated instruments. The seven single items related to psychosocial well-being are not validated, however, they have been used in research on young adults in bereavement in Denmark^{65,66} and are appraised as being valuable in this thesis as they add important aspects of bereavement outcomes.¹⁴⁰⁻¹⁴¹

The reliability of the instruments was tested by measuring the internal consistency by Cronbach's alpha. The associations between self-esteem and symptoms of anxiety and depression in Study IV were controlled for with several covariates. Conclusions of causal relationships should be made carefully, however, the results suggest that self-esteem is associated with symptoms of anxiety and depression. These results are consistent with previous research on self-esteem and outcomes such as anxiety and depression as well as research finding self-esteem to be a stable trait, which strengthens the reliability of the research.

6.5.2.3 External validity

External validity is related to whether the result is generalizable to different persons, settings or times.¹⁴² The young adult sample in this thesis was derived from young adults who had chosen to participate in support groups, which could entail selection bias and may have had an impact on the generalizability of the results. Young adults who are coping well are not likely to seek out supportive interventions if they do not feel a need. On the other hand, young adults who are worse off may avoid accessing supportive interventions because of fear or pain, or not wanting

to show their grief.^{106,111-113} Furthermore, it could be that individuals with low self-esteem have less confidence, making them more reluctant to participate in support groups compared to those with higher self-esteem. Analyses of non-participants was not possible as this information is lacking. Moreover, the young adult sample, which was mainly constituted by women, may also affect the generalizability of the findings to men, as previous studies have demonstrated gender differences in relation to loss.⁴⁰ Women have been found to have more internalized problems, such as anxiety and depression, compared to men, who exhibit more externalized problems, such as aggressive behavior.¹²¹

7 CONCLUSION

This thesis provides valuable understanding about the psychosocial well-being of bereaved family members, and especially among young adults, who have lost a parent to cancer. More comprehensive knowledge has been gained by following the psychosocial well-being of the young adults over time and by studying the complex relationships between factors of importance for psychosocial well-being after loss. Overall, this thesis reveals that the young adults who lost their parent to cancer experienced poor psychosocial well-being in bereavement, such as many reporting symptoms of anxiety, low levels of life satisfaction, and feelings of loneliness and being different from their peers. In addition, a low expectancy of the parent's death was found, which may have influenced their psychosocial well-being. Overall, there were few and minor improvements of psychosocial well-being over the first 18 months after the loss. Furthermore, higher levels of self-esteem seem to be of importance for the young adults as this was associated with less symptoms of anxiety and depression.

The studies involving the young adults support the notion that young adults constitute a specific group in bereavement, and that they differ to some extent from what previous research has shown about younger as well as older bereaved children, and contribute to the limited body of knowledge in this area. The results thus may indicate that this group could benefit from being treated as a special group with specific needs related to their developmental phase while losing a parent.

Despite the poor psychosocial well-being found in young adults during bereavement, indicating a vulnerability in grief, the thesis also shows factors that may serve as being protective. These can be, for example, self-esteem, support from and sharing their grief with their friends and family, as well as a strong belief in a meaningful future. This suggests that the young adults may be resilient in their grief and that they to an extent could be safeguarded from long-term problems due to these protective factors, allowing them to develop good psychosocial well-being instead.

In addition to the suggested potential of protective factors, supportive interactions can contribute to good psychosocial well-being in bereavement if they are perceived as helpful. On the contrary, deficient supportive interactions foster negative emotions, giving rise to poor psychosocial well-being. This supports the conclusion that supportive interactions should be customized to each individual's special need.

8 SWEDISH SUMMARY/SVENSK SAMMANFATTNING

Introduktion

Förlusten av en familjemedlem är en av de svåraste erfarenheterna i livet, som ofta påverkar det psykosociala välbefinnandet. De flesta individer klarar sig genom sorgen utan bestående problem. En grupp av familjemedlemmar som dock kan vara särskilt utsatta är unga vuxna som förlorar en förälder i cancer. Under denna period i livet, som pågår från de sena tonåren och upp till sena 20-årsåldern, sker en utveckling från att vara barn till att bli vuxen. Några drag som särskiljer unga vuxna från yngre åldrar är att de inte längre är i puberteten och att de vid 18-års ålder blir myndiga. Unga vuxna har också en mer utvecklad kognitiv förmåga som gör att de uppfattar en förälders död på ett annat sätt jämfört med yngre barn. De kan också få ta ett större ansvar för familjen och i uppgifter som planering av begravning efter det att föräldern dött, vilket gör att deras situation skiljer sig från yngre barn som förlorar en förälder. Jämfört med äldre åldrar så har unga vuxna oftast inte etablerat den stabilitet i livet som andra vuxna har. Ung vuxen ålder karaktäriseras istället vanligtvis av ett utforskande av den egna identiteten och en frigörelse från föräldrarna. Denna livsfas innebär en tid av förändring då relationer kan vara flyktiga och sysselsättningen instabil. Detta kan medföra att det sociala nätverket inte är lika tillförlitligt vad gäller stöd, om den unge vuxne till exempel förlorar en förälder. Den mentala hälsan, som till exempel inkluderar ångest- och depressionssymptom, har visat sig mindre stabil över tid hos unga vuxna jämfört med dem äldre än 29 år. Unga vuxna som förlorar en förälder har också visat sig påverkas mer av förlusten jämfört med de som förlorar en förälder i 50–60-årsåldern, sannolikt på grund av att dödsfallet är mindre väntat i ung vuxen ålder. Unga vuxna utgör alltså en specifik grupp, som kan vara särskilt sårbar då en förälder dör.

Trots att unga vuxna befinner sig i en specifik position i livet, så är forskningen begränsad kring vad det innebär att förlora en förälder i denna ålder då de inkluderar i hela vuxengruppen dvs 18–65 år eller äldre. Det behövs kunskap om hur deras psykosociala välbefinnande utvecklas över tid och om faktorer som är kända för att vara viktiga för det psykosociala välbefinnandet efter en förlust, som till exempel självkänsla, är förknippade med deras psykosociala välbefinnande, till exempel med symptom på ångest och depression. För att kunna rikta rätt stöd till unga vuxna efter förlust krävs mer kunskap om deras specifika situation.

Tre teoretiska ramverk har använts för guidning och tolkning i denna avhandling; the dual process model of coping with bereavement, the integrative risk factor framework for the prediction of bereavement outcome och systemteori. The dual process model of coping with bereavement beskriver sorgprocessen som en

pendling mellan mer plågsamma förlustorienterade stressfaktorer och mer framtidorienterade, återuppbyggande stressfaktorer. The integrative risk factor framework for the prediction of bereavement outcome utgör ett komplext ramverk av interagerande faktorer och syftar till att tillhandahålla ett sätt att förstå hur individer skiljer sig i sin anpassning efter en förlust. Systemteori ser individen som del av ett system, där alla förändringar påverkar varandra.

Syfte

Det övergripande syftet med denna avhandling var att utforska det psykosociala välbefinnandet hos familjemedlemmar efter en nära persons död, med ett särskilt fokus på unga vuxna som förlorat en förälder i cancer.

Metod

Avhandlingens studier har genomförts med både kvalitativ och kvantitativ forskningsmetod. Två olika studiepopulationer används för att svara på det övergripande syftet.

I studie I intervjuades 25 familjemedlemmar, över 18 år, som förlorat någon närstående på en specialiserad palliativvårdsinrättning. Här pågick ett vårdutvecklingsprojekt med syfte att identifiera närstående med behov av särskilt stöd. Identifieringen gjordes utifrån en checklista med riskfaktorer där familjer med plötsliga eller svåra dödsfall och familjer med barn eller unga vuxna i familjen erbjöds särskilt stöd, exempelvis från läkare eller kurator. Unga vuxna som förlorat en förälder erbjöds stödgruppsdeltagande. Familjer utan riskfaktorer erbjöds ett basutbud av stöd som gavs till alla. Genom ett strategiskt urval intervjuades familjemedlemmar från alla tre riskgrupperna. Av dem som intervjuades var 13 partners, 8 vuxna barn, 2 vänner, 1 förälder och 1 brorson. I intervjuerna tillfrågades de närstående om sina erfarenheter av stödjande interaktioner med vårdpersonal och sina känslomässiga upplevelser i samband med dessa interaktioner. Intervjuerna analyserades med kvalitativ innehållsanalys.

Studie II-IV, involverade 77 unga vuxna, 16–28 år, som förlorat en förälder i cancer och som deltog i stödgrupp. Deltagarna rekryterades från tre olika specialiserade palliativvårdsinrättningar där stödgrupper bedrevs. Stödgrupperna leddes vardera av två professionella gruppledare. Grupperna träffades 7 eller 10 gånger och syftade till att ge deltagarna en tid och plats där de kunde dela sina erfarenheter, känna att de inte var ensamma i sin situation, och där de kunde ge och få stöd från jämnåriga såväl som från professionella gruppledare. Enkäter besvarades vid tre mätillfällen; innan starten av stödgruppsdeltagandet (omkring 5–8 månader efter deras förälder dött), efter den sista då stödgruppträffen (omkring 8–12 månader efter dödsfallet) samt sex månader efter den sista stödgruppträffen (omkring 14–18 månader efter

föräldrarnas död). Enkäterna innehöll frågor relaterade till förlusten och faktorer som kan ha betydelse för återuppbyggnaden efter förlusten. Enkäterna omfattade också frågor om det psykosociala välbefinnandet samt validerade mätskalor för att mäta självkänsla, symtom på ångest och depression och livstillfredsställelse. Studie II var en tvärsnittsstudie där data från det första mättillfället analyserades med deskriptiv statistik. Studie III var en longitudinell studie där det psykosociala välbefinnandet hos de 55 deltagare som besvarat alla tre enkäterna följdes över tid. Studie IV var en associationsstudie där sambandet mellan självkänsla och symtom på ångest och depression analyserades. I studie III och IV användes deskriptiv och analytisk statistik.

Resultat

Studie I visade att familjemedlemmarna hade erfarenheter av stöd både från basutbudet och det specialiserade stödet. Sju av de 17 deltagare som kvalificerat sig för specialiserat stöd hade fått hjälp av en kurator. Den induktiva analysen ledde fram till fem kategorier av stödjande interaktioner som parades ihop med fem kategorier av känslomässiga erfarenheter. Resultatet visade att tydlig information som gavs i en ärlig dialog gav känslor av visshet och säkerhet. Empatiska och flexibla möten med vårdpersonalen gav känslor av värme och tröst. Vårdpersonal som hade sitt fokus på både patienten och den närstående ingav känslor av värde hos de närstående. Positiva upplevelser av den fysiska miljön men också atmosfären, medförde känslor av värdighet och harmoni. Efterlevandestöd gav känslor av säkerhet och styrka. Stödgrupperna till unga vuxna nämndes av de som kommit i kontakt med dem som särskilt betydelsefulla. När interaktionen med personal eller miljö upplevdes som negativ gav det istället upphov till negativa känslor.

I studie II–IV var medelålder 24 år för de unga vuxna vid studiens början. Sysselsättningsgraden var hög och lite mer än hälften hade en partner. Drygt hälften bodde tillsammans med den döde föräldern vid tiden för dödsfallet. Resultatet visar att deltagarna hade ett allmänt dåligt psykosocialt välbefinnande. Många rapporterade symtom på ångest, låg livstillfredsställelse och känslor av ensamhet på grund av att föräldern hade dött samt känslor av att vara annorlunda än sina jämnåriga. Resultatet demonstrerar en begränsad medvetenhet om föräldrarnas nära förestående död, där ett flertal inte förväntade sig dödsfallet då det skedde. Några delar av resultatet visar på styrkor som en normal självkänsla, stöd från och möjlighet att dela sin sorg med familj och vänner liksom en stark tro på en meningsfull framtid. Under uppföljningstiden skedde små förbättringar av välbefinnandet. Symtomen på depression minskade, tron på en meningsfull framtid ökade liksom tillfredsställelsen med sexlivet, relationen till partnern (för de som hade en partner) och den psykologiska hälsan. Resultatet visade vidare att en hög självkänsla vid det första mättillfället var associerad med färre symtom på ångest och depression

både vid det första och det sista mättillfället. Självkänsla var också associerad med förändringar i ångestsymtom mellan det första och sista mättillfället, men inte med förändringar i depressionssymtom.

Slutsatser

Denna avhandling bidrar med värdefull kunskap om det psykosociala välbefinnandet hos familjemedlemmar efter förlust, och särskilt om unga vuxna som förlorat en förälder i cancer. En omfattande kunskap har uppnåtts genom att följa de unga vuxnas psykosociala välbefinnande över tid och genom att studera komplexa förhållanden mellan faktorer som är viktiga för det psykosociala välbefinnandet efter förlust.

Avhandlingen bidrar med kunskap som stöder uppfattningen att unga vuxna utgör en särskild grupp efter förlust, och att de i viss mån skiljer sig från vad tidigare forskning har visat gälla för yngre och äldre som förlorat en förälder. Resultaten indikerar således att unga vuxna som förlorar en förälder i cancer skulle kunna dra nytta av att uppmärksammas som en särskild grupp med specifika behov relaterade till vad som utmärker deras utvecklingsfas.

Trots att resultatet visar på en sårbarhet efter förlusten genom det allmänt dåliga psykosociala välbefinnandet så finns det också faktorer som kan fungera som skyddande för de unga vuxna, till exempel normal självkänsla och ett stödjande socialt nätverk. Detta antyder att de unga vuxna kan ha en resiliens, en motståndskraft, i sin sorg och att de i viss utsträckning skulle kunna skyddas från långvariga problem på grund av dessa skyddande faktorer, vilket gör att de på sikt skulle kunna utveckla ett gott psykosocialt välbefinnande.

Utveckling av ett gott psykosocialt välbefinnande kan också främjas av stödjande interaktioner från vårdpersonal, om de uppfattas som hjälpande. Bristande stöd kan istället ge upphov till negativa känslor som minskar det psykosociala välbefinnandet. Stödinsatser behöver därför anpassas till varje individs unika behov.

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