

# **Improving social network support for partners facing spousal cancer while caring for minors**

A randomized controlled trial

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*“If I had one minute to myself, everything was completely black.”*

- Mother with experience of caring for several minor children while facing spousal cancer



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## **Scientific environment**

The PhD candidate has been employed at the Center for Crisis Psychology (CCP) and affiliated with the Department of Psychosocial Sciences, Faculty of Psychology, University of Bergen (UiB). The doctoral training was conducted at the Graduate School of Clinical and Developmental Psychology (CDP) at UiB.

The main supervisor was Professor Jon Christian Laberg (UiB) until December 2015, followed by Dr May Aasebø Hauken (CCP) in 2016. Co-supervisors were Professor Stig Berge Matthiesen (BI Bergen Business School), Professor Jon Christian Laberg (in 2016) and Dr May Aasebø Hauken (until December 2015).

The PhD candidate attended the Operational Psychology research group at UiB and the interdisciplinary research group at CCP. The study's Advisory Board consisted of experienced researchers and clinicians from Norway, Denmark and the Netherlands.

The PhD candidate had a study visit at Utrecht University in the Netherlands in 2015, as well as at the University of Minho in Portugal in 2016, where she met with researchers in the field of social support and cancer.

The Research Council of Norway and Norwegian Directorate of Health funded the study.

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Bergen, 19<sup>th</sup> of December 2016

Mette Senneseth

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**Abstract**

This is a study of the impact of a psycho-educational social support intervention on partners' social support and well-being in the face of spousal cancer. The study is part of the larger Cancer-PEPSONE study conducted at the Center for Crisis Psychology (CCP) in Bergen, of which the overall aim is to secure children's safety and quality of life (QOL) when living with parental cancer.

The present study's focus is the partners who concomitantly are caring for minors (the "well parents"). The adverse effects of spousal cancer on partners' health and well-being are heavily documented and may affect the well parents' parental capacity. Social support has the potential to reduce the negative impacts of stress on health and well-being, and may be of special value for well parents who are heavily burdened while juggling multiple caregiver roles. Untapped support resources may exist in their informal social networks. However, well parents experience difficulties in initiating support and sustaining support over time, while members of these social networks are often unsure of their supportive roles and call for advice and open communication with the affected families so as to be empowered as supporters. Still, no existing interventions seem to target the enhancement of social networks' support of families facing cancer, and research on this topic is scarce. Accordingly, the Cancer-PEPSONE programme (CPP), which is a psycho-educational intervention that covers these families and their social networks, was developed in Norway. CPP is a manual-based and home-based single-session intervention, provided by a psychologist.

The main aim of the present study was to assess the impact of CPP on the social support received and perceived by well parents, as well as their psychological distress, QOL and parental self-efficacy. Furthermore, the study aimed to explore the well parents' levels of psychological distress, QOL, social support and hardiness, and to explore the relationship between these variables. The study was an open, single-centre randomized controlled trial (RCT) with a longitudinal design, including an intervention group and a control group.



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The sample consisted of 35 well parents who were living with a partner suffering from cancer while caring for at least one minor child (<18 years of age). The intervention group (N=17) received CPP together with their selected social network members, while the control group (N=18) received support as usual from their social networks. Data were collected at three time points: baseline (T1), three-month follow-up (T2, approximately one month after the CPP intervention), and six-month follow-up (T3, approximately four months after the CPP intervention). Data were obtained using validated questionnaires.

Based on the study's baseline data, Paper 1 explored the social support, psychological distress, QOL and hardiness of well parents (N=35). Fifty percent of well parents reported symptoms of psychological distress above the cut-off value for probable psychological illness, which may indicate the need for psychological treatment. Well parents' psychological distress seemed to be associated with their not being in control of their futures. Well parents seemed to have QOL impairments as compared to the QOL of the healthy Norwegian adult population and non-parental caregivers in Norway. Supporting the stress-buffering hypothesis, multiple regression analyses found that the social support provided by social networks seemed to buffer the adverse effects of psychological distress on well parents' QOL. QOL acted as a mediator between personal resilience qualities (hardiness) and psychological distress, meaning that hardiness influenced psychological distress through QOL.

Paper 2 focused on the first two waves (T1 and T2), analysing the short-term effects of CPP, as assessed one month after the intervention. Findings from repeated measures multivariate analyses of covariance (MANCOVA) revealed that the intervention group experienced increased levels of received and perceived social support after one month. This finding was contrasted with a significant decrease in social support for controls. Results did not prove any short-term effects on well parents' psychological distress and QOL. However, a multiple regression analysis suggested that CPP might have an indirect effect on well parents' QOL through the improvement of social support.

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Paper 3 focused on all three waves (T1-T3), analysing the four-month effects of CPP using linear mixed models (LMM) analysis. After four months, CPP seemed effective in sustaining well parents' received and perceived social support, as well as enhancing their parental self-efficacy. Results did not prove any intervention effects on well parents' psychological distress or QOL. However, a multiple regression analysis suggested that CPP might have an indirect effect on well parents' psychological distress through the improvement of social support.

To summarize, the study found that the well parents are largely distressed and that their QOL is at risk, but that social support may buffer the negative consequences of their psychological distress on their QOL. Healthcare professionals ought to have a special focus on these well parents, particularly given that their psychological distress and QOL impairments may affect their capacity to care for their children. Furthermore, healthcare professionals need to acknowledge social support as an important factor for well parents' well-being and help facilitate the optimization of this social support. CPP seems to help improve and sustain social support for the well parents as well as enhancing their parental self-efficacy. Hence, CPP seems to address a gap in the existing psychosocial interventions. These are encouraging results and may be beneficial for the well-being of both well parents' and their children. Nonetheless, a follow-up CPP session may be required in the programme to optimize social support in the longer-term for the well parents. Furthermore, a larger focus on practical support may be required to better target well parents' psychological distress and QOL. Considering the study's small sample size, these results call for confirmation in future studies with larger sample sizes.

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## List of publications

1. Senneseth M, Hauken M, Matthiesen SB, Gjestad R, Laberg JC. Facing spousal cancer during child-rearing years: do social support and hardiness moderate the impact of psychological distress on quality of life? *Cancer Nursing*, 2016. DOI:10.1097/NCC.0000000000000379.[Epub ahead of print]
2. Senneseth M, Dyregrov A, Laberg JC, Matthiesen SB, Pereira M, Hauken M. Facing spousal cancer during child-rearing years: the short-term effects of the Cancer-PEPSONE programme – a single-center randomized controlled trial. *Psycho-Oncology*, 2016. DOI: 10.1002/PON.4329. [Epub ahead of print]
3. Senneseth M, Dyregrov A, Matthiesen SB, Pereira M, Hauken M. Improving social network support for partners facing spousal cancer while caring for minors: four-month outcomes of a single-center randomized controlled trial. *Manuscript submitted for publication*.

In the thesis, these publications are referred to as Paper 1, Paper 2 and Paper 3.

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**Abbreviations**

CPP - Cancer-PEPSONE programme

ISRCTN - International Standard Randomized Controlled Trial Number

LMM – linear mixed models

MANCOVA – multivariate analysis of covariance

ML – maximum likelihood

PEPSONE - Psycho-Educational Programme for Social Networks

QOL - quality of life

REK Vest - Regional Ethical Committee of Western Norway

REML – restricted maximum likelihood

RCT - randomized controlled trial

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# 1. Introduction

## 1.1 Scope of the thesis

This study is part of a larger randomized controlled trial (RCT) named the Cancer-PEPSONE study [1], which focuses on the effects of a psycho-educational social support intervention for families living with parental cancer. The overall aim of the Cancer-PEPSONE study was to test whether the Cancer-PEPSONE programme (CPP) would increase parental capacity through the improvement of social network support, thereby enhancing the children's quality of life, as well as securing their safety, when facing parental cancer [1]. CPP is a single-session psycho-educational programme that targets families living with parental cancer and members of their social network. The Center for Crisis Psychology (CCP) initiated and managed the study, while the Research Council of Norway and the Norwegian Directorate of Health funded the study.

The focus of the present study is the child-rearing partners of cancer patients (the “well parents”). These well parents are juggling multiple caregiver roles, as they are practically and emotionally caring for both their ill partner and their children while taking responsibility for most household and parental tasks, as well as trying to meet the requirements of their paid work [2]. A growing body of literature has documented that such partners struggle with several psychological reactions, such as anxiety and depression [3, 4], and also face QOL impairments [5, 6]. Social support is identified as an essential factor for well parents' QOL [6] and may help to alleviate their burden, thereby reducing psychological distress and improving their parental capacity.

The present study specifically evaluates whether CPP improves the well parents' social network support, QOL and parental capacity, as well as reducing their psychological distress. Data were collected pre-test (T1), at the three-month follow-up (T2, on month post-intervention) and at the six-month follow-up (T3, four months post-intervention).



## 1.2 Structure of the thesis

Chapter 1 covers the introduction and structure of the thesis. Chapter 2 presents the state of current knowledge, derived from an extensive literature search, wherein systematic reviews from the psychosocial oncology field are particularly emphasized. Chapter 3 outlines the study's theoretical framework and the key concepts and definitions of the thesis. Although several theories could have been used to guide this study, a theory of how social support may act as a buffer against stress – the stress-buffering model – was selected. Well parents face a stressful life situation regarding their spouse's cancer illness. Consequently, the stress-buffering model provides an expedient understanding of how social support may influence well parents' well-being in the face of spousal cancer. Accordingly, the improvement of social support provided to these well parents may reduce the impact of the stressful situation on their well-being. Guidelines for social support interventions, emphasizing the essential role of psycho-education, are also outlined in the theoretical framework.

Based on the above-mentioned chapters, chapter 4 provides the study's aims, research questions and hypotheses. Chapter 5 covers the study's methodology, including study design, materials and methods. Findings are presented in chapter 6, and they are structured in accordance with each of the three papers that constitute the research. The three papers follow a chronological structure according to the study's three waves (T1-T3) of data collection. Finally, chapter 7 encompasses critical discussion of the study's findings and methodology, study strengths and limitations, clinical implications and implications for future research, followed by the study's conclusions.

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## 2. Current state of knowledge

### 2.1 Parental cancer has a huge impact on family life

Norwegian family life can be hectic with both parents usually working outside home and with parents and children having tight schedules encompassing school, leisure activities, homework and household tasks. Statistics Norway draw a picture of Norwegian parents highly prioritizing time spent with their children, while having a busy everyday life in which they have less time for communication with their children and adult social interactions than they did only a few decades ago [7]. This busy everyday life, in which parents feel that they do not have enough time with their children because of work or other tasks, is commonly referred to as “the time squeeze” [8].

Parental cancer changes the life situation of all family members [6, 9-12] and has substantial consequences for family life. Every year, in Norway, almost 2000 families with minor children years encounter parental cancer [13]. In 2007, more than 20,000 Norwegian adults with minor children (< 18 years of age) were registered as having or having had a cancer diagnosis [13]. This constitutes a considerable population for whom parental cancer poses special challenges, affecting all family members, including well parents and children [10, 11, 14]. For these families, the time squeeze is subject to a new major factor: parental cancer. As cancer treatment is multimodal, long-lasting and followed by physical and psychosocial side effects [15], the ill parents frequently experience role-loss related to work, domestic tasks and childcare [16]. Filling this gap, the well parents report increased role strains, as well as stress reactions, anxiety and depression [16-18]. For many affected families, this co-occurrence of disease-specific and familiar challenges impose difficulties in maintaining an ordinary everyday life [16, 19].

A key finding from a Norwegian study of children living with parental cancer was that the well parents had too little support to be the “backbone” of the family [16]. In line with findings from other studies [20, 21], both the well and the ill parents reported the need for

more help in order to maintain their parenting capacities. Some parents claimed that meeting their children's needs for living a life closest to their previous “normal” life was impossible without help [16]. Although families facing cancer may experience high support at the time of diagnosis, they often experience difficulties in sustaining support over time [16, 22, 23]. Furthermore, some find it hard to admit to needing help [24], as well as to reach out and ask for help [2, 16, 25]. Moreover, members of social networks may be unsure of their supportive roles and afraid of invading the family’s privacy or saying something “wrong”, and may need guidance in order to be able to provide helpful support over time [26, 27].

Phrases such as “new roles without a script” and “balance artistry” may characterize the roles and lives of well parents while facing spousal cancer [2, 24]. Well parents must balance the needs of their partner and their children, taking over more household and parenting tasks, while simultaneously maintaining their occupational obligations. Some of their main concerns regard changes in marital and family dynamics, disruptions in daily routines and the responsibility of being the main provider of physical and emotional care [28]. Furthermore, they may hold back their emotions and worries, while trying to make the best of the situation for their children [2, 24].

Children living with parental cancer are vulnerable and may need extra parental attention and care [29]. Even if the children are the parents’ first priority and concern [2, 24], parental cancer puts the children’s life out of balance [10], increasing the risk of behavioural, physical, emotional, social and school-related problems [14]. Especially parental illness that is long-lasting, or in a terminal phase, may increase the risk of children internalizing or externalizing problems [30]. However, findings are mixed and inconsistent concerning the specific adverse impacts of parental cancer on children and adolescents. A Norwegian study found small adverse effects on children and adolescents’ mental health (anxiety and depression) and school functioning [31], but included only children and adolescents with parents having a history of cancer, and thus may not reveal the full effects of dealing with current parental cancer. Several studies, however, have

been able to capture the distress of such children [32], and call for more attention and research so as to provide them with appropriate support. Furthermore, several studies emphasize the vulnerability of adolescents in particular, leaving them at risk of internalized psychological problems [32, 33], especially for female adolescents having an ill mother [9, 30, 32-34]. Several studies have emphasized the importance of supporting these children and adolescents, underlining the need for support from both parents, health professionals and other family members [32].

### **2.1.1 The impact of spousal cancer on partners**

A growing body of literature has documented the adverse effects on health and well-being for partners of cancer patients. Partners are at risk of anxiety and depression [3, 35, 36], sleep disorders [37], QOL impairments [6, 28, 38] and physical health impairments [17, 39]. Partners of cancer patients also have more frequent consultations with their general practitioner (GP) than other adults [40]. A large population-based Swedish registry study found that the elevated risk of poorer health for partners, including both the risk of psychiatric and somatic morbidities, was associated with increased healthcare use and healthcare costs [41]. This demonstrates the importance of providing partners of cancer patients with appropriate support, which includes support from tangible informal social networks as well as from health professionals [42].

There seem to be gender differences regarding the adverse impacts of facing spousal cancer. In a meta-analysis comprising of 46 studies of patients and their partners (N=6179), performed by Hagedoorn and colleagues [43], female spouses were found to be more distressed than male spouses. Females spouses were even found to be more distressed than their ill partners, regardless of the stage of illness (early stage/ advanced). Furthermore, a significant association was identified between the level of distress in the patient and the level of distress in the spouse [43].

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### 2.1.2 Parental capacity in the face of cancer

Experiencing a life crisis is linked to impairments in mental health and QOL [44] and may affect parents' parenting capacities [45]. Parental depression, especially, may represent a great risk for their children's development, well-being and school performance [46-48]. Focusing on the ill parent, Rashi and colleagues documented that dealing with cancer while raising children requires the delicate balancing of the illness and parental demands [42]. A similar "balance artistry" is documented by several studies of well parents [2, 24, 49].

One of the first studies to address the parental capacity of the well parent was performed by Siegel and colleagues in 1990 [49]. They found that well parents facing the death of a spouse experienced reduced parenting competence, especially with regard to being emotionally sensitive and responsive to their children's needs, and imposing discipline. In 2005, Helseth and Ulfset noted the limited literature on parenting when a parent has cancer, and they interviewed both the well and the ill parent in a qualitative study [2]. They found that the well parent was trying to make the best of the situation, while living in a state of emergency, striving for normality in an abnormal situation. The needs and well-being of the children were both parents' first priority. The different needs of each family member represented a challenge, where the well parent needed enough energy to care for their family, and both parents needed more energy to be able to make quality time for their children [2]. In line with this, a review of qualitative studies of well parents documented that well parents faced several challenges, such as being unprepared for their children's extra needs, reactions and questions, dealing with own reactions, being concerned about death, and hiding their own fears, and maintaining a job and normal family life [24]. Well parents felt like insufficient "jelly men" in the face of practical and emotional tasks, focusing on anything but themselves [24].

The literature has revealed that the psychosocial functioning of children facing parental cancer largely depends on psychosocial factors, such as family functioning, parental

coping and parental ability to communicate with the children [9, 11]. In line with this, Howell and colleagues [50] found that parental expressive coping and supportive parenting were associated with lower levels of anxiety, depression and post-traumatic symptoms in children, underlining that good parenting while facing cancer is an essential issue. Furthermore, for families facing challenging situations, parental self-efficacy may operate as a protection against risk factors associated with elevated stress [51]. As such, enhancing parental self-efficacy may serve as one potential mechanism by which to improve the well-being of both parents and children. Therefore, some authors have argued that parental self-efficacy should be considered a target for prevention and intervention programmes to improve parenting and support child development [51].

## 2.2 The role of social support for families facing cancer

Support from social networks is highly valued by families coping with cancer [24, 52-54]. A recent study on parents facing paediatric cancer found that social support may reduce parents' psychological distress, and that a large social support network may buffer the relationship between parental anxiety and depression, and later distress [55]. Furthermore, social support has been identified as an essential predictor of the well parents' QOL [6].

Previous studies have shown that families facing cancer may experience that they receive the most support and attention at the early stages of the illness, such as the initial crisis at the time of diagnosis [22]. However, as time passes, this support may diminish and the supporters may withdraw from the family [22]. Furthermore, at the time of diagnosis, the families may perceive immediate offers of support as a sign of sympathy, and may thus find it hard to make use of such offers [56]. Dyregrov and Dyregrov [16] documented that parents facing cancer (both ill and well parents) were in need of more support than they received in order to avoid "hitting the wall". They needed help in taking the children to leisure activities, practical help with domestic tasks and childcare, as well as supportive conversations and social breaks with their friends. Cohering with this, a recent study also revealed unmet needs for these parents, and suggested tangible social networks that meet

the practical needs of the family such as transportation, childcare, meal provision, as well as emotional support [42].

Helseth and Ulfsæt [2] found that parents who were facing their own or their spouse's cancer faced considerable daily practical tasks and logistical challenges. Practical and emotional support was found to be essential, yet the parents found it difficult to ask for help. Fathers, especially, were reluctant to be open regarding their emotional needs. The parents stated that it would be easier if family and friends just came and took over management of such tasks, rather than merely offering their help verbally.

It is also worth mentioning that not all types of support are necessarily entirely positive [57]. Support can fail to meet the needs of people in crisis and certain aspects of support can be experienced as unhelpful or even harmful [26, 58-60]. For example, statements that were intended to comfort, or advice given with good intentions, may minimize the individual's suffering. Furthermore, the support may be unwanted or intrude on private life [22]. In a study of bereaved people, Dyregrov [61] found that the support was considered more helpful when the needs of the bereaved were communicated to their social networks. Likewise, members of these social networks preferred to be guided, advised and trained so as to be able to support the bereaved on their terms [61]. This aligns with research on cancer patients that has found that direct strategies of explicitly requesting support to be more effective in enhancing support than indirect strategies, such as implicit requests [62]. Direct strategies of explicitly requesting support also seem to reduce distress in the supporters, who perceive explicit requests as less demanding than implicit requests [62].

## 2.3 Psychosocial interventions for families facing cancer

Due to its substantial impact on family life, cancer is viewed as a family illness [43, 63]. Accordingly, several psychosocial interventions have been developed to enhance dyadic coping, family functioning and parent-child communication, as well as to support

children's adjustment to cancer and reassure parents in their parenting skills [63, 64]. Findings from a recent systematic review of psychosocial interventions for families with parental cancer reveal that most interventions include either the parents or the children, or both, in meetings with each single family or in groups with several families [64]. Although findings on these interventions' effectiveness are somewhat inconsistent, they generally seem to have beneficial effects regarding family communication, family functioning, individual QOL and mental health, and improving coping strategies. Furthermore, the systematic review identified several barriers for the use of psychosocial support when families are facing parental cancer. Barriers included practical difficulties for the families (e.g., little time), parents impeding emotional engagement (e.g., to prevent overload), disease characteristics (e.g., patient too ill to participate), and lack of collaboration with clinics and institutions (e.g, difficulties in implementation) [64].

Only one programme, Children of Somatically Ill Parents (COSIP) [65], seems to specifically aim to support parents' use of social networks, but does not cover the members of such social networks. Thus, interventions that include these social network members, in order to increase families' social support, seem to be lacking. Furthermore, there seems to be a lack of knowledge in the psychosocial oncology research field on regarding mobilization of social network support for families facing parental cancer.



### **3. Theoretical framework**

#### **3.1 Key concepts and definitions**

##### **Social support**

The term “social support” refers to the processes through which social relationships promote health and well-being [57]. In general, these processes refer to the influence of social support on mental and physical health, through its impact on people’s emotions, cognitions and behaviours [57]. Social support may be defined as the emotional or instrumental resources that are perceived to be available within, or actually provided by, social networks for those in need of such aid [57]. The need for aid in this context is associated with the stressful experience of facing spousal cancer while caring for minors. The social support resources that participants perceive to be available if needed is called *perceived support*, while supportive actions that are actually carried out by members of their social networks are referred to as *received support* [66].

##### **Psychological distress**

Psychological distress often refers to emotional distress symptoms such as symptoms of anxiety and depression [67] and is frequently used in research as an indicator of an individual’s current mental health status [67, 68]. By using a cut-off score in measuring the severity of psychological distress symptoms, one may be able to detect psychological morbidity in a population [67]. Mental health is a significant aspect of the health concept understood by the World Health Organization (WHO) as a state of complete physical, mental and social well-being [69]. As defined by WHO, mental health is a state of well-being in which individuals can cope with the normal stressors of life [69].

##### **Quality of life (QOL)**

QOL is increasingly viewed as an important outcome and evaluation criterion of interventions in health research [70]. QOL is seen as primarily a subjective sense of well-

being encompassing physical, psychological, social and spiritual dimensions [70] (p.738). Hence, QOL is a multidimensional concept covering several areas of life that are seen as essential for an individual's well-being [71]. The concept of overall QOL is specified by summing up the different dimensions, and has been defined as "a person's well-being that stems from satisfaction or dissatisfaction with areas of life that are important to him or her" [72] (p.216). The dimensions included in the overall QOL measure in the present study are "relationships and material well-being", "health and functioning" and "personal, social and community commitment" [73].

### **Hardiness**

Individual resilience refers to one's resistance to and ability to overcome stress or adversity [74]. The concept of hardiness provides a model for understanding an individual's resilient stress response patterns [75-77]. Hardy people seem to stay healthy under stress, while less hardy people seem to be at risk of developing stress-related problems [78, 79]. Hardiness can be said to be constituted by the combination of the three C's: commitment, challenge and control [80]. Commitment relates to seeing life and the world as interesting and meaningful. Challenge relates to seeing change and challenges as opportunities to learn and develop, rather than as problems, while control relates to the belief in one's own ability to influence or control situations and life events [75]. The "hardy style" comprises a strong sense of commitment, control, and challenge [75] and is closely linked to several stress mitigating variables, such as coping strategies and social support [81], as well as QOL [81, 82]. Although individuals' hardiness levels may be relatively stable over time, hardiness may also be influenced by social and environmental factors. Thus, hardiness is seen as a generalized style of functioning rather than a fixed personality trait [75].

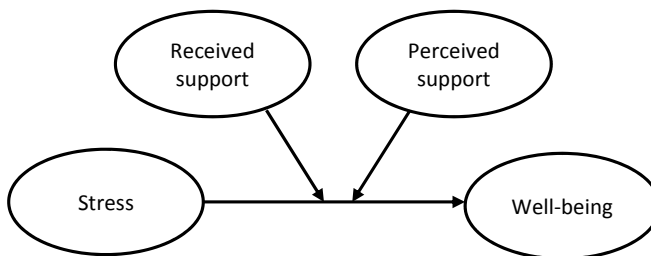
### **Parental capacity and parental self-efficacy**

Parental capacity has been defined as the capacity to parent in a "good enough" manner long-term [83], and refers to the parents' ability to nurture their children, protect them

from risk and enhance their developmental experiences [84]. Parental self-efficacy is a key construct implicated in parental capacity [85] and may be defined as parents' sense of competence in parenting tasks [86]. Parental self-efficacy and psychological well-being, as well as family functioning and parental social support are proposed to constitute the essential factors for the ability to parent despite the presence of risk factors [85].

### 3.2 Social support and the stress buffering-hypothesis

Although the causal mechanisms are not yet fully understood [87], two major models have been proposed to explain the link between social support and well-being: the direct (main) effect model and the stress-buffering model [88]. The main effect model proposes that social support will influence health regardless of any life stressors, while the stress-buffering model proposes that social support will reduce adverse effects on health in the face of stress specifically. Each model represents a different process through by which social support may affect well-being [57]. The present study's focus is well parents who are facing a stressful life situation regarding their spouse's cancer illness. Accordingly, the impact of social support on these well parents' well-being is understood within the theoretical framework of the stress-buffering model (Figure 1).



**Figure 1** The buffering model.<sup>1</sup> © Copyright Oxford University Press

<sup>1</sup> Derived from Cohen et al. (2000). By permission of Oxford University Press, USA.

The stress-buffering model proposes that a stressful life event will give rise to stress reactions that negatively impact upon an individual's well-being, while received and perceived social support are seen as "buffers" (protectors) from the potentially pathogenic consequences of such stress reactions [88]. Hence, the model suggests that a stressed individual's well-being will vary according to the level of social support he or she receives or perceives to be available to him or her.

The stress-buffering model is closely linked to the stress and coping perspective [85], according to which social support is thought to affect a person's well-being through its impact on coping and appraisal [57]. Coping has been defined as the cognitive and behavioural efforts made to master, tolerate or reduce external and internal demands, and the conflicts between them [85]. Furthermore, coping is seen as a process that is constantly changing in relation to the context. Coping may be both problem-focused, aimed at solving the problem causing distress, as well as focused on the regulation of emotions caused by the problem [89]. Appraisal is defined as the cognitive process through which an event is evaluated with respect to what is at stake and what coping resources and options are available [90]. In the face of stressful life events, supportive actions (received support) are thought to promote coping, while perceptions of the availability of such support (perceived support) are thought to promote less negative appraisals of stress. In this way, actual received support and perceived available support may influence well-being and health in different ways [57].

### 3.3 Optimizing social support: when and how

Interventions to optimize social support in the natural network are widely used in relation to a broad range of conditions, including somatic and mental illnesses, as well as developmental disabilities [91]. These interventions are heterogeneous and may differ along a number of elements, yet they all share the aim of improving the quantity and

quality of support provided by family, friends and other social network support members [91]. The most common long-term goals of such interventions are to enhance support in order to prevent or diminish the adverse effects of stress on mental or physical health, to promote and sustain positive health behaviours and to maximize the supporters' capacity to care [91].

According to Benjamin Gottlieb [92], social support interventions within the natural support network may be required in cases in which the fulfilment of health goals depends on key support providers or network members, or when the existing networks need to be strengthened to meet long-term support needs. Families dealing with parental cancer may be in increased need of social support from their social networks over a prolonged period, in order to maintain their well-being throughout the course of the illness. Thus, social support interventions within their natural network may be useful in order to enhance and secure long-term support, as well as to strengthening the social support networks. Cutrona and Cole [91] outline several mechanisms and techniques for increasing support in the natural network. Amongst these are the mechanisms for increasing understanding, changing attitudes, improving interaction skills, increasing communication, coordinating responsibilities, strengthening bonds with positive network members and supporting the supporters. Techniques that may be used to promote these mechanisms are (pp.282):

- ◆ Providing educational programming on the specific problem faced by the individual.
- ◆ Providing opportunities to network members to meet as a group and facilitating open communication.
- ◆ Encouraging network members to commit to specific support responsibilities.

Cutrona and Cole [91] claim that several theoretical frameworks underlie psychosocial interventions that aim to optimize social support within the natural network. For example, empathy-altruism theory (i.e., education may increase understanding and boost the supporters' empathy), diffusion of responsibility theory (i.e., supporters must take action

and not rely on others providing support), and social learning theory (i.e., education and reinforcement). According to all three of these theories, education (or psycho-education) is an essential aspect of interventions to improve social support.

### **3.3.1 Psycho-education**

Psycho-education has proved to be an effective evidence-based practice that has broad potential for many forms of illnesses and life challenges [93]. Psycho-education is a professionally delivered treatment modality that integrates psychotherapeutic and educational interventions through a holistic and competence-based approach, emphasizing health, collaboration, coping and empowerment [93]. Psycho-educational interventions build on several theories, such as ecological systems theory, cognitive behavioural theory and learning theory, providing a framework for understanding one's experience in relation to environmental factors, as well as for problem-solving and coping skills training [93]. Furthermore, psycho-education embraces several models in clinical practice, such as group practice models, stress and coping models and social support models [93].

Psycho-education is well established as a supplemental treatment for cancer. It has proved to be effective in improving the well-being of patients, as well as their family members [93, 94]. The purpose and content of the psycho-education seem to be essential to its effectiveness [95, 96], and psycho-educational interventions provided by professionals seem to be more effective than peer discussion [97]. Lukens and McFarlane [93] states that psychoeducation has the potential to extend the impact of care provisions beyond the immediate situation, by activating and reinforcing support systems, which may supplement and enhance the mechanisms of stress-buffering [91].

## **3.4 The theoretical framework's reflection in the three papers**

This theoretical framework forms the theoretical background for the present study. As a starting point, the stress-buffering model guided the analysis of the baseline data (Paper

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1), in which both perceived and received social support were tested as moderators of the relationship between participants' stress and their well-being. Here, the concept of stress was operationalized through symptoms of psychological distress, while well-being was operationalized through overall QOL. The potential stress-buffering effect of hardiness [81] was also tested in a moderation model, in which hardiness was tested as a potential moderator of the relationship between psychological distress and QOL. To gain more insight into the relationship between hardiness and psychological distress, this relationship was tested in a mediation model with QOL as a potential mediator.

In the following papers (Paper 2 and 3), the scope was the effects of CPP. Intervention effects were assessed in received and perceived social support, psychological distress and QOL (Paper 2 and 3), as well as in parental self-efficacy (Paper 3). In addition to testing the programme's effects, social support was tested as a mediator between receiving CPP and the outcomes, so as to identify whether the programme affected the outcomes through the improvement of support as expected, given the theoretical framework. With reference to how received social support is thought to affect well-being through coping, received social support was tested as a mediator between receiving CPP and well parents' QOL at T2 (Paper 2). In Paper 3, with reference to how social support is linked to (mental) health, total social support was tested as a mediator between receiving CPP and well parents' psychological distress (Paper 3).

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## 4. Aims, research questions and hypotheses

The main aim of the present study was to assess the impact of CPP on the well parents' received and perceived social support, psychological distress, QOL and parental self-efficacy. Furthermore, the study aimed to explore the levels of psychological distress, QOL, social support and hardiness for the well parents, and to explore the relationship between these variables. Based on the above-outlined state of knowledge and theoretical framework, the study had three research questions and six hypotheses. The study had the following research questions at T1:

1. Do well parents facing spousal cancer experience more psychological distress and impairments in their QOL, as compared to other adults and non-parental caregivers in Norway? (Paper 1)
2. Do perceived and received social support, together with hardiness, act as moderators in the relationship between psychological distress and QOL? (Paper 1)
3. Does hardiness affect psychological distress directly or indirectly through QOL? (Paper 1)

The study had the following hypotheses at T2 and T3:

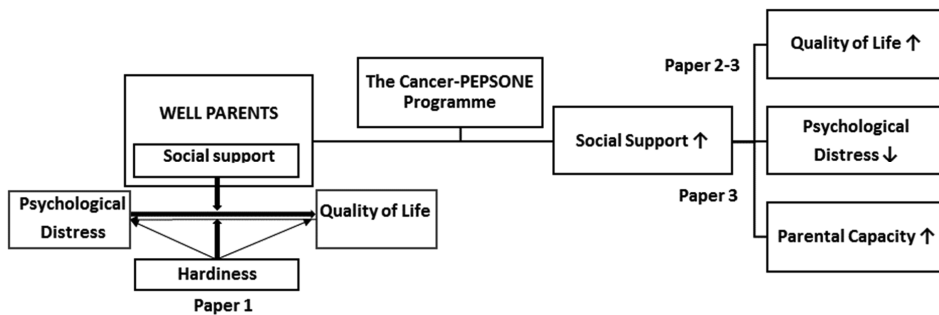
1. CPP will increase the well parents' received and perceived social support in the short-term (after one month). (Paper 2)
2. CPP will reduce psychological distress and improve QOL of the well parents in the short-term (after one month). (Paper 2)
3. Received social support will mediate the impact of the programme on psychological distress and QOL at T2. (Paper 2)
4. CPP will predict improved and/or sustained levels of received and perceived social support for well parents after four months. (Paper 3)
5. CPP will predict less psychological distress, better QOL and more parental self-efficacy in well parents after four months. (Paper 3)



6. Social support will mediate the relationships between receiving CPP and well parents' psychological distress and parental self-efficacy. (Paper 3).

## 4.1 Conceptual model

Figure 2 summarizes the study's conceptual model and outlines the scope of the three papers, which in turn address the above-mentioned aims, research questions and hypotheses.



**Figure 2** The study's conceptual model

At baseline, the well parents were assumed to have high levels of psychological distress and impaired QOL. Social support and hardiness were hypothesized to moderate the relationship between psychological distress and QOL, while QOL was tested as a mediator of the relationship between hardiness and psychological distress (Paper 1). Next it was hypothesized that CPP would improve well parents' social support, thereby reducing psychological distress and improving QOL (Papers 2 and 3) and parental capacity (Paper 3).

## 5. Methodology

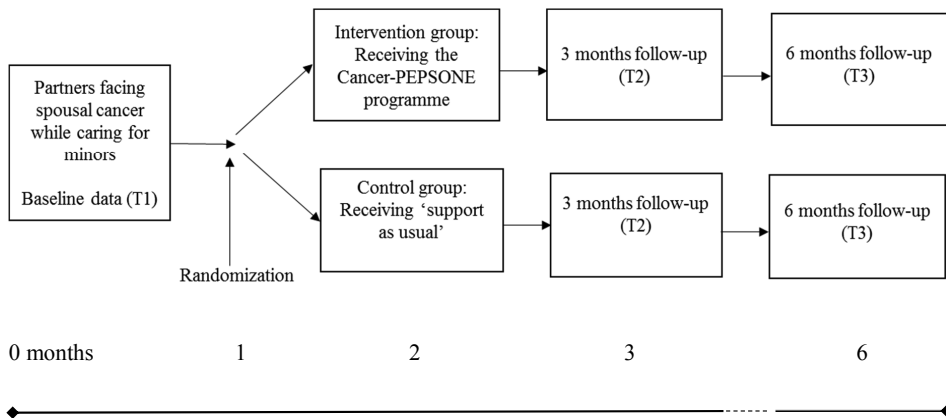
Based on the present study's research questions and hypotheses, the study was conducted as a quantitative experimental study [98]. Quantitative methods facilitate the discovery of quantifiable information [99]. The strengths of quantitative methods are that they can generate factual and reliable outcome data that may be generalizable to a larger population [100]. The quantitative experimental design does not provide in-depth information on the processes and subjective experiences of the study's participants, which could be obtained by using qualitative methods [100, 101].

### 5.1 The study's design

To detect intervention effects, one must eliminate other factors that may influence on, or explain, the study outcomes. The randomized controlled design minimizes the effect of such confounding variables [102]. The randomization (selection by chance) of subjects to the experimental conditions is essential for the strength of this design. Randomly assigning participants to the experimental conditions means that the intervention group and the control group will be similar across important demographic factors, and would have similar outcomes if they were to receive identical interventions [103]. Thus, any observed differences in outcomes are more likely to be attributable to the intervention than to other factors [102, 103]. Due to the power of this design, RCTs represent the "gold standard" in evaluating healthcare interventions [104]. An essential factor in randomization is securing allocation concealment. Allocation concealment is ensured by 1) recruiters/researchers being unable to predict the group to which a participant will be randomized before the he/she is ultimately registered within the study, and 2) recruiters/researchers being unable to change a patient's allocation after they have been randomized [103]. All RCTs should have adequate allocation concealment to avoid selection bias [103]. Randomized trials may also use "blinding" (or "masking") to further minimize bias. Blinding refers to not knowing a participant's allocation throughout the

study, which means that this information is hidden from some, or all, of those who are involved in the study. Thus, blinding eliminates the possibility of response bias due to participants' expectations [105]. However, not all RCTs can, or should, be blinded trials [103]. Due to the nature of the present study, it was not possible to "blind" participants, nor researchers or programme providers, to the group assignment, so the unblinded (open) RCT design was used. This design is common for non-pharmacological RCTs [106].

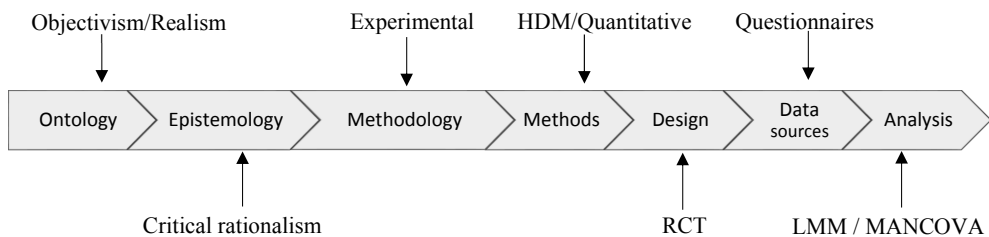
The study was carried out by a single centre, hence, the study is an open single-centre RCT, with a parallel group design, including an intervention group and a control group [98] (Figure 3). Accordingly, the study's methods and results are reported in line with the Consolidated Standards of Reporting Trials (CONSORT) guidelines for RCTs of nonpharmacological treatment [103]. Moreover, this study is longitudinal, in which both groups were studied at three measurement points (T1-T3) during a period of six months. The study was registered in an international database for RCTs, trial number 15982171 (ISRCTN).



**Figure 3** The study's design

### 5.1.1 Positioning the study in the philosophy of sciences

Several philosophical assumptions were made in the choice of the study's research design. Ontologically, it was assumed that psychosocial outcomes exist in a matter that can be observed and measured quantitatively, which relates to ontological objectivism [107]. Furthermore, it was assumed that these outcomes could be objective and stable enough to be subject to measurement even if they are not materialistic, which relates to ontological realism [107, 108]. Accordingly, it was assumed that the psychosocial outcomes could be operationalized in such a way as to render them measurable and accessible through questionnaires. Epistemologically, it was assumed that hypotheses could be tested (or rejected), which may be seen to align with Karl Popper's critical rationalism and his theory of falsifiability [109]. Methodologically, it was assumed that causal relationships could be detected through experimental methods, including both an intervention group and a control group. To be able to accept the alternative hypothesis (there is a difference between the groups' outcomes post-intervention), one must be able to reject the null-hypothesis, based on quantitative data and appropriate statistical analyses (hypothetico-deductive method, HDM) [101]. To summarize, Figure 4 illustrates the study's positioning in the field of philosophy of science.



**Figure 4** Positioning of the study in the field of philosophy of science

## 5.2 Participants

### **Inclusion and exclusion criteria**

Inclusion criteria in this study were Norwegian well parents who: 1) were living with a partner/spouse who had been diagnosed with cancer within the last five years and were treated/in treatment for cancer; 2) were parenting minor children (<18 years of age); and 3) were able to read, understand and write in Norwegian. Exclusion criteria were 1) if the ill partner had died, or 2) if the well parent was presently suffering from their own serious disease (e.g., cancer).

### **Recruitment**

Recruitment took place nationwide in Norway from December 2013 to July 2015. A professional network comprising cancer nurses and child-responsible healthcare professionals at hospitals, as well as cancer coordinators in the municipalities, recruited participants for the study and made contact with the researchers. Participants also self-recruited by responding to information provided in posters and leaflets, as well as on the Internet.

### **Sample**

The sample comprised 35 Norwegian well parents – 21 males and 14 females – who were facing spousal cancer while concomitantly caring for minor children (Table 1). Participants were, for the most part, highly educated and working full-time. They had a mean age of 45 years and an average of two minor children. Participants were spread throughout the country, in the northern, southern, eastern and western parts of Norway. On average, the ill partner was 46 years of age and had been suffering from cancer for more than two years (Table 1). Almost two thirds of the ill partners (22 out of 35) had cancer metastasis (advanced cancer). The cancer types involved were breast cancer, gynaecological cancer, gastrointestinal cancers, lymphoma, lung cancer, sarcoma,

prostate cancer, testicular cancer, leukaemia, neuroendocrine cancer, melanoma, and brain cancer.

The participants in the intervention group invited 130 social network members to participate in the CPP meeting. The participants selected their supporters themselves, based on the people they wanted support from, who had the ability to provide support and who lived nearby. Supporters were friends (44%), close family members (34%), other relatives (8%), colleagues (3%), neighbours (2%) and others (8%) (1% not stated). The median value was seven supporters per family, ranging from two to 15 supporters.

**Table 1** Sample characteristics (N=35)

	<b>n (%)</b>	<b>Mean (SD)</b>
<b>Gender</b>		
<b>Female</b>	14 (40)	
<b>Male</b>	21 (60)	
<b>Age, years</b>		45 (7)
<b>Education</b>		
<b>College /university</b>	19 (54)	
<b>High school</b>	11 (31)	
<b>Primary/grammar School</b>	5 (14)	
<b>Occupation</b>		
<b>Full-time</b>	24 (69)	
<b>Part-time</b>	4 (11)	
<b>Other/none</b>	7 (20)	
<b>On sick leave</b>	4 (11)	
<b>Ill partner</b>		
<b>Age, years</b>		46 (8)
<b>Months since diagnosis</b>		27 (39)
<b>Cancer metastasis</b>	22 (63)	
<b>Children</b>		
<b>Total in sample</b>	64 (100)	
<b>Children per family</b>		2 (1)
<b>Age, years</b>		11 (4)

At T3, 40% of participants had dropped out of the study. A CONSORT 2010 diagram of the participants' flow throughout the study is outlined in Appendix A.

### **Enrolment and randomization**

Upon referral of potential participants, each were contacted by telephone, assessed for eligibility and, if eligible, provided with pre-test (T1) questionnaires by post.

Questionnaires did not ask for any direct identifying personal information, but were pre-marked with a six-digit code for participant identification by researchers. The project leader monitored the randomization procedure. Participants were randomized by equally allocating the returned envelopes to either the intervention or control group (1:1) in the order of their return and prior to their identification, in accordance with a confidential list in a password-protected file. Thus, in line with Vickers [103], allocation was concealed from the recruiters, the researchers, the study's participants and the programme providers until the pre-tests were completed and the randomization had taken place.

All participants received a letter informing them about their allocation. Shortly after randomization, one of the three psychologists, in turn, contacted participants allocated to the intervention group and scheduled an appointment at their home. Participants in the intervention group were asked to select and invite informal social network members to a network meeting at which they would receive the intervention. They were asked to invite persons (>18 years of age) from whom they wanted support and who had the potential to support or improve in their role as supporters, and who lived nearby.

## **5.3 The intervention**

The intervention tested in the present study's was the Cancer-PEPSONE Programme (CPP) [1], which is a manual-based single-session psycho-educational programme for families dealing with parental cancer and their natural social support network.

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## **Programme development**

For decades, psychologists from the CCP have worked with the studied population and provided social network support meetings for families experiencing various life crises. Over years of work, the pre-study steps have followed the phases as described by Campbell et al. [110] and Craig et al.[111]. However, as Craig and colleagues state (p.980), the phases do not necessarily follow a linear or a cyclical sequence. The study was developed based on clinical practice, the current evidence and the aforementioned theoretical framework. The programme's feasibility was tested in a clinical pilot study. Following the first use of a social network support meeting for bereaved parents, the pilot comprised three additional network meetings following the death of a child. Focus group interviews were conducted with the bereaved and their network members based on a theme guide. The feedback from these interviews informed the present intervention. Finally, the intervention was adapted to families living with parental cancer, and the manual was standardized through joint meetings with the psychologists and the researchers [1]. The three programme providers received training on the manual at joint meetings so that their provisions of the programme would be coordinated.

## **CPP elements and implementation**

Participants in the intervention group were provided with the CPP intervention. An experienced psychologist implemented the programme through a three-hour-long home-based network meeting, which included the whole family (both the well and the ill parent, and their children if they wanted to participate) and their selected network members. The intervention was provided in, or near to, the home of the recipients, or at another location of their choice. The manual outlines the detailed elements of CPP and its schedule (Appendix B).

CPP consists of two main parts. The first part (approximately 1.5 hours) is a psycho-educational session, providing information on the challenges faced by families dealing with parental cancer, including challenges related to receiving support. This part covers



the situation and reactions of both the parents and children in the family, their general needs, as well as their needs for support from their social network. The goal of the first part is to increase social networks' understanding of the situation and needs of each individual in the family, emphasize the importance of social network support, and to inform each social network of how to provide support [91]. The second part (approximately 1 hour) is a dialogue-based session, tailored to the particular family. This discussion is intended to increase and improve communication between the family and the members of their natural social network [91]. The families are encouraged to express their specific support needs, while the social network members are encouraged to state the types and frequencies of support to which they can commit. The goals of the second part are to open the communication between the families and their selected supporters regarding support needs and possible support resources, and to strengthening supporters' commitment, removing any barriers to support and avoiding diffusion of responsibility, in order to improve and sustain social support long-term. A detailed description of the background and development of the programme, along with the evidence underpinning it, is provided in a protocol article [1]. An overview of the content and goals of CPP can be found in Paper 3 (Table 2).

Compliance with the planned procedure was reported systematically through standardized written reports from the three psychologists after finishing each intervention session. Additionally, a focus group interview with the psychologists was conducted upon completion of the study interventions, at which they reported that the standardized manual was easy to follow and that it also worked as a checklist. No discrepancies or adverse events were identified or reported by the psychologists.

The control group received "support as usual", including the ordinary care and support from their family, friends and other social network members, as well as from any health professionals involved in their case. Support as usual covered their habitual social support, such as emotional or tangible support, which they may have received from, or perceived to be available, from their social networks. Controls did not receive any

intervention from professionals in relation to the study, however, participation in the study imposed no restrictions on their ordinary support and care. Although support as usual is here equivalent to no intervention, it reflects the only existing “treatment” that is offered to these families. Accordingly, it constituted the “best support available at the time” control group, which should be the control treatment when testing a new intervention [112].

## 5.4 Data collection

Data were collected between December 2013 and January 2016. Data were obtained through questionnaires (Appendix C) at baseline (T1), at the three-month follow-up (T2) and at the six-month follow-up (T3).

A single primary outcome may not make the best use of the data when evaluating complex interventions [111]. Therefore, psychological distress and QOL were selected as primary outcomes together with the received and perceived social support outcomes, which relate to the four primary outcomes outlined in the protocol article [1]. Parental self-efficacy was defined as a secondary outcome. The study’s outcomes were measured at all three time points (T1-T3), while demographic variables and participants’ hardiness were obtained at T1.

Demographic variables were age, gender, education, occupation, number of children in the household and the age of the children. Ill partner variables were age, gender, cancer type and severity (metastasis), and months since diagnosis.

### **Instruments**

To assess participants’ hardiness, the Norwegian version of the *Dispositional Resilience Scale – Revised* (DRS-15-R) was applied [113]. DRS-15-R is reliable and valid, and has demonstrated satisfactory internal consistency [113]. The instrument consists of 15 items scored on a Likert-type scale, ranging from “not at all true” (0) to “completely true” (3). It

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includes the three Cs: commitment (e.g., “most of my life is spent doing things that are meaningful”), challenge (e.g., “changes in routine are interesting to me”) and control (e.g., “how things go in my life depends on my own actions”). The six negatively keyed items were reversed before summation [113], with possible total scores ranging from 0 to 45. A higher score was indicative of more hardiness. At T1, Cronbach’s alpha was .80; for the three subscales: commitment .79, challenge .71, and control .69.

The *Crisis Support Scale* (CSS) was applied to measure received social support. This instrument was selected because it targets social support related to experiencing a life crisis in particular [114], and it has shown satisfactory psychometric properties [115]. The CSS consists of seven items rated from “never” (1) to “always” (7) [115]. The scale includes four positively phrased items (e.g., sympathy and support from others), one negatively phrased item (felt let down), and one overall satisfaction item (overall satisfaction with support received). The negatively phrased item was reversed before summation, such that a higher score indicates more received support. Possible total scores ranged from seven to 49. At T1, Cronbach’s alpha was .75.

The *Multidimensional Scale of Perceived Social Support* (MSPSS), developed by Zimet and colleagues [116], was applied to measure perceived social support available from significant others via the use of the “significant other” subscale. The MSPSS was selected because it has been shown to be psychometrically sound, with adequate construct validity, as well as good reliability and factorial validity [116]. The significant other subscale consists of four items indicating available support (e.g., “there is a special person in my life with whom I can share my joys and sorrows”). Each item is rated on a seven-point scale, ranging from “very strongly disagree” (1) to “very strongly agree” (7). Possible total scores ranged from four to 28. At T1, Cronbach’s alpha was .88.

The 12-item version of the *General Health Questionnaire* (GHQ-12) was applied to measure respondents’ current mental health as compared to their normal states, indicating their level of psychological distress [117]. The GHQ-12 was selected because it is widely

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used as a reliable screening instrument for non-psychotic mental illness outside of a clinical setting [67], and has previously been used with cancer caregivers [118]. The instrument has shown good psychometric properties [119]. The 12 items are scored on a four-point Likert-type scale. Positively worded items (e.g., “been able to enjoy normal day-to-day activities”) are scored from “more than usual” to “much less than usual”. Negatively worded items (e.g., “lost much sleep over worry”) are scored from “not at all” to “much more than usual”. Two different scoring methods were used for this measure in the present study: the Likert scoring method (0-1-2-3) and the GHQ scoring method (0-0-1-1). The Likert method produced a score distribution to assess severity (with possible total scores ranging from zero to 36), while the GHQ scoring method was used for detecting “cases” (with possible total scores ranging from zero to 12) [117]. In both scoring methods, a higher score indicates more symptoms of psychological distress. The threshold (cut-off) for detecting cases was set at 3/4 [119, 120], where a score of four or more may indicate psychological morbidity. At T1, Cronbach’s alpha was .89.

The Norwegian version of the *Quality of Life Scale* (QOLS-N) was selected to measure well parents’ overall QOL [72]. The QOLS-N was selected because it has demonstrated satisfactory psychometric properties in several studies, showing good reliability and validity [72, 73], and has previously been used with cancer caregivers [121]. The QOLS consists of 16 items (e.g., health: being physically fit and vigorous) scored on a seven-point Likert scale ranging from “very dissatisfied” (1) to “very satisfied” (7). A higher score indicates better QOL. The following subscales are suggested by Burckhardt and Anderson [73]: relationship and material well-being (items 3, 4, 5, 6, and 14), health and functioning (items 1, 2, 11, 15, and 16), and personal, social and community commitment (items 7, 8, 9, 10, 12, and 13). At T1, Cronbach’s alpha was .89.

To measure parental self-efficacy, eleven items were chosen from the *Self-Efficacy for Parenting Tasks Index* (SEPTI) [86]. These included seven items in the “discipline” subscale (e.g., “I really don’t have much trouble disciplining my child”), and four items in the “achievement” subscale (e.g., “I am sure my child knows I am interested in his/her life

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at school”) [86]. SEPTI was selected because it is designed to assess parents’ sense of competence in parenting tasks, such as facilitating a child’s achievement in school (“achievement”) and providing structure and discipline (“discipline”). Each of the items were rated on a six-point Likert scale, ranging from “strongly disagree” (1) to “strongly agree” (6). After negatively keyed items were reverse scored and all scores were summed, higher scores indicated higher parental self-efficacy. Possible total scores ranged from 11 to 66. At T1, Cronbach’s alpha of the chosen 11 SEPTI items was .81.

## 5.5 Statistical analyses

An a priori sample size calculation was performed using G\*Power [122]. It estimated that with 34 participants in total, one would be able to detect effects sizes of 0.5 from F-tests at the .05 level of significance and with a statistical power of .80.

All data were coded and processed using the software package IBM SPSS Statistics for Windows version 22.0 (SPSS) [123]. Descriptive statistics, correlation analyses, chi-square tests and independent sample t-tests, as well as repeated measures multivariate analysis of covariance (MANCOVA) [124] and linear mixed models (LMM) [125] analyses were performed using SPSS. The chi-square ( $\chi^2$ ) test was applied to test any differences between sub-groups (completers and non-completers, intervention and control) regarding demographic variables (i.e., gender) and the severity of their partners’ illness (metastasis vs no metastasis), while independent t-tests were used for analysing any group differences in means amongst the dependent variables [124]. There were no statistical significant differences between the intervention group and the control group regarding demographic variables ( $p > .05$ ) or pre-test values ( $p > .05$ ). Non-completers ( $N=14$ , 40%) did not differ significantly from completers in terms of demographic variables or pre-test values ( $p > .05$ ), with the exception of parental self-efficacy, where non-completers reported higher levels than completers ( $p = .02$ ). The non-completers with higher parental self-efficacy had dropped out from both the intervention group and the control group.

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Normally distributed data were reported with the sample mean and standard deviation (SD), while data that were not normally distributed were reported with the median values. Correlations were reported with Pearson's  $r$ . All  $P$  values were two-tailed, judged to be significant if  $\leq .05$ . Effect sizes (Cohen's  $d$ ) were judged against the following criteria: small ( $d \geq 0.2$ ), medium ( $d \geq 0.5$ ), large ( $d \geq 0.8$ ), or very large ( $d \geq 1.3$ ) [126].

To analyse the relationships amongst multiple variables at T1, multiple regression analyses were performed in the statistical programme Mplus version 7.3 [127] using maximum likelihood (ML) estimation. Results were reported with beta weights ( $\beta$ ) and the associated confidence intervals (CI),  $P$  values and explained variance ( $R^2$ ).

Z-tests were performed to analyse differences between the well parents' mean scores and the mean scores in other Norwegian adult samples, providing z-scores and two-tailed  $P$  values [128]. Since there was a lack of norm-population data regarding Norwegian parents' psychological distress and hardiness, well parents' psychological distress (GHQ-12 scores) was compared to a sample consisting of Norwegian married or cohabiting adults ( $N=1750$ ), studied by Nerdrum et al. [129]. Well parents' hardiness (DRS-15-R scores) was compared to that of an adult Norwegian working population ( $N=7280$ ), including both civilians and soldiers in the Norwegian Armed Forces, documented by Hystad et al. [113]. Well parents' QOL (QOLS-N scores) was compared to that of a general population in Norway ( $N=1893$ ) studied by Wahl et al. [130], and non-parental caregivers ( $N=47$ ) studied by Grov et al. [121]. Effect sizes of the differences in means between well parents ( $\text{Mean}_{\text{wp}}$ ) and the other adult populations ( $\text{Mean}_{\text{pop}}$ ) were defined by Cohen's  $d = (\text{Mean}_{\text{wp}} - \text{Mean}_{\text{pop}}) / \text{SD}_i$ , where  $\text{SD}_i$  was the pooled within-groups SD [131].

To test the programme's short-term effects, a repeated measures MANCOVA was conducted, in which the experimental conditions ("group") were the between-subjects factor and "time" was the within-subject factor. Time x group interaction was indicative of an intervention effect. Gender was entered into the analysis as a covariate. Preliminary checks were conducted to ensure that assumptions for MANCOVA were met [124],

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which included changing two outliers for GHQ-12 scores at T1 to a less extreme value (second highest value +1) [132]. The effect sizes of change within groups from T1-T2 were defined by Cohen's  $d = (\text{Mean}_2 - \text{Mean}_1) / \text{SD}_1$ . The effect sizes of the differences in means between the intervention group (I) and control group (C) were defined by Cohen's  $d = (\text{Mean}_I - \text{Mean}_C) / \text{SD}_C$  [133].

Longitudinal data from all three waves (T1-T3) were analysed with LMM analysis, using restricted maximum likelihood (REML) estimation and compound symmetry structure. The fixed factors were "time" and "group", and significant time x group interactions were indicative of intervention effects. Three participants reported that their partner had died before T3 (two from the intervention group and one from the control group). This was controlled for in the LMM analysis by including this variable as a covariate (main effect) in the fixed effect model. Furthermore, the analysis also controlled for the main effect of gender, which was entered as a second covariate. The results from the LMM analysis were reported with the estimated means (EM) and standard errors (SE), the time x group interaction, and the effect sizes of the difference in the changes (gain) from T1 to T3 between groups defined by Cohen's  $d = (\text{EM}_{I\ T3} - \text{EM}_{I\ T1} / \text{SD}_{I\ T1}) - (\text{EM}_{C\ T3} - \text{EM}_{C\ T1} / \text{SD}_{C\ T1})$  [134].

Simple mediation analyses were performed in the PROCESS macro for SPSS (model 4) by Andrew Hayes [135] in order to test social support as a mediator between "group" (receiving CPP or not: 1, 0) and the outcomes at T2 and T3, using bootstrapping with 5000 samples. Received social support was tested as a possible mediator between group and QOL at T2 (Paper 2). In Paper 3, a composite score of received and perceived social support was computed (each divided by the number of items in the scale and then summed) and tested as a mediator in the relationship between receiving CPP and later psychological distress. Results were reported with the unstandardized coefficients, standard errors (SE),  $t$  values,  $P$  values and a bootstrapped confidence interval of the indirect effect. A bootstrapped confidence interval (Boot CI) of the indirect effect that did not include zero represented a statistically significant indirect effect [136]. Due to the

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dichotomous predictor, the partially standardized indirect effect represented an estimation of the size of the indirect effect [136], corresponding to the following criteria: small  $\geq 0.14$ , moderate  $\geq 0.36$  or large  $\geq 0.51$ [137].

## 5.6 Ethical considerations

The study was planned and carried out in accordance with the Declaration of Helsinki [112]. The University of Bergen and the CCP approved the study protocol. The Regional Ethical Committee of western Norway (REK Vest) approved the study (Appendix D).

Participants received both oral and written information about the project and were made aware participation was voluntary (Appendix E). They received information about the study design, covering the fact that the study included both an intervention group and a control group. The information letter included a description of the project procedures and information on how confidentiality would be ensured. It also specifically explained that they could withdraw from participation at any time during the project period without facing any restrictions regarding any treatment at the CCP. Furthermore, participants were informed that no harm was expected from the intervention, but that the CPP would provide support if needed. Written informed consent was obtained from all participants (Appendix E). All participants were adults (over the age of 18) and capable of giving informed consent. The ill partner was not asked to participate in the study, based on an ethical consideration regarding an anticipated burden related to their illness.

Withholding treatment from the control group is an ethical dilemma intrinsic to the RCT design [138]. To address this dilemma, all participants received a DVD (Appendix F) of the psycho-educational content from the intervention after T3, as a gesture of appreciation for their participation efforts. Furthermore, based on positive evaluations and the encouraging preliminary results, it was also decided to give all the study's participants the opportunity to receive the intervention. Participants in the control group were offered CPP after returning their T3.



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## 6. Results

### 6.1 Well parents' psychological distress, QOL, social support and hardiness

Paper 1 aimed to explore well parents' psychological distress, QOL, social support and hardiness, and to investigate whether social support or hardiness moderated the relationship between psychological distress and QOL. Furthermore, the paper aimed to explore the relationship between hardiness and psychological distress, testing QOL as a potential mediator.

Findings from baseline data revealed that the well parents ( $N=35$ ) were highly distressed as compared to other Norwegian married or cohabiting adults [129] ( $z=4.5$ ,  $p<.01$ ). Based on symptoms of psychological distress (GHQ-12 scores), 17 participants were found to be probable "cases", which may indicate their being in need of psychological treatment. In terms of their QOL, well parents' mean score was lower compared to that of a healthy Norwegian population ( $z=2.3$ ,  $p=.02$ ) [130], and the difference was judged to be close to moderate ( $d=0.45$ ). Well parents did not differ in QOL scores from the ill Norwegian population ( $z=0.26$ ,  $p=.80$ ) [130]. Furthermore, well parents seemed to have moderately lower QOL scores compared to that of a sample of nonparental caregivers in Norway [121] ( $d=0.5$ ).

Well parents were less "hardy" as compared to those in a sample of adult Norwegian workers [113] ( $z=2.4$ ,  $p=.02$ ). In terms of the three subscales – challenge, commitment and control – only the control subscale differed from that of the adult Norwegian workers ( $z=2.6$ ,  $p=.01$ ,  $d=0.48$ ). Psychological distress negatively correlated with QOL ( $r=-0.51$ ,  $p=.00$ ), hardiness ( $r=-0.43$ ,  $p=.01$ ) and control ( $r=-0.48$ ,  $p=.00$ ). QOL positively correlated with hardiness ( $r=0.60$ ,  $p=.00$ ) and perceived social support ( $r=0.37$ ,  $p=.03$ ).

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Results from the multiple regression analysis supported the stress-buffering model, given that the well parents' received social support moderated the effect of their psychological distress on their QOL ( $\beta=0.37$ ,  $p=.00$ ).

In conclusion, these findings suggested that a substantial proportion of the well parents were psychologically distressed and impaired in terms of QOL as compared to that of other healthy Norwegian adults. Well parents' psychological distress was associated with feelings of not being able to control or influence their life situation. Social support was found to be important for the well parents, as their received social support seemed to buffer the negative effects of psychological distress on their QOL.

## 6.2 Short-term effects of CPP

The aim of Paper 2 was to measure the short-term effects of CPP on the well parents' received and perceived social support, psychological distress and QOL, and to explore the role of received social support as a potential mediator of intervention effects.

Longitudinal data were collected at the baseline (T1,  $N=35$ ) and at the three-month follow-up (T2, approximately one month post-intervention,  $N=24$ ).

Results from independent t-tests showed that the intervention group reported more received and perceived support, less psychological distress and higher levels of QOL at T2 than did the controls ( $p<.05$ ). The repeated measures MANCOVA revealed significant time x group (intervention) effects ( $p=.03$ , partial  $\eta^2=0.42$ ), whereas the groups (intervention and control) changed differently from T1 to T2 in terms of the combined variable of the four primary outcomes. The univariate tests showed significant intervention effects on both received ( $p=.03$ ) and perceived ( $p=.00$ ) social support. Well parents receiving CPP reported increased levels of received and perceived support ( $d=0.2$  and  $d=0.4$ , respectively) while the control group reported largely reduced received and perceived support ( $d=-0.8$  and  $d=-1.1$ , respectively). The univariate tests did not prove intervention effects on psychological distress or QOL ( $p>.05$ ); however, a mediational

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analysis suggested that CPP might have indirect effects on QOL through received social support (10.06, Boot CI [3.88, 24.56]).

In conclusion, these findings encourage the use of CPP as a tool for increasing received and perceived social support for the well parents in the short-term, which may, in turn, improve their QOL.

### 6.3 The four-month outcomes of CPP

The aim of Paper 3 was to evaluate the four-month impact of CPP on well parents' received and perceived social support, as well as on their psychological distress, QOL and parenting self-efficacy. Furthermore, this paper investigated whether CPP might have indirect effects on psychological distress and parental self-efficacy through social support. Longitudinal data were collected at the baseline (T1, N=35), at the three-month follow-up (T2, N=24) and at the six-month follow-up (T3, N=21).

The LMM analysis revealed significant time x group (intervention) effects of CPP on received ( $p=.04$ ) and perceived ( $p=.01$ ) social support, as well as on parental self-efficacy ( $p=.02$ ), but not on psychological distress and OQL ( $p>.50$ ). At T3, controls reported significantly lower levels of social support than did CPP recipients, while CPP recipients seemed to sustain their support levels, primarily. Furthermore, the parental self-efficacy of controls had decreased from T1-T3, while the intervention group had increased their parental self-efficacy from T1-T3. The size of the difference between the two groups regarding the change from T1 to T3 was moderate for received social support ( $d=0.6$ ), large for perceived social support ( $d=1.0$ ), and large for parental self-efficacy ( $d=1.0$ ). A simple mediation analysis suggested that CPP influenced psychological distress through social support (-2.97, Boot CI [-7.07, - 0.57]).

In conclusion, these findings indicate that CPP may have beneficial effects regarding sustaining social support and enhancing parental self-efficacy for the well parents, for at

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least four months. Furthermore, findings from the mediation analysis suggested that CPP may have the potential to reduce well parents' psychological distress through the improvement of social support.

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## 7. Discussion

### 7.1 Discussion of main findings

The main findings of this study were that the well parents facing spousal cancer while caring for minors had high levels of psychological distress and impaired QOL at the baseline, and that social support seemed to buffer the negative effects of psychological distress on their QOL. Furthermore, CPP seemed to be effective in improving well parents' received and perceived social support in the short-term, as well as improving their parental self-efficacy and sustaining social support over time. The study could not prove any effects of the programme on well parents' psychological distress or QOL. However, simple mediation analyses suggested that CPP might have indirect effects on well parents' psychological distress and QOL through social support.

#### **The well parents are not well, but social support may buffer the adverse effects on their QOL**

At the baseline, half of the well parents had a level of psychological distress that could indicate a psychological disorder. This proportion is at the upper boundary of caseness reported in similar studies of partners of cancer patients [3]. However, the present study cannot confirm that this is the case for the well parents in general, particularly given the small sample size. Furthermore, research on well parents is scarce and there is a dearth of comparable samples. A larger Australian study [139] found an equivalent mean of psychological distress in family caregivers who were caring for a dying relative (N=275), but their parental role was not stated. However, partners who are caregivers for terminally ill patients have been found to be more distressed than other partners are [3]. These findings might indicate that the multiple caregiver burden represents a risk to well parents' mental health, given that such a burden can be a significant predictor of psychological distress [140]. Furthermore, psychological distress was linked to well parents' feelings of control. It is reasonable to believe that the lack of feelings of control arises from the spouse's illness and the potential threat of loss, which surely may cause

psychological distress. This is supported by previous research, which has linked partners' fear of cancer recurrence or death to QOL impairments [38, 141]. Indeed, the well parents may be particularly concerned about the future of the family and children.

In terms of well parents' QOL, they reported a level close to that of a chronically ill population in Norway and significantly different from that of a healthy population. This indicates that the QOL of well parents may be negatively affected by the presence of spousal cancer and its consequences for family life. This finding is widely supported by other studies that document QOL impairments in partners of cancer patients [6, 18, 38, 142, 143]. Satisfaction with "independence" (the ability to do things on their own), especially, was lower than that of the Norwegian general population [130]. Although the QOLS-N is specifically adapted to people with chronic illnesses [72], for whom "independence" may have a slightly different meaning or value, this measure may have captured an important aspect of the well parents' life situation. The effect sizes also suggested a notable difference in "health" (being physically fit and vigorous). Moreover, well parents reported lower QOL compared to that of partners without parental responsibilities [121]. Taken together, this may indicate that the QOL of the well parents' is also impaired due to their reduced abilities to do things on their own and to maintain self-care. This is in line with other studies that have found that well parents may put their own needs aside, while trying to make the best of the situation for their ill partner and their children [2, 24]. Moreover, Wadhwa and colleagues identified a link between multiple caregiver roles and QOL impairments [5]. However, the well parents in the present study were more satisfied with having and raising children than the general Norwegian population. This finding is interesting and may reflect a positive aspect of facing a serious illness, whereby some families experience closer relationships [34] and value being together to a greater extent [2]. This may positively influence their QOL, and thereby outweigh some of the impairments.

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Supporting the stress-buffering hypothesis [88], received social support seemed to moderate the relationship between psychological distress and QOL of well parents. Hence, highly stressed individuals had fewer impairments in their QOL if they were highly supported. Furthermore, the higher well parents' stress and the less support they received, the worse their QOL. This finding is supported by a range of studies linking social support to better psychosocial outcomes in partners [6, 36, 144, 145]. This important finding implies that social support interventions may be of particular importance for well parents who are highly stressed and not well supported.

The main effect (the main effect model) of social support on psychological distress, was not tested in the present study, and thus cannot be excluded to explain the potential effects of social support on well parents' mental health in the face of spousal cancer. A main effect on QOL was supported for received social support (Paper 2, Table 5). Thus, these findings may indicate support for both the main effect- and the stress-buffering models. In line with this, a study of parents of paediatric cancer patients conducted by Harper and colleagues [55] (N=102), suggested that interventions to improve satisfaction with social support would be beneficial for all parents, while a larger network was important for those who had higher levels of psychological distress. In terms of clinical implications, this may indicate that the programme should ensure to include more (at least seven) supporters for highly stressed parents.

Findings at the baseline indicated that the study's participants were less "hardy" as compared to an adult working population in Norway [113], though only in the control dimension. Hardiness is viewed as a generalized style of functioning rather than a personality trait and, hence, an individual's hardiness is thought to be amenable to change [75]. In this way, hardiness may be seen in relation to the life crisis these well parents are facing and their current style of functioning. Control is the belief in one's own ability to control or influence life events [75]. When facing spousal cancer, the belief in one's ability to influence one's life situation may be weakened, as one cannot control the illness, the threat of loss or the future of the family. Hence, well parents' hardiness may

also be seen in line with their current ability to cope, as coping is seen as a process that is constantly changing in relation to the context [89]. The association between hardiness and coping has previously been supported by several authors [81].

In contrast to the literature that has found hardiness to be a moderator in the stress-illness relationship [81], the present study did not find a moderating effect of hardiness in the relationship between psychological distress and QOL. The present study found that the relationship between well parents' psychological distress and their hardiness was mediated by their QOL. This means that well parents' hardiness did not directly affect their psychological distress, but rather indirectly through their levels of QOL. That is, hardy parents may have better QOL and so experience fewer symptoms of psychological distress. In contrast, less hardy well parents have lower QOL and thus are more psychologically distressed. This finding is supported by other studies that have found hardiness to be closely linked to QOL [81, 82]. Although the causal direction could not be determined in these cross-sectional data, these findings suggest that targeting well parents' beliefs in their ability to control their life situation may be useful for improving their QOL and thereby reducing their psychological distress. Health professionals may be aware of this relationship, and should provide the well parents with adequate and sufficient information about the patient's illness, risks and treatments throughout the cancer trajectory to increase feelings of control. Obviously, their concerns and worries regarding their ill spouse dying, which have been documented to negatively influence their QOL [141] and psychological health [3], cannot be removed by any intervention as long as the threat is present. However, the provision of adequate information, as well as advice on coping techniques, may alleviate the distress. Hence, in line with the stress-buffering model [57], involving social networks members (supporters) and enhancing social network support may increase well parents' feelings of control in the sense that they may experience greater ability to cope with the situation (and the potential loss of their partner) with help from their social networks. This may be a topic to be explored in future research.



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**CPP may improve well parents' social support and parental self-efficacy**

The short-term findings showed an improvement of both received and perceived social support for CPP recipients. The gathering of the social networks and the facilitating of an open communication [91], whereby the available support became more “visible” and tangible to the well parents, as well as their requests for support may have become more explicit [62], may explain this finding. The most notable impact of CPP was seen in perceived social support. Well parents may have been reassured that close friends and family members actually wanted to support them, regardless of whether they ultimately received more support. Hence, the effect on perceived support may have appeared independently from the actual support received. This thought is supported by the social support literature, which distinguishes between the actual received and the perceived available support [57, 66]. After four months, the recipients of CPP reported that their received support had decreased to its initial level, while their perceived support was still slightly higher than its initial level. This finding is interesting, as it seems that CPP may have particularly influenced perceived available social support, such that the perception of the availability of support did not dissipate as quickly as did the actual received support. Furthermore, the main effect of CPP seems to be the sustenance of social support over time for the well parents, as the control group experienced a large decrease in support from T1 to T3. This finding may be of particular clinical importance, as previous research has revealed that families facing cancer may experience difficulties in sustaining support as time passes [16, 22, 23].

Although the effects of CPP on well parents' psychological distress were statistically insignificant, a small-sized difference was found between the two groups' change scores from T1-T3. This difference may be of clinical importance [133]. At T3, the controls reported a higher mean of psychological distress (mean 15.2) than that of a population of married and cohabiting adults in Norway (mean 10.3) [129], while the intervention group reported psychological distress nearly at the same level as the Norwegian married/cohabiting adults (mean 10.9). In line with these findings, relatively more cases

were identified among the controls than among the participants who had received intervention. Furthermore, the study's findings suggested an indirect effect of CPP on psychological distress through social support. Although causality could not be determined from the mediation analysis [136], that analysis suggested that the intervention group had higher levels of support after receiving CPP than did controls, and so experienced less psychological distress. However, these findings call for confirmation in future longitudinal studies with larger samples.

The study did not prove any effects of CPP on well parents' QOL. There may be several explanations for this finding. Overall QOL is a broad concept that covers multiple dimensions [70], and may be too broad to detect specific effects of social support in the context of spousal cancer [146]. Facing spousal cancer, and especially the threat of loss [141], may strongly influence several dimensions of partners' QOL. A systematic review of interventions to improve caregivers' QOL, carried out by Waldron and colleagues [146], found that such psychosocial interventions mainly had small effects, with interventions targeting several caregiver needs being more effective. Waldron and colleagues suggest that supportive-educational interventions focusing on a wide range of issues, such as family involvement, optimistic attitude, coping skills, uncertainty reduction and symptom management, may be required to improve the QOL of caregivers [146]. Although CPP covers family involvement and social support, the programme does not specifically cover uncertainty reduction and symptom management. Thus, CPP may be used in addition to other psychosocial interventions targeting the QOL of partners of cancer patients.

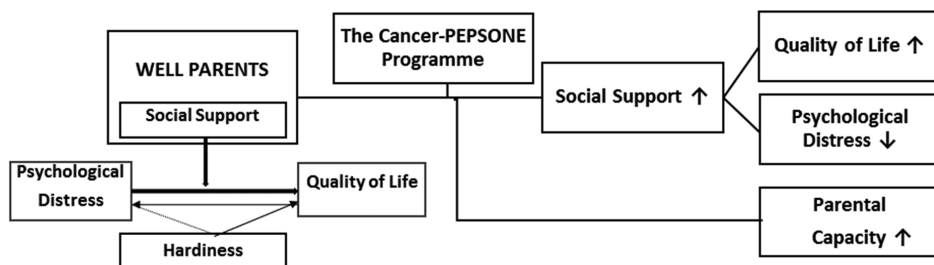
Partners' QOL may also depend on the psychosocial functioning of their ill partner, as well as dyadic communication and satisfaction with the relationship [43, 147]. Hence, the ill partners' psychosocial variables, as well as dimensional QOL instruments and instruments specifically targeting cancer caregivers (e.g., the SF-36 Health Survey and Caregiver Quality of Life Index-Cancer), could also have been included to add more specific information on the QOL of the well parents [146].

The well parents who had attended CPP more frequently reported having the emotional support that they needed than did controls. However, there seemed to be room for more practical support. Rashi and colleagues found that parents dealing with cancer valued practical and tangible support over emotional support [42]. More practical support, such as help with children and domestic tasks, could increase well parents' satisfaction with their "independence" (being able to do things on their own). Therefore, by alleviating the well parents' total burden, one might increase their ability to find time for recreational activities [148] and thereby enhance their QOL. The mediation analysis that suggested received social support as a mediator between receiving CPP and well parents' QOL provided some support for these assumptions. However, the causality of these relationships could not be determined and may be a focus for future research.

CPP seemed to have beneficial effects on well parents' parental self-efficacy. Well parents who received CPP reported to have more parental self-efficacy after four months than did controls. This finding is particularly interesting and encouraging, since parental self-efficacy is linked to child adjustment [51]. In accordance with the literature linking parental psychological distress to lower parental capacity [51, 86, 149], the findings of this study showed that well parents' parental self-efficacy negatively correlated with their psychological distress. Previous studies have found a significant association between more social support and higher parenting self-efficacy in parents dealing with cancer [149]. However, parental self-efficacy did not correlate with the well parents' social support in this study. Hence, it remains unclear whether or not the enhancement of social support contributed to the improvement in parental self-efficacy. The programme provided well parents with information about children's needs and reactions while facing parental cancer, also covering the importance of upholding normal structure for the children, which may have directly influenced or supported the well parents' parental self-efficacy. Furthermore, the programme targeted the whole family, including the ill partner and the children, which also may have influenced the family's communication, functioning and problem-solving, as well as on the family's resilience [149]. These areas

may also be important for well parents' parental capacity, but were not assessed in this study. Furthermore, the selected SEPTI items, used for assessing parents' sense of competence in facilitating the child's achievement in school and provision of structure and discipline, may not have captured the whole picture of well parents' parental capacity. Other important dimensions of parental capacity (e.g., parental ability to provide emotional nurturance, support child recreation and maintenance of child's health) [86] were not assessed in the present study. These dimensions should be included in future studies to gain more knowledge of how CPP may influence on parental capacity and the role of parental social support in this relationship.

Taken together, the study's findings partially confirms the conceptual model. Findings suggest that well parents' social support may buffer the negative effects of psychological distress on QOL. Furthermore, CPP may work in different ways on different outcomes. The programme seemed to directly influence the improvement of social support and the sustenance of support over time, as well as the improvement of parental self-efficacy, while it may have the potential to indirectly influence on well parents' psychological distress and QOL. A conceptual model of the study's findings is outlined in Figure 5.



**Figure 5** A conceptual model of the study's findings

## 7.2 Methodological considerations

In this section, the study's strengths and limitations are discussed, particularly focusing on the issues that must be considered when assessing the reliability and validity of an experimental study's results [101, 138, 150]. Reliability refers to the extent to which the study's findings are replicable and consistent, while validity refers to the extent to which findings measured what was intended to be measured, and not some confounding variable [151]. The reliability and validity of an experimental study's results depends on the study's internal validity, external validity (generalizability), construct validity and statistical conclusion validity [150]. These issues are respectively discussed below.

### 7.2.1 Internal validity

The question of internal validity regards how researchers can be sure that the intervention caused the effects, rather than other factors such as external or internal events [138, 150]. Given the open trial design, results may be biased by participants' expectations, as all participants were aware of their group allocation [151, 152]. Those who received the intervention may have overestimated their self-reported outcomes due to positive expectations, while controls might have been disappointed at not being allocated to receive intervention and may have thus reported worse scores for the outcome measures than actually experienced [152]. On the other hand, there may also be the possibility of trial contamination [153], with the controls having raised awareness of their own social support needs, and perhaps initiating its improvement, or getting access to CPP content from participants in the intervention group. Such response bias cannot be denied or disproved by this study, and should be taken into consideration when interpreting the generalizability of the results. However, this limitation is tied to the open trial design, and to all open trials in general, and not the present study in particular.

A possible means of single-blinding the study [154] could be to include a placebo intervention, e.g., a psychologist providing psycho-education to the control families

(without gathering their social networks). However, such a placebo intervention was beyond the time and resources of the present study. Nonetheless, to try to minimize the response bias and study drop-out rate, the families in the control group received a DVD (Appendix F) containing the main elements of the intervention after they had returned the last (T3) questionnaire. Distribution of the DVD was also a result of an ethical consideration, so as to give something back to the control group who had not received the intervention. In addition, control families were offered the CPP intervention after they had finished T3, though only one control family accepted this invitation.

An inevitable risk was that of participants' losing their ill partner during the study. Three participants reported that their ill partner had died before T3 –two in the intervention group and one in the control group. This crucial, life-changing internal event was controlled for in the LMM analysis. The death of the ill partner was entered into the analysis as a covariate, and was found to be a significant predictor of the well parents' levels of psychological distress and QOL. However, the study's results regarding the intervention effects did not change when these cases were deleted from the analysis. Since female partners have shown to be more distressed than male partners in previous research [43], gender was also controlled for in the analysis.

The relatively large (but typical) study drop-out rate (40%) may also be a threat to internal validity [138, 150]. However, the severity of bias in this regard depends on the extent to which the partially observed participants differ from the fully observed participants [155, 156]. This was investigated by doing analyses of completers vs. non-completers on all of their demographic variables and dependent variables at T1 [156]. No significant differences were found, with exception of parental self-efficacy, where both groups lost the participants with the highest levels of parental-self-efficacy to follow-up. More participants were lost to follow-up in the control group than in the intervention group. However, covariate-dependent missingness, such as missingness related to the experimental conditions, may not represent a threat to the missing at random (MAR) assumptions for the complete case analysis (MANCOVA) or the intention-to-treat

analysis (LMM) [156]. However, particularly given the small sample size, there may be a possibility that the estimated effects are either under- or overestimated.

### **7.2.2 Generalizability**

The small sample size represents a threat to the present study's external generalizability [138]. The small sample size may be explained by reference to several factors. The study population is naturally limited in a small country like Norway [13], and difficulties with recruiting participants is a well-known challenge for RCT studies [157]. Furthermore, other authors have highlighted specific recruitment issues regarding cancer patients and their partners [121, 158, 159] and high refusal rates [160]. Previous studies have documented that cancer caregivers may refuse participation in studies because they are "too busy", "not interested" and "too overwhelmed" [139]. Therefore, recruitment difficulty was anticipated. Nevertheless, recruitment was even harder and more time-consuming than expected. Cancer nurses and cancer coordinators all over the country recruited participants for the study for almost two years. In addition, the study was advertised in leaflets and posters in hospitals and on the Internet. In spite of this effort, reaching the required sample size was a struggle. The fact that this study concerned the well parents may also contribute to accounting for the small sample size, because most healthcare professionals are primarily in contact with the ill parent. Moreover, one cannot be sure that all recruiters did, in fact, ask all potentially eligible families for the study to participate in the study [159]. To explore this matter further, the experiences of the recruiters were surveyed after the end of the recruitment phase. In cases where families had declined to participate, the majority had answered that it would be "too much" for them to participate in research, aligning with the findings of Hudson et al. [139] and the barriers identified by Inhestern et al [64]. Only 50% of recruiters had asked potential families to participate in the study and 30% reported that they could have asked more families. This indicates that more work could have been put into engaging recruiters. Studies have found that, if clinicians are fully engaged and understand the benefits to both themselves and patients of participating in RCTs, recruitment may improve significantly

[157]. In the present study, this issue was partly addressed via a free kick-off seminar in Bergen and monthly updates by email to a large network of contacts. Nonetheless, more attention could have been paid to personal contacts throughout the study, yet limitations of time and accessible resources again applied.

Even though the required sample size was reached at T1, the study's statistical power was reduced due to attrition at T2 and T3. Ideally, the sample size calculation would have covered the expected proportion of drop-outs throughout the study and the recruitment phase would have continued until the study reached a larger sample size [150, 151]. However, due to the abovementioned limitations, the recruitment process had to be concluded before a larger sample size was achieved, leaving the study underpowered. This may thus limit the generalizability of the results. Nonetheless, samples of similar size are common in this field [43, 161, 162], and may not be judged to be *too* small to provide clinically meaningful information.

A successful randomization procedure strengthens the study's external validity, but systematic differences between the groups would represent a selection bias and a threat to generalizability [103]. However, in the present study the groups did not differ significantly in any of the demographic variables or outcome variables at the baseline. Furthermore, the randomization procedure was performed in accordance with the criteria outlined by Vickers [103]. These criteria were met with the project leader monitoring the randomization procedure while the author assessed the potential participants for eligibility, and recruiters and researchers were unable to predict the group to which a participant would be randomized. The order of the returned questionnaires was unpredictable, and the randomization was carried out prior to participant identification. Importantly, programme providers did not meet with any participants prior to allocation, which avoided any potential selection bias on the part of the psychologists regarding who they might think would benefit from the intervention. Nevertheless, more optimal randomization procedures, such as a computer programme using block randomization



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[103], could have been applied, preferably with help from a person external to the research team.

### **7.2.3 Construct validity**

Shadish et al.[150] highlights the twin problems of construct validity when there is no natural unit of measurement: understanding constructs and assessing them (p. 65). Furthermore, they state that research cannot be performed without using constructs. Thus, to capture the “true” and relevant aspects of concepts such as social support, QOL, hardiness, psychological distress and parental self-efficacy, as well as any change in each variable, may be a challenge in research. Importantly, the instruments used in this study were all validated and involved satisfactory psychometric properties. The reliability of the instruments was assessed using Cronbach’s alpha. Cronbach’s alpha determines the internal consistency (average correlation) of items in an instrument and this measure was satisfactory for all instruments ( $>0.7$ ) [132]. Furthermore, most instruments had previously been used with people who either had cancer caregiving experience (QOLS, GHQ-12 and MSPSS) [121, 139, 163] or experienced life crises (CSS) [115].

### **7.2.4 Statistical conclusion validity**

Regarding the causal relationship between the intervention and the outcomes, two statistical conclusion errors are possible: type I and type II errors. A type I error is made when researchers claim that there is an effect when in fact there is not, while a type II error is made by incorrectly concluding that there is no effect when in fact there is [132, 150]. To avoid type I errors, robust statistical analyses were applied [125, 164] with an alpha level or significance level of .05. Type II errors were harder to avoid due to the small sample size [132]. Some have argued that, for small sample sizes, it might be necessary to adjust the alpha level to avoid type II errors, e.g., to .10 rather than .05 [132]. Since type I errors are seen as the most serious violations in research [150, 165], this adjustment was not applied in the present study. Nevertheless, due to the low statistical power of the present study, one cannot be sure that the findings would be replicated in a

fully powered study, and caution should be applied in interpreting its findings, particularly the study's null-findings.

### **7.2.5 Summary of strengths and limitations**

Taken together, the strengths of this study are the randomized controlled design, the use of validated questionnaires and the robust statistical analyses. However, the major limitation is the small sample size, which limits the generalizability of results and the ability to draw strong conclusions of CPP's effectiveness. Furthermore, the study's design did not capture the detailed, in-depth experiences and perspectives of participants in the present study [100]. An additional qualitative approach could have provided the study with useful information, e.g. explaining the findings of the study through the perspectives of the participants. Thus, especially given the recruitment difficulties for RCT studies and studies within this field, integrating quantitative and qualitative methods (mixed methods studies) may be considered in future research [100].

## **7.3 Clinical implications**

Despite the present study's limitation regarding the small sample size, its findings may have some implications for clinical practice. Healthcare professionals should address well parents' substantial distress and QOL impairments. Although some well parents may be in need of psychological treatment, such treatment may not be required for well parents in general. Well parents' distress may be viewed as a normal reaction to the situation they are facing [117], and defining such reactions as a "psychological disorder" may be incorrect. Pitceathly and Maguire [3] conclude in their review that only a minority of partners of cancer patients develop psychiatric morbidity, while a larger number develop higher levels of emotional distress that can be prolonged or chronic. Thus, well parents' needs might also be addressed by informal support systems in addition to the healthcare systems. Healthcare professionals may consider facilitating improvements of social support systems in order to reduce the negative effects of stress on such parents' well-

being. In particular, health professionals' must consider well parents' parental capacity and the well-being of their children. Norwegian healthcare professionals are responsible by law for ensuring that children of seriously ill parents are identified and provided with interventions that put them, and their parents, in a better coping position [166].

Findings of the present study are encouraging with respect to effects of CPP. CPP may be a useful clinical tool for increasing or sustaining social support and enhancing parental capacity for well parents who are facing spousal cancer while caring for minors.

Experienced psychologists facilitated the programme in the present study, but other healthcare professionals, such as cancer nurses, cancer coordinators in municipalities and public health nurses, could also provide CPP given training in the manual. This would make the programme easy to implement and accessible for most families dealing with cancer throughout the country.

The survey that was carried out following the end of the recruitment phase revealed that more than 60% of the cancer coordinators (N=65) thought that they would be able to implement the programme within the time frame and resources of their ordinary work, while 35% stated that they "maybe" would be able to do so. This is encouraging, as the costs associated with the implementation of programme in that case may be very low. Furthermore, the elevated risk of poorer health for partners of cancer patients, including the risk of both psychiatric and somatic morbidities, is associated with increased healthcare use and healthcare costs [41]. Hence, less help may be required from healthcare professionals and healthcare costs may be reduced if social network support is mobilized for the well parents.

Families should select their supporters themselves to maintain privacy and control [22]. A larger network may represent more support resources and may be of special importance of those who are highly distressed [55]. Although flexibility should be applied on the upper and lower limits of numbers of social network members included in the programme, approximately seven supporters seem to be suitable and achievable for most families.

The findings of this study indicate that at least one follow-up meeting after two to three months may be required to increase social support in the longer-term. A follow-up meeting after two to three months should include a review of the communication between the families and their networks and the effectiveness of the support, as well as discussion of how the network can better meet the family's further support needs. A greater focus on practical support needs and provisions may be beneficial in order to target well parents' psychological distress and QOL. Furthermore, it may be considered whether the support could be coordinated by a particular person in the network or through a support group on Facebook. Such practical arrangements may improve the support, share the support burden across the networks and secure longer-term support.

CPP may also benefit from an extended module for bereaved families, as bereavement can pose extra challenges for families' well-being and their social support.

## 7.4 Implications for future research

Future longitudinal studies with larger samples are needed to further assess the impact of CPP on the well parents and their children where single-blind designs should be considered. Furthermore, mixed methods studies should be considered to gain more insight into the processes and the experiences of the well parents when participating in the programme.

Since couples seem to react as emotional systems [43, 167], the psychosocial outcomes of the ill partners, in addition to well parents' perceptions of their support from their ill partner, should be included in future studies. Furthermore, a family perspective may be useful in future research, where family functioning or family interactions, as well as family resilience [168, 169], may be similarly important factors to study in this context of the whole family.

Future studies should consider including more dimensions of parental capacity, for instance by including all subscales of SEPTI. Furthermore, assessing specific cancer-related and dimensional QOL may reveal more adequate information on participants' QOL. Other social support measures that more specifically assess the amount of received support, as well as the entire MSPSS instrument, may also be relevant to include in future studies.

Future research should also determine who may be in most need of CPP (e.g., by analysing gender differences, low vs. high support families, hardy vs. low hardy parents, and by studying single parents) as well as on the best time points for receiving CPP. Furthermore, the programme's effectiveness may differ across various nations and cultural contexts, which may be a topic for future research.

## 7.5 Conclusions

This study aimed to assess the social support, psychological distress, QOL and hardiness of well parents who are facing spousal cancer while caring for minors, and to evaluate the effect of CPP on well parents' social support, psychological distress, QOL and parental self-efficacy.

The findings of the study revealed that well parents were highly psychological distressed, and that half could be regarded as requiring psychological treatment. Well-parents' psychological distress seemed to be associated with their lack of control over their situation and future. Well parents' QOL seemed to be impaired as compared to that of other adults in Norway and non-parental partners. Social support was found to buffer the impact of psychological distress on well parents' QOL. Moreover, the study provided encouraging results regarding the impact of CPP on well parents' social support and parental self-efficacy. This may be of importance for both the well parents and their children. The programme seemed to be effective in improving social support for well parents in the short-term and sustaining social support for at least four months. Although

the findings suggested indirect effects of receiving the programme on well parents' psychological distress and QOL, the programme was not proven to be effective in improving psychological distress or QOL, and more research is required regarding these outcomes. In future applications, a follow-up CPP meeting should be included in the programme after two to three months in order to secure longer-term support. A larger focus on practical support may be beneficial in order to alleviate well parents' psychological distress and enhance their QOL. Considering this study's small sample size, these results call for confirmation in future studies and replications with larger samples are required.

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