



Published in final edited form as:

*Semin Oncol Nurs.* 2019 August ; 35(4): 337–341. doi:10.1016/j.soncn.2019.06.004.

## Dyadic Interventions for Cancer Survivors and Caregivers: State of the Science and New Directions

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### Abstract

**Objectives:** To describe caregiving and relationship challenges in cancer and the state of the science of dyadic interventions that target survivors and caregivers.

**Data Sources:** Narrative review.

**Conclusion:** Viewing the survivor-caregiver dyad as the unit of care may improve multiple aspects of survivor and caregiver quality of life. However, several questions remain regarding how, why, and for whom dyadic interventions are effective.

**Implications for Nursing Practice:** Nurses should consider survivor, caregiver, and relationship needs when formulating supportive care protocols. Screening for survivor distress and extending distress screening to caregivers is an important first step in providing comprehensive psychosocial care.

### Keywords

survivors; caregivers; dyadic interventions; psychological distress; quality of life; couples

A cancer survivor is a person diagnosed with cancer, current or past, who is still living.<sup>1</sup> Thanks to an aging population and improvements in cancer screening, detection, and treatment, the number of cancer survivors in the US is now over 15.5 million.<sup>2</sup> Survivors have complex unmet psychosocial, physical, and behavioral needs that the health care system is struggling to address.<sup>1,3,4</sup> For example, cancer survivors experience higher rates of psychological distress (ie, depression and anxiety symptoms) than the general population.<sup>5</sup> This is problematic because increased psychiatric morbidity is related to treatment nonadherence,<sup>6–8</sup> hospital readmissions,<sup>9</sup> and poorer subjective quality of life.<sup>10</sup> Cancer survivors must also deal with debilitating and sometimes disfiguring side effects of treatment, progressive functional disability/risk of recurrence, and financial problems.<sup>11</sup>

Hundreds of evidence-based interventions have been developed to reduce survivor distress, enhance positive coping and quality of life, and improve health behaviors. For the most part,

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these interventions have had low to moderate effects.<sup>12–14</sup> One possibility is that programs that solely target survivors fail to consider that problems with the survivor (eg, distress, lack of adherence to self-care recommendations) could be driven by unexamined factors in their caregivers – who are often responsible for providing symptom management, emotional support, and support with rehabilitation in the outpatient oncology setting.<sup>15</sup> Caregivers are individuals (eg, spouses/partners, family members, neighbors, close friends) who provide care that is typically uncompensated and usually at home, involves significant amounts of time and energy for an extended period of time, and requires the performance of tasks that may be physically, emotionally, socially, or financially demanding.<sup>16</sup> Caregivers play a critical role in cancer care, but they also experience high psychological distress rates, lack basic health care knowledge and skills, and report increased tension and power struggles with both survivors and the health care team.<sup>17–19</sup>

Dyadic interventions hold great promise in cancer because they can simultaneously address survivor, caregiver, and relationship factors that hinder effective symptom management, caregiving, and rehabilitation.<sup>20</sup> This review describes the state of the science of dyadic interventions that target survivors and caregivers. It will also highlight opportunities and new directions for this burgeoning field as well as implications for nursing practice.

## Caregiving and Relationship Challenges across the Cancer Continuum

Caregivers play different roles across the cancer trajectory. For example, following diagnosis, they are actively involved in treatment decisions either through active participation in informed decision-making or supporting survivor preferences.<sup>21,22</sup> During cancer treatment (see Table 1), caregivers provide emotional (eg, expressing empathy, validating feelings) and instrumental support (eg, symptom management, helping with errands, household tasks, transportation, and finances). Likewise, after survivors have been definitively treated, caregivers provide assistance with rehabilitation, assist with surveillance, and encourage healthy lifestyle behavioral changes to decrease the risk of second cancers and other chronic diseases.<sup>23–25</sup>

Even though caregivers play a critical role in health care, they experience numerous challenges that can adversely affect their health and well-being as well as that of the survivor. For example, as the primary setting for care has shifted from hospital to home, caregivers have found themselves in the position of replacing skilled health care workers in the delivery of care.<sup>26</sup> Their role has also changed dramatically from promoting convalescence to undertaking complex care tasks (eg, symptom assessment/management, hygiene care, and medication administration) and engaging in care coordination.<sup>27,28</sup> The time-consuming tasks that caregivers perform may disrupt their own self-care practices.<sup>29</sup> A significant proportion of cancer caregivers report low engagement in all forms of self-care<sup>30</sup>; 50% are below population norms on physical health,<sup>31</sup> and they experience problems such as fatigue, weight loss, burn out, social isolation, and general deterioration in health as a result of their caring role.<sup>32</sup> Caregivers with lower engagement in self-care also have lower preparedness and decision-making self-efficacy.<sup>30</sup> Another challenge that caregivers experience is lack of training and support. Many leave the hospital with a lack of confidence in their ability to perform complex care tasks (eg, how to use and care for stomal appliances,

recognize infection, catheterize the survivor).<sup>33,34</sup> The increasing demands placed on caregivers combined with the lack of training and support may not only contribute to caregiver strain and burden but also adversely affect their ability to care for the survivor.

Survivor-caregiver relationships can be a tremendous resource, but these relationships are challenged and tested at each juncture along the cancer continuum. In the weeks following diagnosis, survivors and caregivers must start to negotiate changes in roles and responsibilities, deal with interference with life plans, and think about making changes to established patterns of managing household and child care responsibilities.<sup>35</sup> Survivors and caregivers also struggle with feelings of blame/self-blame regarding lifestyle behaviors (eg, smoking, drinking alcohol, obesity) that may have caused the cancer or with different paces or readiness to return to a normal life after cancer treatment.<sup>36,37</sup> If left unaddressed, such issues could adversely affect their relationship and contribute to both partners' distress.<sup>38</sup>

During cancer treatment, declines in physical functioning may interfere with household responsibilities and integrating cancer into the everyday routines can become increasingly demanding.<sup>39</sup> Given this, it is not surprising that some survivors and caregivers report that the cancer experience brought them closer together, and others experience significant adjustment difficulties that lead to feelings of decreased intimacy and greater interpersonal conflict.<sup>40</sup> In addition, survivors and caregivers experience communication challenges that can adversely affect coordination of care. Both partners may be reluctant to discuss fears and concerns in an effort to protect one another from distress.<sup>41,42</sup> Even well-meaning caregivers may not know how to effectively communicate with medical personnel<sup>43</sup> or try to assist the survivor in ways that are controlling or over-protective rather than supportive.<sup>44</sup> Caregivers can also engage in maladaptive communication (eg, criticism, nagging)<sup>45,46</sup> that can undermine survivor self-care and adversely affect survivor outcomes.<sup>47</sup> Increased caregiving responsibilities and treatment side effects can also alter sexual expression and increase tension between partners.<sup>48</sup> In fact, a survey study of men with prostate cancer and their wives found high rates of sexual dysfunction associated with cancer treatment. Greater sexual dissatisfaction was associated with poorer marital adjustment, particularly in the absence of constructive communication.<sup>49</sup> Declining functional abilities may bring about the necessity for survivors and caregivers to discuss how care and assistance with daily activities will be provided to the ill partner.<sup>50,51</sup> Survivors and caregivers also typically negotiate difficult choices regarding end-of-life treatments and care together, and cope with anticipatory grief.<sup>52,53</sup>

Finally, for survivors and caregivers who enter the post-treatment survivorship phase, the primary challenge is negotiating the transition to "normal" life—particularly in the case where partners may have different pace preferences.<sup>36</sup> For most, the main tasks include resuming a sexual relationship, discussing changes in life plans, discussing health behavior changes, dealing with disease and treatment-related late effects that may influence the survivor's functioning, managing worry about disease recurrence, and discussing the meaning of the cancer experience for themselves and the relationship.<sup>54,55</sup>

## Dyadic Interventions in Cancer: State of the Science

Given the growing acknowledgement that survivors, caregivers, and their relationships are profoundly affected by the cancer experience, there has been a growing emphasis on dyadic interventions that are offered to cancer survivors and their caregiver as the unit of care.<sup>20,56–58</sup> Although some dyadic interventions have had no explicit or implied theoretical framework, most have been framed using one of three models: 1) individual stress and coping theories, which view social support as a form of coping assistance<sup>59</sup> and posit that person-, social-, and illness-related factors influence how people appraise and cope with an illness; 2) resource theories, which view the partner and relationship as resources survivors can draw upon for assistance during difficult life events<sup>60,61</sup>; and 3) dyadic models, which focus on joint problem-solving, coordinating everyday demands, and approaching cancer together as a team.<sup>40,62–64</sup> Regardless of theoretical perspective, dyadic interventions often include psychoeducational and skills training components (eg, information about cancer and caregiving, self-care/self-management skills, stress management, training regarding caregiving tasks, and/or relationship-enhancement skills including communication skills training and dyadic coping).<sup>20,56</sup> Therapeutic techniques that have been used include cognitive behavior therapy, education, interpersonal counseling, behavioral marital therapy, and emotion-focused therapy<sup>20</sup>; most interventions have been delivered by a nurse or specialist health care provider, such as a behavioral therapist, psychologist, or mental health professional.<sup>20,56,65</sup>

Recent meta-analyses<sup>20,56</sup> have shown that dyadic intervention delivery formats have been relatively evenly divided between in-person visits (eg, either interventionists come to participants' homes or participants go to a clinic/hospital to receive the intervention), telephone contact, or a combination of both. Few studies have involved group formats, video-conferencing, or Web-based approaches.<sup>66,67</sup> The vast majority of interventions have also included print materials, such as instructional manuals or booklets; however, some have also included audio/video materials to reinforce skills taught. Most have involved six sessions; however, the number of sessions has ranged from one to 16,<sup>68,69</sup> and session length varies from 20 to 120 minutes.<sup>56</sup> In addition, most studies have compared dyadic intervention with a usual care or wait list control condition as opposed to an active control condition.<sup>56</sup>

For the most part, caregivers have been involved in dyadic interventions in one of two ways. The first method treats the caregiver as an assistant or “coach” to facilitate learning and coping skills in the survivor. This approach, sometimes described as “partner-assisted”<sup>70,71</sup> conceptualizes the role of the partner in the intervention as being supportive of the survivor.<sup>72</sup> The second method seeks to actively involve the caregiver by focusing on how the dyad functions together as a unit and addressing both partners' needs and concerns.<sup>20</sup> Future research efforts may thus benefit from determining whether there are particular survivor, caregiver, or dyad factors that might influence when it is more appropriate to conceptualize the partner's role as either supportive or active.

Overall, dyadic interventions targeting survivors and caregivers have had different effects depending on the outcome being examined. For example, small to moderate effects have

been observed for survivor and caregiver psychological functioning (eg, depression, anxiety, hopelessness, mental health).<sup>20,56</sup> Small to large effects on marital functioning have been observed for survivors,<sup>20,56</sup> but these effects may only be short-term in nature (ie, assessed at 3-month follow-up).<sup>56</sup> Effect sizes for marital functioning for caregiving partners have been small.<sup>20,56</sup> Likewise, small to moderate effects have been observed for survivor physical well-being, but this may be largely dependent on stage of cancer and it may be unrealistic to expect improvement in physical well-being in individuals who have metastatic disease. More work is needed to clarify the definition of clinically meaningful changes in the outcomes examined because even small effect sizes can still be clinically significant and important.

Meta-analyses have highlighted a number of methodologic limitations in the dyadic intervention literature.<sup>20,56</sup> For example, studies do not consistently state details of their randomization procedures, and because interventions are often delivered by trained nurses or psychologists, they often cannot be blinded. Some studies do not include information on refusal or attrition rates, suggesting reporting standards could improve. Studies do not always articulate a theoretical model and few have examined the mechanisms by which interventions affected outcomes, so there are questions as to whether the theoretical basis of the intervention is as hypothesized. A related issue is that most studies have focused on either spousal or family caregivers and have not examined differences in effects based on type of caregiver (eg, close friend, neighbor, adult child, spouse/partner).

To date, most dyadic intervention studies have had small sample sizes ( $N < 100$ ), which means they were likely underpowered to examine changes in the multiple outcomes that were measured. This could have contributed to the small to moderate effect sizes observed. At the same time, documented barriers for clinical trial participation, such as distance from the trial center, fear of randomization, and perceived burden, are only compounded when recruiting for dyadic studies because the survivor and caregiver both need to agree to participate. Incorporating strategies to reduce burden, such as approaching survivors and caregivers at routine clinic visits instead of at the time of diagnosis, scheduling study-related appointments with medical appointments, decreasing the number of sessions or assessments, and conducting sessions by phone, the Internet, or in participants' homes, may help to bolster enrollment and engagement. Likewise, having physicians or nurses introduce the study instead of research coordinators who may not have interacted previously with the survivor or caregiver may also be helpful.

## Future Directions

As this narrative review suggests, there is a robust and growing literature on dyadic processes in cancer and dyadic interventions for cancer survivors and their caregivers, and these interventions have demonstrated beneficial effects in terms of improving multiple aspects of survivor and caregiver quality of life. However, several scientific gaps remain regarding how, why, and for whom these interventions are effective, which can help drive future research (see Table 2).

First, more work is needed to identify individual and dyadic characteristics that either protect or increase the risk for poor survivor and caregiver outcomes to enhance our understanding of the role of dyadic relationships in cancer adaptation. For example, the vast majority of dyadic interventions have enrolled white, middle-class participants.<sup>20</sup> This ignores the possibility that culture may influence survivor and caregiver expectations and interactions, attributions about cancer cause and relationship with the health care team, and the centrality or importance of the survivor-caregiver relationship in cancer adaptation. To date, very few studies have investigated the cancer experience of racial/ethnic minority survivors and caregivers, despite the fact that studies suggest that cultural differences do exist around gender roles, family boundaries, and perceptions of personal control and interdependence.<sup>73</sup> In addition, survivors and caregivers at different stages of the life cycle may experience different stressors and therefore have different expectations regarding not only social support but also interaction with one another and with the health care team. There also needs to be greater recognition that relationships and roles change across the cancer continuum. Most studies have evaluated outcomes shortly after diagnosis, but very little is known about what happens as survivors and caregivers move into the survivorship phase and have to cope with the long-term side effects of cancer and its impact on their relationship and finances. Finally, individuals with low socioeconomic status have been woefully underrepresented in this literature. Socioeconomic status likely reflects who has access and ability to attend intervention programs. Thus, creating interventions that can be easily and widely disseminated is critical to advancing this field and providing equal access.

Second, the standard of efficacy for dyadic interventions has not been definitively established. Some interventions have demonstrated benefit for survivors and caregivers, whereas others have demonstrated benefit for either the survivor or caregiver. Given the time and resource-intensive nature of dyadic interventions, it is unclear whether benefit for only one partner is sufficient to justify dyadic intervention. Future research may benefit from an increased focus on couples' interactions to address ways that couples can adaptively cope together. More work is also needed to compare the effects of individual and dyadic interventions on survivor and caregiver outcomes.

Third, most dyadic interventions in cancer have included a communication skills training component because communication is an important process through which couples make sense of cancer, negotiate role changes, and coordinate coping responses. However, scholars still know very little about what they should instruct couples to talk about, how often they should talk, and when talking (or not talking) is beneficial (and for whom – the survivor, caregiver, or both).<sup>67</sup> In a study of naturalistic communication in advanced-cancer couples, Reblin et al<sup>74</sup> found that couples rarely engaged in communication about cancer or about their relationships, and that the majority of observed communication was logistical or social small-talk. The authors concluded that there appear to be few naturalistic cues encouraging couples to discuss potentially difficult topics, and that more work is needed to determine appropriate levels of communication. Couples' need for talk may also change across the illness trajectory, so refining the prescription for spousal communication in dyadic interventions is an important area for future research.

Finally, even though dyadic interventions have had many beneficial effects, they are seldom implemented in clinical practice settings. In an effort to inform implementation efforts, Ratcliff et al<sup>75</sup> conducted qualitative interviews with individuals representing different oncology stakeholder groups. Questions focused on existing support services, barriers to integrating dyadic and caregiving interventions in routine survivor care, and possible models for clinical uptake and dissemination. Findings suggested that researchers should evaluate intervention outcomes that are important to stakeholders, including cost/cost savings, health care utilization (eg, readmissions, emergency department visits), and clinical outcomes (eg, increased adherence, early detection of adverse events, survival) to translate effective interventions from research to practice. They also suggested that, given limited personnel and financial resources, more pragmatic trials are needed that allow for flexibility in the delivery of dyadic and family-based interventions. Emerging communication technologies (eg, Internet, mobile health, social media) may allow for more efficient delivery and widespread dissemination, but more research is needed to determine survivor and caregiver intervention preferences, whether factors such as advanced disease status, age, or comfort with technology affect receptivity and uptake, and whether such interventions are feasible and cost-effective. Studies evaluating the relative cost of different modes of administration (ie, in person, over the phone, Internet) are also needed.

## Implications for Nursing Practice

This review highlights several implications for nursing practice (see Table 3). First, nurses working with cancer survivors should consider the individual-level needs of the survivor and caregiver, as well as their relationship needs when formulating supportive care protocols. Second, more work is needed to identify and assess survivors who are at higher risk for developing psychological problems and caregivers who may be at increased risk for experiencing strain or burden as a result of their caregiving role so that appropriate interventions can be targeted to them. Finally, this review underscores the importance of screening for survivor distress and extending distress screening to caregivers as an important first step in providing comprehensive psychosocial care. In sum, there is mounting evidence to suggest that viewing the survivor-caregiver dyad as the unit of care may help to improve survivor and caregiver health and well-being.

## Acknowledgments

This research was supported by National Institutes of Health (grant no. R01CA187143 [to H. Badr]); and National Institutes of Health (grant no. P30CA125123).

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**Table 1.**

Caregiver's tasks.

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- Emotional support
- Symptom management, knowing when to seek medical advice
- Helping with errands
- Household tasks
- Transportation to and from appointments and tests
- Finances
- Rehabilitation
- Surveillance and monitoring
- Encourage healthy lifestyle behaviors

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**Table 2.**

## Future research areas.

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- Need to identify the individual and dyadic characteristics that either protect or increase the risk for poor survivor and caregiver outcomes
  - Studies need to include minorities: race, ethnicity, and religion
  - Studies need to include individuals with low socioeconomic status
  - Need dyadic studies of relationships other than husband/wife
  - Dyadic studies should examine various stages of the cancer trajectory, not just after diagnosis
  - A standard of efficacy for dyadic interventions needs to be established
  - Analysis of individual v dyadic interventions on survivor and caregiver outcomes are needed
  - The most beneficial way to instruct people to communicate needs to be studied based on varying dyad relationships and communication styles
  - Studies are needed to determine why dyadic interventions are seldom implemented in clinical practice settings and what can be done to overcome the barriers
  - Trials are needed that test for flexibility in the delivery of dyadic interventions; Internet, mobile health, and social media to allow for efficient delivery and widespread dissemination

Studies are needed to evaluate the cost of different modes of administration (ie, in person, over the phone, Internet)

**Table 3.**

## Patient/survivor and caregiver assessments.

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- Include the caregiver in the care plan and assess their abilities and capacity because their health/knowledge and skills can negatively impact the cancer patient/survivor
  - Assess the survivor and caregiver's relationship and how it may affect the care plan
  - Assess survivors to determine if they are at a risk for developing long-term psychological problems. If they are at risk, target interventions to help them
  - Assess caregivers to determine if they are at risk for strain, burden, or distress. If they are, target interventions to help them

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