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Running head: Effects on dyadic coping in specialized palliative care intervention

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Abstract

Objective Specialized palliative care (SPC) interventions increasingly include patient–caregiver dyads, but their effects on dyadic coping are unknown. We investigated whether an SPC and dyadic psychological intervention increased aspects of dyadic coping in patients with advanced cancer and their caregivers, whether dyad characteristics moderated effects and whether aspects of dyadic coping mediated significant intervention effects on caregivers’ anxiety and depression.

Methods We randomized 258 patients with incurable cancer and their caregivers to care as usual or accelerated transition from oncological treatment to home-based SPC and dyadic psychological support. In secondary outcome analyses, using mixed-effects models, we estimated intervention effects and 95% confidence intervals (CIs) for communication of stress and common coping, and moderation by dyad type and demographics. In path analyses, we investigated whether stress communication and common coping mediated intervention effects on caregivers’ symptoms of anxiety and depression. (Clinicaltrials.gov NCT01885637)

Results The intervention significantly increased common coping in patients and caregivers in couples (estimated difference, 0.68; 95% CI, 0.11 to 1.24) and stress communication by partner caregivers (0.97; 0.24 to 1.24). We found some support for different intervention effects for spouses and other dyads, but no evidence of mediation.

Conclusions SPC and dyadic psychological intervention may affect aspects of dyadic coping. Common coping and stress communication did not mediate the previously found significant intervention effects on caregiver anxiety and depression, indicating that other mechanisms may have been central in the intervention.
Background

The stressful life with advanced cancer requires patients and caregivers to cope individually and together. Multidisciplinary specialized palliative care (SPC) aims to relieve suffering in patients with life-threatening illness and their families and can significantly improve quality of life of patients with advanced cancer. According to the systemic transactional model of coping (STM), couples may cope with stressors such as cancer in individual and interactional ways. Dyadic coping is a reciprocal process in which each partner’s communication of stress serves to elicit support from the other partner, like helping with or taking over tasks (supportive/delegated coping), and common coping, i.e. managing a problem together. In patients with cancer, stress communication has been related to better dyadic adjustment and quality of life. Greater common coping efforts, such as joint problem-solving or relaxation, have been found to predict increased relationship quality and lower depressive symptoms in dyads coping with cancer, but have also been associated with lower distress in caregivers and increased distress in patients. Psychological interventions targeting dyads of patients with advanced cancer and their partners or caregivers may significantly improve e.g. psychological distress, quality of life, coping, and marital function.

Trials of SPC increasingly include patient–caregiver dyads and are likely to affect not only patients’ or caregivers’ individual coping and well-being but also their interaction. No trials of multidisciplinary SPC have yet assessed effects on dyadic coping. After partners, adult children are the most common caregivers in SPC-trials. Yet, it is unclear whether interventions are equally effective for different types of dyads.

We investigated whether SPC and dyadic psychological intervention (the ‘Domus' intervention) increased stress communication and common coping and whether effects differed according to dyad-characteristics. We previously reported that the Domus intervention significantly reduced symptoms of anxiety and depression in caregivers. In developing the psychological intervention, we hypothesized that supporting dyadic coping would be one mechanism by which the intervention would decrease distress in dyads. We therefore also investigate whether effects on stress
communication and common coping mediated effects on caregivers’ symptoms of anxiety and depression in the same RCT.

Methods

The Domus RCT investigated home-based SPC with dyadic psychological support for patients with advanced cancer and their caregivers. Dyads were recruited at the Department of Oncology, Rigshospitalet, Copenhagen University Hospital, Denmark. Patients with incurable cancer, limited antineoplastic treatment options, and 18 years of age or older were eligible (supplementary table 1). Patients could invite a caregiver to participate. Upon written consent, dyads were randomized 1:1 to care as usual or intervention. The study was conducted in accordance with the Declaration of Helsinki, approved by the Danish National Committee on Health Research Ethics (37237) and the Danish Data Protection Agency (2007-58-0015), and registered at clinicaltrials.gov (NCT01885637). A paper presenting outcomes for patients is currently in preparation.

We previously described the design of the Domus RCT and the psychological intervention component in detail. Briefly, the intervention consisted of accelerated, coordinated transition from hospital-based oncological treatment to home-based SPC, alongside care as usual. The primary aim was to increase home deaths and patients’ time spent at home. The intervention group received needs-based SPC, beginning in a home-care conference with representatives of the SPC team, municipal nursing services, and if possible the general practitioner and project psychologist. In addition, participants received a dyadic intervention conducted by psychologists, integrated into SPC until early bereavement. The psychological intervention was guided by a treatment manual, describing principles of the therapeutic approach (Existential-phenomenological therapy), the course of sessions, and criteria to determine need for sessions. Sessions were based on a dyadic understanding of coping with cancer and aimed to decrease distress in patients and caregivers by increasing their flexibility to adapt. Sessions could address any issues preventing dyads from adjusting to their situation, like worries about treatment, changed family roles, or fear of loss or death. Session content was thus not
predefined but chosen with the dyad to address salient issues. Two dyadic sessions initiated the intervention, followed by monthly telephone needs assessments and needs-based sessions. Sessions could be either dyadic or individual, lasted up to 1½ hours, and were conducted in person (with few exceptions by telephone as requested by participants). Need for sessions was defined as presence of psychiatric disease or distress preventing dyads from adjusting to their situation, relational barriers to receiving SPC, such as disagreements in the dyad, or risk factors for future distress identified in the literature. Sessions were offered by psychologists based on the combined needs assessment. To enhance dyads’ adaptation, psychologists helped dyads explore ways of relating to their situation and identify aspects of their world-view that might prevent them from e.g. accepting help. The majority of psychological intervention sessions were conducted in a dyadic setting, which necessitated and encouraged increased communication about stress and other challenges between patient and caregiver. Further, the dyadic setting was expected to increase dyads’ awareness of their interrelatedness and the potential to cope with challenges together, thus increasing common coping.

Measures

Dyads completed mailed self-report questionnaires before randomization, 2, 4, 8 weeks, and 6 months after randomization. Frequent measurements shortly after randomization were based on short expected survival. Measures included the Symptom Checklist-92 anxiety and depression subscales and the Relationship Ladder, which assesses overall relationship quality (rated 0 ‘worst possible’ - 10 ‘best possible’). To measure communication and common coping, two subscales of the Dyadic Coping Inventory (DCI) were included. Patients and caregivers each reported their own stress communication to the other (e.g. “I show my relative that I feel stressed and unwell”) and their perception of the dyad’s common coping (e.g. “We help each other see the problem in a new light”). Subscale scores ranged from 5 to 25. The DCI has been validated in several languages but not yet in Danish. It was translated using a forward-and-backward procedure and adapted for use with non-couple dyads for the present study by changing item wording to include caregivers. We further changed two items on the common coping subscale assessing couple specific behaviors, such as...
relaxing together while bathing or showing affection by making love, to more inclusive behaviors, like listening to music and hugging.

Statistical analyses

Descriptive statistics were calculated for baseline characteristics, and paired t-tests for differences in dyadic measures between patients and caregivers. To investigate whether the intervention increased stress communication and common coping, we used mixed-effects models which account for repeated measures and clustered data. We estimated intervention effects on the change from baseline throughout follow-up (2, 4, 8 weeks and 6 months) and 95% confidence intervals (CIs). Initial models included fixed effects for dyad member (patient, caregiver), dyad type (couple, parent-adult child, other), age, sex, randomization group (intervention, control), baseline scores for the outcomes, relationship quality at baseline, and follow-up assessments (weeks 2, 4, 8 and month 6, categorical). Models were hierarchical, with follow-up assessments nested within dyad members, nested within the dyad. As dyad members were distinguishable as patients or caregivers, initial models included interactions between dyad member and all other variables. We removed nonsignificant interactions stepwise. We explored effect modification by including interactions between randomization group and age, sex, and dyad type. The final models comprised initial fixed effects and interaction terms significant at $P = 0.1$. Covariance structures were modeled as “unstructured@CS”, and model assumptions assessed by visual inspection of residual plots. We calculated effect sizes from the standard deviation of the control group’s baseline assessment.24

To explore whether effects on caregivers’ symptoms of anxiety and depression reported earlier16 were mediated by stress communication and common coping, we estimated direct and indirect intervention effects. Indirect effects are those that are due, in part or wholly, to effects on another variable, the mediator (effect A), which in turn has an effect on the outcome (effect B) (Figure 1). Because of differences found in mixed-effects models, we estimated models separately for couples and parent–child dyads; but not ‘other’ dyads, as the group was too heterogeneous for meaningful interpretation. We used path analysis with maximum likelihood, adjusting for baseline values of mediator and outcome, and caregivers’ age and gender in analyses of couple dyads. Because of limited power,
gender and age were omitted in analyses of parent–child dyads. The Huber–White–Sandwhich estimator, which relaxes assumptions about normally distributed errors, was used to estimate variance and 95% CIs. Model fit was evaluated with fit statistics (SRMR, coefficient for determination $R^2$) and possibly improved by consulting modification indices. The primary mediation analyses were carried out for complete cases to investigate effects on symptoms of anxiety and depression at 6 months and their mediation by stress communication and common coping at 8 weeks. As sensitivity analyses, we repeated models for anxiety and depression at 8 weeks and their mediation by stress communication and common coping at 4 weeks. We further estimated models with imputed missing observations, based on assumptions of joint normality and missing at random.

**Results**

Between 19 June 2013 and 22 August 2016, 340 patients and 258 caregivers were included (supplementary figure 1). Nine dyads were excluded because baseline measures were completed after randomization, written informed consent was missing, or the patient did not fulfill eligibility criteria. Data on one or more dyadic coping measures at baseline was missing for up to 6% of patients or caregivers. Thus, 243–245 dyads were available for mixed-effects analyses. Small differences between the intervention and control group seemed to occur for cancer diagnosis (central nervous system tumors: 18% vs 12% in control (C) vs. intervention (I); prostate tumors: 4% (C) vs 13% (I); ‘other’: 1% (C) vs 7% (I)), caregiver type (adult child: 9% (C) vs 18% (I)), and patients’ marital status (single patients: 12% (C) vs 4% (I)) (Supplementary table 2). At baseline, caregivers reported significantly lower levels on all measures of dyadic coping than patients (data not shown). On average, dyads received a total of four psychological intervention sessions before the patient’s death (interquartile range 2 - 6). Overall, 63% of sessions were conducted with the patient and caregiver together (92% during first month after randomization).

We found no significant main intervention effects on stress communication or common coping in mixed-effects models, and no moderation by caregivers’ age and gender; however, significant effects
emerged for subgroups of couples and parent–child dyads. Patients and caregivers in couples in the intervention group reported significantly higher levels of common coping than couples in the control group (estimated difference, 0.68; 95% CI, 0.11 to 1.24; effect size, 0.15; Table 1). The intervention significantly increased stress communication for partner caregivers (0.97; 0.24 to 1.71; effect size, 0.29), but significantly decreased stress communication in parents cared for by an adult child (−2.54; 4.19 to −0.90; effect size, −0.55).

We found no evidence for mediation of effects on caregivers’ anxiety or depression regardless of outcome, mediator, or dyad type (Table 2). Sensitivity analyses confirmed the absence of indirect effects (data not shown). Figure 1 illustrates the path model for intervention effects on caregivers’ symptoms of anxiety 6 months after randomization and mediation by caregivers’ reports of common coping at 8 weeks for couples. The pattern of previously reported intervention effects on caregivers’ symptoms of anxiety and depression was confirmed in mediation analyses among couples (table 2).

No conclusive pattern of direct effects was observed for parent–child dyads.

Discussion

We found no main intervention effects on stress communication and common coping. The intervention did, however, significantly change common coping and stress communication in subgroups of dyads. Caregivers often view their needs as secondary to those of patients and the psychological intervention likely increased dyads’ awareness of caregivers’ needs. The significant increase in partner caregivers’ stress communication can be seen in light of previous findings that caregivers may shield patients from their own concerns. Caregivers in the Domus trial also reported less stress communication than patients at baseline. The dyadic delivery and focus of sessions may have encouraged partner caregivers to disclose their needs and they may have experienced talking with the patient about their concerns as beneficial. In parent–child dyads, the increased attention to child caregivers’ needs may have prompted parents to shield their children by limiting stress communication. While the psychological intervention did not contain skills training or exercises to
directly increase stress communication or common coping, the dyadic therapeutic setting was set up to facilitate both. This setting required communication between patient and caregiver, as both were included in the dialogue by the psychologist. Within sessions the psychologist’s approach modeled communication skills for dyad members, e.g. through attentive listening, and facilitated their communication. The existential phenomenological approach also aimed to increase attention toward shared and diverging needs or issues within each dyad, as psychologists helped explore how dyad members related to a given issue together and as individuals. Hence, we believe that the experience of (successful) communication and increased attention to common issues and coping strategies during sessions may lead dyads to adopt similar strategies outside sessions. Including direct skills training might have increased intervention effects.

The observed effects on stress communication may not be unequivocally beneficial or detrimental. The STM sees stress communication as a precursor of dyadic coping efforts, serving to elicit support from the partner. Although open communication is often expected to benefit dyads, a more nuanced view may be necessary. Patients with advanced cancer and their caregivers may experience different needs for communication, and one-sided self-disclosure has been found to increase depressive symptoms. Further, beneficial effects of disclosing thoughts and feelings may depend on more aspects of the communication process not measured in the Domus trial, such as the partner’s disclosure and perceived responsiveness, and the patient’s need for emotional expression. The optimal level of communication likely depends on each dyad’s situation and preferences.

Psychologists in the Domus intervention used their clinical judgement and we believe the intervention was in keeping with a differentiated approach.

We found no evidence that common coping or stress communication mediated the effects on caregivers’ symptoms of anxiety and depression. Previous psychological interventions for patients with advanced cancer or their caregivers have documented that specifically targeted mechanisms, such as mindfulness or sense of meaning and peace, mediated intervention effects. The Domus intervention only indirectly targeted dyadic coping, which may explain the lack of mediation, and
mechanisms more directly targeted should be assessed, such as increased flexibility in adapting, e.g. by exploring the range of coping strategies employed.

The reason for the differential effects found among different dyad types is not immediately evident. The STM was developed to describe dyadic coping within couples and emphasizes the importance of common goals, such as maintaining the couple’s relationship. The different effects may depend on relational differences between dyad types, such as couples having more common goals or being more likely to construe cancer as a common stressor, or on communication and self-disclosure being less reciprocal among parents and children than couples. Cancer and caregiving may impact relationships and communication in both couples and parent-child dyads, and it might be necessary to investigate whether the effect of dyadic interventions differs for different dyad types. While power limitations prevent firm conclusions, we found no clear positive or negative direct intervention effects on symptoms of anxiety and depression in children caring for their parents. Although many intervention studies in advanced cancer and SPC include dyads with different types of caregivers, to the best of our knowledge, very few have investigated whether dyad type moderates intervention effects. A previous psychosocial intervention found no moderation, although all non-spouse caregivers were analyzed together.

The strengths of our study include the RCT design and inclusion of a manualized psychological intervention, which increases the confidence with which we can attribute effects to the intervention, although fidelity was only addressed through group supervision. All patients attending the Department of Oncology at Rigshospitalet, Copenhagen University Hospital, were screened systematically for eligibility, and participation of both patients (57%) and caregivers (96%) was good, increasing the generalizability of our findings.

**Dyadic coping at the end of life**

Applying the concept of dyadic coping at the end of life is relatively new, and the role of dyadic coping at very advanced stages of disease is not clear. As patients become weaker and caregivers
increasingly burdened, the need for communication and patients’ ability to engage in dyadic coping may change and the wish to protect one another, particularly from death-related fears, increase. Further, caregivers may already begin adapting emotionally to their loss. Ultimately, the relationship will cease in its current form. Studies are needed to clarify the changes that may occur in dyadic coping during the end of life.

Conclusion

Clinical implications

Our results indicate that dyadic delivery and focus of an intervention may affect aspects of dyadic coping, even without including specific skills training, and that effects might differ across dyad types. This suggests that clinicians delivering talk-interventions involving both patients and caregivers should keep in mind the potential effect on patients’ and caregivers’ communication and coping outside the clinical encounters.

Study limitations

Our study has certain limitations. The DCI was developed for healthy couples but has been used in e.g. couples coping with breast cancer and hematological cancer, and (in a previous version) in dyads with metastatic breast cancer. We adapted the common coping scale to cover behaviors not exclusive to romantic couples but representative of the same underlying concepts; however, the validity of the DCI in non-spouse dyads is unknown. Further, although appraisal of stressors is included in the STM, it is not assessed in the DCI, and we do not know whether appraisal was affected by the intervention. The lack of mediation effects may be due to the specific aspects of dyadic coping measured. While a study using the DCI in a Danish sample found that common coping significantly predicted decreased depressive symptoms in patients with breast cancer and their partners, other aspects of dyadic coping not measured in our study, such as ambivalent or hostile coping, may be more closely related to anxiety and depression. Participants were recruited without considering their relationship to caregivers, which resulted in a majority of couple-dyads and limited statistical power to detect effects and include covariates in analyses of parent–child dyads.
both mediation and moderation analyses were planned post hoc, results should be interpreted with caution, as findings might be due to chance. Dyads reported high relationship quality at baseline, and our findings may not generalize to dyads in distressed relationships.

The Domus intervention had significant effects on aspects of dyadic coping among subgroups of dyads. Dyadic coping did not mediate previously found significant decreases in caregivers’ symptoms of anxiety and depression. To the best of our knowledge, this study represents the first attempt to assess effects of SPC on dyadic coping and to investigate effect moderators for caregivers in a trial of SPC. Our results indicate that psychological interventions with a dyadic format integrated in SPC may affect stress communication and common coping, but that other aspects of dyadic coping not investigated here, may mediate effects on caregivers’ symptoms of anxiety and depression.

Acknowledgements

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Conflict of interest

The authors report no conflicts of interest.
References


Table 1. Estimated differences and 95% CI for the effect of the Domus intervention on outcomes for patient–caregiver dyads

<table>
<thead>
<tr>
<th></th>
<th>Overall effect</th>
<th>Subgroup effect</th>
<th></th>
<th></th>
<th></th>
<th>P for interaction between intervention and dyad type</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Estimated difference (95% CI)</td>
<td>Estimated difference (95% CI)</td>
<td>Estimated difference (95% CI)</td>
<td>Estimated difference (95% CI)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Common coping†</td>
<td>n=243</td>
<td>n=191</td>
<td>n=32</td>
<td>n=20</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>0.4 (-0.1; 0.9)</td>
<td><strong>0.68 (0.11; 1.24)</strong></td>
<td>-1.16 (-2.73; 0.41)</td>
<td>-0.18 (-2.06; 1.71)</td>
<td>0.0833</td>
<td></td>
</tr>
<tr>
<td>Stress communication‡</td>
<td>n=245</td>
<td>n=193</td>
<td>n=32</td>
<td>n=20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>0.66 (-0.04, 1.36)</td>
<td><strong>0.97 (0.24; 1.71)</strong></td>
<td>-1.53 (-3.18; 0.12)</td>
<td>0.29 (-1.63; 2.22)</td>
<td>0.0142</td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>-0.38 (-1.08; 0.32)</td>
<td>-0.04 (-0.78; 0.70)</td>
<td><strong>-2.54 (-4.19; -0.90)</strong></td>
<td>-0.72 (-2.64; 1.20)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

† adjusted for dyad member, baseline coping*dyad member, baseline relationship quality, age, gender, follow-up assessment
‡ Included interaction between dyad member and randomization group. Adjusted for dyad member, baseline communication*dyad member, baseline relationship quality*dyad member, age, gender, follow-up assessment
Table 2. Direct and indirect intervention effects on caregivers’ anxiety and depression at 6 months, mediated by dyadic measures at 8 weeks

<table>
<thead>
<tr>
<th></th>
<th>Couple dyads, n = 195</th>
<th>Parent-child dyads, n = 9-32</th>
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<tbody>
<tr>
<td></td>
<td>Common coping</td>
<td>Stress communication</td>
</tr>
<tr>
<td></td>
<td>Estimate (96% CI)</td>
<td>Estimate (96% CI)</td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct effect</td>
<td>-0.26 (-0.50, -0.03)</td>
<td>-0.28 (-0.52, -0.04)</td>
</tr>
<tr>
<td>Caregiver report</td>
<td>-0.02 (-1.02, 0.99)</td>
<td>0.36 (-0.01, 0.73)</td>
</tr>
<tr>
<td>Patient report</td>
<td>-0.01 (-0.04; 0.02)</td>
<td>-0.02 (-0.06, 0.02)</td>
</tr>
<tr>
<td>Indirect effect</td>
<td>-0.01 (-0.04; 0.02)</td>
<td>-0.02 (-0.06, 0.02)</td>
</tr>
<tr>
<td></td>
<td>-0.03 (-0.16, 0.09)</td>
<td>-0.15 (-0.42, 0.12)</td>
</tr>
<tr>
<td>Depression</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct effect</td>
<td>-0.11 (-0.32, 0.11)</td>
<td>-0.16 (-0.39, 0.06)</td>
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<tr>
<td>Caregiver report</td>
<td>-0.30 (-1.33, 0.73)</td>
<td>0.30 (-0.22, 0.82)</td>
</tr>
<tr>
<td>Patient report</td>
<td>-0.01 (-0.04, 0.02)</td>
<td>-0.01 (-0.04, 0.02)</td>
</tr>
<tr>
<td>Indirect effect</td>
<td>0.01 (-0.09, 0.11)</td>
<td>-0.17 (-0.44, 0.10)</td>
</tr>
</tbody>
</table>

† Based on 12 dyads, ‡ Only nine dyads available for analyses at 6 months, therefore these are at 8 weeks.
Figure 1. Direct and indirect intervention effects on symptoms of anxiety in caregivers in couples at 6 months, mediated by caregivers’ report of common coping at 8 weeks. Final model after adjustment based on modification indices.

Path A corresponds to the direct effect of the intervention, the product of paths B and C to the indirect effect mediated by common coping. Remaining paths show the influence of variables adjusted for in the model.

Footnote: Path A corresponds to the direct effect of the intervention, the product of paths B and C to the indirect effect mediated by common coping. Remaining paths show the influence of variables adjusted for in the model.