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Different Coping and Support Types in Cancer - About the Couple and the Special Role of the Spouse

Cumulative Dissertation

for the degree of

Dr. rer. nat

at the Faculty of Engineering,

Computer Science and Psychology at Ulm University

by

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from Weißenhorn

2024

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Day of Promotion: 11.11.2024

Acknowledgements

The journey is the reward. This dissertation was a long journey and finding my own way through wasn't always easy. Of course, it was not a straight way through. But without the dead-ends, detours and stumbling blocks I encountered, I would not have gained important experiences. I am also grateful for all the people who have crossed and accompanied my path. First of all, I want to thank Dr. Klaus Hönig, who accompanied and supported my way from the beginning. Thank you for always having an open ear for my concerns and questions and for always keeping my motivation high. I am happy for all the projects we have done together and hope there will be more to come. I also thank Prof. Dr. Harald Baumeister very much for supervising my dissertation and for all his support at each part of my path. And thank you, Prof. Dr. Tanja Zimmermann from the lovely city Hannover, for your prompt and straightforward commitment of the second review.

I want to thank the teams I worked together with. Thank you, Prof. Dr. Jochen Ernst and Dr. Gregor Weißflog from the University of Leipzig, for giving me the opportunity to work with the data of the couple study. And thank you, Dr. Ute Goerling from the Charité Comprehensive Cancer Center Berlin, for doing the second rating of the interviews.

A big thank you goes to the team of the Department of Clinical Psychology and Psychotherapy of the University of Ulm, who welcomed me very warmly right from the start. In special, I thank all the members of our LADEN. Working with you is so much fun and I will keep our travels, adventures and coffee dates always in mind.

I also thank several colleagues of the Department of Psychosomatic Medicine and Psychotherapy of the University Medical Center Ulm. There are just too many people to mention here individually, who accompanied my way and supported me on different steps. Thanks to all of you.

Many thanks to Damon for accompanying me all the way of this dissertation. Thank you for just being there and always calming me down, no matter how stressful a situation seemed to be. Thanks to the little wonder for pushing my motivation to finish this dissertation. Thank you to my family and friends, who are a big part of my life and without whose support and love this journey would not have been possible. And thank you, Bodsch, for always being by my side.

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Abstract

Background: A cancer diagnosis affects patients and spouses with a variety of psychological burden. Both can be burdened to a comparable extent. To cope with cancer-related burden, patients and spouses may use several strategies, such as individual coping, dyadic coping, social support or professional support. In this context, spouses have a special role: on the one hand, they are often the primary supporters of the patients, and on the other hand, they receive only little support for their own burden. Professional support offers for spouses are scarce and existing ones can only be used to a limited extent by spouses due to inflexibility of time and location or fears of stigmatization. Internet interventions may overcome these barriers by providing a low-threshold, easily accessible and flexible support offer. Thus, this dissertation aims to provide a deeper insight into the support system of the couple and into a tailored internet intervention for spouses.

Methods: This dissertation is divided into two parts: The first part investigates couples of cancer patients and their spouses. The three research questions from this part are investigated with a sample of couples facing hematological cancer, because it is assumed that they experience a particularly high level of distress and therefore having a high need for support. The investigations are conducted using different methodological approaches: (1) Couple interviews provide an overview among different coping and support types as well as a deeper insight within these types used by the patients and their spouses. (2) The Actor-Partner-Interdependence Model investigates associations between two different support types with psychological distress in patients and their spouses. (3) Differences in coping and support types used by patients and spouses are examined by using both a qualitative and a quantitative approach. The second part of this dissertation takes spouses of cancer patients into focus. The research question of this part is investigated with a sample of spouses of several cancer types. This takes into account the lack of evaluated professional support offers for spouses in general and therefore the intervention is offered not only to a limited group. (4) A randomized controlled feasibility trial examines feasibility and acceptability as well as preliminary efficacy of the newly developed internet intervention PartnerCARE targeting spouses of cancer patients.

Results: With this dissertation (1) different coping and support types in couples facing hematological cancer are identified and classified into three main categories with several subcategories. (2) Facets of dyadic coping and social support are shown to be related to psychological distress in hematological cancer patients and their spouses in different ways. Crossover effects demonstrate interdependency within the couple. (3) Patients and spouses

differ regarding type and amount of coping and support types reported. Compared to patients, spouses have a overall lack of support for themselves. (4) The newly developed internet intervention for spouses of cancer patients is promising with high feasibility, acceptability and potentially efficacy. A randomized controlled efficacy study is indicated to investigate reliable evidence about the efficacy of PartnerCARE.

Discussion: Taken together, couples facing hematological cancer use a variety of different types of coping and support strategies. Knowledge of the differences in strategies used by patients and spouses could be beneficial for health care professionals and interventions to deal with individual deficits that may occur. Overall, there is need of more research regarding the entire support system of couples to better understand how it works. As perceived negative dyadic coping has consistently relations to the own psychological distress, it should be a greater focus in research. However, there is also a need for investigation of the underlying causal mechanisms and more knowledge about when a strategy is useful. An internet intervention may reduce the lack of support for spouses, as it seems to be an appropriate way to reach and support spouses in a flexible way.

1 General Introduction

1.1 Cancer and Mental Health

Every year, about 500,000 new cases of cancer are diagnosed in Germany (Robert Koch-Institut, 2021). The incidence of cancer in Germany is projected to increase by 23% between 2015 and 2030, mainly due to demographic trends. At the same time, a more sensitive diagnostic and early detections as well as new treatments and intensive therapies lead to increasing survival rates (Miller et al., 2022). In detail, the relative 5-year survival rates in Germany increased from 2007/2008 to 2017/2018 from 64% to 66% for women and from 59% to 62% for men (Center for Cancer Registry Data, 2023). Taken together, more and more people are being diagnosed with cancer and a high percentage of them are becoming cancer survivors. Based on these facts, it is clear that 'living with cancer' has become an important issue in today's world.

Cancer includes a wide variety of different forms, which are related to various forecasts, treatments and progression. For example, hematological cancer accounts for approximately 9% of all cancers, is thereby the fourth most common cancer diagnosis in women and men (Smith et al., 2011), and causes particularly high levels of distress in cancer survivors and their spouses (Lambert et al., 2013; Linden et al., 2012). Hematological cancer comprises various heterogeneous syndromes that affect the hematopoietic system. These malignant diseases can originate in the stem cells of the bone marrow, in the blood or in the lymphatic system. Due to frequent overlaps of the different forms, a distinct classification of hematological cancer is not possible, but in general the following groups can be distinguished: leukemia, lymphomas and plasma cell neoplasms (Rodriguez-Abreu et al., 2007). The individual diseases show different clinical appearances and differ with regard to their treatment plan, the course of the disease and the prognosis (Rodriguez-Abreu et al., 2007). Often highly aggressive, intensive and long lasting chemotherapies and a stem cell transplantation are required (Smith et al., 2011).

Through a life with cancer, not only patients but also their family environment may suffer from a variety of physical, psychological and psychosocial burdens. Especially because of shared anxiety, shared life circumstances and shared uncertainty about the future, cancer is widely described as 'we-disease' (Kayser et al., 2007). Although, a large part of the family and friends may also be strongly affected by the disease, this thesis will focus on patients and their spouses, as the couple represents the closest circle affected.

1.1.1 Burden of Cancer Patients

Patients with cancer report frequently symptoms, such as fatigue, mood disturbance, sleep disturbance, cognitive limitation and pain (Shi et al., 2011; Wu & Harden, 2015). The most common psychological burden in cancer patients are anxiety and depression symptoms. The prevalence of distress can vary in cancer patients due to the kind of treatment, tumor type, age at diagnosis, gender, psychological and social characteristics (Boyes et al., 2011; Linden et al., 2012). The prevalence of anxiety is about 19.0% to 24.0%, of depression is 12.9% to 14.0% and of comorbid anxiety and depression is 10% in patients with cancer (Boyes et al., 2011; Linden et al., 2012). With increasing time since diagnosis, the risk for depression decreases, while anxiety remains on the same level (Mitchell et al., 2013). High fatigue, depression and pain were associated with poorer quality of life (Shi et al., 2011; Wu & Harden, 2015). In addition, through the cancer trajectory, patients face new challenges, such as medical knowledge, financial worries or changing roles, and the uncertainty about the future can be burdensome in different ways (Serçe & Günüşen, 2021; Smith et al., 2019).

Due to the highly aggressive and often prolonged treatments, patients with hematological cancer can be particularly strained (National Institute for Clinical Excellence, 2003). Therefore, patients with hematological cancer suffer from one of the highest levels of distress compared to other cancer types (Linden et al., 2012). In several studies, up to 27% of the participants with hematological cancer report anxiety and up to 17% depression, respectively (Boyes et al., 2011; Clinton-Mcharg et al., 2014; Linden et al., 2012). Subclinical burden may be even higher (subclinical anxiety: 49.7%, subclinical depression: 38.0%) (Linden et al., 2012).

In addition to the multiple burden and new challenges, cancer survivors also report positive changes. They report more confidence, assertiveness and a better ability to listen to the needs of their own bodies (Mcgrath, 2004). In addition, patients report that their perception of values has changed, such as trivial things taking a back seat, and they are more aware of their trusted friends and family (Mcgrath, 2004). Patients report also improvements in the partnership, such as growing closer together, and a increased desire to enjoy life to the fullest (Drabe et al., 2013; Mcgrath, 2004).

1.1.2 Burden of Spouses

Spouses often provide the primary care and support for patients with cancer and many of them feel overwhelmed by the situation (Preisler & Goerling, 2016). There is a double

burden for the spouses: they provide help to the patient, but also suffer from the disease and need support for themselves (Hodgkinson et al., 2007). Spouses can be equally affected by the fears and anxieties about the course of the disease and often adapt their entire lives to the patient's limitations and needs (Künzler et al., 2010). Thereby, spouses are often taken a backseat to their ill partner by withholding their own strains and anxieties to not further burden the patient (Fergus & Gray, 2009). Caring for a patient with cancer can be equivalent to a full-time job, which results into negative effects on physical and mental health, social activities and relationships, as well as financial burdens for the spouse (Girgis et al., 2013). Caregiving spouses report psychological and physical burdens, such as depression (16.0%), anxiety (24.0%), insomnia (20.7%), headaches (13.7%), migraines (21.6%) and gastrointestinal disease conditions (26.9%) (Goren et al., 2014; Lee et al., 2021; Stenberg et al., 2010; Teixeira et al., 2018). In some studies, spouses and patients with cancer do not differ significantly in prevalence of depression and anxiety (Mitchell et al., 2013). Caregiving for cancer patients is even related to physical impairments, such as increased blood pressure, immune changes or poor health-related behaviors (Teixeira et al., 2018).

The nature of the burden of spouses of hematological cancer patients may not differ extremely from the burden of spouses of other cancer types (Beattie & Lebel, 2011; Serçe & Günüşen, 2021; Yucel et al., 2021). But the extent of the burden can be increased by the highly aggressive treatments and the corresponding particularly uncertainty about treatment effectiveness (Beattie & Lebel, 2011; Serçe & Günüşen, 2021; Yucel et al., 2021). Regarding anxiety and depression, high levels have been reported from spouses of hematological cancer patients at 6 and 12 months post diagnosis (anxiety: 46.8% and 43.6%, depression: 17.7 and 27.4%) (Lambert et al., 2013).

A longitudinal study shows that the burden of spouses is not only related to their own well-being, it may also influence well-being and burden of cancer patients (Litzelman & Yabroff, 2015). Higher depression rates in spouses lead to higher depression rates reported by cancer survivors (OR:4.27, 95% CI [2.01,9.07]), while a higher quality of life in spouses lead to a lower risk for depression in survivors (mental quality of life: OR: 0.72, 95% CI [0.53,0.97], physical quality of life: OR: 0.68, 95% CI [0.53,0.87]) (Litzelman & Yabroff, 2015). In addition, higher levels of depressive symptoms (OR:1.06, 95% CI [1.01,1.13]) and poor health (OR:3.76, 95% CI [1.76,9.55]) in caregivers lead patients to feel worse cared for (Litzelman et al., 2016). It seems that the influence of spouses on patients is more substantial than the other way round, because the inverse associations from patients' distress on spouses' well-being did not reach significance (Litzelman &

Yabroff, 2015).

In summary, cancer patients and spouses are considerably burdened, often to a comparable extent. Additionally, well-being of the spouse may also affect the patient's condition.

1.2 Coping and Support Types

To overcome or to cope with a high stressor like cancer and the related multiple psychological and psychosocial burden, patients and spouses can access different types of coping and support (Applebaum, 2019; Bodenmann, 2005; Brandão et al., 2017). These types can be divided into four categories according to the Stress-Coping-Cascade Model: individual coping strategies, dyadic coping strategies, social support from friends and family and professional support (Bodenmann, 2005).

Individual coping comprises a wide range of strategies to manage stress. There are different categorizations of these individual strategies. Most common is the classification into problem-focused and emotional-focused strategies (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). Problem-focused coping involves trying to deal with the existing external problem (cancer) using strategies such as seeking instrumental support or creating a problem-solving plan. Emotional-focused coping aims to regulate emotional stress caused by cancer using strategies, such as distancing or self-control. Other researchers added a third category named less useful, problematic or dysfunctional strategies (Carver, 1997; Carver et al., 1989; Cooper et al., 2008).

Dyadic coping is divided into six different types: supportive, delegated, common, ambivalent, hostile and superficial dyadic coping. The first three of them can be classified as positive dyadic coping forms and the second three as negative forms (Bodenmann, 1995, 2005). The peculiarity of the dyadic coping construct is, that both the one's own dyadic coping behavior and the perceived dyadic coping behavior of the partner can be considered (Bodenmann, 2008). In addition, stress communication is an important part of the dyadic coping process in couples because it results in the other person knowing about the current stress and, in response, the listening person being able to respond with a dyadic coping strategy (Bodenmann, 2005).

There is no uniform definition for social support (Pearson, 1986). Social support can be provided from family, friends, colleagues, neighbors or other acquaintances and may involve instrumental support or emotional support.

Professional support can comprise support from health care professionals, such as psychologists, social workers, nurses or physicians. As this is a very broad field, this thesis

only refers to professional support in the form of psychological interventions. But like for social support, there is also a lack for a clearly definition for psychological interventions (Hodges et al., 2011). This may be due to different outcome measures, such as psychological burden, physical burden or quality of life, and different intervention formats, such as individual, couple or group interventions.

The previous assumption in the stress-coping-cascade model comprised that all these strategies are used successively in prolonged stress situations (first, individual coping strategies are used, and only when these are exhausted, second, dyadic coping strategies are added, etc.) (Bodenmann, 2005). Recent studies indicated that different coping and support strategies are often used concurrently to deal with the complexity of burden (Paschali et al., 2021). Another study could also not support the assumption of the temporal order (Holmberg et al., 2011). Particularly in stress situations that require rapid support, the use of different strategies may depend on their availability (Paschali et al., 2021). Nevertheless, there is no research which considers all different coping and support forms together in cancer patients and their spouses.

1.3 Relations between Coping and Support Types with Psychological Distress

Research in the last decades showed different associations of coping and support with improved or decreased physical and psychological condition in cancer patients and their caregiving spouses. Evidence for these relations are displayed successively for each type of coping and support according to the order in the previous chapter. Differences regarding cancer patients and spouses are displayed within each section if applicable.

Individual coping strategies, such as acceptance (r = 0.22, 95% CI [0.07,0.37]), positive reappraisal (r = 0.27, 95% CI [0.11,0.41]) (Kvillemo & Bränström, 2014) and problem solving were associated with less psychological distress and better quality of life in patients (Brandão et al., 2017). In contrast, strategies, such as avoidance, denial, resignation or even less sports activity were associated with more depression and anxiety symptoms in patients and caregivers (Brandão et al., 2017; García-Torres et al., 2020).

Positive dyadic strategies, such as supportive (r = 0.22, 95% CI [0.15, 0.29]) and common dyadic coping (r = 0.42, 95% CI [0.39, 0.46]), as well as stress communication (r = 0.17, 95% CI [0.09, 0.25]) were associated with higher relationship quality in patients and spouses (Ştefănuţ et al., 2021). In addition, other studies found that positive dyadic coping and open communication alleviate psychological distress, facilitate couples' intimacy and improve relationship functioning in patients and spouses (Chen et al., 2021;

Lupinacci et al., 2021; Papp & Witt, 2010). Contrary, negative dyadic coping was associated with lower relationship quality (r = -0.28, 95% CI [-0.42, -0.13]) (Ştefănuţ et al., 2021), lower quality of life and higher distess in couples (Chen et al., 2021).

Social support for patients and caregivers was found to buffer from anxiety, depression and distress (García-Torres et al., 2020; Lotfi-Jam et al., 2019). In addition, crossover effects were found in the way that social support perceived by caregivers significantly improved not only their own well-being (standardized coefficient $\beta = 0.30$, p <.001), but also the well-being of the patient ($\beta = 0.25$, p <.001) (Ferraris et al., 2022). In contrast, also negative aspects of social support, such as detrimental interactions, are increasingly investigated (Geue et al., 2019; Sauer et al., 2019). Overall, social support is frequently focused on the patients, while caregivers report less amount of received or perceived social support (Hasson-Ohayon et al., 2010). Recent research about a new online assessment of the social network and social support among cancer patients and their caregivers opens a new avenue to gain a deeper insight into the social support process (Reblin et al., 2022).

In case of professional support this thesis focuses on psychological interventions as mentioned in the previous chapter. Regarding the effectiveness of interventions there is an inconsistent picture. Several systematic reviews provided unconvincing or limited evidence of the effectiveness of researched interventions on quality of life, depression, physical health or distress, rated several of the trials with a high risk of bias and therefore call for more rigorous future trials (Lepore & Coyne, 2006; Treanor et al., 2019). Other reviews showed that psychosocial interventions have been demonstrated to be beneficial for patients and spouses (Badr & Krebs, 2013; Kedia et al., 2020; Kleine et al., 2019; Luo et al., 2020; McAlpine et al., 2015; Skrabal Ross et al., 2020; Teo et al., 2019), but with small effects (range of effect size Hedges g from 0.21 to 0.31) (Badr & Krebs, 2013). By simply comparing reviews about psychosocial interventions for cancer patients and for spouses, it becomes apparent that there are far fewer interventions for spouses (e.g. n = 68 interventions for advanced cancer patients (Teo et al., 2019) and n = 9 interventions for spouses (Kleine et al., 2019)). In addition, none of the nine spouses intervention studies was conducted in Germany (Kleine et al., 2019) and only one recent published feasibility study for family caregivers is known (Grapp et al., 2022). This leads to the assumption that there may be a lack of evaluated interventions for German speaking spouses. Favored by improved access to new technologies and the increasing number of patients and spouses using the internet to search for cancer related information, the trend of development in current and future professional support points into the direction of internet interventions

(Lleras de Frutos et al., 2020; Luo et al., 2020). Especially for spouses of cancer patients the low-threshold character, the time and location flexibility and the easy accessibility of internet interventions are advantageous (Heynsbergh et al., 2019). In the area of anxiety and other mood disorders internet interventions are already suggested as similar effective as face-to-face therapies for patients (Andersson et al., 2019).

Taken together, there are beneficial and less beneficial strategies in each coping and support category. The effectiveness of coping and support may additionally dependent on situational conditions such as cancer stage or current treatment, measurement instruments used and fit between support offered and support needed (Kvillemo & Bränström, 2014; Vodermaier & Linden, 2019). Due to diversity of the strategies examined and the inconsistency of underlying definitions of the strategies, this research area consists mainly of reviews. Lack of meta-analyses leads to the consequence that no detailed statements about effect sizes can be made. Another issue is that a large proportion of these studies evaluate coping and support strategies still on an individual level, although several associations and dependencies between each other were demonstrated already (Papp & Witt, 2010; Paschali et al., 2021). Thus, as mentioned in the previous chapter, further research is needed that incorporates different coping and support strategies to better reflect their simultaneously occurrence (Paschali et al., 2021). Furthermore, as interventions delivered over the internet are a growing and promising research field, this thesis considers internet interventions in cancer in more detail.

1.4 Challenges and Opportunities of Internet Interventions

Internet interventions are the part of professional support that is increasing and on which high aspirations have been placed since the last decades. Cancer patients and spouses can be heavily occupied by several time-consuming tasks and appointments, such as treatment appointments or clinical appointments for aftercare. Therefore, internet interventions could be a suitable support for patients and spouses, as they do not require additional appointments and can be used flexibly in terms of time and location. The following chapter addresses the different challenges and chances of this type of intervention.

The existing internet interventions differ concerning targeted participants (e.g. couples, patients or spouses alone), primary aim (e.g. reducing cancer distress, improve quality of life), used technology (e.g. web-based, mobile-based, telehealth), level of guidance and underlying therapeutic concepts (e.g. psychoeducation, cognitive behavioral therapy) (Ebert et al., 2018; Luo et al., 2020; Skrabal Ross et al., 2020). Since the last decades,

internet interventions for cancer patients or dyadic formats are widespread (Leslie et al., 2022; Luo et al., 2020). In contrast, recent systematic reviews on interventions solely for cancer caregivers found only two and seven internet delivered interventions, respectively (Li et al., 2022; Sak-Dankosky et al., 2022). This emphasizes that the research about internet interventions for caregivers is still in its infancy and that there are mainly feasibility studies so far (Heynsbergh et al., 2018).

Major challenges in internet intervention are difficulties due to participants' concerns about technology and the anticipated time burden caused by the intervention (Leslie et al., 2022). The high importance of these challenges is reflected in the fact that they concern both intervention uptake and intervention engagement (Leslie et al., 2022). In addition, recruitment can be very challenging, particularly in the case of cancer caregivers. This is due to the reason that caregivers are not an easily accessible group, as evidenced by the variation in recruitment rates from 20% to 66% (Heynsbergh et al., 2018). Additionally, underestimation of psychological suffering or the neglect of own mental and psychosocial needs may prevent uptake of professional help offers, which is equally especially true for cancer caregivers (Heynsbergh et al., 2019). But also feared stigma and shame for seeking help can inhibit intervention search and uptake (Mosher et al., 2015). General negative attitudes towards internet interventions may be a further barrier for interventions uptake (Schröder et al., 2018). Therefore, a extensive education in advance of the intervention is needed to overcome existing prejudices and anxieties (Köhle et al., 2015). Intervention adherence, often defined as completion of a predefined number of modules, can have an impact on the usefulness of an intervention (Teo et al., 2019). Adherence in internet interventions is under reported in case of cancer caregivers (Coumoundouros et al., 2022). There is also a lack of consistent definition (Beatty & Binnion, 2016), which makes it difficult to make a summary statement about adherence. Overall, identifying predictors and reasons of high adherence could be important in order to increase adherence (Beatty & Binnion, 2016; Luo et al., 2020). More work is also needed to explore how to successfully overcome barriers of implementation of internet interventions (Coumoundouros et al., 2022; Ugalde et al., 2019). Last but not least, a methodological challenge is the comparability and summary of internet interventions due to their high variability in aim, delivery methods, underlying mechanism and lack of explicit definition (Hodges et al., 2011; Luo et al., 2020).

On the contrary, internet interventions appear to provide several beneficial effects on cancer patients' and spouses' psychological well-being with good ratings for feasibility and usability (Coumoundouros et al., 2022; Luo et al., 2020). Overall, the advantages

of internet over face-to-face interventions are flexibility of time and location, quick availability, time savings due to eliminated travel to intervention place, a low-threshold access, anonymity and conservation of resources of the healthcare system (Griffiths et al., 2006; Heynsbergh et al., 2019). In addition, internet interventions have the opportunity to reach more patients and their spouses in need than other treatment delivering formats. Especially in rural areas where health care access is poor and affected people have higher needs (Butow et al., 2012), internet interventions may be a flexible, low-threshold offer. This is also true for time inflexible spouses or for people with inhibitions towards psychosocial offers (Heynsbergh et al., 2019). The internet is the secondary if not the primary source of information and support for caregivers since at least a decade (Kinnane & Milne, 2010). Taken together, internet interventions could be an appropriate form of support for cancer patients and especially for their frequently under-supported spouses.

1.5 Aims of this Thesis

The overall aim of this thesis is to contribute to the understanding of the different types of support that cancer patients and their spouses use to cope with the disease and its associated burden. Particular attention is paid to the spouse, since the spouse was often perceived only as a caregiver and not as a co-burdened person in the past. In this dissertation, different methodological approaches are applied to gain different insights into this research field.

This thesis is divided into two parts: Starting from a couple's view, looking at both patients and spouses, the second part narrows the view and focuses on spouses. Thus, as a first step, **Publication I** gives a qualitative insight beyond quantitative, questionnaire-based studies about the inside and outside support system of a couples facing hematological cancer. Furthermore, one focus is the identification of possible differences in coping and support behavior of patients and spouses. One particular characteristic of this study is the joint interview setting of the couple. **Publication II** focuses on the two support strategies perceived dyadic coping and perceived social support of hematological cancer patients and spouses and their association with psychological burden. In addition, possible differences between patients and spouses are also examined here by quantitative measurement. Hematological cancer patients and their spouses were selected as the sample for the first part of this dissertation because this type of cancer is assumed to have a particularly high burden and thus a high need for support.

In burdened spouses, individual coping strategies for enhancing their own well-being can be exhausted or insufficiently available as they provide a high amount of support for the

patient. Dyadic coping strategies are also frequently focused on the patient, and beneficial dyadic coping from the patient to the spouse can be rare due to physical and psychological condition of the patient. In addition, social support from family, friends and colleagues is mainly solely focused on the patient, while the burden of spouses is neglected. Therefore, professional support may be a suitable way for spouses to receive help and support for their own needs, concerns and burden. Review of previous research showed that professional support for spouses is both scarce and struggle with some challenges, such as time and location constraints.

As a result, the second part of this thesis focuses on professional support especially for spouses in the format of a newly developed internet intervention. **Publication III** initiates a consecutive development and evaluation process of the internet intervention PartnerCARE for spouses of cancer patients. The study protocol includes a description of the intervention development and the pre-planned procedure of the randomized controlled feasibility study. **Publication IV** presents and discusses the results and lessons learned about feasibility and acceptability, as well as first insights into the potential efficacy of PartnerCARE.

These four publications aimed to address the following research questions:

1. What different types and deeper insights of coping and support can be identified in couples facing hematological cancer?

2. How are perceived dyadic coping and perceived social support associated with psychological distress in hematological cancer patients and their spouses?

3. How do cancer patients and their spouses differ in the types of coping and support they use?

4. Is the newly developed guided internet intervention PartnerCARE a feasible and acceptable way to support spouses of cancer patients? Can potential intervention effects be identified exploratory?

2 Publication I

Couples Coping with Hematological Cancer: Support Within and Outside the Couple - Findings From a Qualitative Analysis of Dyadic Interviews

Reference:
Bodschwinna D, Weissflog G, Döhner H, Niederwieser D, Mehnert-Theuerkauf A, Gündel H, Ernst J, Goerling U and Hönig K (2022). Couples Coping With Hematological Cancer: Support Within and Outside the Couple – Findings From a Qualitative Analysis of Dyadic Interviews. *Frontiers in Psychology* 13:855638. doi: 10.3389/fpsyg.2022.855638

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frontiers | Frontiers in Psychology

ORIGINAL RESEARCH
published: 19 May 2022
doi: 10.3389/fpsyg.2022.855638

Couples Coping With Hematological Cancer: Support Within and Outside the Couple – Findings From a Qualitative Analysis of Dyadic Interviews

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OPEN ACCESS

Edited by:
Linda Charvoz, University of Applied Sciences and Arts of Western Switzerland, Switzerland

Reviewed by:
Kristopher Lamore, Université de Lille, France
Emanuela Saita, Catholic University of the Sacred Heart, Italy

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Specialty section:
This article was submitted to Psycho-Oncology, a section of the journal Frontiers in Psychology

Received: *15 January 2022*
Accepted: *11 April 2022*
Published: *19 May 2022*

Citation:
Bodschwinna D, Weissflog G, Döhner H, Niederwieser D, Mehnert-Theuerkauf A, Gündel H, Ernst J, Goerling U and Hönig K (2022) Couples Coping With Hematological Cancer: Support Within and Outside the Couple – Findings From a Qualitative Analysis of Dyadic Interviews. Front. Psychol. 13:855638. doi: 10.3389/fpsyg.2022.855638

Objective: Cancer affects the patients as well as their partners. Couples use different strategies to cope with cancer and the associated burden: individual coping, dyadic coping, and support from the social network and from professional health care. The aim of this qualitative dyadic interviews is to gain a deeper and more differentiated understanding of the support system inside and outside of the couple.

Methods: Ten heterosexual couples (patients: seven men and three women) with different ages (patients: range = 22–75; spouses: range = 22–74), different hematological cancer (e.g., acute myeloid leukemia, non-Hodgkin's lymphoma) and cancer stages (initial diagnosis or relapse) participated in the study. Semi-structured dyadic interviews were conducted. Data of the verbatim transcripts were systematically coded and analyzed following structuring content analysis.

Results: Three main categories (individual coping, dyadic coping, and outside support) and ten subcategories about coping and support strategies in hematological cancer patients and their spouses could be identified. All couples described cohesion in relationship as an essential common dyadic coping strategy. Most strategies were focused on the patient's wellbeing. Furthermore, couples reported different common plans for the future: while some wanted to return to normality, others were reaching out for new goals.

Conclusion: Couples used various coping and support strategies, that differed in type and frequency between patients and spouses. Most of the strategies were perceived as beneficial, but some also triggered pressure. Overall, spouses seem to need more psychological support to improve their own wellbeing.

Keywords: hematological cancer, couple (spouses), dyadic interview, individual coping, dyadic coping, social support

INTRODUCTION

Hematological cancers include various heterogenous disease patterns that affect the hematopoietic system. Diseases like lymphoma, multiple myeloma and leukemia differ in treatment, progression, and forecast (Robert Koch Institute & Association of Population-Based Cancer Registries in Germany., 2021). Due to uncertainty about treatment effectiveness and cancer trajectory both patients and spouses suffer from psychological distress (Lambert et al., 2013; Kuba et al., 2019; Raphael et al., 2020). The couple faces new challenges (e.g., lack of knowledge about disease, financial burden), changing roles (e.g., single earner, family roles) and is concerned about their future together (Li et al., 2018; Serçe and Günüşen, 2021). In addition, highly aggressive treatments like high-dose chemotherapy, total body irradiation as well as treatment-related isolation of the patient in the case of stem cell transplantation leads to high burden in couples (Bishop et al., 2007; Beattie and Lebel, 2011).

Coping with cancer and its related burden can take place at different levels. Traditional models such as the transactional stress theory by Lazarus and Folkman (1984) focus on the individual centered view of stress management, in which coping efforts are described as an individual process. Over time dyadic approaches, in which couples respond to a shared stressor through a collaborative process, have gained increasing attention (Bodenmann, 1995). As cancer is a stressor that affects both patients and spouses as well as the close social network, coping and support efforts from all these parties should be considered (Bodenmann, 2005).

Individual coping, dyadic coping, and outside support are exceedingly important for couples facing cancer due to positive effects in adaption to the disease. Individual coping strategies such as reduction of negative mood, positive reappraisal or problem solving were generally associated with less psychological distress, fewer depression and anxiety symptoms (Brandão et al., 2017), higher quality of life, health and relationship satisfaction (Papp and Witt, 2010; Kvillemo and Bränström, 2014; Brandão et al., 2017). However, negative individual strategies like avoidance, denial, or resignation were related to higher psychological distress (Brandão et al., 2017). Dyadic coping strategies like open communication, positive and common dyadic coping were associated with improved relationship functioning and satisfaction, facilitation of couples' intimacy, higher relationship quality, and fewer depression symptoms (Papp and Witt, 2010; Regan et al., 2014; Rottmann et al., 2015; Traa et al., 2015; Pankrath et al., 2018; Meier et al., 2019; Lupinacci et al., 2021; Ştefănuţ et al., 2021). In contrast to the positive effects, higher use of negative coping forms (e.g., avoidant coping), higher level of interference in regular activities, and perception of dyadic support behavior were associated with depression and anxiety in oneself (Lambert et al., 2013; Regan et al., 2014; Rottmann et al., 2015; Bodschwinna et al., 2021). Social support like support from friends, family, or colleagues usually has a buffering effect on depression, anxiety, and distress (Hasson-Ohayon et al., 2010; Fong et al., 2017; Lotfi-Jam et al., 2019; Bodschwinna et al., 2021), with the limitation that this may only be true if the support is wanted (Vodermaier and Linden, 2019). Regarding professional support, interventions appear to be beneficial for patients, spouses and couples and future direction points toward online interventions (Badr and Krebs, 2013; Badr et al., 2019; Luo et al., 2020).

A recent study supports the assumption that different coping strategies occur simultaneously and are used depending on availability (Paschali et al., 2021). This is in line with Bodenmann's supplement of his sequential stress-coping-cascade model, which suggests that in continuous and cumulative stress situations people draw on different support simultaneously (Bodenmann, 1995, 2005). Furthermore, as individual and dyadic coping strategies are highly associated with each other (Papp and Witt, 2010; Paschali et al., 2021) it might be that combining specific forms of both strategies facilitate adaptation to cancer.

Despite the extensive quantitative research about coping with cancer, there have been fewer qualitative studies in this area. A recent interview study with hematological cancer patients and their family caregivers reported coping strategies like hiding emotions, thoughts and needs, a stronger dyadic relationship than in the past and changed roles within the dyad (Serçe and Günüşen, 2021). A systematic review of qualitative studies of men with prostate cancer identified coping strategies such as avoidance, employing positive focus, support seeking, retain pre-illness lifestyle and symptom management (Spendelow et al., 2018). However, less is known about the specific way in which different categories of coping strategies and support from outside of the couple are used by patients and their spouses as well as about the frequency with which they are used by each.

With the present interview study, we aim to explore how couples, in which one person is diagnosed with hematological cancer, cope individually and together with the disease and what coping and support strategies they use. Furthermore, we want to identify possible differences in coping behavior between the patient and partner. The deeper insights into specific types of coping and support strategies could improve the development of more detailed and tailored intervention programs for patients and their spouses suffering from cancer.

MATERIALS AND METHODS

Data of this qualitative study were collected as part of the project 'Dyadic coping in hematological patients over time' funded by the Deutsche José Carreras Leukämie-Stiftung between 2012 and 2015 (grant: DJCLS R 12/36). The corresponding multi-center longitudinal study examined a total of 330 couples at baseline and 217 couples at 6-month follow-up regarding their dyadic coping. Associations of dyadic coping with quality of life, relationship satisfaction, supportive care needs and psychological distress were investigated (Ernst et al., 2017; Weißflog et al., 2017; Pankrath et al., 2018; Bodschwinna et al., 2021). Since dyadic coping was a central aspect of the study, additional couple interviews were conducted to gain a deeper insight into the couples' coping and

support network. Ethics approval was obtained from the Ethics Committees of the Medical Faculty of the University of Leipzig (No. 298-12-24092012) and the University of Ulm (No. 243/12) and carried out in accordance with the Declaration of Helsinki.

Participants and Procedures

Eligibility was based on the following criteria: Being a patient with hematologic cancer, living in partnership, age between 18 and 75 years, proficient in German. Both patients and partners were required to provide written informed consent prior to enrolment. The selection of couples for the interviews was made from a subsample of 100 couples early in the study process, who already finished the longitudinal survey. In order to reach a heterogeneous sample of couples with respect to age, gender, duration of relationship, type of hematological disease and total score of dyadic coping the maximum variation method was used (Moser and Korstjens, 2018). All couples were already made aware during participation in the longitudinal study that an interview request could be made afterward. Eligible couples for the interviews were contacted and informed about the procedure of the study via phone call and were invited to the clinic to a suitable appointment. In order to overcome challenging recruitment of couples (participation agreement of both), an expense allowance of 20€ per couple was provided. However, this did not significantly increase the willingness to participate.

Data Collection

At baseline assessment of the longitudinal study sociodemographic information including sex, age, employment, education, marital status, living together, duration of relationship and medical information including diagnosis, disease type, disease status, and time since diagnosis were collected via paper–pencil questionnaire. In addition, dyadic coping was assessed with the Dyadic Coping Inventory (DCI) (Bodenmann, 2008). With 37 items, different aspects of dyadic coping are recorded and an overall sum score (range: 35–175) can be calculated. A higher score reflects more reported dyadic coping.

We conducted semi structured face-to-face couple interviews by one interviewer each (GW and DL) in Leipzig and Ulm between May 2014 and April 2015. The interviews were performed using a guideline prepared by the study team. The guideline consists of three thematic areas with open-ended questions: introductory question about the disease and its course, a question about how the couple talks about cancer and questions about what kind of support and coping is experienced within and outside the couple. The interview aimed to go beyond standardized questionnaires to gain a deeper insight into the couples' coping system. A dyadic interview setting was used allowing participants to respond directly to each other's statements, leading to more dynamism and more relevance to everyday life during the interviews (Froschauer and Lueger, 2003). The interviews were conducted in an undisturbed atmosphere, mostly in a clinic office and once in the couple's home. All interviews were audio recorded, transcribed verbatim according to the predefined transcription rules and anonymized (Dresing et al., 2015).

Data Analyses

Sociodemographic and medical information were reported with basic descriptive statistics using IBM SPSS Statistics 26. Total score of dyadic coping was calculated using sum score of all items of the DCI (Bodenmann, 2008). The transcripts of the interviews were analyzed using MAXQDA version 2020. The structuring qualitative content analysis by Kuckartz (2018) was applied. First step of this analysis process included the initial work with the interviews, where important text passages were highlighted. Within the second step, main categories were developed deductively according to the basic theory. The third step included a first coding of all interviews using the main categories. In the fourth step all these passages were compiled per main category. Based on these collected text passages, subcategories were inductively formed in the fifth step. Since the subcategories of dyadic coping and outside support already exist theoretically, their configuration was not purely inductive. The remaining subcategories were formed inductively on basis of the interviews conducted. All these subcategories could be confirmed by the interviews. The resulting category system was discussed within the research team, adjusted twice through back-and-forth comparison with literature and interview content. Afterward an associated coding guide was developed with definitions, anchor examples of each subcategory and coding rules. The sixth step included coding of the entire material with this category system. Within the seventh and last step each subcategory was analyzed thematically and presented in summary (Kuckartz, 2018). The coding steps three and six were conducted by two researchers (DB and UG) independently. Inconsistent coding decisions were discussed by the coders to reach consensus. Interrater agreement was calculated with Kappa according to Brennan and Prediger (1981) and amounts $\kappa_n = 0.77$.

RESULTS

Sample Characteristics

Of 35 couples approached, 25 couples (71.4%) declined to participate, either by both partners or by one partner. The final sample comprised 10 heterosexual couples (seven male and three female patients). Since no substantial new information was obtained after the 10 interviews, data saturation could reasonably be assumed and re-recruitment was declined. The mean age in patients was 57.0 years (SD = 16.09, range = 22–75) and in partners 54.3 years (SD = 17.68, range = 22–74). The duration of relationship ranged between 2 and 52 years. Five patients had acute leukemia, three had non-Hodgkin lymphoma, and one each had multiple myeloma and chronic leukemia. The majority of patients were either in full remission ($N = 5$) or partial remission ($N = 2$) and time since diagnosis was less than 2 years for seven patients. The interviews lasted between 47 and 116 min. Sociodemographic and medical characteristics are given in **Table 1**. Structuring content analysis resulted into three main

TABLE 1 | Patient and spouse characteristics.

Characteristics		Patient	Spouse
		N	*N*
Sex	Male	7	3
	Female	3	7
Age mean (SD, range)		57.0 (16.1, 22–75)	54.3 (17.7, 22–74)
Employment	Pension/early retirement	7	4
	Employed	2	5
	Unemployed	1	1
Education	<10 years	2	1
	10 years	3	6
	>10 years (High school)	5	3
Total dyadic coping mean (SD, range)		131.8 (20.3, 89–155)	127.5 (15.1, 108–152)

		Couples
		N
Marital status	Married	8
	Not married	2
Living together	In same household	9
	In separate households	1
Duration of relationship – years, mean (SD, range)		24.4 (21.6, 2–52)

		Patient
		N
Diagnosis	Acute leukemia	5
	Chronic leukemia	1
	Non-Hodgkin	3
	Multiple myeloma	1
Disease type	Initial diagnosis	8
	Relapse	2
Disease status	Full remission	5
	Partial remission	2
	Not assessable	3
Time since diagnosis	≤2 years	7
	3–5 years	2
	>5 years	1

categories: individual coping, dyadic coping, and outside support, each with several associated subcategories. **Table 2** shows the identified categories as well as the proportions of coping and support strategies used by patient and the spouse.

Individual Coping

Emotional Focused Strategies

Patients reported a variety of activities they undertook to improve their emotional wellbeing and relieve their stress, such as exercise, walking, reading books, playing games, watching movies, writing, practice rituals, meditation and relaxation techniques. In addition, some enjoyed trivia like trying to keep one's sense of humor or enjoyed motivational sayings. Acceptance of the disease and its consequences was perceived to promote serenity thus fostering calmness and relaxation. The spouses reported overall fewer strategies for improving their wellbeing. They also done some exercise, but indicated more emotional strategies such as rumination, distraction, crying or feelings of anger and helplessness while staying home alone during the hospitalization period of the patient.

Problem Focused Strategies

Among patients, problem focused strategies were characterized by seeking information about treatment and medicine and engaging in health-promoting activities. Moreover, prioritizing by importance to focus on what is most essential and being realistic overall were also mentioned as problem focused strategies. In contrast, some also wanted to cope with problem avoidance through suppression and downplaying. Some spouses

TABLE 2 | Patients' and spouses' quotes and frequency of categories identified.

Categories and subcategories	Number of interviews (*n* = 10)	Number of total text passages (*n* = 520)	Patients' text passages (*n* = 272)	Spouses' text passages (*n* = 248)	Representative quotes
Individual coping					
Emotional focused	10	79	56 (70.9%)	23 (29.1%)	"You have to do something. I can't sit around somewhere and lie and think about it and do nothing. I can't do that. So, I have to get out as much as I can. Even into the woods or whatever. I did wood, I did the horses. Everything I could do, I did. I did the garden, I planted hedges. So just those things." [P7]
Problem focused	10	72	44 (61.1%)	28 (38.9%)	"But I think I have started making lists right from the day of diagnosis: I have to resolve all this, and I have to do all this." [S3]
Positive reframing	9	60	31 (51.7%)	29 (48.3%)	"And the confidence that I have always shown. Just the diagnosis didn't cause hysteria in me, in any way. So, I'm not jumpy around and now I have to make a will and this and that. Nothing like that. It was simply: We can do it together! [. . .] That is a danger, but not the end. And that's actually what kept us going" [P9]
Dyadic coping					
Stress communication	8	40	30 (75.0%)	10 (25.0%)	"We have actually addressed everything, as said whether positive or negative." [P4] "Yes, we actually talked through all facets of the disease in our minds. Always together. As hard as it may be." [S4]
Supportive dyadic coping	9	41	7 (17.1%)	34 (82.9%)	"So, I was there every day. I went to work, then I went home and organized everything, cooked him something and then stayed as long as I could." [S1]
Delegated dyadic coping	7	16	0	16 (100%)	"I then took over that at home. Washing clothes, cleaning, and shopping and so on." [S6]
Negative dyadic coping	4	10	4 (40.0%)	6 (60.0%)	"So, he meant many things well. But I have also felt under pressure from time to time. And he didn't realize that. Because he had such stress and then he said: 'Do this, do that.' And it always had to be done immediately." [P10]
Common dyadic coping	10	110	38 (34.5%)	72 (65.5%)	"Of course, I would say that we got through it quite well and stuck together." [S3] -*cohesion* "It was important to me that everything is done at home as we are used to it, in this case. There was a bit of a handicap, but we have actually maintained the daily routine." [P9] – *return to normality* "But you should also turn to new things every now and then. We try to practice that now always?" [P6] – *new goals*
Outside support					
Social Support	10	50	42 (84.0%)	8 (16.0%)	"They [family and friends] can't help you either, but they can give you moral support. And they have supported. They came then. They always asked when we could visit [the patient] and they did, even if it was only for 10 min but at least they visited [the patient]." [S6]
Professional support	8	42	20 (47.6%)	22 (52.4%)	"But I'm glad when I have my doctor. Someone who understands me. Someone who says, yes, you have a hard time at the moment, but you can do it and you'll get out of it." [P5]

S = Spouse, P = Patient.

also searched for information, created lists for their tasks, planed the way back into everyday life, set boundaries and reduced extra work to have more time for themselves and the patient.

Positive Reframing

In all couples except one, patients and spouses reported different kinds of positive attitude and positive reframing. Positive reframing showed itself in hope and confidence, encouraging yourself, a new courage to live in patients and gratitude even for small advances. A wide variety of plans for the future reflected an optimistic outlook, both among patients and spouses.

Dyadic Coping

Stress Communication

While at the beginning of the disease there was a daily exchange about the disease and treatment, over time the disease fades into the background in communication. Some couples described an open communication, where they talked about everything, all facets of the disease, both positive and negative. Most of the stress communication, including fear and frustration, came from the patient, who reported that it is relaxing to have someone to communicate with. Spouses, on the other hand, who are often the first point of contact for any problems, reported that the patient's stress communication is very exhausting, but often this was the only way for the patient to relieve stress.

Supportive Dyadic Coping

Most supportive dyadic coping was provided by the spouses. One major part of this was simply being there for the patient including almost daily visits in hospital. Other spousal support includes instrumental, emotional and informational support, such as driving to appointments, physical closeness, providing distraction and encouragement, and gathering information about the disease and related issues. Not being alone and the presence of someone who is interested in the patients' sensitivities was perceived as very important by the patients, and for the spouses the feeling of being able to do something was also important. For their part, the patients were also concerned about their spouses and tried to support them again more over time.

Delegated Dyadic Coping

Only spouses reported temporarily taking over of certain tasks to relieve the patient's burden. This comprised instrumental support such as daily household tasks, childcare and organization of paperwork associated with the disease and sick leave, but also continuing of patients' leisure activities until they can take them over again. In addition, the spouses provided informational support by obtaining information from physicians or internet research. Patients appreciated this support as extremely helpful. One spouse reported the fear of being seen only as a caregiver and no longer as an equal partner.

Negative Dyadic Coping

Both patients and spouses indicated types of negative dyadic coping. Two patients reported individual situations in which the spouse does not take seriously their stress and alternative coping attempts. Moreover, some advice from spouses were perceived as triggering pressure by patients. Similarly, spouses reported conflict and feeling rejected when some of their support efforts were described as exaggerated and unhelpful by the patients. Mentioned examples of mutual negative dyadic coping were wordy disputes and not considering the other's point of view.

Common Dyadic Coping

Across couples, common dyadic coping was most frequently mentioned. Patients and spouses described multiple topics within common dyadic coping. The cohesion in the partnership, getting through the illness together and being there for each other were reported by all couples. These actions are associated with the deeper feeling of "we" and the strengthening of relationship. Some couples share that they show understanding of each other's feelings and regulate intense emotions together. There was also joint problem solving and joint decision-making regarding treatment and related areas (e.g., joint meal changes). Additionally, couples demarcate themselves together by taking distance from negative things and people or by relinquishing burdensome as well as time-consuming things. Moreover, while some couples reported that they try to live a normal everyday life again after the disease moved into the background, other couples used it as opportunity for new joint ventures, hobbies, and interests.

Outside Support

Social Support

Family and friends provided emotional support through visits and contact via telephone. They inquired about the patient's condition, while the partner tended to take a back seat. Partly the contact decreased over time, especially when they were afraid to talk about the disease. Exchange with other patients from the circle of friends was more open-minded and intensive. Family and friends also provided helpful instrumental support and friends with medical background helped with information and explanations. However, patients also felt pressured by some recommendations from friends. Various joint activities and spending time with friends and family provided joy and distraction for the couple. Only one spouse reported that a relative directly took care about the spouses' condition and advised a break. Another important factor was the support from the boss, who allowed to vary the working hours for the spouse to get more flexibility.

Professional Support

Both patients and spouses used professional offers for support services. Spouses emphasized the importance of supervision by a psychotherapist and the exchange with this neutral person. Patients perceived the assistance from social workers in making applications and referrals to other services as very helpful. Understanding and moral support from friendly, patient, and well-trained physicians and nurses, who treated the patient as a human being, was also reported by patients. Overall, many would recommend psychological support, especially for the partner. The wish for more proactive offers from the clinical side was expressed.

DISCUSSION

Coping and support strategies are key factors in improving wellbeing and adjustment in couples facing cancer. The purpose of this qualitative study was to go beyond quantitative data from prior questionnaire studies and to gain deeper insight into the specific strategies that are summarized in the theoretical categories. Compared to our previous quantitative studies (Ernst et al., 2017; Weißflog et al., 2017; Bodschwinna et al., 2021), we were able to confirm the main coping and support categories, as well as show similarities in the distribution of coping and support proportions between patient and partner. In addition, with the deeper insight new distinctions within these categories could be identified as well as the extensive scope of some categories. To our knowledge, this is the first study considering different coping and support strategies in cancer patients and their spouses using a dyadic interview setting.

Not only the frequency of individual coping strategies reported within a subcategory but also the type of strategy differed between patients and spouses. Regarding emotional strategies, patients focused on a variety of activities improving emotional wellbeing, while spouses reported more unfavorably strategies such as rumination or distraction. This is in line with previous research indicating that spouses commonly neglect their own need regarding wellbeing and are always with the patient in thought (Heynsbergh et al., 2019). Differences in problem focused strategies may be explained by role: patients reported more strategies which are directly associated with the diagnosis, while spouses focused more on tasks around and duties to path the way back to everyday life. The realistic approach of patients to the disease has already been reported as a strategy for advanced cancer patients (Walshe et al., 2017). The high level of positive reframing and future plans reported in both patients and spouses may be due to the fact that the majority of patients were in remission and therefore in a positive mood overall. On the other hand, this high level of positivity could be also due to patients' misunderstanding of their prognosis, which seems to be very common in palliative patients (Jacobsen et al., 2013). Positive reframing in our study was also expressed through gratitude and enjoyment of little things, which is a way of living in the now that has also proven important for patients with advanced cancer (Cottingham et al., 2018).

Open communication is essential for couples coping with cancer (Goldsmith and Miller, 2014; Li et al., 2018), but due to individual differences in couples, research should avoid the general and abstract concept of openness and move on to more differentiated descriptions (Goldsmith and Miller, 2014). As in previous dyadic studies, we found that communication within the dyad can change over cancer trajectory (Siminoff et al., 2020). Communicating stress in particular is positively related to better relationship quality, facilitates couples' intimacy and reduced distress (Badr et al., 2018; Lupinacci et al., 2021; Ştefănuţ et al., 2021). The relaxing effect of stress communication was also reported by patients in our study, while some spouses complained about how burdensome patients' stress communication was for them. To address these differences, couple-based interventions should change the generic notion of open communication into more individual approaches (Badr, 2017).

Because of the role-effect it is not surprising, that spouses provided more supportive dyadic coping than patients (Kroemeke et al., 2019). Spousal support was especially strong in the post-diagnosis period and during hospitalization (Antoine et al., 2013), while patients tried to reestablish support after recovery and return home (Kroemeke et al., 2019). Being there for the patient was a salient issue for the couple, helping both not to feel alone. Besides supportive behavior, spouses also took over tasks completely when the patients were unable to do so (Palmer Kelly et al., 2019). Thus, spouses may also worry about being perceived as caregivers only which may turn the relationship out of balance (Serçe and Günüşen, 2021).

The overall less reported negative dyadic coping may likely be due to a selection bias given that well-functioning couples might have been more willing to be interviewed. The fact that the interview was conducted jointly with both partners might additionally have reduced the chance to observe negative dyadic coping. Apart from this reasoning well-intentioned support from spouses can also cause negative acknowledgment from patients, if support does not match patient's needs (Palmer Kelly et al., 2019).

Within common dyadic coping, which was the most frequent coping strategy in our sample, cohesion in relationship was important in all couples and manifested in various manner. In addition to joint activities, it also seems to be essential to jointly distance oneself from negative and stressful things. Through all these experiences, couples achieve mutual growth, more intimacy and improvement in their relationship (Beattie and Lebel, 2011; Hasson-Ohayon et al., 2016; Lupinacci et al., 2021; Serçe and Günüşen, 2021). In addition, the couples could be divided into two groups: those who wanted to return to normality of the everyday life (Antoine et al., 2013) and those who wanted to discover new things together. This distinction in different future plans was also partially reflected in the individual coping strategies.

Like in our previous quantitative study as well as in other studies, spouses in the present sample reported less direct social support from friends and family compared with patients (Hasson-Ohayon et al., 2010; Bodschwinna et al., 2021). Nevertheless, instrumental social support for the patient can also be indirectly relieving for the spouse. Support from friends and family is perceived as helpful by most patients, while some recommendations cause patients to feel pressure. Therefore, it seems that social support should also meet the expectations or needs of patients in order to be beneficial (Reynolds and Perrin, 2004; Vodermaier and Linden, 2019). Over time social networks changed and received social support decreased for some of the participants, which can be due to burnout of support providers or because patients no longer needed outside support (Arora et al., 2007; Palmer Kelly et al., 2019).

Professional support is widely used in couples. Spouses in our sample were more likely to go to psychotherapist, while patients reported more instrumental help from social workers. More proactive support offers in general and psychological support for the spouses were desired, as perception of available support is low (Li et al., 2018; Heynsbergh et al., 2019).

STUDY STRENGTH AND LIMITATIONS

The combination of deductive and inductive categorization strategies is clearly the strength of the present qualitative study. This approach is well in line with previous research and theories, and additionally allows for more flexibility in identifying additional subcategories. Furthermore, the dyadic interview setting has the advantage to explore coping and support strategies of the couple with both partners together, since they also concern both of them. Some limitations of the study should be considered. Given that both partners had to agree to participate, there may be a selection bias in the sample toward couples who are in highly functional relationships and tend to communicate more openly. Furthermore, the high dropout rate is to be considered as a limitation. The reasons for this probably lie in the logistical challenge for the couples to appear together for an on-site appointment. Due to the large catchment area of the clinics, long distances often also had to be covered. Another limitation is, that the assumption of theoretical data saturation after 10 interviews did not follow the typical process. Initially, an unexpected high percentage of the couples approached declined to participate. Only subsequently re-recruitment was declined, as a review of the processed interviews revealed that no significant new information had been added in the most recent interviews. The ineffectiveness of the expense allowance may be due to the fact that a financial incentive is not a consideration for couples facing life-threatening cancer. Conducting the interview together may also have resulted in social desirability influencing the two partners' communication. While an effort was made to include heterogenous couples, some important variables were not considered. Therefore, our sample consisted mainly of patients in remission and the currently attenuated symptoms could account for the low proportion of negative coping strategies reported. Furthermore, generalization of our findings to other cancer types is not applicable, as this study was conducted only with hematological cancer patients and their partners.

CLINICAL IMPLICATION

Couples facing cancer use a variety of different coping and support strategies. In this context, patients and spouses differ in some of their used strategies and received support. Clinicians should keep track of the strategies used, intervene when they prove not to be useful, and recommend tailored improvement of the strategies. First, open communication should not be generally recommended, as stress communication has been shown to be both beneficial and burdensome (Badr, 2017). Furthermore, it should be highlighted, that we could identify two different types of future plans in couples: returning to normality and reaching out for new goals. These new insights could serve as a new direction for couple interventions by adding tools that help realizing the couples' individual plan for the future. Tailored support in couple-based online interventions could be a suitable implementation for this purpose (Luo et al., 2020). In addition, health care system should provide more proactive offers for psychosocial support for spouses, as their suffering still seems to be rather neglected. Emotional coping, in particular, should be improved in spouses, as they used very few strategies to relax and to improve their own wellbeing. Especially during the patients' hospitalization, clinicians should observe spouses' condition and recommend appropriate support services.

CONCLUSION

We identified various coping and support strategies regarding individual coping, dyadic coping, and outside support. Most of them were perceived as beneficial, but some triggered pressure. With qualitative research we were able to get a more detailed and deeper insight into the different strategies. For example, common dyadic coping showed various facets that a representation with a numerical value could not do justice to. We were also able to identify some differences in patient and spouse strategies that should be considered in couple intervention development. Further research in the area of coping and support strategies could gain even deeper insights by examining real-time interactions between patients and spouses (Lau et al., 2019).

DATA AVAILABILITY STATEMENT

Data are only available from the corresponding author on request, because of privacy or ethical restrictions.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Ethics Committees of the Medical Faculty of the University of Leipzig (No. 298-12-24092012) and the University of Ulm (No. 243/12). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

JE, GW, KH, and HG were responsible for funding and design of the study. AM-T, DN, and HD supervised design and conduction of the study in terms of psychological or hematological expertise. GW, JE, KH, and DB were responsible for recruiting participating couples and conducting the interviews. DB was responsible for

the evaluation method and the development of the code system, performed the first coding of the interviews, supervised and contributed to the qualitative data analysis and interpretation, performed the quantitative analysis, and drafted the manuscript. UG was responsible for second coding of the interviews. All authors have read the manuscript critically and approved the final manuscript.

FUNDING

The study was funded by the Deutsche José Carreras Leukämie-Stiftung (grant no. DJCLS R 12/36).

ACKNOWLEDGMENTS

We thank Dirk Lang for conducting the interviews in Ulm and Tim Poessnecker for his support in qualitative research methods. We also would like to thank all the couples who participated in the interview study.

SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2022.855638/full#supplementary-material

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3 Publication II

Dyadic coping and social support: Various types of support in hematooncological patients and their spouses – Associations with psychological distress

Reference:
Bodschwinna D, Ernst J, Mehnert-Theuerkauf A, Gündel H, Weissflog G, Hönig K (2021). Dyadic coping and social support: Various types of support in hematooncological patients and their spouses – Associations with psychological distress. *Psycho-Oncology* . 30:1041-1050. https://doi.org /10.1002 /pon.5631

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Check for updates

Received: 22 December 2020 | Revised: 12 January 2021 | Accepted: 12 January 2021

DOI: 10.1002/pon.5631

ORIGINAL ARTICLE

WILEY

Dyadic coping and social support: Various types of support in hematooncological patients and their spouses—Associations with psychological distress

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Funding information

José Carreras Leukämie-Stiftung
Open access funding enabled and organized by Projekt DEAL.

Abstract

Objective: Patients and spouses use various support strategies to deal with cancer and its associated burden. Support can be perceived within the dyad [perceived dyadic coping (PDC)] or from others [perceived social support (PSS)]. The present study investigates the association of PDC and PSS with depression and anxiety symptoms experienced by hematooncological dyads.

Methods: A total of 330 hematooncological dyads participated in the study. Dyadic Coping Inventory (DCI) including perceived stress communication and four PDC strategies (supportive, negative, delegated, common), ENRICHED Social Support Instrument (ESSI) and Patient Health Questionnaire-4 (PHQ-4) are used for assessment. To take nonindependence of patient's and spouse's variables into account, data are analyzed with the Actor-partner-interdependence model (APIM).

Results: Hematological cancer patients and their spouses reported a similar level of depression and anxiety symptoms. Perceived negative dyadic coping (DC) was adversely related with both patient's and spouse's outcomes (all $p < 0.01$) and perceived positive DC was adversely related with depression symptoms in both and anxiety symptoms in spouses (all $p < 0.05$). More PSS was associated with less depression and anxiety symptoms in both (all $p < 0.05$), and spouse's PSS ($b = -0.04$, $p < 0.05$) was significantly associated with patient's depression symptoms.

Conclusions: This study highlights the association between perceived negative DC, perceived positive DC and PSS with depression and anxiety symptoms. Focus should be on enhancement of PSS especially in spouses, as they experience a comparable amount of psychosocial distress and have considerable impact on the patient's wellbeing.

KEYWORDS

actor-partner interdependence model, anxiety, cancer, couples, depression, dyadic coping, psychological distress, psycho-oncology, social support, spouse

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1 | BACKGROUND

Cancer affects patients and their spouses with a variety of psychosocial and emotional burden.[1] Hematological cancer is often highly aggressive, life-threatening and thus necessitates prolonged and intensive treatments, which can be extremely exhausting.[2] Therefore, patients with hematological cancer and their spouses may report higher levels of psychological distress compared to other cancer populations.[3,4] Up to 27% (17%) of hematological cancer survivors suffer from anxiety (depression) disorder[5] and up to 44% (27%) of their spouses.[4] Although evidence suggest that patients and spouses are interdependent in physical and mental health,[6,7] the majority of studies capture the individual instead of the dyadic level.

For coping with a persistent stressor (like cancer) and the associated burden, patients and spouses rely on a diverse range of support and coping strategies: individual coping, dyadic coping (DC), social support from friends and family and professional support.[8,9] Bodenmann describes a stress-coping-cascade model that includes different coping and support forms applied in sequence.[10] It is supposed that after the onset of stress, people start with individual coping, and in case of prolonged stress, they seek out for other support resources such as DC, social support or professional support. In most cases, different support types can occur simultaneously, especially in continuing and cumulating stressful situations.[10,11] To date, usually individual coping and DC are considered together in research,[12,13] while a study regarding breast cancer also includes social support from others.[14] Overall, studies that examine different forms of support together are scarce.

Research concerning perceived support from the other partner [perceived dyadic coping (PDC)] and its association with psychological distress on a dyadic level in cancer population are scarce. A study with couples facing prostate cancer found no associations between perceived supportive DC and common DC with distress, but a positive association between perceived negative DC and distress in both,[15] while a study with breast cancer couples report an association with common DC, an less depression symptoms.[16] Furthermore, a study with breast cancer couples reports only a significant association of perceived spousal support of healthy spouses and less anxiety in patients (partner effect) and no associations with own levels of distress.[14] Additionally, individual research with cancer survivors reports significantly lower levels of depression in patients if they perceive high support from their spouses.[17]

Perceived social support (PSS) has repeatedly been associated with psychosocial outcomes in cancer patients and their spouses. Decreased quality and quantity of PSS are associated with increased depression symptoms and stress in breast cancer survivors.[18] A negative association between PSS and psychological distress has been identified by other studies in different cancer populations.[8,14,19] This association was also evident in spouses, although they report lower levels of support from family and friends.[14] It should be noted that the provider of PSS is not specified in some studies[8,18,19]; therefore, it can include family and friends as well as spouses.

The present study aims to examine the association of different support forms with psychological distress experienced in hematological cancer dyads. First, it will be examined whether patients and their spouses differ regarding psychological distress, PDC and PSS. While this question has been addressed in other cancer populations,[14,15] evidence at the level of dyads is hitherto still scarce, especially with regard to PSS in couples facing hematological cancer. Second, our study will examine to which extent PDC and PSS reported by patients and spouses are related to their psychological distress, considering the interdependence of the dyadic data. Based on the assumption that different support forms are used simultaneously in situations with a persistent stressor, PDC and PSS are simultaneously included in the analysis. Since research in this area regarding cancer population is scarce, the present analysis has explorative character and aimed to more thoroughly explore the association between PDC and psychosocial distress in a comparably large sample of patient-spouse dyads. Adding to previous research,[8,14,18,19] we hypothesize that more PSS would be associated with less depression and anxiety symptoms in patients and their spouses.

2 | METHODS

2.1 | Participants and procedures

Between January 2013 and October 2014, patients and their spouses were recruited from three university cancer centers in Germany (Leipzig, Ulm and Regensburg). The study has been approved by the Ethics Committee of the Medical Faculty of the University of Leipzig (No. 298-12-24092012). Potential participants were identified by reviewing the cancer centers medical charts. The following inclusion criteria had to be fulfilled: (a) a patient with any hematologic cancer (diagnosis validated by medical records), (b) partnership (married or cohabiting), (c) age of the patient between 18 and 75 years and (d) adequate knowledge of German language. Exclusion criteria were (e) severe mental disorders (ICD10 diagnoses F0-F2) and (f) severe cognitive and/or physical impairments. Eligible couples were approached via the patient by a study research assistant at the cancer centers. After detailed information about the study and written informed consent of both, patient and spouse received a questionnaire with the request to fill in alone. The completed questionnaire could be postal returned, handed in at the clinic or was picked up again from a research assistant. Out of 568 eligible couples, 330 participated in the study (58%). Reasons for not participating were: no response to study request (56.2%), lack of interest in study (38.0%) and other reasons (5.8%). Participating patients did not differ from non-participating patients in terms of age and sex ($p > 0.05$).

2.2 | Assessments

2.2.1 | Sociodemographic and clinical data

Sociodemographic variables were assessed via self-report. Medical characteristics were extracted from patients' medical records.

2.2.2 | Dyadic coping

The 'Dyadic Coping Inventory' (DCI)[20] assesses the own DC and the PDC from the partner with different subscales. Since the present study examines different forms of the perceived received support, only subscales of PDC are used: perceived stress communication (four items, e.g., 'My partner let me know that he/she appreciate my practical support, advice or help'), perceived supportive DC (five items, e.g., 'My partner show empathy and understanding'), perceived negative DC (four items, e.g., 'My partner blame me for not coping well enough with stress'), perceived delegated DC (two items, e.g., 'My partner take on things that I would normally do in order to help me out') and common DC (five items, e.g., 'We try to deal with the problem together and look for concrete solutions'). All Items are rated on a five-point Likert scale (from 1 = 'very rarely' to 5 = 'very often'). Thus, higher scores on each subscale indicate more of the respective behavior. Internal consistency of the subscales varied from $\alpha = 0.71$ to $\alpha = 0.92$.[20] In comparison, internal consistency in our sample varied from $\alpha = 0.70$ to $\alpha = 0.88$ in patients and from $\alpha = 0.71$ to $\alpha = 0.91$ in spouses.

2.2.3 | Perceived social support

The ENRICHED Social Support Instrument (ESSI) is a valid and reliable instrument for assessment of PSS.[21] The five items (e.g., 'Is there someone available to give you good advice about a problem?') are rated on a five-point scale from 1 to 5 ('at no time' to 'always'). Higher values indicate higher PSS while values below 18 (sum score range from 5 to 25) indicate lack of PSS.[21] The internal consistency of the scale is Cronbach's $\alpha = 0.93$. In our sample the internal consistency is equal (patients: $\alpha = 0.93$; spouses: $\alpha = 0.94$).

2.2.4 | Psychological distress

Psychological distress is assessed with the screening scale Patient Health Questionnaire-4 (PHQ-4).[22] It consists of a two-item depression scale (PHQ-2) and a two-item anxiety scale (GAD-2). The items are rated on a four-point Likert scale from 0 to 3 ('not at all distressed' to 'nearly every day distressed') related to distress of the last two weeks (e.g., 'Feeling down, depressed ore hopeless over the last two weeks'). A cut-off score of ≥ 3 in PHQ-2 and GAD-2 indicates elevated scores of depression and anxiety symptoms. In regard to the small number of items the internal consistencies are adequate with $\alpha = 0.78$ for PHQ-2 and $\alpha = 0.75$ for GAD-2 in a representative German sample.[23] Internal consistencies in our sample are similar: PHQ-2 $\alpha = 0.77$ (patients) and $\alpha = 0.76$ (spouses) and GAD-2 $\alpha = 0.76$ (patients) and $\alpha = 0.75$ (spouses).

2.2.5 | Relationship satisfaction

Relationship satisfaction, a control variable, is assessed with a short version of the 'Partnership Questionnaire' (PFB-K)[24] with nine items on a four-point Likert scale from 0 ('never') to 3 ('very often') (Cronbach's $\alpha = 0.84$ (patients) and $\alpha = 0.85$ (spouses)).

2.3 | Statistical analyses

Data analyses are conducted with IBM SPSS Statistics 26 and IBM SPSS Amos 26. Socio-demographic and medical data are reported using descriptive statistics. To examine differences in psychological distress, PDC and PSS between hematological cancer patients and their spouses *t*-tests for paired samples are calculated. Additionally, effect size Cohen's *d* is calculated (effect sizes from 0.2 are considered small, from 0.5 as moderate, and from 0.8 as large).[25] Due to the multiple testing a significance level of $p < 0.006$ is projected (after Bonferroni adjustment).

Before model estimation, Pearson correlations are calculated over all variables of patients and spouses to determinate the nonindependence of the dyad.[26] To take this interdependency of dyadic data into account, data are analyzed using the Actor-Partner Interdependence Model (APIM). With the APIM both actor and partner effects are determined for patients and their spouses. In the present study the actor effect specifies the impact of the own predictor variable (PDC, PSS) on the own dependent variable (psychological distress), and the partner effect specifies the impact of the own predictor variable on the partner's dependent variable. In order to avoid mix-up in concepts, 'partner' is only used referring to partner effect of the APIM and 'spouse' when referring to the patient's life partner. Two APIMs are calculated, one for each dependent variable (depression and anxiety symptoms). Structural equation modeling (SEM) is used for statistical analysis of the APIM as recommended for distinguishable dyads. The standardized coefficients (for better comparability of the different scales) are computed using mean and standard deviation across the entire sample (patients and spouses).[26] Age, gender and relationship satisfaction of patients and spouses are examined for potential correlations with psychological distress and DC[1,5] and are controlled in the APIMs. Power calculation was conducted with APIMPowerR Program (https://robert-a-ackerman.shinyapps.io/APIMPowerRdis/) and resulted in a sample size of 321 dyads ($\alpha = 0.05$, 1 β = 0.80, estimated beta for actor effects = 0.35 and for partner effects = 0.15).

The following requirements are revised before APIMs are estimated using SEM: (1) test of collinearity with squared multiple

correlation (R^2 > 0.90 imply extreme multivariate collinearity), (2) analysis of multivariate outlier by using the mahalanobis distance statistic with a recommended conservative significance level of $p < 0.001$, (3) analysis of missing values with Little's Missing Completely at Random (MCAR)-test and (4) test of univariate and multivariate normal distribution.[27] Univariate normal distribution is evaluated with measure of skew and kurtosis (limit for skew |>3| and for kurtosis |>10|), because in large samples and surveys with rating scales statistical tests such as Kolmogorov–Smirnov or Shapiro–Wilk test become even with slight discrepancy from normality statistically significant. Furthermore, in most studies with rating scales multivariate normal distribution is not existent. As recommended, only a moderate breach of multivariate normal distribution will be assumed if univariate normal distribution is proven.[27] After confirmation of requirements, missing values of type MCAR are imputed via Full Information Maximum Likelihood (FIML)-Estimation.[28] FIML is selected due to comparable performance to multiple imputation[29] and exceeded performance compared to other methods (listwise deletion, pairwise deletion, similar response imputation) for MCAR.[30]

3 | RESULTS

3.1 | Sample characteristics

The study included a total of 330 couples (209 male and 121 female patients). The mean age in patients is 57 years and in spouses 56 years. Majority of couples are married (85%) and are living together (96%). Thirty-seven percent of patients are employed and more than a half are retired. The mean duration of relationship is 30 years with a range from 3 months up to 56 years. The most frequently diseases in our sample are acute and chronic leukemia, non-Hodgkin lymphoma and multiple myeloma. For about two-quarter (69%) of the sample, time since cancer diagnosis is more than one year. Demographic and medical sample characteristics are given in Table 1.

3.2 | Levels of perceived dyadic coping, perceived social support and psychological distress in patients and spouses

Patients and their spouses differ significantly in four of five PDC subscales. Patients report significantly less perceived stress communication ($d = 0.26$), significantly more perceived supportive DC ($d = 0.30$), significantly less perceived negative DC ($d = 0.29$) and significantly more perceived delegated DC ($d = 0.38$) compared to their spouses. Furthermore, patients report significantly more PSS ($d = 0.45$) than their spouses. Patients and their spouses do not differ significantly in their reported amount of depressive and anxiety symptoms (Table 2).

3.3 | Requirements for actor-partner-interdependence model calculation

Significant correlations among variables between and within dyad members imply nonindependence on individual level (Table S1). All requirements for SEM are met as followed: (1) The highest R^2 is calculated for PHQ-2 from patients with $R^2 = 0.62$ and therefore extreme multivariate collinearity is not assumed. (2) Three multivariate outliers were detected. Because of missing values, mahalanobis distance could not be estimated for 13 dyads. Conduction of analyses with and without outliers does not result in different outcomes. Since it can also be assumed that these participants actually responded more extremely than the remaining sample, no cases are excluded. (3) All variables have less than 2% missing values and missing completely at random can be assumed ($\chi^2(180) = 158.65$, $p = 0.87$). (4) All skew and kurtosis values are below the limit with the highest skew value of | −1.4| (SD = 0.13) and the highest kurtosis value of |1.46| (SD = 0.27) for PSS of patients. Therefore, univariate and multivariate normal distribution are assumed.

3.4 | Perceived dyadic coping and perceived social support on depression symptoms

More perceived stress communication ($b = -0.24$, SE = 0.09, $z = -2.70$, $p = 0.007$) and more PSS ($b = -0.09$, SE = 0.02, $z = -4.26$, $p < 0.001$) in patients are associated with less depression symptoms in patients (actor effect). In contrast, more perceived supportive DC ($b = 0.40$, SE = 0.12, $z = 3.37$, $p < 0.001$), more perceived negative DC ($b = 0.62$, SE = 0.12, $z = 5.13$, $p < 0.001$) and more perceived delegated DC ($b = 0.19$, SE = 0.08, $z = 2.27$, $p = .023$) in patients are associated with more patient's depression symptoms (actor effects). Additionally, two variables of the spouse are significantly associated with patient's depression symptoms (partner effects): more perceived stress communication ($b = 0.35$, SE = 0.09, $z = 3.87$, $p < 0.001$) in spouses is associated with more depression symptoms in patients and more PSS ($b = -0.04$, SE = 0.02, $z = -2.27$, $p = 0.023$) in spouses is associated with less depression symptoms in patients. More perceived supportive DC ($b = 0.31$, SE = 0.11, $z = 2.85$, $p = 0.004$) and more perceived negative DC ($b = 0.30$, SE = 0.11, $z = 2.66$, $p = 0.008$) in spouses are both significantly related with more own depression symptoms (actor effects). In contrast, more PSS ($b = -0.07$, SE = 0.02, $z = -4.27$, $p < 0.001$) is associated with less depression symptoms in spouses. There are no significant associations with common DC of both patients and spouses. The variance explanation of the model for depression symptoms is $R^2 = 0.29$ in patients and $R^2 = 0.21$ in spouses. Age, gender and relationship satisfaction are controlled in the APIM. Only regression weights with a significance level of p <.05 are displayed in the APIM (Figure 1).

TABLE 1 Patient and spouse characteristics: Descriptive statistics of raw data

Characteristics		Patient		Spouse	
		N	%	*N*	%
Sex[a]	Male	209	63.3	122	37.0
	Female	121	36.7	208	63.0
Age mean (SD, range)		57.0 (12.2, 22–76)		56.0 (12.6, 20–78)	
Employment	Pension/early retirement	178	53.9	119	36.0
	Employed	122	37.0	179	54.2
	Unemployed	6	1.8	16	4.8
	Other	15	4.5	13	3.9
	Missing values	9	2.7	3	0.9
Education	<10 years	65	19.7	72	21.8
	10 years	161	48.8	149	45.2
	>10 years (high school)	99	30.0	103	31.2
	Other	5	1.5	4	1.2
	Missing values	-	-	2	0.6
		Couples			
		N	%		
Marital status	Married	281	85.2		
	Not married	49	14.8		
Living together	In same household	315	95.5		
	In separate households	12	3.6		
	Missing values	3	0.9		
Duration of relationship – years, mean (SD)		30.2 (15.2)			
		Patient			
		N	%		
Disease type	Acute leukemia	85	25.8		
	Chronic leukemia	73	22.1		
	Non-Hodgkin	69	20.9		
	Multiple myeloma	61	18.5		
	Other	42	12.7		
Time since diagnosis	≤1 year	104	31.5		
	>1 year	226	68.5		

[a]Five same-sex couples.

3.5 | Perceived dyadic coping and perceived social support on anxiety symptoms

More perceived negative DC in patients ($b = 0.59$, SE = 0.13, $z = 4.63$, $p < 0.001$) is associated with more anxiety symptoms in patients. In contrast, more PSS ($b = -0.08$, SE = 0.02, $z = -3.54$, $p < 0.001$) is significantly related to less anxiety symptoms in patients. Additionally, there is one significant partner effect: more perceived stress communication of the spouse ($b = 0.43$, SE = 0.10, $z = 4.53$, $p < 0.001$) is associated with more anxiety symptoms in the patient. Regarding spouse's variables, perceived supportive DC ($b = 0.27$, SE = 0.11, $z = 2.45$, $p = 0.014$) and perceived negative DC ($b = 0.35$, SE = 0.12, $z = 2.99$, $p = 0.003$) are positively related to anxiety symptoms in spouses. In contrast, PSS ($b = -0.03$, SE = 0.02, $z = -1.98$, $p = 0.048$) is negatively associated with anxiety symptoms in spouses. There is also a significant partner effect: perceived supportive DC of the patient

TABLE 2 Comparison of dyadic coping, perceived social support and psychological distress in patient-spouse dyads

	Patient		Spouse				
Characteristics	***M***	**SD**	***M***	**SD**	***T***	***p*[a]**	***d***
Dyadic coping (DC) [range of scales: 1–5]							
Perceived stress communication	2.84	0.87	3.15	0.90	−4.64	<0.001	0.26
Perceived supportive DC	3.77	0.89	3.50	0.94	5.38	<0.001	0.30
Perceived negative DC	1.59	0.67	1.81	0.77	−5.15	<0.001	0.29
Perceived delegated DC	3.86	0.95	3.33	1.01	6.89	<0.001	0.38
Common DC	3.36	0.83	3.37	0.83	−0.18	0.860	0.01
Perceived social support (ESSI) [range of scale: 5–25]	21.91	3.85	19.77	4.75	8.10	<0.001	0.45
Psychological distress [range of scales: 0–6]							
Depression symptoms (PHQ-2)	1.63	1.39	1.39	1.26	2.68	0.008	0.15
Anxiety symptoms (GAD-2)	1.55	1.47	1.46	1.33	0.91	0.363	0.05
	N	**%**	***N***	**%**			
Lack of social support (ESSI cut-off ≤ 18)	54	16.4	102	30.9			
Missing values	-	-	2	0.6			
Elevated scores of depression symptoms (PHQ-2 cut-off ≥ 3)	74	22.4	48	14.5			
Missing values		-	6	1.8			
Elevated scores of anxiety symptoms (GAD-2 cut-off ≥ 3)	66	20.0	53	16.1			
Missing values	1	0.3	4	1.2			

Abbreviations: DC, dyadic coping; ESSI, ENRICHED social support instrument; GAD-2, anxiety scale of patient health questionnaire; PHQ-2, depression scale of patient health questionnaire.

[a]After Bonferroni adjustment: p values < 0.006 are significant; d = Effect size (Cohens' d); calculations with raw data.

($b = 0.33$, SE = 0.12, $z = 2.82$, $p = 0.005$) is positively related to spouse's anxiety symptoms. There are no significant associations with perceived delegated DC and common DC of both patients and spouses. The variance explanation of the model for anxiety symptoms is $R^2 = 0.28$ in patients and $R^2 = 0.24$ in spouses. Age, gender and relationship satisfaction are controlled in the APIM. Only regression weights with a significance level of p <.05 are displayed in the APIM (Figure 2).

4 | DISCUSSION

In this dyadic study with hematological cancer patients and their spouses, it was investigated in which way PDC and PSS are related to patient's and spouse's depression and anxiety symptoms. First, we identified some differences in patient's and spouse's levels of PDC. In our sample, patients reported significant less perceived stress communication from their spouses while spouses reported more perceived stress communication from the patient. This is consistent with both the tendency of spouses not wanting to burden the patient additionally with their problems[31] and spouses being the primary source of conversation for patients.[32] Furthermore, patients in our sample reported significant more perceived supportive DC and delegated DC, which means that they receive more support and get more tasks taken on compared to spouses. Rottmann et al. (2015) explained this by a patient-caregiver role effect, which implies that the patient needs help, and the spouse provides it.[16] Patients reported significant less perceived negative DC than spouses, what can be explained by spouses are motivated to support the patient in this life-threatening situation and do not want to burden them additionally with ambivalent or hostile behavior. In addition, spouses reported significant less PSS, which is in line, that patients are in focus of the care and support system, while spouses are only perceived as caregivers, and therefore, they are neglected in their support needs.[14] Taken together it seems that hematological cancer dyads were similar in their PDC and PSS to other cancer types.[14,15,33] Since scores of depression and anxiety did not differ significantly between patients and spouses, both were burdened similarly.

Perceived stress communication First, we found that patient's perceived stress communication from the spouse was related with less depression symptoms in patients, which emphasizes the importance of open communication. This association was not found in spouses. Comparison of these results to previous studies is difficult, since stress communication was assessed in different ways: perception of common stress communication[34] or own provided stress communication.[35] In contrast, spouse's perceived stress communication from the patient was positively associated with patient's

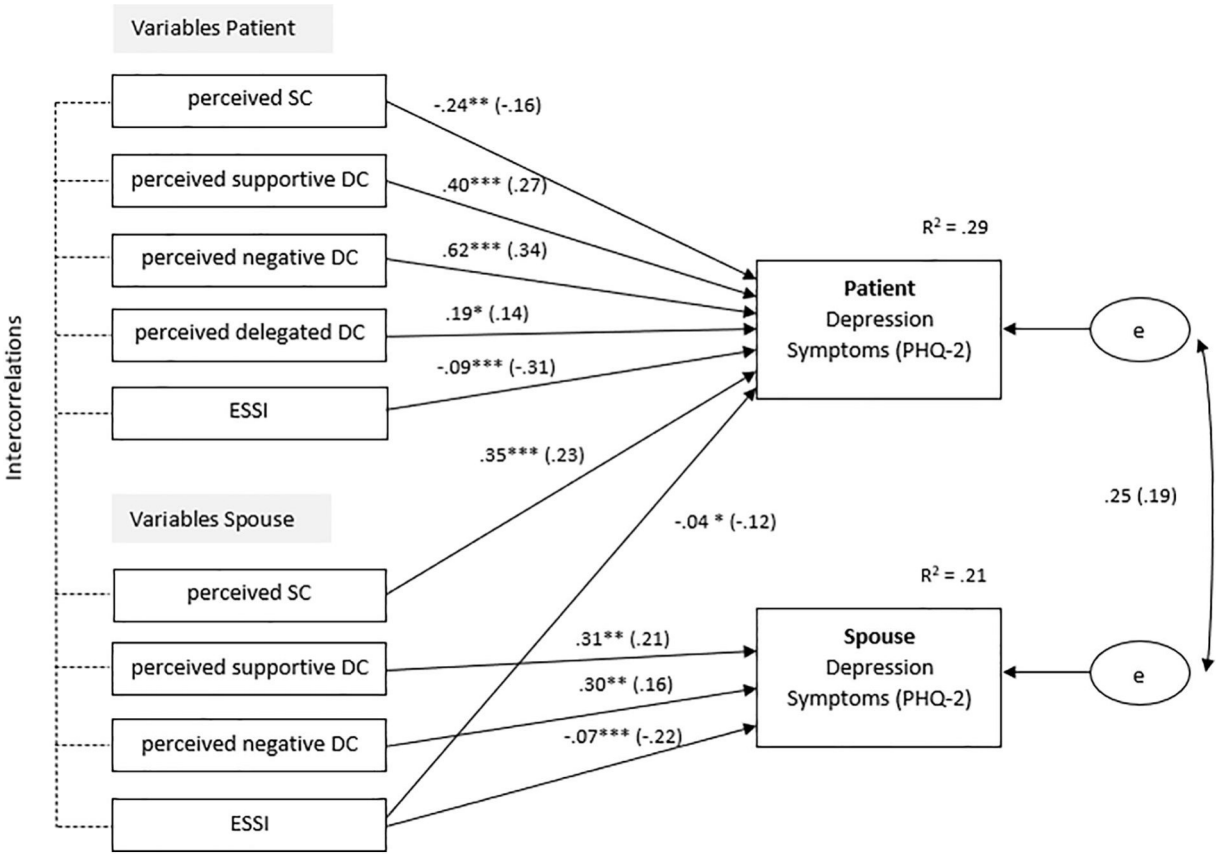

FIGURE 1 Actor-partner interdependence model of depression symptoms. Depression symptoms (PHQ-2) of patients and spouses is controlled for gender, age and relationship satisfaction of patients and spouses; values on arrows are unstandardized beta coefficients (standardized coefficients are in parentheses); *p<.05, **p<.01, ***p<.001. Abbreviation: DC, dyadic coping; ESSI, ENRICHED Social Support Instrument; PHQ-2, Patient-Health-Questionnaire depression scale; SC, stress communication

depression and anxiety symptoms. This positive association seems clearly comprehensible: it might either suggest that the more spouses perceive stress communication from the patients, the more the patient is likely to report their distress or the more distressed patients feel, the more spouses perceive their stress communication about it.

Perceived supportive dyadic coping Perceived supportive DC was associated with more depression symptoms in both. Realizing how much supportive behavior the other offers, may both feel less self-efficacy[36] and therefore feeling more depressed. It could also indicate that when both perceived more supportive DC (e.g., 'My partner makes me feel that he/she understand me and that he/she care about my stress'), they are more likely to report their depression symptoms. These findings are in contrast to a previous study, who did not find a relationship between perceived supportive DC and depression or anxiety.[15] The significant partner effect from perceived supportive DC of patients and anxiety symptoms of spouses could imply the association of patients perceiving more supportive behavior from the spouse when spouse is feeling more worries about the patient and thus provide more support.

Perceived negative dyadic coping Patient's and spouse's perceived negative DC were positively associated with their own depressive and anxiety symptoms. This suggests that more perceived negative DC from the other (e.g., get allegations) was associated with severe levels of depression and anxiety symptoms, but only for oneself (no significant partner effects). This is in line with previous studies with other cancer types[15,33] as well as with the strong association of perceived negative DC with supportive care needs of patients and spouses.[37]

Perceived delegated dyadic coping Patients perceiving more delegated DC from the spouse were associated with feeling more depression symptoms in patients. This might be due to patients see how many tasks spouses were taking over and therefore feel more helpless.

Perceived social support Regarding PSS, there was a consistent association: more PSS was related to less depression and anxiety symptoms in patients and spouses (actor effects). This finding is in line with previous research in different cancer populations and their caregivers.[14,18,19] It is to highlight that more spouse's PSS is also associated with less patient's depression symptoms (partner effect). It might be that patients experience stress from burdening their spouses with the disease, and therefore, feel less distressed when they see the spouse is receiving support for themselves. A similar effect was found in a study with breast cancer patients, where family support received by spouses has a negative association with anxiety

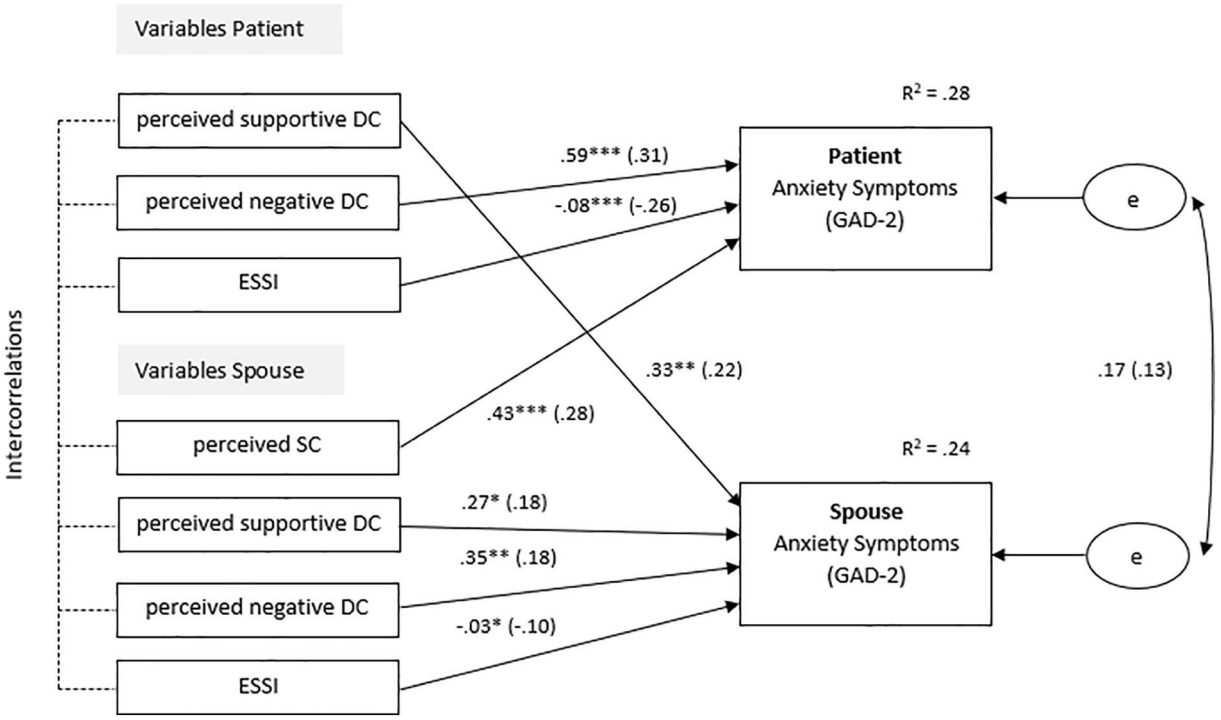

FIGURE 2 Actor-partner interdependence model of anxiety symptoms. Anxiety Symptoms (GAD-2) of patients and spouses are controlled for gender, age and relationship satisfaction of patients and spouses; values on arrows are unstandardized beta coefficients (standardized coefficients are in parentheses); *p<.05, **p<.01, ***p<.001. Abbreviation: DC, dyadic coping; ESSI, ENRICHED Social Support Instrument; GAD-2, Patient-Health-Questionnaire anxiety scale; SC, stress communication

and global distress of the patient.[14] Moreover, there is recent research which identified that PSS only buffers against depressive and anxiety symptoms if the support is explicitly wanted from cancer patients.[38] This should be considered in further research. Since another recent study found only partner associations between PSS and patient/caregiver health in lung cancer dyads but not in colorectal cancer dyads,[39] it should be considered to evaluate analyses separately for the diverse hematological cancer types in subsequent studies.

In summary, first we found differences in the level of PDC (except common DC) and PSS in hematooncological patients and their spouses, but they show similar levels of depression and anxiety symptoms. Second, perceived negative DC was associated with more depression and anxiety symptoms in both and perceived positive DC with more depression symptoms in both and more anxiety symptoms in spouses. Third, PSS of patients and spouses shows a consistent picture in direction of the buffering effect. Finally, more partner effects from spouses were significant, which emphasizes the influence of spouses on the patients.

4.1 | Study limitations

Some limitations need to be taken into consideration. Since our variables were measured via self-report survey at home, there is uncertainty about a potential social desirability bias and whether the instruction to fill out the questionnaire alone was followed. Furthermore, the cross-sectional design of the study limits conclusions about causality relationships between PDC and PSS with psychological distress. Assessment of depression and anxiety symptoms with the PHQ-4 can be critical despite adequate internal consistency of the questionnaire because the brief form might not cover all dimensions of distress. In addition, assessment of PSS can be viewed critically, as we cannot definitely determine whether participants only considering other family and friend support than the spouse in the questionnaire. Moreover, discussing our findings in relation to previous research is challenging. First, because PDC scores are rarely used in cancer samples to date and second, because this is the first study measuring PDC and PSS in hematological cancer patients and their spouses and comparability with other cancer types[15,16,35] is not clear. Nevertheless, the overall large sample size and common investigation of hematological cancer patients and their spouses with consideration of the existent nonindependence were major strength of the present study.

4.2 | Clinical implication

Cancer burdens hematological patients and spouses to a comparable extent. Both depression and anxiety symptoms of patients and spouses were related to PDC and PSS. Interventions for

hematological couples should draw couples' attention to the strong association between perceived negative DC as well as perceived supportive DC and psychological distress. It has already been assumed that interventions focusing on negative DC behavior could be more beneficial for couples.[15] Since PSS of the spouse was beneficial for both spouses and patients, spouses should be brought more into focus for receiving support. Interventions could highlight the importance of PSS for spouses and encourage spouses to increase their search for support, because this can be also indirectly beneficial for patients.

5 | CONCLUSION

Hematological cancer patients and their spouses use different forms of support to cope with cancer and the associated psychological distress. Overall more attention should be paid on the PDC, since for example PDC was found to be stronger predictor for relationship satisfaction than own behavior scales.[40] In order to gain a deeper insight of the interplay of support, future research should examine all different forms of support collectively in cancer population. Furthermore, enhancement of PSS should be focused, as PSS is beneficial for both patients and spouses.

ACKNOWLEDGEMENTS

We thank all the couples who participated in the study. The study was funded by the Deutsche José Carreras Leukämie-Stiftung (Grant No. DJCLS R 12/36).

Open access funding enabled and organized by Projekt DEAL.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

DATA AVAILABILITY STATEMENT

Data are only available from the corresponding author on request, because of privacy or ethical restrictions.

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How to cite this article: Bodschwinna D, Ernst J, Mehnert-Theuerkauf A, Gündel H, Weissflog G, Hönig K. Dyadic coping and social support: Various types of support in hematooncological patients and their spouses—Associations with psychological distress. *Psycho-Oncology*. 2021;30:1041–1050. https://doi.org/10.1002/pon.5631

4 Publication III

PartnerCARE – a psycho-oncological online intervention for partners of patients with cancer: study protocol for a randomised controlled feasibility trial

Reference:
Bodschwinna D, Lorenz I, Bauereiss N, Gündel H, Baumeister H, Hönig K (2020). Partner-CARE – a psycho-oncological online intervention for partners of patients with cancer: study protocol for a randomised controlled feasibility trial. *BMJ Open*. 10:e035599. doi:10.1136 /bmjopen-2019-035599

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BMJ Open

PartnerCARE—a psycho-oncological online intervention for partners of patients with cancer: study protocol for a randomised controlled feasibility trial

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To cite: Bodschwinna D, Lorenz I, Bauereiss N, *et al*. PartnerCARE—a psycho-oncological online intervention for partners of patients with cancer: study protocol for a randomised controlled feasibility trial. *BMJ Open* 2020;**10**:e035599. doi:10.1136/bmjopen-2019-035599

► Prepublication history for this paper is available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2019-035599).

Received 07 November 2019
Revised 28 July 2020
Accepted 30 July 2020

Check for updates

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ABSTRACT

Introduction Cancer burdens not only the patient but also the partner to a comparable extent. Partners of patients with cancer are highly involved in the caring process and therefore often experience distress and report a low quality of life. Interventions for supporting partners are scarce. Existing ones are rarely used by partners because they are often time-consuming per se and offer only limited flexibility with regard to schedule and location. The online intervention PartnerCARE has been developed on the basis of caregiver needs and consists of six consecutive sessions and four optional sessions, which are all guided by an e-coach. The study aims to evaluate feasibility and acceptance of the online intervention PartnerCARE and the related trial process. In addition, first insights of the putative efficacy of PartnerCARE should be gained.

Methods and analysis A two-arm parallel-group randomised controlled trial will be conducted to compare the PartnerCARE online intervention with a waitlist control group. The study aims to recruit in total n=60 partners of patients with any type of cancer across different access paths (eg, university medical centres, support groups, social media). Congruent with feasibility study objectives, the primary outcome comprises recruitment process, study procedure, acceptance and satisfaction with the intervention (Client Satisfaction Questionnaire adapted to Internet-based interventions), possible negative effects (Inventory of Negative Effects in Psychotherapy) and dropout rates. Secondary outcomes include quality of life, distress, depression, anxiety, caregiver burden, fear of progression, social support, self-efficacy, coping and loneliness. Online measurements will be performed by self-assessment at three time points (baseline/pre-randomisation, 2 months and 4 months after randomisation). Data analyses will be based on intention-to-treat principle.

Ethics and dissemination Ethics approval has been granted by the Ethics Committee of the University of Ulm (No 390/18). Results from this study will be disseminated to relevant healthcare communities, in peer-reviewed journals and at scientific and clinical conferences.

Trial registration number DRKS00017019.

Strengths and limitations of this study

- ► Randomised controlled feasibility trial of a novel online intervention specifically tailored to the care needs of partners of patients with cancer.
- ► The PartnerCARE online intervention comprises evidence-based psychological support including psychoeducational, cognitive behavioural and guided imagery components.
- ► Low-threshold intervention for partners with low utilisation of psychosocial services due to time and logistic limitations, low self-awareness of own care needs as well as gender-related concerns (eg, male partners).
- ► Possible adverse effects of the intervention will be monitored.
- ► Challenges of the trial comprise the diverse target group (regarding, eg, age, diagnosis of the patient, progress of the disease) and technical comprehension of the participants.

INTRODUCTION

Family members, particularly partners, are increasingly involved in the care of individuals with cancer.[1] They support the patient in daily life (eg, they manage treatment appointments, take over additional tasks in the household, manage medication and provide emotional support) and are often not aware of their own needs.[2 3] The disease and the corresponding challenging situation can lead to a great impact on the partner's well-being and health. Partners are at high risk to suffer from various types of problems including social and emotional problems.[4] Hence, caregivers of patients with cancer reported significantly more impairments than non-caregivers regarding work productivity, activity and quality of life.[5] Whereas the physical quality of life of caring partners is similar to a norm population, their reported mental quality of life is significantly lower.[6] Compared with non-caregivers, caregivers

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show a significantly higher occurrence of stress-related comorbidities like depression (odds ratio (OR)=1.50), anxiety (OR=1.97) or insomnia (OR=2.01),[5] and compared with patients they show a similar prevalence of depression (pooled relative risk (RR)=1.01) and anxiety (RR=0.71).[7 8] Concurrently, caregivers' burden often stays invisible, due to the fact that the healthcare system focuses on the patient, which leaves partners' supportive care needs often neglected or under-reported.[9] Male partners as caregivers are a particularly under-recognised and undersupported group.[10]

Several psychosocial interventions have been designed to address the needs of cancer caregiver. The interventions differ regarding aim (eg, reduce caregiver burden, improve quality of life), underlying approaches (eg, psychoeducation, cognitive behavioural therapy, existential therapy), delivering format (eg, face-to-face, online, telephone and group therapy, dyadic, individual) and addressed participants (eg, couple, caregiver alone). Systematic reviews have shown that these interventions have small to medium positive effects on multiple outcomes for caregivers.[11–13] Interventions exclusively relying on cognitive behavioural therapy had only negligible effects on caregivers.[14] Especially in couple interventions, the effects for caregivers have to be considered critically because numerous interventions focus on patient care and include caregivers only as support resource.[11] In general, intervention studies often lack reporting how to implement the interventions into practice.[15] There are two main challenges about interventions for caregivers: first, the target group is difficult to reach, which is evident from low recruitment rates.[12 16] Second, the existing face-to-face interventions are rarely used by caregivers (eg, they are too time-consuming, caregivers are unaware of own needs).[17 18] As a result, online interventions have moved into focus over the last decade. They have broadly been perceived as suitable, acceptable and helpful for cancer caregivers.[16 17 19] Online interventions have several advantages over other treatment delivering formats: online interventions are easily and quickly accessible as well as flexible regarding time and location independency, and they allow caregivers privacy while seeking for information and support.[20 21] Furthermore, nearly a half of the caring partners are interested in using online interventions and would prefer an intervention that takes less than 1 hour per week, lasts minimum 5 weeks, is addressed to the partner only and contains information as well as peer support.[22 23]

In the context of the German National Cancer Plan, the Federal Ministry of Health requests appropriate psycho-oncological care for all patients and caregivers in need,[24 25] irrespective of inpatient or outpatient treatment. A recent report on the psycho-oncological care in Germany recommends to develop and promote innovative offers like ehealth programmes.[26] Despite the structures and recommendations, a lot of patients and caregivers receive no or no promptly and no low-threshold psycho-oncological care in Germany.[27]

Already developed or planned online interventions for caregivers address couples,[28 29] informal caregivers in general (including partners, children, parents)[30 31] or male caregivers and caregivers of patients with a specific type of cancer,[32 33] while only one hitherto known intervention particularly addresses partners.[34] None of them is available in German. The results from online interventions for caregivers are rare because to date most of them did only publish study protocols[33 34] or promising trend results from feasibility studies.[28–32]

Aim

The present study has two aims. First, feasibility of the online intervention PartnerCARE and the extent of participants' satisfaction with the intervention will be evaluated. Second, the potential efficacy of PartnerCARE on the partner's well-being will be investigated compared with the waitlist control group post-treatment and over 4-month follow-up. The results of this feasibility study will be used to optimise PartnerCARE via participant feedback. Subsequently, a comprehensive efficacy evaluation of the online intervention is planned.

METHODS

Study design

This is a two-arm, parallel randomised controlled trial (RCT) comparing the online intervention PartnerCARE (intervention group, IG) with a waitlist control group (CG). Participants of the IG will receive the guided version (with individual feedback from an e-coach) of PartnerCARE. The CG will receive no intervention during the study. After a waiting period of 4 months, participants of the CG will get the opportunity to work on the unguided version (with automatic feedback) of PartnerCARE. Assessments of the primary and secondary outcomes will take place at baseline (T0), 2 months after randomisation (post-treatment, T1) and 4 months after randomisation (follow-up, T2).

This clinical trial will be conducted and reported in accordance with the Consolidated Standards of Reporting Trials (CONSORT) Statement for pilot RCTs[35] as well as the guidelines for executing and reporting internet intervention research.[36] The study protocol is reported according to the SPIRIT (Standard Protocol Items: Recommendations for Interventional Trials) 2013 Statement.[37] This study is registered in the German clinical trial register.

Inclusion and exclusion criteria

The primary inclusion criterion for participation is to be in a relationship with a partner who is diagnosed with any type of cancer (initial diagnosis or relapse, regardless of the onset of the disease or stage of the patient's treatment). Participants are required (1) to be age 18 years or above, (2) have an internet access and an appropriate device, (3) provide the study team an email address for contact reasons and (4) sign an informed consent.

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Participants do not have to live with the patient, but participants will be excluded if the partner with cancer has died before the start of the study. Inclusion and exclusion criteria will be checked at the first online assessment (T0) via self-report.

Recruitment

To overcome the challenge of recruiting cancer caregivers, recruitment takes place in a multiplicity of online and offline fields in the complete German-speaking area (includes Germany, Austria and Switzerland). Participants are recruited in relevant social media groups (eg, groups for caregivers of patients with cancer), in online communities, via flyers and circular emails in university medical centres, links on clinic homepages, online and offline support groups, cancer counselling centres and comprehensive cancer centres. All recruitment routes lead to the PartnerCARE study homepage (www.esano.klips-ulm.de/de/trainings/krebserkrankung/partnercare/), where potential participants get information and can register for the study via contact form or sending an email to the study team. Recruitment started in April 2019 and is still ongoing until the target sample size will be reached. Due to further project plans and financial reasons, recruitment will be closed after 18 months, even if the target sample size could not be reached.

Study procedure

After initial contact via study homepage or email, interested partners will receive an email from the study team including a document with detailed participation information and an informed consent form attached. After given informed consent (via email, fax or mail), participants will get an invitation to the online baseline assessment (T0) and will be randomised afterwards either to the IG (immediate access to the guided version of PartnerCARE) or to the waitlist CG (access to the unguided version of PartnerCARE after about 4 months according to the follow-up assessment). Participants will be informed via email about group affiliation. Two months and 4 months after randomisation, all participants will receive an invitation for post-treatment and follow-up assessment (figure 1).

Randomisation

Randomisation and allocation of participants to two groups will be conducted by an independent researcher, who is not involved in other processes of the study, using an automated online randomisation programme (www.sealedenvelope.com). Permuted block randomisation with randomly arranged block sizes (2 and 4) with an allocation ratio of 1:1 (allocation to IG and CG will be equally distributed in each block) will be performed. This

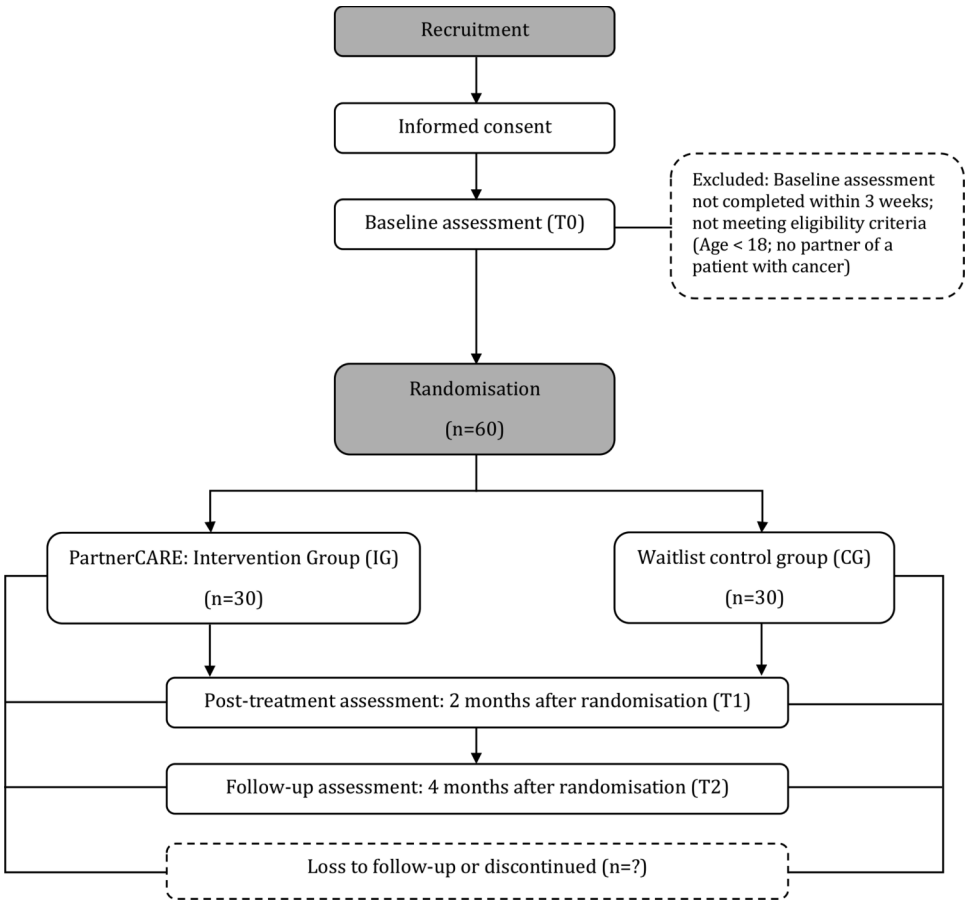

Figure 1 Flow diagram of the study procedure.

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Table 1 Overview of needs of cancer caregivers

Needs of caregivers		Literature
Information	About illness and treatment, how to provide care	8 23 40 41
Comprehensive cancer care	Contact with healthcare professionals, knowledge of available services like, for example, peer support	8 21 23 40 41
Emotional and psychological support	Sleep disturbances, depression, anxiety, fatigue, weight gain	8 23 40 42
Impact in daily life	Financial, uncertainty, looking after own health, balance own needs with needs of patient	8 21 23 40–42
Relationship	Communication, sexuality	8 23 40
Spirituality		40 42

results in a preferably balanced group distribution and that the data collector is not able to forecast the allocation of participant.

Intervention

Development of the intervention

The development of PartnerCARE was inspired by a therapy manual for a structured group intervention about psychoeducation with patients with cancer[38] and internet intervention standards established by the research group (eg, Lin *et al*[39]). Thus, the intervention is based on various concepts that are widely used in cancer context: psychoeducation, behavioural therapy, supportive therapy and guided imagery.[12] The group intervention was adapted to an individually online format and to the specific needs of caregivers. A literature search was conducted, focusing on current reviews, qualitative and quantitative research about needs of cancer caregivers.[8 21 23 40–42] An overview of caregiver needs is listed in table 1. The most relevant topics out of the caregiver needs are included into the PartnerCARE intervention, and some topics that may only be relevant to some are provided as optional additional sessions (eg, sexuality, death and dying). As PartnerCARE is an offer to partners of patients with any kind of cancer, we abstained from putting detailed information about specific cancer disease and treatment into the intervention to avoid an overload of the single sessions. Instead, a list of relevant websites with further information and help services is provided in the sixth session.

In order to ensure participant motivation, several persuasive elements were integrated in the design of PartnerCARE.[43–45] The reduction principle is used by providing a weekly activity plan where participants record small activities for each day to learn in small and simple steps to improve self-care. At the beginning of each session, experience with the activities is queried (rehearsal principle). The tunnelling principle is implemented by guiding the participants through the intervention with feedback after each session from the e-coach. Reminders are sent if the weekly session exceeded 2 days. Three exemplary partners are specifically developed regarding the similarity and social learning principle by telling their story, giving exemplary answers on exercises and accompanying the participants through the sessions. These exemplary partners are introducing themselves in the first session via picture and written text. In all following sessions, participants can click on the picture of the exemplary partners and read their exemplary answers to various exercises. The exemplary partners are provided to show participants that they are not alone with their burdens. The online intervention is offered through Minddistrict (www.minddistrict.com), an ehealth platform where a secure access to the online intervention and a secure exchange between participant and e-coach are granted. The internet platform and the intervention are available 24 hours a day and 7 days a week.

The first version of PartnerCARE (main sessions) was evaluated by four independent psycho-oncologists (three psychologists, one psychiatrist) who were not involved in the development process. Each psycho-oncologist valued one session via the think aloud method[46]: while they were working on the session, they were encouraged to vocalise what they are thinking at the moment. Participant comments were collected on a list and used to further develop PartnerCARE regarding user-friendliness (eg, insert of progress bars on each page), text formulations (eg, incomprehensible and too psychological phrases verbalised more generally understandable) and content adjustments (eg, connections to previous sessions). The overall development process lasted from January 2018 until February 2019.

Content of the intervention

The content of the online intervention PartnerCARE (table 2) is composed of different empirically evaluated and clinically established manuals (eg, Weis *et al*[38], Geuenich[47]). In the intervention, we combined content of different reliable approaches, which are shown to be effective for caregivers (eg, Applebaum and Breitbart[12]): psycho-education, cognitive behavioural therapy, supportive therapy and guided imagery elements. Therefore, the intervention focuses on activating resources, positive activities, communication skills, improving self-care and self-help strategies to manage caregiver burdens. In addition to psychoeducative text, the intervention contains visual and audio materials to enhance understanding and readability as well as to increase adherence and efficacy.[48] Practical exercises and the three exemplary partners make the intervention interactive. The guided imagery exercises facilitate awareness of inner soul processes and they are used for relaxation. To create a transfer of the learnt content and strategies into daily life, examples and exercises for home practice between the sessions are contained. PartnerCARE consists of

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Table 2 Structure and content of the PartnerCARE sessions

Sessions	Content	Example exercise
Introduction	► Technical issues and functions ► Overview of the training	*Aim:* train the ability to use the online intervention
Main sessions		
1. Specific burdens	► Specific burdens (eg, exhaustion, anxiety) from partners ► Identification of own resources ► Plan for positive activities	We ask the partner to write down their story and how they cope with it. *Aim:* awareness of burden and perception of how to deal with the burden using existing resources
2. Inner drivers	► Identification, interpretation and meaning of personal drivers (eg, 'be perfect', 'please others') and their possible impact in caregiver context ► Giving yourself permissions	Partners identify their inner drivers via questionnaire and are asked to phrase self-permissions. *Aim:* recognising and downscaling of excessive expectations on the own person to facilitate daily life
3. Partnership communication	► Basic rules of successful communication (non-verbal, gender differences) ► Communication in the context of disease	Partners are asked to write down their communication problems. Afterwards they should plan a conversation with implementing the learnt communication rules. *Aim:* improve open communication between partner and patient
4. Handling negative feelings	► Focus on anxiety ► Mindfulness as strategy to deal with anxiety	Partners are encouraged to try different mindfulness exercises. *Aim:* reduction of dysfunctional coping and regain of control
5. Control and acceptance	► Discrimination between things that are controllable or should be accepted ► Enjoyment in everyday life	Partners are asked which actuality they want to accept because it is not controllable. Furthermore, they learn how to enjoy little things. *Aim:* awareness of dysfunctional control and awareness of little positive things in everyday life
6. Paths and goals	► Further support offers ► Reflection of the training ► Outlook: next steps/goals	We ask the partner what was helpful and what they want to continue. *Aim:* motivation of the partner to be his own trainer
Booster session	► Repetition of two basic elements of the training: activity plan and open communication	Partners are asked how they have fared in the past 2 weeks and which exercises they continued. *Aim:* reminder and consolidation of training content
Optional additional sessions		
Support of own children	► Burdens of children ► Suggestions for a conversation about the disease/situation	Partners are asked to write down their experience with their children and they get conversation examples. *Aim:* support with communication with children
Healthy sleep	► Rules for healthy sleep ► Sleeping problems ► Relaxation exercises	Quiz about healthy sleep and sleeping problems. *Aim:* support with sleep problems
Closeness and sexuality	► Open communication about sexuality ► Relaxation/massage exercises	Partners learn about other types of sexuality, for example, relaxation and closeness through massage exercises. *Aim:* removal of taboos regarding communication about sexuality and encouragement to try something new
Existential burdens	► Thinking about end of life ► Hope, farewell, grief	Partners can write about their thoughts about the end of life and they are encouraged to write about the sense of the time together with their spouse. *Aim:* removal of taboos regarding thinking and talking about death

one introduction session (overview of the intervention, introduction in technical handling of the intervention), six main consecutive sessions, four optional additional sessions with specific content and one booster session. The optional sessions are presented at the third main session and can be selected by the participant. Duration of each session varies from 30 to 60 min, but there is no time limit. Participants work on their own and can take breaks within a session whenever and how often they want. It is recommended to work on one session each week to have enough time between the sessions for practising. Therefore, at the end of each session participants are asked to set an appointment for working on the next session.

To have a clear structure over the whole intervention, every session follows the same process:

1. Today's feeling: rating on a burden thermometer from 0 ('no burden') to 10 ('high burden') and describing the current feeling.
2. Report of home practice from the last week.
3. Basic information: psychoeducation about the topic of the session.

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4. Practical exercises: during the session or for practice between the sessions.
5. Preview of the main topic from the next session.
6. Guided imagery exercise: guided audio imagination of approximately 10 min with different topics.

Online intervention process and guidance

After baseline assessment (T0), participants of the IG will get immediate access to PartnerCARE. Therefore, they will receive an email with log in information for the Minddistrict platform. After log in, the participant can start directly with the introduction session. At the end of each session, the participant clicks on a send button and the e-coach receives a note that a session was finished. Afterwards, the e-coach logs in to Minddistrict, reads the filled in text fields from the participant and writes a feedback. The participant also receives a note via email when feedback on a session is available.

The feedbacks from the e-coach will be partly standardised and individualised dependent on entries from the participant, encouraging them to stay motivated working on the intervention. Since it is aimed that e-coaches need about 10 min in average for writing a feedback due to time efficiency, the actual feedback time is measured. Participants will receive the feedback within the next 2 weekdays after completing a session. Participants can also write a personal message to the e-coach via the Minddistrict platform if they have questions or technical problems. The communication between participant and e-coach will be asynchronous. Guidance in online intervention is used to increase efficacy, adherence and decrease dropout.[49 50]

Text message coach

Participants can choose in session 1 if they want to be supported additionally with two SMS per week during the intervention (at no charge for the participant). SMS will be sent via online platform MessageBird (www.messagebird.com). The text message coach is thematically matched with the intervention and accompanies each session with two messages and after the main sessions one message per week until the booster session (in total 15 SMS). The text messages include motivational quotes, mini-tasks and reminders of positive activities or exercises, for example, 'Before you go to bed tonight, look back on your day. Remember: What beautiful moments have you experienced today?' It has been shown that SMS support may have the effect to enhance the intervention effect.[51]

Control condition

Participants of the waitlist CG will receive no intervention during the study phase but they are free to use other treatment options in standard care. Four months after randomisation and after completing the follow-up questionnaire (T2), they will get access to the unguided version of PartnerCARE. The intervention is the same as in the IG and participants will have the possibility to choose the text message coach in session 1 as well. But instead of individualised feedback, they will receive a short automatic feedback after each session.

Sample size/power calculation

Since with this study the practicality and feasibility of PartnerCARE will be evaluated as the primary outcome, a formal sample size calculation is not required. A total sample size of n=60 (30 partners per arm) was chosen as a recommendation for pilot trials.[52] Part of the feasibility study will be to explore the feasibility of recruitment and rating of the different recruitment strategies.

Assessments

All assessments will take place at the online survey platform Unipark (www.unipark.de). Table 3 shows all outcomes and time points. Sociodemographic variables include age, sex, marital status, nationality, education, occupational situation and number of children. In addition, clinical characteristics from the diseased partner will be assessed with single questions: cancer diagnosis, date of diagnosis, phase of the disease and current medical treatments. Participants will be reminded via email to complete surveys if they do not respond to invitation email.

Primary outcome

Primary outcome of this pilot RCT study is the feasibility of the PartnerCARE online intervention. To characterise the different aspects of feasibility, a variety of questionnaires will be used. The measurement of feasibility will be composed of satisfaction with the online intervention, possible negative effects, attitudes toward psychological online interventions, evaluation of the SMS Coach, individual feedback from participants, processing duration of the sessions (via feedback from participants), participant flow, dropout rates, duration of the intervention, effort from the e-coaches and technical difficulties.

User satisfaction with web-based health interventions will be measured with the *Client Satisfaction Questionnaire adapted to Internet-based interventions (CSQ-I)*.[53] Eight items are rated on a 4-point Likert scale from 1 ('does not apply to me') to 4 ('does totally apply to me'), which leads to a sum score range from 8 to 32. The scale demonstrated good reliability and construct validity. The CSQ-I is being only submitted to the IG post-treatment and follow-up.

Possible negative effects of the online intervention will be assessed with an online adapted version of the *Inventory for the Assessment of Negative Effects in Psychotherapy (INEP)*.[54] The original 21 items were adapted at the online setting by modifying text ('online intervention' instead of 'therapy') and replacing items about the relationship between participant and therapist with items about the e-coach. The adjusted inventory consists of 8 items with a 7-step bipolar format (−3='definitely a negative effect'; 0='unchanged'; +3='definitely a positive effect') and 14 items with a 4-step unipolar format (from 0='strongly disagree' to 3='fully agree'). Additionally, the first 17

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Table 3 Overview of the assessments

Instruments	Aim	Time of measurement T0	T1	T2
Primary outcome—feasibility				
CSQ-I*	Participant satisfaction		✔	✔
INEP-On/INEP-CG	Negative effects online interventions (IG)/ participation in study (CG)		✔	✔
APOI	Attitudes psychological interventions	✔	✔	✔
Dropout rate	Participant adherence		✔	✔
Evaluation SMS Coach*	SMS Coach satisfaction		✔	
Secondary outcome				
DT	Distress	✔	✔	✔
PHQ-8	Depression	✔	✔	✔
GAD-7	Anxiety	✔	✔	✔
VR-12	Quality of life	✔	✔	✔
BSFC-s	Caregiver burden	✔	✔	✔
PA-F-P-KF	Fear of progression	✔	✔	✔
ESSI	Perceived emotional social support	✔	✔	✔
OSS-3	Received social support	✔	✔	✔
SWE	General self-efficacy expectation	✔	✔	✔
Brief COPE	Coping	✔	✔	✔
Loneliness	Feeling lonely	✔	✔	✔
Other assessments				
Sociodemographics	Age, sex, occupation, children	✔		
Clinical characteristics patient	Diagnosis, onset, disease phase, current treatment	✔		
Psychotherapy (yes/ no, how long)		✔	✔	✔

T0: baseline, T1: 2 months, T2: 4 months.
*Recorded in intervention group only.
APOI, Attitudes towards Psychological Online Interventions Questionnaire; Brief COPE, abbreviated version of the COPE (Coping Orientation to Problems Experienced) inventory; BSFC-s, short version of the Burden Scale for Family Caregivers; CSQ-I, Client Satisfaction Questionnaire adapted to Internet-based interventions; DT, Distress thermometer; ESSI, ENRICHD Social Support Instrument; GAD-7, Generalised Anxiety Disorder-7; INEP-On/INEP-CG, Inventory of Negative Effects in Psychotherapy—online/-control group; OSS-3, 3-item Oslo Social Support scale; PA-F-P-KF, Fear of progression questionnaire for partners; PHQ-8, Patient Health Questionnaire-8; SWE, General Self-efficacy Expectation scale; VR-12, Veterans RAND 12-item health survey.

items record whether any negative effect is attributed on the online intervention or on other circumstances in life. For the last 5 items, there is an open question in what way the statement applies. The internal consistency for the original INEP was good (α=0.86). Participants of the IG will receive the online adapted version of the INEP (INEP-On) post-treatment and follow-up. In contrast, participants of the CG will receive an abridged and adjusted INEP version with 14 items (INEP-CG) about the participation in the study and whether any negative effect is attributed on the participation in the study or on other circumstances in life post-treatment and follow- up. Both questionnaires include the question 'Since or during the online intervention/participation of the study I had suicidal thoughts/intentions for the first time'. Participants who score 1 ('agree a little bit') receive automatically an email with information about available healthcare services in case of emergency. They are advised to seek for help if the symptoms increase. Participants who score 2 or 3 ('agree partly' or 'fully agree') receive likewise the automatically emergency email and additionally a psychotherapist of the study management calls the participant to clarify if they distance themselves from suicidal ideation.

The attitude towards online interventions will be assessed with the *Attitudes towards Psychological Online Interventions Questionnaire (APOI)*.[55] The APOI consists of 16 five-step items (from 1='totally agree' to 5='totally disagree'), which can be integrated into four subscales: Scepticism and Perception of Risks (SCE), Confidence in Effectiveness (CON), Technologisation Threat (TET) and Anonymity Benefits (ABE), with a theoretical range of 4 to 20 for each subscale. The total sum score ranges from 16 to 80, whereas higher scores imply a positive attitude towards online interventions. The medians of the scales can be used to classify the scores (56 for the total sum score, 9 for SCE, 16 for CON, 12 for TET and 12 for ABE). Cronbach's alpha with α=0.77 shows an acceptable to good internal consistency. The APOI is given to all participants at all three measurement points.

The SMS Coach will be evaluated with three items at post-treatment from participants of the IG: 'The SMS Coach was helpful', 'The content of the SMS was pleasant' and 'The SMS Coach was motivating'. The items are scored on a five-point scale from 1 ('never') to 5 ('always').

After each finished PartnerCARE session at the Mind-district platform, the participants will have the possibility to give individual feedback to the session. First, they can rate the session from 1 ('did not like at all') to 10 ('did like very much'). One question is about the scope of the session ('too extensive', 'too short', 'just right'). Then four open questions ask about which exercise was most helpful, what was positive, what could be improved and how long it took to complete the session.

Participant flow and dropout rates will be recorded during the study period. Duration of the intervention for each participant, effort from the e-coach (needed time for written feedback and quantity of sent reminders) and technical difficulties are collected by the e-coach.

Secondary outcomes

The *NCCN Distress Thermometer (DT)* that has been developed by the National Comprehensive Cancer Network (NCCN) is a valid and reliable measure of psychological distress.[56 57] It consists of a single item with a scale from

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0 ('no distress') to 10 ('extreme distress'), illustrated by a thermometer and a list of 36 potential problems, which can cause distress (rationed into five categories: practical problems, family problems, emotional problems, spiritual/religious concerns and physical problems; all rated with yes/no). A cut-off value of 5 or higher is recommended for a clinically significant level of distress.

The German version of the *Patient Health Questionnaire-8 (PHQ-8)* is a reliable and valid self-report tool for assessing current depression symptoms.[58] Given that the online intervention is preventive and does not focus on depression or suicidality, the PHQ-8 will be used instead of the PHQ-9 to assess depressive symptoms as secondary outcome. In this case, the PHQ-8 is an acceptable alternative to the PHQ-9. The sensitivity, specificity and positive predictive value of the PHQ-8 are comparable with the PHQ-9.[59] The questionnaire consisting of eight items asks about impairments of the last 2 weeks and the items are scored on a four-point Likert scale from 0 ('not at all') to 3 ('nearly every day') with a total range from 0 to 24. Higher values indicate increased severity of symptoms and a cut-off point of ≥10 is defined for current depression symptoms.[58]

The *Generalised Anxiety Disorder-7 Questionnaire (GAD-7)* is a valid and efficient tool for assessing symptoms of a generalised anxiety disorder.[60] The seven items are scored on a four-point Likert scale from 0 ('not at all') to 3 ('nearly every day'), a total score from 0 to 21 is possible. Like for the PHQ-8, a cut-off point of ≥10 is recommended to screen for symptoms of a generalised anxiety disorder. The reported internal consistency in a German sample is Cronbach's α=0.89.[61]

Quality of life will be assessed with the *Veterans RAND 12-Item Health Survey (VR-12)*, an abbreviated version of the Veterans RAND 36-Item Health Survey (VR-36), which was developed on the basis of the validated SF-36 (Short form 36 health survey) questionnaire.[62 63] The VR-12 consists of different scaled questions (three-point scale, five-point scale and six-point scale) with different rating descriptions. The 12 items can be separated into two scores: physical and mental health. Standard norms of the summary scores are available for the US population: Mean for physical health summary is M=48.60 (SD=11.1) and for mental health summary M=51.01 (SD=10.0).[64]

The *Short Version of the Burden Scale for Family Caregivers (BSFC-s)* will be used to assess the amount of burden in caregivers.[65 66] The 10 items are rated on a scale from 0 ('strongly disagree') to 3 ('strongly agree'). The score can range from 0 to 30, where higher scores indicate greater caregiver burden. For interpreting the BSFC-s scores, a classification system was developed: 0–4 means 'none to low' burden, 5–14 means 'moderate' burden and 15–30 means 'severe to very severe' burden.[66] Cronbach's alpha for the complete scale with α=0.92 is very high.[65]

Fear of progression in spouse caregivers will be assessed with the German version of the questionnaire *Fear of Progression in Partners of Chronically Ill Patients (FoP-Q-SF/P; German: PA-F-P-KF)*.[67] The 12 items are responded on a five-point Likert scale from 1 ('not at all') to 5 ('very much'). The scale will be evaluated through addition of the items, whereupon higher values show higher fear of progression. A cut-off with 34 or higher indicates dysfunctional fear of progression. The internal consistency of the complete scale is high (Cronbach's α=0.87).

The *ENRICHED Social Support Inventory (ESSI)* is a short questionnaire to assess the perceived emotional social support.[68 69] The five items are measured with a five-point scale (1='at no time' to 5='always') with a minimum of 5 and a maximum of 25. The internal consistency of the scale is α=0.89. Lack of social support is defined by values below 18.

Received social support will be assessed with the three-item *Oslo Social Support scale (OSS-3)*.[70] The questionnaire consists of one question with a four-point scale and two questions with a five-point scale with different descriptions. The evaluation is based on the sum score of the raw scores (3 to 14). A score of 3–8 can be interpreted as 'poor support', 9–11 as 'moderate support' and 12–14 as 'strong support', respectively. The internal consistency with α=0.64 is acceptable considering the number of items.[71] While loneliness can be an important challenge for caregivers,[72] we added one question about loneliness to this questionnaire: 'How lonely do you feel at the moment?' with a five-point scale from 1 ('not at all') to 5 ('very much').

The German version of the *Generalised Self-Efficacy scale (GSE, German: SWE)* measures the perceived self-efficacy.[73] This one-dimensional scale was primarily developed for students and teachers but it is also used in cancer context.[74 75] The 10 items have a response range from 1 ('not at all true') to 4 ('exactly true'). The internal consistency is α=0.86 and the validity is confirmed by numerous findings.[76]

Coping will be assessed with the German version of the *BriefCOPE (Brief Coping Orientation to Problems Experienced) Inventory*.[77 78] It consists of 28 items that are rated on a four-point Likert scale ranging from 1 ('not at all') to 4 ('very much'). The questionnaire is divided into 14 subscales, each represented by two items. The internal consistency for the subscales ranges from α=0.50 to α=0.90.

Patient and public involvement

Before start of the feasibility trial, psycho-oncologists and partners of patients with cancer were invited to value the main sessions of PartnerCARE. Since only four psycho-oncologists responded to the request, only the feedback from these four psycho-oncologists could be included in the development process. As a subsequent step, feedback from participants of the feasibility study will be used to further optimise the online intervention for the following efficacy evaluation study. We intend to disseminate the main results of the feasibility study with a short report at suitable platforms where partners of patients with cancer are reached (eg, online communities).

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Statistical analysis

Demographic data will be reported using descriptive statistics. A chart of participant flow during the whole study will be plotted. Quantity of dropout and reasons for dropout will be displayed. With basic psychometric analyses, the scale structure and internal consistency of the used questionnaires will be verified. χ^2 (for categorical variables) and t-tests will be performed to analyse whether randomisation leads to comparable groups with no significant differences at baseline. Before starting with the analyses, we will examine if the data is normally distributed, else we will use a non-parametric test. The significance level for all analyses will be $p \leq 0.05$.

All statistical analyses will be performed based on the intention-to-treat principle with multiple imputations to replace missing data. Per-protocol analyses for completers will be additionally conducted to investigate the influence of intervention attrition on study results.

Qualitative individual feedback from participants via the Minddistrict platform regarding the feasibility and acceptance of the online intervention will be summarised. Feasibility measurements from the online questionnaire will be analysed descriptive (INEP-On; dropout) and with t-test (APOI; CSQ-I (only in IG)).

To test a potential intervention effect, that is, an indication for the potential efficacy of PartnerCARE, continuous outcome parameters at post-treatment (T1) will be analysed using an analysis of covariance (ANCOVA), controlling for the baseline measurement (T0) and further covariates (eg, age, sex). For follow-up (T2) effects, a repeated measure ANCOVA will be conducted with time as within-subject factor (baseline vs post-treatment vs follow-up) and group as between-subject factor (IG vs CG). In case of a significant main effect, post hoc tests will be conducted to analyse between which measurement points the significant differences exist. Cohen's d will be calculated to report effect sizes (effect sizes smaller than 0.32 are considered small, 0.33–0.55 are considered moderate and those larger than 0.56 are considered large[79]).

DISCUSSION

Partners of patients with cancer are confronted with a variety of challenges and new, additional tasks regarding the disease, resulting in a decrease of mental health. These burdens are often overlooked and psycho-oncological support or specific interventions for partners are rare. The online intervention PartnerCARE was developed to provide tailored support for partners of patients with cancer. The main purpose of the feasibility study is to evaluate the feasibility and acceptance of PartnerCARE and of the study process itself through an RCT. Furthermore, we aim to gain first preliminary evidence for the potential efficacy of the online intervention that is hoped to pave the way for a comprehensive efficacy evaluation study. An online intervention is, from our point of view, particularly suitable for partners because of the flexibility (time and place independency), easy accessibility, possible anonymity and low-threshold format. We expect that the online intervention facilitates access to psychosocial services for partners with hitherto low utilisation of conventional face-to-face psychosocial care (eg, because of logistic and time reasons, discomfort or other objections towards psychosocial services or gender-related reasons).[17 18] Although to date there is evidence that the majority of online intervention users are female[17] and female caregivers are more negatively affected by the caregiving process,[1] male caregivers should not be neglected. We assume that online interventions could suit particularly for male caregivers because of their tendency to have to be strong (no public searching for help) and their potential difficulties to express their concerns and emotions (could be easier for them in an online setting).[10] There is recent research about an online intervention especially for male caregivers,[33] but definitely more research is needed to investigate specific needs of male caregivers and how to better reach male participants for online interventions.

Recruitment of partners of patients with cancer can be challenging due to the fact that partners are often busy and therefore not reached at the clinic, recruitment via patient is not always effective (information is not passed to the partner) and there are not many typical areas where partners can be reached. Recruitment rates for caregivers of patients with cancer tended to be poor and varied from 20% to 66%.[16] To overcome the challenges of recruitment, we try to use a wide variety of online and offline recruitment strategies and will evaluate their adequacy.

PartnerCARE is the first online intervention for partners of patients with cancer available in German language. The newly developed online intervention for partners of patients with cancer is adjusted to the needs of cancer caregivers and takes several persuasive principles into account. The online intervention uses a variety of different elements (relevant topics, varying exercises, practical tips, guided imagery exercises) to motivate participants to go on with the intervention. If the pilot study verifies feasibility and acceptance of PartnerCARE, it is conceivable to translate PartnerCARE in different languages and evaluate the online intervention in further studies worldwide.

With this pilot study, we will initiate a continuous development and evaluation process of the online intervention PartnerCARE. During the online intervention, we assess satisfaction, positive and negative estimations of the intervention via written feedback. These insights from partners of persons with cancer will be used to improve and further develop PartnerCARE to an even more user-tailored intervention. We will also assess possible negative effects in our RCT to evaluate potential side effects of the online intervention for partners. The measurement of e-coach time for feedback every week and quantity of sent reminders will give a first insight in the estimation of costs for the online intervention for implementation in usual healthcare.

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A few limitations need to be taken into consideration. As all outcomes will be assessed via self-report and the contact with participants is only online, there is uncertainty regarding the identity of the participants. With signed informed consent and control questions with automatic premature termination at the first online assessment, this problem will be reduced. Online interventions in general and online interventions specifically for caregivers have to face with high dropout rates (29%–38%).[80 81] To reduce a potential adherence problem and to enhance motivation, the participants of the IG will be accompanied by an e-coach with feedback and reminders[50 82] and the development of the online design includes persuasive elements.[45] As participation in the study is only possible with access to internet and some technical affinity, we designed the online intervention as simple and intuitive as possible and will offer technical use basics at the introduction session. Furthermore, it has been discussed that including a waitlist control condition leads to an overestimation of the effect sizes compared with a no treatment or psychological placebo condition.[83] However, all participants in our study will be free to use care as usual and they receive a list of other treatment options like cancer counselling centres if they are interested. Furthermore, we will be able to have a look on possible long-term effects (4-month follow-up), but this leads to a long waiting time for the waitlist CG. In addition, our online intervention for partners could not cover all relevant topics: a recent study showed 'home care interventions', 'impact of financial demands on caregiver, 'impact of health reforms, programmes and policies on caregivers' as some of the most important topics for caregivers.[84] The further development of PartnerCARE should take these insights into account.

Regarding the future outlook, PartnerCARE could be included into the healthcare routine: by the time a patient becomes diagnosed with cancer, also the partner should be screened for psycho-social and physical burdens. PartnerCARE can also provide a communicative benefit for healthcare professionals with enhanced awareness of caregivers and the opportunity of having a special offer for partners. If needed, PartnerCARE could be immediately offered as a tool for partners to work on their burdens regardless of where and when. It can also be used to overcome the waiting time for partners until a local psycho-oncological treatment is available.

ETHICS AND DISSEMINATION

This study has been approved by the Ethics Committee of the University of Ulm (No 390/18). Results will be published in peer-reviewed journals and presented on local, national and international conferences.

Acknowledgements Authors would like to thank Sabrina Heil for her engagement in enrolling participants and for her support in study organisation. Furthermore, authors thank Daniel Neveling for his support as e-coach and Miriam Stock for providing the imaginary exercise audio files. Authors also thank Eileen Bendig for her supporting role in planning the trial process, Ann-Marie Kuechler for her support at the Minddistrict Platform as well as Robin Kraft and Sebastian Broetzler for creating the PartnerCARE homepage. Special thanks go to the psycho oncologists who valued the PartnerCARE sessions and thus support the enhancement of the intervention.

Contributors DB, NB, HG, HB and KH contributed to the study design. DB and IL compiled the content of the intervention sessions. The online design and structure of the intervention was carried out from DB building on prior online interventions of the Department of Clinical Psychology and Psychotherapy (HB). Intervention development was supervised by NB, HG, HB and KH. DB is responsible for recruitment and coordination of the study. DB drafted the manuscript. All authors provided critical revision and approved the final manuscript.

Funding This work was supported by a grant from the German Cancer Aid to the Comprehensive Cancer Center Ulm (grant number: 70112209). The German Cancer Aid had no role in study design, decision to publish or preparation of this manuscript. The German Cancer Aid will not be involved in data collection, analyses, decision to publish or preparation of future papers regarding the PartnerCARE project.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

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BMJ Open: first published as 10.1136/bmjopen-2019-035599 on 5 October 2020. Downloaded from http://bmjopen.bmj.com/ on October 6, 2020 at KIZ - Abt. Literaturverwaltung Zeitschriftenerwerbung. Protected by copyright.

5 Publication IV

A psycho-oncological online intervention supporting partners of patients with cancer (PartnerCARE): Results from a randomised controlled feasibility trial

Reference:
Bodschwinna D, Lorenz I, Bauereiss N, Gündel H, Baumeister H, Hönig K (2022). A psycho-oncological online intervention supporting partners of patients with cancer (PartnerCARE): Results from a randomised controlled feasibility trial. *Psycho-Oncology*. 1-13. https://doi.org/10.1002/pon.5917

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Check for updates

Received: 9 December 2021 | Revised: 18 February 2022 | Accepted: 27 February 2022

DOI: 10.1002/pon.5917

WILEY

ORIGINAL ARTICLE

A psycho-oncological online intervention supporting partners of patients with cancer (PartnerCARE): Results from a randomized controlled feasibility trial

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Funding information
Deutsche Krebshilfe, Grant/Award Number: 70112209

Abstract

Objective: Partners of cancer patients are the primary supporters and burdened at the same time. Support for partners is hitherto scarce and existing offers are rarely used. The PartnerCARE online intervention was specifically developed to address the caregiving partners' needs. This two-arm parallel randomized controlled trial (RCT) evaluates the feasibility, acceptability, and potential efficacy of PartnerCARE.

Methods: Sixty German-speaking partners of patients with various cancer entities were randomized into two conditions: intervention group (IG) with PartnerCARE (N = 30) or waitlist-control group (N = 30). Participants completed online questionnaires at baseline (T0), post-treatment (T1) and 4-months follow-up (T2). Feasibility and acceptability outcomes included dropout rates, use and acceptance of PartnerCARE, individual user/e-coach feedback as well as negative effects. Relevant efficacy outcomes were assessed to test for potential intervention effects.

Results: Recruitment success illustrates demand for and acceptability of PartnerCARE. Satisfaction with the intervention was high (Client Satisfaction Questionnaire adapted to Internet-based interventions, T1: M = 24.66, SD = 6.42) and 73.3% of participants completed the intervention. Study dropout rate was low (T1: 17%, T2: 29%). More positive than negative side effects of the intervention were identified, and negative ones were mainly related to ”intrapersonal change”. For efficacy outcomes we found effects over time, with strongest effects within the IG from T0 to T1 in psychological distress (d = 0.73, 95%-CI: [0.34; 1.12]) and anxiety (0.66, [0.26; 1.04]), but no group effects were significant at T1 and T2.

Conclusions: PartnerCARE is feasible, acceptable and potentially efficacious. Based on received feedback, PartnerCARE is currently undergoing further development and subsequently efficacy will be investigated in a RCT.

Trial Registration: German Clinical Trial Registration: DRKS00017019. Registered on 08 April 2019.

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KEYWORDS
cancer, caregiver, caregiver burden, distress, e-health, online intervention, partner, psycho-oncology, quality of life, spouse

1 | INTRODUCTION

It is well known that a cancer diagnosis also places a heavy burden on partners of cancer patients.[1] Partners not only often take over the patients' household tasks and provide financial and emotional support, they also share the anxieties associated with the diagnosis.[2,3] The increased household responsibilities, the personal emotional burden, the existential uncertainty due to a life-threatening disease exhibit a substantial impact on social activities as well as relationships. This may increase the risk for depression, anxiety and various somatic symptoms in partners.[4] Despite these conditions, partners are often unaware of their own needs and prioritize the patients' needs.[2,5] Therefore, partners rarely seek support for themselves. Furthermore, healthcare systems often neglect burden of caregiving partners because focus is on the patients.

Low threshold support, such as online interventions may overcome this barrier and help to introduce partners to support offers.[6] Additionally, online interventions are advantageous in being much more flexible in time and location, easily and quickly accessible and anonymous if preferred.[5,7] So far, online support offers especially for caregiving partners are rare[8] and the field of research associated with it is still in its infancy.[9] Existing online offers for partners include interventions addressing couples[10] or spouses,[11–13] a smartphone app[14] and a self-management application.[15] None of them are available in German. Statements about the efficacy of these offers are difficult because they are largely in the development or feasibility testing stage.[11,13–15] Likewise the comparison of these studies is difficult as they targeted different outcomes like quality of life,[11] psychological distress,[12] emotional well-being[13] and caregiver burden.[15]

The PartnerCARE online intervention has been the first online intervention in Germany, which was especially developed to address the support needs of partners of cancer patients. PartnerCARE includes psychoeducational information, practical exercises like other interventions.[12,14] This is additionally combined with exemplary partners (via image and text) who accompany the participants through the intervention and relaxing guided imagery exercises with the intention to increase well-being and improve selfcare in partners (cf. for a detailed description of development process and content of PartnerCARE in the corresponding study protocol[16]). The herein presented development and feasibility study of PartnerCARE is only the first step of a consecutive development and evaluation process. One important aspect of our study is, that it observes both possible positive and possible negative effects of PartnerCARE. This follows the CONSORT-Guidelines[17] as well as recommendations from Rozental and Colleagues.[18]

The present study aims to explore the feasibility and acceptance of the newly developed online intervention PartnerCARE. It specifically focusses on recruitment, dropout, adherence, and satisfaction with PartnerCARE. Moreover, possible negative effects of the online training are examined. In addition, first findings on the potential efficacy of the intervention are discussed. With this feasibility study a consecutive development and evaluation process was initiated to provide a reliable support offer for partners.

2 | METHODS

This randomized controlled trial with a two-arm parallel design compares an intervention group (IG) receiving the guided online intervention PartnerCARE with a waitlist control group (CG). Intervention description and results of this clinical trial are reported according to the CONSORT-Statement for feasibility RCTs[17] and the template for intervention description and replication.[19] The study design is described in detail in the corresponding study protocol.[16] The study was approved by the Ethics Committee of Ulm University (No. 390/18) and registered in the German clinical trial register (DRKS00017019).

2.1 | Study population and recruitment

To overcome the challenging recruitment of partners of patients with cancer,[20] a wide variety of recruitment routes was used, both online (e.g. social media groups, online support groups, links on clinic homepages) and offline (e.g. flyers, cancer counseling centers). Participants were recruited in German-speaking countries from April 2019 to March 2020. Interested partners registered for the study via a contact form on the PartnerCARE study homepage (https://esano.klips-ulm.de/de/trainings/tumor/partnercare/) and subsequently received an email with detailed study information and a detailed consent form. After providing written informed consent, participants were invited to the online baseline assessment (T0). Before questionnaires started, the following inclusion criteria were checked via self-report: (1) age 18 years and older, (2) being in a relationship and (3) the partner is diagnosed with cancer (any type, any disease stage, any treatment stage). Additional inclusion criteria ((4) having Internet access and a corresponding terminal device, (5) providing an email address for contact and (6) giving a signed informed consent) were checked through the previous study process. If inclusion criteria were not fulfilled, baseline assessment was canceled and the participant received an automated email with recommendations for already available support.

Since this was a feasibility study, a formal sample size calculation was not performed. A sample size of 60 participants (30 per group)

was the predefined target, based on recommendations for sample sizes in feasibility studies.[21]

2.2 | Randomization

After completing baseline assessment, participants were randomly allocated to the study conditions IG and CG (1:1). For this, a permuted block randomization with randomly arranged block sizes of two and four was used. An independent researcher (TD) conducted the randomization using an automated generated randomization list via an online program (www.sealedenvelope.com). Therefore, allocation of participants was not able to be forecasted by any other member of the study team. After randomization, all participants received an email including information about group allocation and the resulting study procedure.

2.3 | Intervention

PartnerCARE is a guided individually psycho-oncological online intervention delivered on the online platform minddistrict (www.minddistrict.com). It aims to improve quality of life, self-efficacy, and caregiver burden in partners of patients with cancer by creating awareness of one's own needs and learning to meet them. The intervention is based on psychoeducation, cognitive behavioral therapy, supportive therapy and guided imagery elements, which have previously been proven to be beneficial concepts for cancer caregivers.[22] PartnerCARE consist of an introductory session, six weekly main sessions (topics: specific burdens, inner drivers, partnership communication, handling negative feelings, control and acceptance, path and goals), four optional additional sessions (topics: support of own children, healthy sleep, closeness and sexuality, existential burdens) and one booster session (2 weeks after the last main session). Detailed information about structure and content of the intervention is provided in Table S7 and in the corresponding study protocol.[16] Sessions were multimodally and interactively conceptualized through text, visual and auditory material, practical exercises, and homework assignments, as well as three exemplary partners. Each session has a duration of 30–60 min. In addition to the intervention, participants had the option of choosing an automated Short Message Service- (SMS) Coach, who sent two motivational text messages per week.

All participants of the IG received a personal account for the online platform minddistrict and were assigned to an e-coach (trained and supervised postgraduate psychology student and psychologists). After initial login, participants were able to start with the introductory session of the PartnerCARE intervention. Each completed session had to be sent to the e-coach who replied within two weekdays after session completion by a partly standardized and partly individualized feedback for the respective session. Additionally, participants had the possibility to message the e-coach via minddistrict, for example, to report technical problems or to inform the e-coach in case they were not able to work on the session at the agreed time. The e-coach also reminded the participants when they missed a session (three times in intervals of two weekdays). All communication and feedback between participant and e-coach was asynchronous.

Participants of the CG received access to the unguided PartnerCARE intervention after completion of the follow-up questionnaire (4 months after randomization). All participants had unrestricted access to standard care treatments.

2.4 | Outcomes

Self-report measurements took place at baseline (T0), post treatment (T1, 2 months after randomization) and at follow-up (T2, 4 months after randomization) via an online-based assessment platform (www.unipark.de). Sociodemographic variables and clinical characteristics of the diseased partner were assessed at baseline via self-report by the partner. Use of psychotherapy by partners as well as their level of information about help services was recorded at all assessment time points. Participants were reminded to complete assessments up to five times in interval of two weekdays, to reduce dropouts.

2.4.1 | Feasibility and acceptability outcome

Feasibility and acceptability of the PartnerCARE online intervention was assessed using various questionnaires to display the different aspects of this outcome.

The *Client Satisfaction Questionnaire adapted to Internet-based interventions (CSQ-I)* measured satisfaction with the online intervention in the IG.[23] Sum score of the eight items ranged from eight to 32 and reliability was excellent (T1: $\omega = 0.96$, T2: $\omega = 0.98$), with values >23 are being defined as good treatment satisfaction.[24] Side effects of the online intervention were assessed with a 22 item-version of the *Inventory for the Assessment of Negative Effects in Psychotherapy (INEP)* adapted to online intervention (INEP-ON).[25] Additionally, an abridged and adjusted version of the INEP (14 items) measured negative effects about participating in the study in the CG (INEP-CG). Both INEP questionnaires (IG: INEP-ON, CG: INEP-CG) included a question about suicidal thoughts. To provide adequate support in case a participant scored on this item, a stepped emergency plan was implemented.[16] The *Attitudes towards Psychological Online Interventions Questionnaire (APOI)* consists of 16 items with a total sum score between 16 and 80.[26] Reliability of the total scale can be considered acceptable to good (T0: $\omega = 0.72$, T1: $\omega = 0.86$, T2: $\omega = 0.88$). Median score can be used to classify the sum score (median of total scale = 56). Satisfaction with the SMS Coach was assessed with three self-compiled questions about helpfulness, motivation, and comfort of the message content. In addition to the questionnaire assessments, participants were able to give a short voluntary feedback after each finished PartnerCARE

session. They were asked on a scale from one (not at all) to 10 (very good), to rate the length of the session and how they liked the session. Furthermore, four open questions measured, what the most helpful and positive exercise was, what may be improved and what the required processing time of the session was.

2.4.2 | Efficacy outcomes

The *Distress Thermometer (DT)* measured psychological distress with a scale from 0 to 10.[27] A score of five or higher indicated an increased level of distress. The *Patient Health Questionnaire-8 (PHQ-8)* was applied to measure current depression symptoms.[28] The total score ranged from 0 to 24 and the scale achieved good reliability (T0: $\omega = 0.80$, T1: $\omega = 0.87$, T2: $\omega = 0.88$). With the *Generalised Anxiety Disorder-7 Questionnaire (GAD-7)* current symptoms of the generalized anxiety disorder were assessed (total score 0–21).[29] Reliability was good (T0: $\omega = 0.86$, T1: $\omega = 0.88$, T2: $\omega = 0.89$). The *Veterans RAND 12-Item Health Survey (VR-12)* assessed quality of life regarding physical and mental health.[30] The scale reached good reliability (T0: $\omega = 0.86$, T1: $\omega = 0.89$, T2: $\omega = 0.91$). The amount of burden was measured with the *Short Version of the Burden Scale for Family Caregivers (BSFC-s)*.[31] The scale consists of 10 items (sum score ranges from 0 to 30) and shows excellent reliability (T0: $\omega = 0.87$, T1: $\omega = 0.91$, T2: $\omega = 0.93$). The Questionnaire *Fear of Progression in Partners of Chronically Ill Patients (FoP-Q-SF/P)* assessed fear of progression specifically in partners based on 12 items (sum score range: 12–60).[32] Reliability was good (T0: $\omega = 0.84$, T1: $\omega = 0.88$, T2: $\omega = 0.89$). Perceived social support was assessed with the *ENRICHD Social Support Inventory* with five items and a scale range from five to 25.[33] Reliability of the scale was excellent (T0: $\omega = 0.91$, T1: $\omega = 0.95$, T2: $\omega = 0.97$). Received social support was measured with the *Oslo Social Support scale*.[34] Reliability of the 3-item scale (range: 3–14) was acceptable (T0: $\omega = 0.72$, T1: $\omega = 0.76$, T2: $\omega = 0.76$). Loneliness experienced by partners was measured with a single self-formulated question: "How lonely do you feel at the moment?" (five-point scale from one "not at all" to five "very much"). Perceived self-efficacy was rated on the *Generalised Self-Efficacy scale*.[35] The total score of the 10 items ranged from 4 to 40 and the scale reached excellent reliability (T0: $\omega = 0.91$, T1: $\omega = 0.92$, T2: $\omega = 0.92$). The *BriefCOPE (Brief Coping Orientation to Problems Experienced) Inventory* was used to measure coping.[36] The three subscales achieved up to acceptable reliability (emotion T0: $\omega = 0.66$, T1: $\omega = 0.78$, T2: $\omega = 0.74$; problem T0: $\omega = 0.72$, T1: $\omega = 0.80$, T2: $\omega = 0.76$; dysfunction T0: $\omega = 0.46$, T1: $\omega = 0.54$, T2: $\omega = 0.68$).

2.5 | Data analyses

All statistical analyses were performed using SPSS 26 (IBM SPSS Statistics). All tests were two-tailed with a significance level of $p \leq 0.05$. McDonald's omega (ω) was calculated to estimate the reliability of outcome scales.[37] To investigate significant differences at baseline between IG and CG as well as differences between intervention completers and non-completers, *t*-tests, Mann-Whitney-tests and χ^2 tests were conducted.

All statistical analyses were conducted following the intention-to-treat principle (ITT). Additionally, per-protocol analyses were conducted based on participants who adhered to treatment protocol (=completers; completing at least 80% of the intervention, five out of six main sessions). Multivariate imputation was performed by fully conditional specification with Markov Chain Monte Carlo algorithm.[38] Missing data was assumed to be missing at random.[39] Predictive mean matching was applied as imputation method.[40] Based on recommendations $m = 20$ data sets were imputed.[39] The imputed data sets were each analyzed and results were pooled using Rubin's Rule.[41]

Feasibility and acceptability outcomes were analyzed descriptively (participants' adherence, feedback from participants and e-coaches, side effects, attitude towards online interventions) and with *t*-test (satisfaction). Efficacy outcomes for testing a potential intervention effect were analyzed using repeated measures analyses of variance (ANOVA; factor one: group [IG, CG], factor two: time [T0, T1, T2]). Since SPSS 26 does not run this analysis on Multivariate imputation data, a SPSS macro was used.[42,43] Significant results were reported using Cohen's d along with the corresponding 95% CI.[44]

3 | RESULTS

3.1 | Participants

A total of 94 potential participants expressed their interest in the study. Based on inclusion criteria 33 applicants were excluded. The most common reason for exclusion was the absence of a written informed consent (after two reminders). Hence, 61 of the applicants received an invitation for baseline assessment. Through the proceeded screening of inclusion criteria, one participant was excluded. Thus 60 participants completed baseline assessment and were randomized afterward to IG ($n = 30$) and CG ($n = 30$). Post-assessment was completed by $n = 49$ (81.7%) with a higher proportion of completers in CG ($n = 27$, 93%) than in IG ($n = 22$, 73%). Follow-up was completed by $n = 42$ (70%) participants, likewise more completers in CG ($n = 22$, 76%) than in IG ($n = 20$, 67%) (Figure 1).

Participants had a mean age of 47 years (SD = 9.62, range = 28–71). The majority was female (69.5%), married (88.1%) and had children (69.5%). Other personal characteristics as well as patients' cancer related characteristics are displayed in Table 1. At baseline, one third of participating partners rated themselves as well informed about help services (30.5%), one third as moderately informed (33.9%) and one third as poorly informed (35.6%). Over time, the proportion of well-informed participants increased (T1: 34.7%, T2: 52.4%), while the proportion of poorly informed decreased (T1:

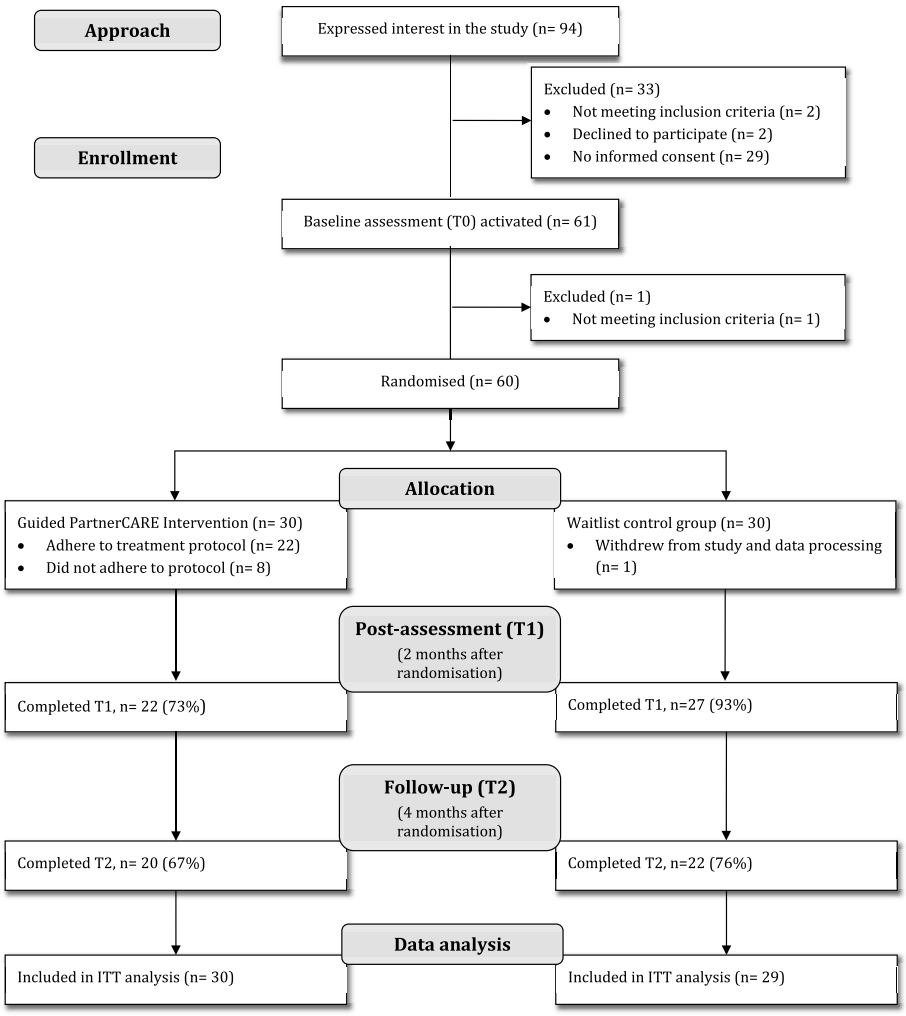

FIGURE 1 Flowchart of participants

26.5%, T2: 16.7%). Looking at the IG separately, the proportion of well-informed participants is already highly increased at T1 (T1: 54.5%, T2: 55.0%).

On average, participants are burdened at baseline: they reported a clinically significant level of distress (DT: $M = 6.39$, SD = 2.61), mild depression and anxiety symptoms (PHQ-8: $M = 8.54$, SD = 4.61; GAD-7: $M = 7.68$, SD = 4.57), low mental health (VR-12 mental: $M = 34.99$, SD = 11.34), moderate caregiver burden (BSFC-s: $M = 12.42$, SD = 6.74) and a dysfunctional fear of progression (FoP-Q-SF/P: $M = 37.39$, SD = 9.02) (see separate results for IG and CG in Table 2).

3.2 | Feasibility of PartnerCARE

3.2.1 | Recruitment

Recruitment started in April 2019 and concluded in March 2020 when the target sample size of 60 participants was reached. The most successful recruitment route was via online platforms (online forum, social media, clinic homepages, search engine, etc.) where 61% of participants became aware of the study. 18.6% were informed through cancer counseling centers, 8.5% through the diseased partner and 3.4% through doctor consultation. Other access routes were reported by 8.5%.

3.2.2 | Use of and adherence to the online intervention

All except one participant of the IG have logged in and completed at least the introductory session (Figure 2). Twenty-two out of 30 participants (73.3%), who were randomized to the IG, were classified as intervention completers by adhering to treatment protocol. With this subsample, PP-Analyses were conducted. All intervention completers finished all six main sessions within 2 months after randomization. The average intervention duration was 7 weeks (SD = 1.93) for intervention completers. On average 9.79 days (SD = 4.85) were between two completed main sessions. The booster session was completed by 46.6% of participants. Over all six main sessions, participants spent 64.5 min (SD = 37.02) at one session on average (Table S1). Twenty-two participants of the IG completed at least one

TABLE 1 Baseline partners' characteristics and patients' cancer related characteristics

Characteristic	Total sample ($n = 59$)	Intervention group ($n = 30$)	Waitlist control group ($n = 29$)	p[a]
Partners' characteristics				
Age (M±SD [range])	47.17 ± 9.62 [28–71]	47.67 ± 8.86 [30–61]	46.66 ± 10.48 [28–71]	0.690
Gender				0.223
Male	18 (30.5%)	7 (23.3%)	11 (37.9%)	
Female	41 (69.5%)	23 (76.7%)	18 (62.1%)	
Relationship				0.723
In partnership	7 (11.9%)	4 (13.3%)	3 (10.3%)	
Married	52 (88.1%)	26 (86.7%)	26 (89.7%)	
Duration of relationship in years (M±SD [range])	18.35 ± 11.32 [0.67–50]	17.73 ± 11.29 [1–47]	18.99 ± 11.50 [0.67–50]	0.644
Children				0.296
Yes	41 (69.5%)	19 (63.3%)	22 (75.9%)	
No	18 (30.5%)	11 (36.7%)	7 (24.1%)	
Nationality				0.321
German	58 (98.3%)	29 (96.7%)	29 (100%)	
Other	1 (1.7%)	1 (3.3%)	0	
Level of education				0.799
< 10 years	3 (5.1%)	1 (3.3%)	2 (6.9%)	
10 years	9 (15.3%)	5 (16.7%)	4 (13.8%)	
> 10 years	47 (79.7%)	24 (80.0%)	23 (79.3%)	
Employment status				0.122
Employed (full time)	26 (44.1%)	17 (56.7%)	9 (31.0%)	
Employed (part time)	21 (35.6%)	9 (30.0%)	12 (41.4%)	
Unemployed	12 (20.3%)	4 (13.3%)	8 (27.6%)	
Psychotherapy (current or last 8 weeks)				0.942
Yes	14 (23.7%)	7 (23.3%)	7 (24.1%)	
No	45 (76.3%)	23 (76.7%)	22 (75.9%)	
Patients' characteristics				
Cancer diagnosis				0.375
Breast cancer	9 (15.3%)	3 (10.0%)	6 (20.7%)	
Prostate cancer	2 (3.4%)	1 (3.3%)	1 (3.4%)	
Colon cancer	6 (10.2%)	3 (10.0%)	3 (10.3%)	
Lung cancer	4 (6.8%)	3 (10.0%)	1 (3.4%)	
Pancreatic cancer	4 (6.8%)	0	4 (13.8%)	
Brain tumor	6 (10.2%)	4 (13.3%)	2 (6.9%)	
Hematological tumor	18 (30.5%)	11 (36.7%)	7 (24.1%)	
Other	10 (16.9%)	5 (16.7%)	5 (17.2%)	
Time since diagnosis				0.512
≤ 1 year	24 (40.7%)	11 (36.7%)	13 (44.8%)	
1–2 years	14 (23.7%)	9 (30.0%)	5 (17.2%)	
> 2 years	21 (35.6%)	10 (33.3%)	11 (37.9%)	

TABLE 1 (Continued)

Characteristic	Total sample ($n = 59$)	Intervention group ($n = 30$)	Waitlist control group ($n = 29$)	p^a
Disease stage (UICC)				0.817
I–II	16 (27.1%)	7 (23.3%)	9 (31.0%)	
III–IV	30 (50.8%)	15 (50.0%)	15 (51.7%)	
Remission	5 (8.5%)	3 (10.0%)	2 (6.9%)	
Not known	8 (13.6%)	5 (16.7%)	3 (10.3%)	
Treatment status				0.714
Currently in treatment	40 (67.8%)	21 (70.0%)	19 (65.5%)	
Completed	11 (18.6%)	6 (20.0%)	5 (17.2%)	
Pausing	8 (13.6%)	3 (10.0%)	5 (17.2%)	

Abbreviation: UICC, union for international cancer control.

[a]*t*-test for independent sample for age, Mann-Whitney test for duration of relationship and χ^2 tests for the remaining variables.

of the optional additional sessions. Most of them worked on the additional session "Healthy sleep" ($n = 17$, 77.3%). Eleven participants completed "Closeness and sexuality" (50%), 10 completed "Existential burdens" (45.5%) and five completed "Support of own children" (22.7%). In addition, 20 participants of the IG used the automated SMS coach (66.6%).

3.2.3 | Feedback from e-coaches

The e-coaches spend an average of 14.34 min (SD = 5.89, range = 4–27) reading the entries of the participant and writing feedback for a session (Table S2). Time for feedback continuously decreased from 17.54 min (average with SD = 6.09, range = 4–27) for session 1 to 7.27 min (average with SD = 2.99, range = 4–16) for session 6. In total, the e-coaches sent 74 reminders resulting to a mean of 2.47 reminders per participant (SD = 2.32, range = 0–7).

3.3 | Acceptability of PartnerCARE

3.3.1 | Attitude towards online interventions and satisfaction with PartnerCARE

Overall, participants of the study displayed a positive attitude towards online interventions. Attitudes towards Psychological Online Interventions Questionnaire median scores from IG remained stable over time (T0: Mdn = 56.0, T1: Mdn = 56.1, T2: Mdn = 54.3), while median scores from CG participants decrease after baseline (T0: Mdn = 56.0, T1: Mdn = 51.0, T2: Mdn = 51.1). One participant of the IG had prior experience with online interventions. In PP-analysis, APOI median scores from IG increased lightly (T0: Mdn = 54.5, T1: Mdn = 57.6, T2: Mdn = 55.6) (Table S3).

Participants' satisfaction with PartnerCARE according the CSQ-I was high at both timepoints, post-treatment and follow-up (T1: $M = 24.66$, SD = 6.42; T2: $M = 22.97$, SD = 7.27). Difference in intervention satisfaction was not statistically significant (t[29] = 1.69, $p = 0.09$). PP-Analysis also showed no significant difference.

3.3.2 | Individual user feedback

Across all main sessions we received written feedback 145 times (range per session: 22–27 feedback statements) from IG participants. 82.7% ($n = 120$) of these rated the length of the sessions as just right (Figure S1). Overall, participants rated the sessions as quite good ($M = 8.15$, SD = 2.0, scale range 1–10, Table S4). Open questions indicate that the following elements of the intervention were perceived as positive and most helpful: respective practical session exercises ($n = 62$), guided imagery exercises ($n = 33$), basic information ($n = 27$), and the possibility to write openly ($n = 20$). Some participants reported also improvable elements: more information and assistance at session five (session topic: "Control and Acceptance") and six ("Paths and Goals") ($n = 7$), technical difficulties in saving or final sending of sessions to the e-coaches at session one ("Specific Burdens") and two ("Inner Drivers") ($n = 5$) and distracting noises at the guided imagery exercises ($n = 6$). Fifteen of 20 SMS Coach users provided feedback at T1. 53.4% ($n = 8$) of them rated the SMS Coach as helpful, 73.4% ($n = 11$) as motivational and 73.4% ($n = 11$) rated the content of the SMS as comfortable.

3.3.3 | Side effects

Overall, participants of the IG reported 51 negative, 339 neutral, and 94 positive side effects at T1 (based on observed data from $n = 22$). Of these, participants attributed 13 (25.5%) negative, 30 (8.9%) neutral and 76 (80.9%) positive side effects to the online intervention. Four (18.2%) participants of the IG reported at least one negative side effect which was attributed to the online intervention. Participants of the CG reported overall 74 negative, 290 neutral and

TABLE 2 Acceptability and efficacy outcomes pre, post and follow-up and results of *t*-test and repeated measures ANOVA and effect sizes of significant within group effects (ITT analyses)

	n	Pre-assessment (T0)	Post-assessment (T1)	Follow-up (T2)	ANOVA: F Main effect (time)	Pre-post Within-group d (95% CI)	Pre-follow up Within-group d (95% CI)
CSQ-I[a]					1.69		
IG	30	-	24.66 ± 6.42	22.99 ± 7.27		-	-
DT					9.80***		
IG	30	6.67 ± 2.60	4.93 ± 2.12	4.69 ± 2.25		0.73 [0.34; 1.12]	0.81 [0.31; 1.30]
CG	29	6.10 ± 2.62	5.68 ± 2.89	4.81 ± 3.00		0.15 [−0.22; 0.52]	0.46 [0.04; 0.87]
PHQ-8					6.81**		
IG	30	8.90 ± 4.77	7.43 ± 4.39	6.56 ± 4.18		0.32 [0.01; 0.62]	0.52 [0.21; 0.83]
CG	29	8.17 ± 4.50	8.41 ± 5.19	6.61 ± 4.11		−0.05 [−0.38; 0.28]	0.36 [−0.03; 0.74]
GAD-7					7.49***		
IG	30	8.30 ± 4.63	5.62 ± 3.46	5.74 ± 3.86		0.66 [0.26; 1.04]	0.60 [0.27; 0.92]
CG	29	7.03 ± 4.50	6.77 ± 4.79	5.87 ± 3.32		0.06 [−0.28; 0.39]	0.29 [−0.09; 0.68]
VR-12 physical					2.30		
IG	30	48.03 ± 8.70	49.84 ± 6.86	47.18 ± 8.90		-	-
CG	29	50.27 ± 6.45	51.24 ± 6.73	49.53 ± 4.88		-	-
VR-12 mental					11.45***		
IG	30	34.63 ± 10.59	39.20 ± 10.88	40.53 ± 10.15		−0.43 [−0.67; −0.18]	−0.57 [−0.92; −0.21]
CG	29	35.37 ± 12.25	35.65 ± 11.65	41.83 ± 10.57		−0.02 [−0.35; 0.30]	−0.56 [−1.03; −0.09]
BSFC-s					2.48		
IG	30	12.97 ± 6.44	11.33 ± 6.89	10.42 ± 6.70		-	-
CG	29	11.86 ± 7.10	12.31 ± 7.06	10.59 ± 6.67		-	-
FoP-Q-SF/P					12.96***		
IG	30	37.83 ± 9.26	35.07 ± 8.47	32.94 ± 8.56		0.31 [−0.03; 0.65]	0.55 [0.27; 0.82]
CG	29	36.93 ± 8.90	36.57 ± 9.40	31.95 ± 9.13		0.04 [−0.23; 0.30]	0.55 [0.16; 0.93]
ESSI					1.73		
IG	30	16.60 ± 5.85	18.39 ± 6.10	18.30 ± 6.55		-	-
CG	29	17.97 ± 5.02	17.69 ± 5.10	18.35 ± 5.58		-	-
OSS-3					0.78		
IG	30	9.20 ± 2.78	9.66 ± 2.95	9.62 ± 2.75		-	-
CG	29	8.93 ± 2.53	9.02 ± 2.23	9.28 ± 2.55		-	-
GSE					4.06*		
IG	30	27.23 ± 5.14	29.47 ± 5.17	28.36 ± 5.52		−0.43 [−0.78; −0.08]	−0.21 [−0.61; 0.19]
CG	29	28.93 ± 4.58	29.85 ± 4.44	30.35 ± 3.55		−0.20 [−0.44; 0.03]	−0.35 [−0.66; −0.03]
BriefCOPE emotion					1.59		
IG	30	20.53 ± 5.20	22.15 ± 5.65	22.13 ± 4.76		-	-
CG	29	21.10 ± 3.62	20.67 ± 4.04	21.43 ± 4.14		-	-

TABLE 2 (Continued)

	n	Pre-assessment (T0)	Post-assessment (T1)	Follow-up (T2)	ANOVA: F Main effect (time)	Pre-post Within-group d (95% CI)	Pre-follow up Within-group d (95% CI)
BriefCOPE problem					0.22		
IG	30	15.17 ± 3.45	16.07 ± 3.79	15.80 ± 3.48		-	-
CG	29	15.79 ± 3.12	15.29 ± 3.09	15.67 ± 3.46		-	-
BriefCOPE dysfunction					0.69		
IG	30	20.97 ± 3.35	21.05 ± 3.42	20.13 ± 3.13		-	-
CG	29	20.38 ± 3.75	20.98 ± 3.40	20.87 ± 4.41		-	-
Loneliness					1.15		
IG	30	2.60 ± 1.20	2.36 ± 1.26	2.37 ± 1.25		-	-
CG	29	2.48 ± 0.87	2.51 ± 1.00	2.21 ± 1.02		-	-

Note: Data is imputed and analyses are based on ITT. Reported are mean ± SD.

Abbreviations: ANOVA, analyses of variance; BriefCOPE, brief coping orientation to problems experienced inventory; BSFC-s, short version of the burden scale for family caregivers; CG, control group; CSQ-I, client satisfaction questionnaire adapted to Internet-based interventions; DT, distress thermometer; ESSI, ENRICHED social support inventory; FoP-Q-SF/P, fear of progression in partners of chronically ill patients; GAD-7, generalised anxiety disorder-7 questionnaire; GSE, generalised self-efficacy scale; IG, intervention group; ITT, intention to treat; OSS-3, Oslo social support scale; PHQ-8, patient health questionnaire-8; VR-12, veterans RAND 12-item health survey–physical and mental health scale.

[a]Recorded in intervention group and at T1 and T2 only, paired *t*-test was calculated.

$^{*}p < 0.05$. $^{**}p < 0.01$. $^{***}p < 0.001$.

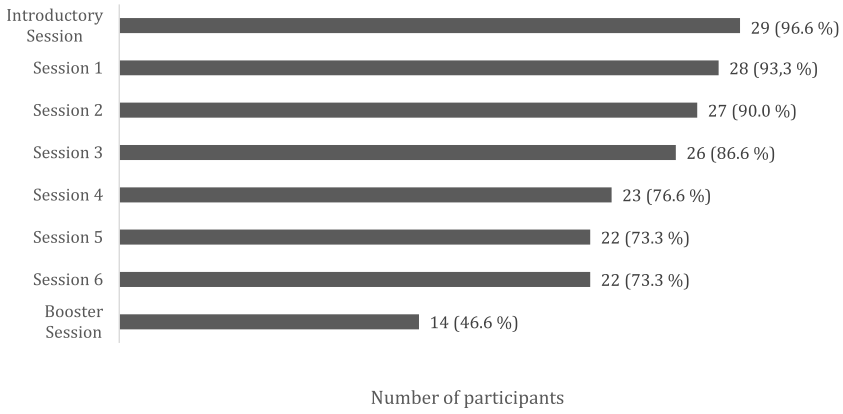

FIGURE 2 Number of completed sessions of the guided PartnerCARE intervention until 2 months after randomization (T1) per intervention group participants ($n = 30$)

14 positive side effects at T1 (based on observed data from $n = 27$). Of these, 0 (0%) negative, 7 (2.4%) neutral and 1 (7.1%) positive side effects were attributed to study participation.

Participants of the IG reported overall 52 negative, 320 neutral and 68 positive side effects (based on observed data from $n = 20$) at T2. Three (5.8%) of the negative, 29 (9.1%) of the neutral and 54 (79.4%) of the positive side effects were attributed to the online intervention. Three (15%) participants of the IG each reported one negative side effect attributed to the online intervention. Participants of the CG reported overall 64 negative, 213 neutral and 33 positive side effects (based on observed data of $n = 22$). Of these, four (6.5%) negative, 21 (9.9%) neutral and 11 (33.3%) positive side effects were attributed to study participation. Two (0.9%) participants reported the four negative side effects which were attributed to study participation. A detailed overview of side effects is displayed in Table S5.1–S5.4.

3.4 | Potential intervention effect on efficacy outcomes

The main effect of time was significant for some outcomes (Table 2). Distress decreased significantly over time ($F[2106.48] = 9.80$, $p < 0.001$), as well as depression ($F[2106.66] = 6.81$, $p = 0.002$), anxiety ($F[2109.75] = 7.49$, $p < 0.001$), and fear of progression ($F[2110.60] = 12.96$, $p < 0.001$). Both, the mental component of quality

of life (F[2111.51] = 11.45, $p < 0.001$) and general self-efficacy (F [2106.90] = 4.06, $p = 0.02$) increased significantly over time. For all these outcomes, changes between T0 and T1, represented by effect size d, are higher for IG than for CG. For IG these effects remain stable over time or even increase (e.g., PHQ-8: T0 and T1: $d = 0.32$, [95% CI: 0.01–0.62]; T0–T2: $d = 0.52$, [95% CI: 0.21–0.83]). For CG, effect sizes are small or even zero when comparing T0 and T1, whereas effect sizes are higher when comparing T0–T2 (e.g., PHQ-8: T0 and T1: $d = -0.05$, [95% CI: −0.38 to 0.28]; T0–T2: $d = 0.36$, [95% CI: −0.03–0.74]). A detailed description of the proportion of participants in the clinical categories can be found in Table S6. In contrast, there was no statistically significant main effect of group (IG vs. CG) and no significant interaction for all efficacy outcomes. In PP-analyses similar effects were found with slight differences in effect sizes (Table S3).

4 | DISCUSSION

Findings from this feasibility trial indicate that the newly developed psycho-oncological online intervention PartnerCARE is both feasible and acceptable. Feasibility was particularly evident in high intervention completion rate, less drop out and choice of recruitment strategy. The high intervention completion rate (73.3%) indicates that once participants begin the intervention, they are likely to finish it. This treatment adherence is comparable to other online intervention studies with caregivers, but substantially higher than average intervention adherence in online intervention studies with patients.[12,45,46] This rather high intervention adherence rate might result from the intervention being guided by e-coaches,[47] provided as internet-based intervention with mobile app features instead of a mobile application only,[48] developed using persuasive design principles[49] and used by more female, middle aged, educated participants.[9,50] The overall study procedure can be classified as feasible since the study dropout rate was low (T1: 17%, T2: 29%) compared to other online caregiver studies (14%–77%).[20] Furthermore, the challenging recruitment due to time limitations and logistic constraints of partners[20] was overcome with a wide recruitment strategy with the most successful recruitment route being online recruitment (61%). As proportion of male participants was similarly low to other online partner interventions (approximately 30%),[20] recruitment strategies need to be explored that reach male caregivers better.

In terms of acceptability outcomes, attitudes towards online interventions are positive across the whole sample and satisfaction with PartnerCARE is high and stable over time. Assessments in this area are necessary to adequately evaluate the intervention as participant satisfaction and positive attitude may increase adherence and intervention efficacy.[9,50,51] However, some technical difficulties such as saving and sending of sessions must be solved in the optimization process of PartnerCARE. Likewise, the text messages from the SMS Coach need to be revised to increase their helpfulness (e.g., improve content more towards daily and practicable exercises).

As highly recommended, our study assess possible negative side effects.[18] The advantage of this assessment is that one can only react to negative side effects when aware of them. Participants of PartnerCARE attributed a small number of the negative side effects to the intervention, which were mainly related to the category "intrapersonal change", for example, by reporting "feeling dependent on the online program" or "having longer periods of feeling bad". As the intervention encouraged participants to reflect on personal problems and conflicts, negative feelings can commonly increase initially with an increase of self-awareness.[52] This common fluctuation of symptoms is also indicated by the decrease of these negative side effects again from T1 to T2. All reports of suicidal ideation could be clarified by using our emergency plan (including telephone interviews to guarantee credible distancing from suicidal thoughts). Although caregivers are not at high risk for suicide (they want to take care of the patient and not leave him or her alone), the occurred cases highlight the need for an emergency plan. In contrast to the negative side effects, it needs to be pointed out that about 80% of the positive side effects were attributed to the intervention at T1 and T2.

There are first insights in potential post-intervention effects of PartnerCARE on the efficacy outcomes. The potential post-intervention effect is reflected in the higher effect sizes for IG than for CG in the pre-post comparison regarding distress, depression, anxiety, mental quality of life, fear of progression and general self-efficacy. These preliminary findings are consistent with the aim of PartnerCARE making partners aware of their own needs and feelings and showing them that they can effectively help themselves. For the IG these effects seem to be stable or even increase over time (like for distress, depression, mental quality of life, fear of progression), which may reflect a potentially delayed effect of the intervention.[22] In the pre-follow up comparison, also participants of the CG experienced some improvements over time. Since that effect only occurs at follow up, it may be, that through their repeated involvement with the topics of the questionnaires, they were encouraged to reflect and changed their behavior in the meantime. It should be emphasized, that all these results are only interpretable to a limited extent and a larger study sample is needed to make reliable statements about group differences as well as to verify the potential intervention effects.

4.1 | Study limitations

The first limitation of our study concerns the sample population. As has been seen in comparable other studies[12,20] the majority was female and highly educated, which does not reflect the population of partners in real-life. In addition, generalizability of the results is limited, because it can be assumed that only partners with an existing affinity for online tools have expressed their interest in the study via homepage. A reason for non-significant group effects may be the small sample size, which was however appropriate for the feasibility study.[21] A further limitation of the present online assessment is the uncertainty regarding the diagnosis of the ill spouse as this was recorded via self-report. The additional collection of medical data

(through a physician's report) is more costly and may increase the barrier for participation, but this should be weighed against possible certainty gains in future studies. Likewise, the different time periods of questionnaires (last 2 weeks, last 4 weeks, current) should be viewed critically and there is also uncertainty whether participants take these periods into account in their answers. In addition, although we recorded the number of participants undergoing psychotherapy treatment, subgroup analyses were not possible due to the small group size. Moreover, subgroup analyses with high and low burdened participants were not practicable, but it would be as well interesting for the upcoming efficacy study to investigate whether the level of burden has an influence on efficacy of the intervention. As dropout rate in IG was higher than in CG, identification of reasons for not attending post-assessment or follow-up will be a future interest. One reason may be that participants from the waitlist-group were more motivated to complete assessments, because afterward they received access to the unguided version of PartnerCARE. Concerning the overall dropout, participants might also be very busy and prone to forgetting the questionnaire, which we tried to prevent with sending three reminders to complete the questionnaires. Further studies should consider asking for dropout reasons, thereby taking incentive strategies into account for receiving this important information from those not willing to further participate.

4.2 | Clinical implications

Partners of patients with cancer frequently experience low quality of life as well as depression and anxiety at a subsyndromal level.[4] Therefore, it is necessary to provide support offers for partners as an integral part of the healthcare routine. Online interventions may be a suitable offer to support partners in a flexible way.[6] But there are two barriers that must be overcome before partners use such support offers: partners' lack of awareness of their own needs[2] and how to reach burdened partners.[22] Providing informational material about the potential impact of cancer to caregiving partners and an accompanying distress screening of partners in clinical routine could help to increase the partners' awareness of their own burden and thereby their own needs. Such screenings could be easily conducted via mobile app and additionally linked with PartnerCARE, to provide support instantly in case of increased burden. Since the current study demonstrated online recruitment as an effective way to reach partners and, as previous studies showed, partners are comfortable in using the Internet to search for information and help,[8] reach of partners via Internet should be focused. In addition, despite limited time resources of healthcare professionals, they should also pay attention to the partner by handing out relevant support information during visit hours. As PartnerCARE itself increase the proportion of participants who rate themselves as well informed about help services for caregivers in general, such online-interventions might have the potential to be a low threshold entry into the psycho-social support system for caregivers.

5 | CONCLUSION

The present study demonstrated feasibility and acceptance of the online intervention PartnerCARE and the corresponding study process. Online interventions can overcome barriers regarding the use of psychosocial health care offers and improve the care for partners of patients with cancer.[20] Based on the received feedback, PartnerCARE is currently being further developed to improve content, modify how content is displayed (in form of short videos), solve technical problems and enhance the audio quality of the guided imagery exercises. Subsequently, the promising preliminary results and implementation of PartnerCARE into standard care will be further investigated in a randomized controlled efficacy evaluation trial. The process was initiated to provide a reliable, long-lasting support offer for partners.

ACKNOWLEDGEMENT

The authors would like to thank all partners for their participation and their adjuvant written feedback. Furthermore, authors thank Sabrina Heil for her support in the study process and her and Daniel Neveling for e-coaching. The authors also thank Tim Dretzler (TD) for conducting the randomization of the study participants. This work was supported by a grant from the German Cancer Aid to the Comprehensive Cancer Center Ulm (grant number: 70112209). The German Cancer Aid had no role in study design, decision to publish or preparation of this manuscript. The German Cancer Aid was not involved in data collection, analyses, decision to publish or preparation of future papers regarding the PartnerCARE project.

CONFLICT OF INTEREST

Harald Baumeister received consultancy fees, reimbursement of congress attendance and travel costs as well as payments for lectures from Psychotherapy and Psychiatry Associations as well as Psychotherapy Training Institutes in the context of E-Mental-Health topics. He has been the beneficiary of study support (third-party funding) from several public funding organizations. All other authors declare no conflict of interest.

AUTHOR CONTRIBUTIONS

Daniela Bodschwinna, Natalie Bauereiß, Harald Gündel, Harald Baumeister and Klaus Hönig contributed to the conception and design of this study. Daniela Bodschwinna and Inga Lorenz collected the content of the intervention sessions. The online design and structure of the intervention was carried out from Daniela Bodschwinna building on prior online interventions of the department of Clinical Psychology and Psychotherapy (Harald Baumeister). Intervention development was supervised by Natalie Bauereiß, Harald Gündel, Harald Baumeister and Klaus Hönig. Daniela Bodschwinna was responsible for recruitment, coordination of the study and data analyses. Daniela Bodschwinna drafted the manuscript. All authors provided critical revision and approved the final manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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How to cite this article: Bodschwinna D, Lorenz I, Bauereiß N, Gündel H, Baumeister H, Hönig K. A psycho-oncological online intervention supporting partners of patients with cancer (PartnerCARE): results from a randomized controlled feasibility trial. *Psychooncology*. 2022;1-13. https://doi.org/10.1002/pon.5917

6 General Discussion

6.1 Summary of Main Findings

The aim of this dissertation was to obtain a deeper insight into the different coping and support strategies of cancer patients and their spouses, with special focus on spouses as they have often been neglected in their support needs in the past. To gain insight into the support system within and outside the couple, a sample of hematological cancer patients and their spouses was investigated, as it is assumed that they experience a particularly high level of distress and therefore they have a high need for support. Examination of differences in support and burden from hematological cancer patients and their spouses lead to the second part of this dissertation, which focused on professional support via internet intervention for spouses.

Publication I was able to identify different types of coping and support through qualitative analysis of couple interviews with hematological cancer patients and their spouses. They could be classified into three main categories: individual coping, dyadic coping and outside support (Bodschwinna et al., 2022b). An additional consideration of subcategories of the outside support, which includes social support and professional support, shows that the four categories of the stress-coping-cascade model from Bodenmann (2005) could be confirmed. In addition, due to the division into subcategories, a deeper look at the different facets contained therein was possible. These findings went beyond standardized questionnaires and resulted in new insights, such as the different types of future plans within the common dyadic coping category (Bodschwinna et al., 2022b). In response to the first research question, the following categories and subcategories of coping and support within and outside the couple could be identified: *Individual Coping* (Emotional Focused, Problem Focused, Positive Reframing); *Dyadic Coping* (Stress Communication, Supportive Dyadic Coping, Delegated Dyadic Coping, Negative Dyadic Coping, Common Dyadic Coping); *Outside Support* (Social Support, Professional Support). Deeper insights could be drawn within the subcategories, for example, by identifying different future plans within the common dyadic coping category.

Subsequently, Publication II picked out two types of coping and support and investigated the association of them with psychological distress in hematological cancer patients and their spouses. With this study the hitherto underrepresented research field of joint investigation of different support types by additionally consideration of interdependency of patient and spouse has been extended. With the Actor-Partner-Interdependence Model this

interdependency has been taken into account and so-called actor- and partner-effects could be calculated (Kenny et al., 2006). Actor-effects specify associations from one's predictor variable on the own dependent variable, while partner-effects describe associations from one's predictor variable on the other's dependent variable (Kenny et al., 2006). Regarding actor-effects it was shown that both more perceived supportive (patients: $\beta = 0.27$, p <.001; spouses: $\beta = 0.21$, p <.01) and more perceived negative dyadic coping (patients: $\beta = 0.34$, p <.001; spouses: $\beta = 0.16$, p <.01) were associated with higher level of depression symptoms in oneself (Bodschwinna et al., 2021). These associations were also true for anxiety symptoms. In contrast, a higher amount of perceived social support was associated with less psychological distress in patients (depression symptoms: β = -0.31, p <.001; anxiety symptoms: β = -0.26, p <.001) and spouses (depression symptoms: β = -0.22, p <.001; anxiety symptoms: β = -0.10, p <.05) (Bodschwinna et al., 2021). Partner-effects, mainly from spouse's predictor variables on the patient's dependent variable, showed the interdependence within the couple and, in particular, the potential influence from spouses on patients (Bodschwinna et al., 2021). The answer to the second research question is that both perceived positive and negative dyadic coping forms were positively associated with one's psychological distress. In contrast, perceived social support showed a consistent negative relation with one's psychological distress. Due to cross-sectional design of the study conclusion about causality of results are limited (Bodschwinna et al., 2021).

The qualitative study from Publication I as well as the quantitative study from Publication II demonstrated differences in coping and support types between hematological cancer patients and spouses (Bodschwinna et al., 2022b, 2021). Spouses reported significantly less perceived social support (d=0.45), less perceived supportive dyadic coping (d=0.30) and less perceived delegated dyadic coping (d=0.38) compared to the patients (Bodschwinna et al., 2021). This ratio of differences was also evident in the qualitative study (Bodschwinna et al., 2022b). Based on these results, it can be concluded that there is a lack of support for spouses (Bodschwinna et al., 2022b, 2021). In Publication II it was additionally evident that there is less support from outside for the spouse, although spouses are frequently similarly burdened to patients (Bodschwinna et al., 2021). Further differences included more perceived stress communication (d=0.26) and more perceived negative dyadic coping (d=0.29) in spouses compared to the patients (Bodschwinna et al., 2021). The answer to the third research question is that hematological cancer patients and their spouses differ in several coping and support types, into the direction that lack of support for spouses can be assumed (Bodschwinna et al., 2022b, 2021).

Given the comparable level of psychological distress and burden of patients and spouses (Bodschwinna et al., 2021) and a low amount of psychological interventions for spouses (Kleine et al., 2019), the focus of the second part of this dissertation is on support for spouses. Thus, Publications III and IV were the first steps in reducing the research gap of the lack of appropriate support for spouses of cancer patients in Germany. Due to the difficulty of accessibility and time constraints of the spouses, an online format was chosen for intervention delivery (Heynsbergh et al., 2019). The publications focused on development and feasibility testing of the guided internet intervention PartnerCARE for spouses of cancer patients (Bodschwinna et al., 2022a, 2020). To reach a wide proportion of spouses, all types of cancer, all stages of disease and treatment were included to the study without restriction by spouses burden cut-off score. The successfully reached sample size, the high rate of intervention completion (73.3%) as well as low study dropout over time (T1: 17% and T2: 29%) reflected feasibility of the study process and the intervention (Bodschwinna et al., 2022a). Acceptance was demonstrated by a high level of satisfaction with PartnerCARE that remained stable over time (Bodschwinna et al., 2022a). Potential efficacy of PartnerCARE, for example by the increase of mental quality of life from T0 to T1 (d= -0.43, 95% CI [-0.67; -0.18]), needs to be investigated in the planned efficacy evaluation trial. The answer to the fourth research question is that PartnerCARE is a feasible, promising and appropriate way to support spouses of cancer patients, which will be pursued further in order to improve the hitherto low level of spousal support offered (Bodschwinna et al., 2022a).

6.2 Comparison with Previous Research

The purpose of this dissertation was to provide an overview of coping and support strategies used among couples facing cancer and expand research in the area of underrepresented evidenced support options for spouses. In the following, the results of the included publications are embedded and discussed in the state of research to date.

It is appropriate to examine different coping and support strategies together, as previous research has shown that they occur together in prolonged stressful situations (Paschali et al., 2021). Therefore, the dyadic interview study (Publication I) aimed to identify different types of coping and support strategies used among couples facing cancer. Results of the study confirmed the four main coping and support categories of Bodenmann's Stress-Coping-Cascade Model (Bodenmann, 2005) and detected some deeper differences in strategies of patients and spouses (Bodschwinna et al., 2022b). To our knowledge, this is the first time this have been explored in its entirety in qualitative research with couples facing

cancer. Some deeper insights into the support subcategories were in line with previous research in other cancer populations: such as less emotional strategies for well-being in spouses (Heynsbergh et al., 2019), positivity strategies like living in the now and enjoying little things (Cottingham et al., 2018) and the both favorable and stressful facets of stress communication within the couple (Badr, 2017). Moreover, the finding that cohesion in relationship and joint activities was essential for all interviewed couples (Bodschwinna et al., 2022b), is comparable with previous studies emphasizing the importance of cohesion to increase intimacy and relationship growth (Lupinacci et al., 2021; Serçe & Günüşen, 2021). Another result regarding the differentiation of future goals within the common dyadic coping into 'return to normality' versus 'new targets' has extended the research field (Bodschwinna et al., 2022b). Only 'return to normality' was found in spouses so far (Antoine et al., 2013). In addition, patients and spouses reported that they sometimes feel pressured by support of the other partner or social support (Bodschwinna et al., 2022b). This finding is in line with previous research, that postulated to give negative forms of social support more attention (Geue et al., 2019) or that social support only is helpful if the support is desired by the recipient (Vodermaier & Linden, 2019). Trough the deeper insight into the coping and support categories it becomes apparent that in addition to the stresses and strains experienced, the disease can also provide an impulse for positive and new joint experiences. Further research is needed to prove the different coping and support types in other cancer types and explore potential moderators that may enable support to be beneficial.

Overall, there is also little quantitative research in cancer couples including different coping and support strategies regarding their joint effect on psychological outcomes. This is incomprehensible, as previous research found reciprocal dependency and associations of different types of coping and support (Bottaro et al., 2022; Papp & Witt, 2010; Paschali et al., 2021). So far, only some studies considered individual and dyadic coping together (Badr & Acitelli, 2017; Papp & Witt, 2010) or different social support from others (e.g. family, friends) together in cancer couples (Hasson-Ohayon et al., 2010). Publication II expanded this area of research by including findings on perceived support from the partner and other close relatives or friends and its association with psychological distress (Bodschwinna et al., 2021). The association of more perceived supportive dyadic coping and higher level of own depression symptoms in patients and spouses (Bodschwinna et al., 2021), could be explained by a sense of lower self-efficacy in one's by perceiving the supportive behavior of the other (Mcclure et al., 2014). This finding is in contrast to results of earlier studies, which found supportive behavior was related to beneficial outcomes such

as higher relationship functioning and satisfaction (Chen et al., 2021; Traa et al., 2015) and better psychological adjustment (Chen et al., 2021). At this point it is necessary to highlight that the previous studies did not use the perceived dyadic coping scales. Thus, it could be that a crucial difference has been uncovered here: Providing supportive behavior is associated with alleviation of burden (Chen et al., 2021), while perception of supportive behavior is associated with higher psychological burden (Bodschwinna et al., 2021). In contrast, findings regarding perceived negative dyadic coping and its strong association with higher level of psychological distress is in line with previous research (Badr et al., 2010; Regan et al., 2014). Also the finding of no association of common dyadic coping with psychological distress was consistent with a previous study (Regan et al., 2014). Taken together these dyadic coping findings, it seems that the focus should be on negative dyadic coping forms as they are consistently related to both depression and anxiety symptoms in patients and spouses. There was a consistent association of more perceived social support with less own psychological distress in patients and spouses, which was also shown in previous research (Fong et al., 2017; Hasson-Ohayon et al., 2010; Lotfi-Jam et al., 2019). As in the dyadic study of Ferraris et al. (2022), Publication II also found only the crossover effect from perceived social support by spouses and depressive symptoms in patients (Bodschwinna et al., 2021). This emphasizes the importance of support for the spouses, as it also could be beneficial for patients' outcomes.

Results from Publication I and II support previous findings of differences and similarities in cancer patients and spouses. Spouses perceived significantly more stress communication from their patients with hematological cancer and in turn communicate less about their own stress to the patient (Bodschwinna et al., 2021). This is in line with the tendency of spouses who do not want to put additional stress on patients (Fergus & Gray, 2009). Furthermore, it reflected that spouses are often the most important contact persons for patients (Kayser et al., 2007). The result that patients perceived significantly more supportive dyadic coping and delegated dyadic coping compared to their spouses (Bodschwinna et al., 2021), can be explained by the role effect between patient and spouse (Rottmann et al., 2015). Similarly, the finding that patients perceive significantly less negative dyadic coping compared with their spouses can be explained by a role effect which implies that spouses do not want to burden their patients additionally with negative behavior (Bodschwinna et al., 2021). Another result was that hematological cancer patients and their spouses reported similar amount of burden, but spouses reported significantly less perceived social support compared to the patients (Bodschwinna et al., 2021). This is consistent with studies of

other cancer populations (Brandão et al., 2017; Hasson-Ohayon et al., 2010; Lotfi-Jam et al., 2019). This additionally confirmed the assumption that spouses are seen primarily as caregivers and therefore their personal support needs are neglected by others (Soothill et al., 2003). All these differences and similarities of dyadic coping and social support, with the exception of negative dyadic coping, among hematological cancer patients and their spouses could also be shown in the qualitative study (Bodschwinna et al., 2022b).

Based on the findings from the first part of this dissertation, it can be assumed that similarly burdened spouses are often neglected in their needs and therefore do not receive adequate support from patients, friends and relatives. Uptake of professional support such as face-to-face interventions can be limited in spouses because of time or place restrictions, concerns about stigma or wanting to hide their burden (Kaltenbaugh et al., 2015; Mosher et al., 2015; Sinfield et al., 2012). These barriers could be overcome by internet interventions, as they can offer a low-threshold support including the possibility of anonymity and time and location independent participation (Heynsbergh et al., 2019). Due to few amount of evaluated internet interventions for spouses of cancer patients and the lack of such an intervention available in German, development and evaluation process of PartnerCARE was initiate to reduce this gap.

Development of the internet intervention PartnerCARE took findings from previous research into account, in order to create a tailored support offer for spouses. As results from Publication I indicated few and mainly unfavorable emotional strategies among spouses (Bodschwinna et al., 2022b), PartnerCARE included a selection of strategy offers, such as planning positive activities, guided audio imaginations and other relaxation techniques (Bodschwinna et al., 2020). Also the finding of different future goals (Bodschwinna et al., 2022b) was addressed in PartnerCARE by including detailed exercises and suggestions in the last main session named 'Path and Goals' (Bodschwinna et al., 2020). A meta-analysis on different interventions for family caregivers showed that caregivers benefit more if interventions solely targeted caregivers and thereby focused on caregiver needs compared to joint patient-caregiver interventions (Northouse et al., 2010). Rather than most caregiver interventions being directed at the patient-caregiver dyad, as is still the case (Heynsbergh et al., 2018; Kedia et al., 2020; Treanor et al., 2019), PartnerCARE was designed for spouses participation only.

Feasibility study (Publication IV) demonstrated feasibility and acceptability of the guided internet intervention PartnerCARE (Bodschwinna et al., 2022a). High adherence rate (73.3 % completed intervention) is comparable or even higher than other recent internet

interventions for caregivers (Grapp et al., 2022; Köhle et al., 2021; Pensak et al., 2021). Similarly, dropout of the study (T1: 17%, T2: 29%) was comparable low to recent internet interventions (22% - 46%) (Grapp et al., 2022; Köhle et al., 2021; Pensak et al., 2021) and partial considerably low compared to findings from a systematic review (dropout rates between 14% and 77%) (Heynsbergh et al., 2018). In contrast to other research of internet intervention in cancer populations (Leslie et al., 2022) our trial could reach the predefined sample size. This indicates also feasibility for the wide recruitment strategy used. Internet interventions found to be beneficial for several spousal outcomes: management of emotions and distress (Grapp et al., 2022), mindfulness (Kubo et al., 2019), stress management skills (Pensak et al., 2021), positive dyadic coping (Fergus et al., 2022) and psychological flexibility and resilience (Köhle et al., 2021). Preliminary insight into PartnerCARE's efficacy suggested effects from pre to post intervention regarding distress, anxiety, self-efficacy and mental quality of life (Bodschwinna et al., 2022a). So far, no reliable statements about efficacy of PartnerCARE can be made.

Recently published research, which consist mainly of feasibility and pilot trials, targeting solely at caregivers or jointly with patient (Fergus et al., 2022; Grapp et al., 2022; Kubo et al., 2019; Pensak et al., 2021) confirm the assumption that this research area is still in its infancy (Shin & Choi, 2020). Several published study protocol of planned caregiver internet interventions (Schuit et al., 2020; Song et al., 2022) also indicates good quality of research. In addition, it is promising to observe that the important and previously neglected area of research around caregivers is now gaining more attention.

Comparison of the results of this dissertation with previous research is limited to some extent. In case of the qualitative couple study comparability is limited by the restricted amount of interview studies in hematological cancer couples and none of them was conducted in a jointly interview setting. Similarly, there are few studies using the perceived scales of the Dyadic Coping Inventory. Likewise, there are only few internet interventions for spouses and existing ones differ hardly in content, underlying therapeutic concept, aim and related primary outcome. However, this taken together suggests a need for more research in this area to further explore the found insights, associations and preliminary effects.

6.3 Strength and Limitations

This dissertation has several strengths and limitations. A methodological strength of Publication I and Publication II is the joint investigation of hematological cancer patients and their spouses. Due to cancer is widely described as 'we-disease' (Kayser et al., 2007) and the couple represents the inner circle, this chosen approach is appropriate. By joint couple interviews in the study of Publication I, a more naturally and realistic couple conversation was created that may be more related to the daily real-life (Bjørnholt & Farstad, 2014). Due to the mutual consternation and the shared experiences by the disease and it's treatment, joint interviewing may provide a better picture of the support system in the couple. Furthermore, each partner can both confirm and deny the other's statements, which can lead to a higher level of validity (Bjørnholt & Farstad, 2014).

Another methodological strength is the performed Actor-Partner-Interdependence Model in Publication II, which takes the interdependency of the couple into account (Kenny et al., 2006). This model represents the gold standard in dyadic analyses, but nevertheless in cancer couple studies it is still not regularly used (Chen et al., 2021; Kayser et al., 2018).

Besides these two methodological strengths, the use of both a qualitative and a quantitative approach can be considered as an overall strength of the first part of this dissertation. Thus, different layers of insights into the support system of couples could be obtained.

The newly developed internet intervention PartnerCARE and the corresponding study process have several strengths, too. The first strength of PartnerCARE is the extensive development process, which included a literature research of cancer caregivers needs, the compilation of intervention content based on a manualized intervention (Weis et al., 2006) as well as on established concepts commonly used in cancer context (Applebaum & Breitbart, 2013) and the adaption of the entire content to an online design. The second strength was the high spouses' adherence to the intervention. Guidance, high amount of female participants (Beatty & Binnion, 2016) as well as used parts of persuasive system design (Kelders et al., 2012) could have led to this adherence. Additionally, guidance may be beneficial with regard to efficacy of online interventions (Baumeister et al., 2014), which could be one factor for the promising preliminary efficacy results of the PartnerCARE intervention (Bodschwinna et al., 2022a).

The assessment of potential negative effects of internet interventions is highly recommended (Rozental et al., 2015) and has the advantage of being able to respond to the negative effects recorded. In PartnerCARE potential negative effects were recorded via a specific questionnaire (Ladwig et al., 2014) post intervention and in case of a negative effect

occurring, such as suicidal ideation, an emergency process automatically took place.

Another strength is the previous registration of the randomized controlled feasibility trial, the previously published study protocol according to the SPIRIT Statement (Standard Protocol Items: Recommendations for Interventional Trials) (Chan et al., 2013) and the followed guidelines for conduction and report of feasibility trials (CONSORT Statement - CONsolidated Standards Of Reporting Trials) (Proudfoot et al., 2011). Adherence of these guidelines fulfill a high quality research standard in order to achieve a reliable, evidence-based and well evaluated support offer for spouses. The feasibility study conducted so far is only the first step of a development and evaluation process, which is intended to lead to implementation of the intervention in the health care system.

Several limitations have to be considered. First, the qualitative couple study had a high dropout rate (Publication I: 71.4%) (Bodschwinna et al., 2022b). This reflects the challenging recruitment and organization of joint couple interviews. Besides the advantage of a naturally couple conversation, interviewing the couple jointly may have resulted in higher couple desirability and thus in a sense of being influenced by the other partner's expressions and being inhibited to speak openly (Zarhin, 2018). This may have additionally resulted in relatively few reports of negative dyadic coping experiences within the couples (Bodschwinna et al., 2022b). The quantitative couple study of Publication II had also a high dropout rate of 42.0% (Bodschwinna et al., 2021), which reflects likewise the difficulty of recruiting couples for surveys.

In addition, recruitment of couples could be affected by a selection bias in the samples, resulting in better functioning and lower burdened couples being more likely to participate in a study. This could be true both for Publication I and Publication II. Similarly, self-selection of participants of PartnerCARE may have led to a selection bias in the sample, as spouses who had more positive attitudes toward internet support or greater interest in internet support were more likely to participate.

Another limitation is that spouses of hematological cancer patients reported a lower amount of burden than expected (Publication II). For comparison: 14.5% and 16.1% of spouses of Publication II reported elevated scores of depression and anxiety respectively (Bodschwinna et al., 2021). In the study of Lambert et al. (2013) spouses of hematological cancer patients reported up to 27.4% depression and 43.6% anxiety one year after diagnosis. The low amount of psychological distress in sample of Publication II could be due to a selection bias, as discussed before, and a high proportion of participants with more than one year since diagnosis (Bodschwinna et al., 2021).

The generalization of the results to other cancer types is not given, as the Publication I and Publication II were only conducted with hematological cancer patients and their spouses. Further studies with other cancer samples are needed to make valid statements across different cancer types. Furthermore, associations of coping and support with psychological distress of Publication II are restricted to correlation analyses and therefore no causal conclusions are possible.

A methodological limitation of Publication I and Publication II is the lack of study pre-registration at the German Clinical Trials Register. Pre-registration promotes transparency of clinical research. Nevertheless, the studies were pre-defined within the project proposal to the Deutsche José Carrerase Leukämie-Stiftung and were approved by the Ethics Committees of the Medical Faculty of the University of Leipzig and the University of Ulm. Furthermore, the theoretical data saturation in the qualitative study of Publication I did not follow the typical procedure due to recruitment problems (Bodschwinna et al., 2022b). By screening the already performed interviews, it seemed that no new information occurred in the last interviews, and a new recruitment was rejected (Bodschwinna et al., 2022b). Nevertheless, there is uncertainty whether additional information was overlooked as a result. As Publication II is a secondary analysis, a further methodological limitation has to be considered. The problem with that kind of anaysis is that overpowering or underpowering of results cannot be completely ruled out. With regard to this exploratory analysis the a posteriori power analysis gives also no indication for overpowering or underpowering (Dziak et al., 2020).

A methodological limitation of Publication IV has to be considered, too. It has been discussed that study designs with a wait-list control group might lead to overestimation of effects compared to no treatment or psychological placebo groups (Furukawa et al., 2014; Mohr et al., 2014). This is explained by the assumption that the expectation of future access to the internet intervention may lead to less motivation in help seeking (Mohr et al., 2014). Despite the fact, that the control group of PartnerCARE was a waitlist, all participants had access to treatment-as-usual and were informed about alternative help options via email at group assignment. As selection of control arms might have impact on participants behavior, it should be considered carefully in further studies (Mohr et al., 2014).

The uncertainty of a potential social desirability bias applies to all publications of this dissertation, as all variables were collected via self-report. In further studies the use of a social desirability scale in surveys should be considered, which can be an appropriate way to deal with this limitation (Perinelli & Gremigni, 2016).

6.4 Implications

Findings of this dissertation result in both research and clinical implications. The first research implication can be derived from Publication I, which demonstrated insights about the support system in hematological cancer patients and their spouses. Besides the different categories of coping and support, some small insights were gained about the usefulness of the strategies used, such as social support that can be experienced as useful or stressful. As it is not enough just to know what types of coping and support couples use, more research is needed on what support types are beneficial and under what conditions. Technical data collection tools could be the recording of support networks and their interactions over time to better understand how support systems work (Reblin et al., 2022). Subsequently, intervention content could be improved in that way to provide support for the insufficient parts of a couple's support system.

Publication II leads to a further research implication. Significant partner-effects such as the association of higher perceived social support in spouses with lower reported depression symptoms in patients needs to be further investigated. Therefore, study designs should certainly consider longitudinal studies to investigate the underlying causal mechanisms.

By comparing Publication I and II with previous research it became apparent that little attention has been paid to the entirety of the different types of support together. This is needed to gain a more comprehensive knowledge of the entire support system within and outside a couple facing cancer. Thus, there is a need for further research about the entire support system in couples facing different cancer types. Furthermore, use of perceived dyadic coping scales instead of own dyadic coping is recommended when examining different support types a participant received from various agents. An intermixture of provided and perceived support should be avoided, as these are two different concepts: one concerning how the person feels by providing support for others, and the other concerning how the person feels by receiving support from others.

There are several implications for clinical practice that could be drawn from the publications of this dissertation. Findings of differences in use of support types between patients and spouses (Publication I and II) should lead to greater awareness among health care professionals that patients and spouses may have individual support needs. Intervention development should also take this into account by tailoring support options for patients and spouses separately. For example, emotional individual coping as well as seeking for social support should be encouraged in spouses, as a lack of these were identified in Publication I and II.

Knowledge about the associations of coping and support strategies with psychological distress (Publication II) could be a first of two steps for further development of interventions. As a second step the underlying causal mechanisms need to be investigated using longitudinal studies. Subsequently, if assumption of impact of coping and support strategies on psychological distress could be confirmed, interventions might seek to improve deficits in coping and support strategies to indirectly reduce psychological distress. For example, the strong association between perceived negative dyadic coping and psychological distress in Publication II could support the conclusion of Regan et al. (2014), that an intervention may be more useful if it aims to improve identification of negative behavior in couples. In addition, the fact that no relation of common dyadic coping with psychological distress was found (Bodschwinna et al., 2021; Regan et al., 2014) supports the assumption, that focus of intervention content should be reconsidered. This could be used for further content development of PartnerCARE, which so far only takes identification of negative communication behavior into account. But it also could be used for substantive development of other interventions, that seemed to focus more on improving positive behaviors rather than identifying and modifying negative behaviors (Luo et al., 2020; Treanor et al., 2019).

Promising findings of the randomized controlled feasibility trial of PartnerCARE implicate that this internet intervention could be an appropriate way to support spouses of cancer patients. The initiated consecutive development and evaluation process comprises several steps: initial development of PartnerCARE (completed), randomized controlled feasibility study (completed), optimizing of PartnerCARE (in work), randomized controlled efficacy trial (in concept phase), further optimizing of PartnerCARE (planned) and implementation as a permanent support offer (planned). As a conclusion from the completed steps, it can be drawn that the guided internet intervention PartnerCARE can be a suitable way to support spouses and that a subsequent confirmatory trial to explore efficacy is indicated. Furthermore, such a successive process is also recommended for other internet intervention studies, because adjustments of the intervention content or process can be made after each partial evaluation phase.

An internet intervention for spouses could be beneficial for the healthcare system in three different ways. First, it may improve mental health of the spouse and thus potential consequential costs due to psychological distress could be reduced. Second, internet interventions may improve well-being in spouses and thus they could have enough energy for relieve burden in patients and no additional professional caregivers are needed.

Third, physicians and psychologists in all sectors of care have the possibility to serve a low-threshold and promptly available offer to psychosocial stressed spouses of people with cancer at any time.

In summary, several implications regarding research on the couple's support system, further intervention development and internet interventions for spouses could be derived from this dissertation. Finally, based on these implications, future perspectives can be considered.

6.5 Future Perspectives

Overall, the studies of this dissertation show a considerably amount of burden in cancer patients and their spouses and thus the importance and need of more knowledge about the support system within and outside the couple. There is a need for more research about the entire support system including all types of support as well as more couple research, because they are together highly affected by the cancer diagnosis. A combination of qualitative and quantitative research approaches could reveal different facets of the coping and support system and could lead to a more comprehensive overall concept.

Furthermore, this dissertation contributes to a greater focus on the challenging role of spouses, including considerable burden and deficits in receiving support. Growing awareness of spouses' burden is an important development of the past decade. Now it has to be emphasized that the research effort in this field needs to be further expanded, especially in tailored and appropriate support offers for spouses.

In case of future interventions, the barrier regarding spouses not seeking independently for help should be considered. Therefore, more proactive offers of support options and more promotion of available interventions are needed. An introductory video was found to reduce potential fears and misconceptions about internet interventions (Köhle et al., 2015). In addition, for facilitating individual access and attitude to an internet intervention right at the beginning or even at recruiting, informational videos were found to increase acceptance of the intervention (Ebert et al., 2015). To use this facilitating effect, a promotion video for the upcoming PartnerCARE efficacy study was developed to be included into the recruitment process.

It is also suggested that the content and amount of content of future interventions should be more personalizable for participants (Beatty et al., 2021). In the case of PartnerCARE it is considered to release the order of the main lessons to allow participants to choose the topics they want to work on first by themselves. Another advanced possibility are Just-

in-time interventions, which provide support by responding to tracked information via a mobile device exactly when it is needed (Nahum-Shani et al., 2018). For example, an additional diary could be provided as a part of the intervention, where participants record their daily well-being. For example, the report of sleep difficulties in the diary could lead to the automatically suggestion to carry out the additional session about healthy sleep.

As videos are known to be more motivating and convey knowledge more sustainably than text (Choi & Johnson, 2005), informing whiteboard videos for each main session of PartnerCARE were developed. Since communication in couples facing cancer is particularly important and can comprise both beneficial and stressful facets (Badr, 2017; Bodschwinna et al., 2022b), the session about couple communication was extended with several conversation videos to help with typically difficult conversations in cancer couples. Both extensions will be integrated into PartnerCARE before the upcoming efficacy study starts.

To gain implementation of such interventions in usual healthcare, there is a need for implementation research (Ugalde et al., 2019). For successfully implementation consideration about the right timing for an internet intervention may be crucial (Grapp et al., 2022). If the offer of such an intervention takes place too early after diagnosis, caregivers might not be ready to get involved to that time (Grapp et al., 2022). Similarly, at a late stage of the disease, caregivers might not have time, as other things are now in the priority (Grapp et al., 2022). In addition, a directly linked cost-effectiveness analysis is recommended for upcoming studies about psychological interventions (Treanor et al., 2019).

The outlook on the planned randomized controlled efficacy study of PartnerCARE will close the circle of this dissertation on the couple's view again, as the upcoming trial will include couples instead of spouses alone. While spouses will still participate in the internet intervention solely, patients will take part in online questionnaires pre and post intervention. The content of PartnerCARE continues to focus on improving spouses' quality of life and their ability to cope with caregiver burden. Therefore, the primary aim of the trial will be the investigation of efficacy of PartnerCARE on spouses' quality of life. But in addition, a secondary aim is to investigate a potential influence of changes in spouses' well-being on patients' well-being and thus whether PartnerCARE could have an indirect impact on patients. This could expand and verify previous research that has already demonstrated associations between well-being and quality of life in spouses with well-being in patients (Litzelman & Yabroff, 2015).

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Declaration

I hereby certify that I have written this thesis independently and have not used any sources or aids other than those indicated, and that I have marked the passages taken over verbatim or in content as such and have observed the currently valid statutes of the Ulm University to ensure good scientific practice (§ 8 Abs. 1 Nr. 5 Rahmenpromotionsordnung).
I agree that the dissertation may also be used for the purpose of checking compliance with generally applicable scientific standards, in particular also by using electronic data processing programm (§ 8 Abs. 1 Nr. 8 Rahmenpromotionsordnung).

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Date

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Daniela Bodschwinna