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# A Couple-Based Communication Intervention for Hematopoietic Cell Transplantation Survivors and Their Caregiving Partners: Feasibility, Acceptability, and Change in Process Measures

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### A B S T R A C T

Hematopoietic cell transplantation (HCT) poses significant challenges for recipients and their caregiving partners. Couples may refrain from talking about treatment-related fears and concerns to minimize distress. This single-group, pre-post study examined feasibility and acceptability of an intervention designed to optimize communication between HCT patients and partners; it also assessed change in process measures. Couples met with a therapist 5 times to learn skills for disclosing illness-related thoughts and feelings and responding supportively to one another. The extent to which participants disclosed thoughts, feelings, and information during the session and felt supported was assessed at the close of each session. Forty of 89 eligible couples consented (45%). Thirty couples commenced intervention 1-month post-transplant; 26 of these completed all sessions (87%) and 27 completed follow-up (90%). Ratings of self-disclosure and feeling supported by one's partner increased linearly across intervention sessions among both patients and caregivers (all  $P \geq .01$ ). Ratings of satisfaction with the intervention were high. HCT couples can be recruited and retained for this intervention. They found it acceptable and were amenable to skills training. A randomized trial is needed to test efficacy and to identify moderators of treatment response.

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### INTRODUCTION

Cancer and its treatment impact not just patients but also significant others. For married or partnered patients, the spouse/partner is typically the primary caregiver and most important confidante [1]. Effective communication, specifically the ability to express illness-related thoughts and feelings to one's partner and to feel understood, is central to the functioning of both individuals and the couple as a whole [2]. Indeed, several studies have demonstrated that open, supportive discussions about cancer-related concerns (those characterized by self-disclosure and partner responsiveness) are adaptive [3–6], whereas interactions characterized by avoidance and nondisclosure are maladaptive [7–12]. For example, “holding back” from sharing cancer-related

concerns has been associated with increased psychological distress among patients [11,13] and partners [10,13]. Similarly, protective buffering, or “hiding one's concerns, denying one's worries, concealing discouraging information... and yielding in order to avoid disagreement” [8], has been associated with increased psychological distress and decreased relationship satisfaction among patients and partners [8,9,14–16]. Although most findings are intrapersonal (linking an individual's self-reported buffering of his or her partner to his or her own adjustment), some are interpersonal (linking the individual's self-reported buffering of his or her partner to the partner's adjustment) [8,16]. Findings from cancer-specific research closely parallel those from the social psychological literature on emotional suppression, or “conscious inhibition of emotional expressive behavior while emotionally aroused” [17]. Recent meta-analytic findings indicate that emotional suppression has both personal and relational costs, ranging from depressed mood and lowered self-esteem to feeling less accepted by one's partner [18]. In contrast, emotional expression confers benefits: greater

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relatedness (connectedness) and greater relationship satisfaction [18].

Although it may seem unlikely, patterns of avoidance and nondisclosure *can* emerge, even in otherwise well-adjusted relationships. Erroneous beliefs about the need to stay cheerful and not bring up reminders of the cancer can lead to avoidance [19]. There is also fear of saying or doing the wrong thing or causing harm [19]. In addition, sensitive issues such as sexual functioning or disease progression and death are often avoided versus addressed [12,20]. Accordingly, the need exists to intervene with couples to provide psychoeducation about these communication patterns and training in effective disclosing and responding. Porter et al. [21] designed and tested such an intervention. In their study patients with gastrointestinal cancer were encouraged and trained to disclose their illness-related thoughts and feelings to their partners. The intervention was termed “partner-assisted” because partners were encouraged to play a supportive role. In this sense the intervention involved both patients and partners, but only patients were targeted. Although effective in improving marital quality relative to an attention control condition, the intervention was arguably 1-sided in that partners were not given opportunities to disclose and patients were not trained in supportive listening. In the present study we adapted the protocol developed by Porter et al. [21] to include disclosure and supportive listening for *both* dyad members, potentially increasing the intervention's efficacy. We also adapted the timing and dose of the intervention for couples facing hematopoietic cell transplantation (HCT), 1 of the most aggressive forms of cancer treatment requiring high levels of partner involvement and entailing a prolonged recovery time.

Used to treat hematologic malignancies and other blood disorders, HCT entails administration of high-dose chemotherapy, sometimes in combination with total body irradiation, followed by infusion of healthy stem cells. Complete immune recovery, often taking many months, requires social isolation to protect against infections and a complex medication regimen for disease prophylaxis and symptom control. Early and late medical sequelae are well established and include acute and chronic graft-versus-host disease (GVHD), pulmonary complications, neurologic complications, infection, infertility, secondary malignancy, disease recurrence, and even death [22]. Psychosocial sequelae include anxiety, depression, fatigue, sleep difficulties, sexual dysfunction, and employment disruption [22-24].

Family caregivers and significant others are also greatly affected by the HCT process. Families must relocate to a transplant center for an extended period, and partners are faced with intensive caregiving responsibilities involving the provision of instrumental and emotional support. For example, caregivers must manage the patient's many medications, monitor and change dressings on the patient's central line, and comply with strict food safety and household cleanliness guidelines. Like patients, caregivers report psychosocial impacts. Qualitative and quantitative research reveals recurrent themes for caregivers: uncertainty, depression, guilt, loneliness, role changes, fatigue, sleep and sexual problems, and financial concerns associated with medical and housing costs [25-27]. Spouses of HCT patients report elevated levels of depression and anxiety relative to their survivor counterparts and nonmedical control subjects [28]. They also report lower levels of marital satisfaction, social support, and spiritual well-being and higher levels of loneliness [25,28]. Furthermore, HCT patients and partners engage in protective buffering [9,15], and such behavior is associ-

ated with decreased relationship satisfaction and decreased mental health [9]. This collective body of research suggests that HCT patients and partners experience stress and negative affect but may not express such. Accordingly, they may benefit from structured opportunities to disclose their HCT-related concerns and receive validation and understanding from one another.

The present study were three-fold. First, we sought to examine feasibility of a couple-based communication intervention adapted for HCT patients and partners, specifically, feasibility of recruitment, retention, and assessment. Would patients and partners agree to participate? Among those commencing intervention, what proportion would complete all intervention sessions, and what proportion would complete follow-up assessments? Second, we sought to determine acceptability of the intervention. Would patients and partners perceive the intervention as useful, want to recommend it to others, and report satisfaction with services received? Third, we sought to examine change over time in process variables (ie, our key intervention target, communication). We hypothesized that by building disclosure and responsive listening skills, these skills would improve across the intervention period.

## METHODS

### Participants

Participants were identified and recruited from the Seattle Cancer Care Alliance, an alliance of the University of Washington and the Fred Hutchinson Cancer Research Center. Inclusion criteria for patients were age 21 or greater; married or in a committed, cohabiting relationship; planning to receive an allogeneic, myeloablative or nonmyeloablative bone marrow or peripheral blood stem cell transplant; and ability to speak and comprehend English. Patients planning to receive an autologous transplant were excluded because of their dramatically different hospitalization, discharge, and recovery trajectories. Inclusion criteria for partners were age 21 or greater, ability to speak and comprehend English, and intended presence at the transplant site during the intervention period.

### Design and Procedure

The study used a quasi-experimental, single-group, pretest/post-test design. Patients and partners were enrolled and assessed before transplant (T1). Initial screening was conducted via medical records to identify incoming allogeneic HCT patients and rule out anyone listed as refusing to participate in research. Incoming patients meeting these initial criteria were approached by phone or in the transplant clinic, at which point further eligibility criteria were determined and partners were approached. The study purpose, procedures, risks, and benefits were described in detail, and it was made clear to patients and caregivers that given the couple-based nature of the study, both parties needed to independently consent. If 1 party was interested but the other was not, that was their right and perfectly acceptable.

The intervention commenced 1 month post-transplant. Because a month elapsed between the initial baseline assessment (T1) and intervention, we conducted a second baseline assessment just before the first intervention session (T2). A follow-up assessment (T3) was administered 1 week after the last intervention session. All study procedures were approved by the Institutional Review Board of the University of Washington. Because the present article focuses on feasibility, acceptability, and change in process measures during the intervention, we do not present pre- and postintervention data. We do, however, present data on assessment *completion*, an important component of feasibility.

### Intervention

The intervention, adapted from Porter et al. [21], was designed to deliver psychoeducation regarding typical couple interaction patterns that commonly occur in the context of cancer and its treatment (including holding back and protective buffering) and to teach effective tools for communication in a supportive framework. As noted previously, the intervention was originally designed and tested with patients with gastrointestinal cancer and their partners but was adapted for the HCT population in this study with examples and practice situations relevant to the experience of HCT. The rationale provided noted the importance of communication processes in all close relationships but emphasized the particular challenges faced by couples when 1 partner is undergoing cancer treatment, especially a difficult treat-

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