

A preliminary study to develop an intervention to facilitate communication between couples in advanced cancer

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ABSTRACT

Objective: Psychosocial interventions directed to couples where one has advanced cancer can reduce distress, enhance communication, and provide an opportunity for relational growth. The present study aimed to develop an intervention to facilitate communication about living with advanced cancer using the Patient Dignity Inventory (PDI) as the focus of a clinical interview with couples toward the end of life.

Method: Couples were recruited from oncology and palliative care services at a Sydney hospital. After the PDI was developed and manualized as an intervention for couples, the PDI–Couple Interview (PDI–CI) was delivered by a clinical psychologist and comprised the following: (1) the patient completed the PDI; (2) the patient’s identified partner completed the PDI about how they thought the patient was feeling; and (3) the clinician reviewed the results with the couple, summarizing areas of concurrence and discordance and facilitating discussion.

Results: Some 34 couples were referred, of which 12 consented, 9 of whom completed the clinical interview. Reported benefits included enabling couples to express their concerns together, identifying differences in understanding, and giving “permission to speak” with each other. The focus of the interview around the PDI provided a structure that was particularly acceptable for men. Most couples confirmed that they were “on the same page,” and where differences were identified, it provided a forum for discussion and a mutual understanding of the challenges in managing advanced cancer within a supportive context.

Significance of Results: Participant couples’ experiences of the PDI–CI provide valuable insight into the benefits of this intervention. This preliminary study indicates that the intervention is a relatively simple means of enhancing closer communication and connection between couples where one has advanced cancer and may be an important adjunct in helping prepare couples for the challenges inherent toward the end of life. Further investigation of feasibility with a larger sample is recommended.

KEYWORDS: Couple communication, Advanced cancer, Patient dignity inventory, Intervention

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INTRODUCTION

There is growing acknowledgment of the importance of research into interventions focusing on the psychosocial needs of family caregivers of cancer patients (Northouse et al., 2010; Candy et al., 2011; Song et al., 2012; Badr & Krebs, 2013; Waldron et al., 2013). The progression of cancer impacts both quality of life and relationships as the burdens of care increase (McLean & Jones, 2007). The end-of-life period may be particularly stressful for caregivers of those with advanced disease, who are reported to suffer the poorest quality of life (Northouse et al., 2007; Waldron et al., 2013). While all informal caregivers of patients with cancer may need support, there is recognition that spouses often provide all aspects of care and thus are often identified by patients as their most important source of support (Badr & Krebs, 2013; Waldron et al., 2013).

Coping with cancer brings about particular challenges for couples, difficult conversations about plans for the future, and changes in prior roles and responsibilities, along with varying levels of adjustment as they respond to the increasing demands of the disease and ultimately to the death of one partner and bereavement of the other (Weitzner et al., 1999; Carlson et al., 2000; Steinglass, 2000). This can test a couple's usual communication pattern and can lead to a decrease in communication, increased uncertainty, and increased avoidance of talking about illness-related distress, leading to worse outcomes (Manne et al., 2006; Arden-Close et al., 2010; Song et al., 2012, Badr & Krebs, 2013). Thus, while the need to communicate increases for couples, communication often decreases over time after the diagnosis (Song et al., 2012). Relational aspects, including understanding the experiences of the person with cancer and the impact of cancer on the relationship of the person with cancer, are among the top-ranked unmet care needs of caregivers during the first two years post-diagnosis (Girgis et al., 2009; 2013).

Studies indicate that couples-based interventions at the end of life may ease a partner's worries, assist in bringing about better communication for both spouse and patient, identify gaps in communication about end-of-life issues, facilitate sharing of new understandings, reduce distress levels, provide an opportunity for relational growth, and help better prepare a partner for and ease the bereavement process, thereby reducing the potential for future complicated grief and mental health difficulties (Mohr et al., 2003; Murillo & Holland, 2004; McWilliams, 2004; Hodges et al., 2005; Northouse et al., 2007; Baik & Adams, 2011; Metzger & Grat, 2008). For caregivers in particular, interventions targeting problem-solving and communication skills may ease

the burden of care and improve quality of life (Waldron et al., 2013). A study in head and neck cancer suggested that disclosing cancer-related concerns enhances relationships and may assist in adjustment for both partners (Manne et al., 2012). Furthermore, a recent review indicated that couples-based interventions enhance psychosocial adjustment and are just as efficacious as patient- or caregiver-only interventions (Regan et al., 2013). Other reviews have indicated that studies in this area are still rare and that there is a need for clarification on the timing and duration required, as well as clearly focused intervention contents for couples facing cancer, particularly near the end of life (McLean & Jones, 2007; Baik & Adams, 2011).

Aims

Our single-site preliminary study had the following aims: (1) to develop and utilize the Patient Dignity Inventory Couple Interview (PDI-CI) to promote shared patient and partner communication in meeting the challenges of disease progression, and ultimately facing the end of life, (2) to develop a manual for the intervention to provide a standardized approach, (3) to test the feasibility of the intervention with referred couples, and (4) to generate data on the acceptability of the intervention prior to moving on to a larger randomized control trial.

METHODS

The idea for the current study came from research that determined how psychosocial oncology professionals (e.g., social workers, psychologists, psychiatrists) would use the PDI within their practice and what utility it might have across the broad spectrum of cancer (Chochinov et al., 2012). Some 90 participants utilized the PDI and reported that in 76% of instances the inventory revealed one or more previously unreported concerns, while in 81% of instances clinicians reported that the PDI facilitated their work (Chochinov et al., 2012). We therefore hypothesized that the PDI had the potential to be the basis for a psychosocial intervention to improve communication between patients and their partners by facilitating discussions regarding aspects related to advanced cancer in a supportive context.

The Intervention

The PDI-CI intervention is a one-off clinical interview that aims to improve communication around end-of-life issues for couples where one has advanced cancer. The Patient Dignity Inventory was developed from a model of dignity in the terminally ill that

emerged from qualitative studies identifying a broad range of issues that can be subsumed under the heading of “dignity-related distress” (Chochinov et al., 2002; 2005; 2006; 2008; 2009; 2012). To measure this distress, a 25-item PDI was developed and tested, with individual questions being written to correspond to specific dignity model themes and subthemes (Chochinov et al., 2006; 2008). Each PDI item is rated on a scale of 1 to 5 in order to indicate the degree to which the patient experiences various kinds of end-of-life distress—symptom distress, existential distress, or lack of social support. (1 = not a problem; 2 = a slight problem; 3 = a problem; 4 = a major problem; 5 = an overwhelming problem). Sample statements from the PDI include the following:

Feeling that how I look to others has changed significantly.
 Worrying about my future.
 Not being able to think clearly.
 Not feeling worthwhile or valued.
 Not being able to carry out important roles.

Feeling I have unfinished business.
 Feeling I am a burden to others.
 (see Table 1)

The psychometric properties of the PDI were tested in a sample of 253 patients, where it demonstrated good internal consistency, with a Cronbach’s alpha calculated to be 0.93, a test–retest reliability for the full PDI of $r = 0.85$, and individual variable test–retest reliabilities ranging from $r = 0.37$ to 0.76 (Chochinov et al., 2008).

The PDI–CI was manualized to provide a standardized approach. Input was sought from two clinical psychologists in developing the manual, with a step-by-step guide included. This guide provided a background to the purposes and aims of the study: evidence to support the use of the PDI and details of planned recruitment and data collection. Part 1 included information on assessment and orientation in using the PDI to enhance communication, and part 2 provided information on facilitating a discussion using the PDI, scoring, and sharing answers. Scenarios were given on how to introduce the PDI, how to

Table 1. *The Patient Dignity Inventory*

For each item, please indicate how much of a problem or concern these have been for you within the last few days. Example of scoring:

1	2	3	4	5
Not a Problem	A slight Problem	A problem	A major problem	An overwhelming problem
1. Not being able to carry out tasks associated with daily living (e.g., washing, getting dressed).				
2. Not being able to attend to bodily functions independently (e.g., needing assistance with toileting-related activities).				
3. Experiencing physically distressing symptoms (such as pain, shortness of breath, nausea).				
4. Feeling that how I look to others has changed significantly.				
5. Feeling depressed.				
6. Feeling anxious.				
7. Feeling uncertain about my health.				
8. Worrying about my future.				
9. Not being able to think clearly.				
10. Not being able to continue with my usual routines.				
11. Feeling like I am no longer who I was.				
12. Not feeling worthwhile or valued.				
13. Not being able to carry out important roles (e.g., spouse, parent).				
14. Feeling that life no longer has meaning or purpose.				
15. Feeling that I have not made a meaningful and/or lasting contribution in my life.				
16. Feeling I have “unfinished business” (e.g., things that I have yet to say or do; things that feel incomplete).				
17. Concern that my spiritual life is not meaningful.				
18. Feeling that I am a burden to others.				
19. Feeling that I don’t have control over my life.				
20. Feeling that care needs have reduced my privacy.				
21. Not feeling supported by my community of friends and family.				
22. Not feeling supported by my healthcare providers.				
23. Feeling like I am no longer able to mentally cope with challenges to my health.				
24. Not being able to accept the way things are.				
25. Not being treated with respect or understanding by others.				

Source: Chochinov et al. (2008).

facilitate discussion, and strategies for troubleshooting (e.g., one partner not wanting to talk about issues).

The intervention was designed to be delivered in a one-hour clinical interview that comprised the following steps: (1) the patient and their identified partner met with the psychosocial clinician; (2) the patient completed the PDI from their own perspective and rating each item; (3) the patient's identified partner completed the PDI as they perceived the patient would rate each item; (4) the psychosocial clinician reviewed the results, with the couple summarizing areas of concurrence and discordance; and (5) the clinician then facilitated a discussion with the couple, focusing on items on the PDI in which the patient and/or partner both scored ≥ 3 (an indicator that a particular area of distress was problematic), on areas of discordance between their scores, and on areas of concurrence. The clinician also discussed whether additional psychosocial follow-up was indicated.

Sample and Recruitment

This preliminary study was conducted at a major tertiary hospital in Sydney, New South Wales, Australia, and the PDI–CI was administered by an experienced clinical psychologist at the Cancer Care Centre. The study received institutional ethics approval. Potential patients were identified by five participating oncology/palliative care clinicians as physically and cognitively competent to participate and given a letter of invitation and a study information sheet. Eligibility criteria for patients included: being over 21 years of age, speaking English, having a clinician-diagnosed cancer and prognosis of 2–12 months, receiving ambulatory or outpatient care, and identifying a spouse/partner who resided with them.

The details on eligible patients (and their partners) expressing an interest were released (with permission) to the researcher, who then contacted them to discuss the study and answer questions. After verbal consent was obtained from the patient and partner, an appointment time was set for the couple to participate in taking the PDI–CI with the clinical psychologist. Consent forms, participant information sheets, and baseline questionnaires were mailed along with a stamped self-addressed envelope for reply.

Two weeks after the PDI–CI, couples were contacted to arrange a face-to-face semistructured interview with a research assistant in their home to assess the feasibility, acceptability, and utility of the PDI they had completed with the clinical psychologist. Consent was obtained from both couple members for the interview to be audiotaped and then tran-

scribed verbatim and analyzed. At week 8, couples were mailed the follow-up questionnaires with a stamped self-addressed envelope for return.

Measures

The sociodemographic information was obtained for all patients and partners at baseline assessment, including age, gender, ethnicity, education, employment history, and marital status. Patients and their partners also completed the Couples Illness Communication Scale (CICS), a self-report measure designed to provide insight into both patient and partner illness communication (Arden-Close et al., 2010), the Quality of Life Scale–QoL (Graham & Longman, 1987), and the Spielberger State–Trait Anxiety Inventory (Marteau & Bekker, 1992). Partners also completed the Caregiver Quality of Life Index–Cancer (CQoLC) (Weitzner et al., 1999). The post-intervention follow-up questionnaires included the CQoLC and CICS.

Post-Intervention Semistructured Interview

A semistructured interview held in the patient's home explored each couple's experience of the PDI–CI, including whether the intervention revealed new information, gave "permission to speak" about issues, allowed them to feel more connected, and elicited their reflections on the helpfulness, appropriateness, and acceptability of the PDI–CI. An interview was also conducted with the clinical psychologist involved in the delivery of the PDI–CI to retrospectively assess its usefulness, benefits, and drawbacks (if any) to their working practice when treating couples facing a diagnosis of advanced cancer.

Data Analysis

Descriptive statistics were employed to describe the demographic data. Statistical analyses of questionnaires were not undertaken due to the small sample size ($N = 9$ couples). Additionally, 4 of the 9 participating couples did not complete the follow-up questionnaire, despite having received reminders. Interview transcripts were analyzed using a constant comparative technique separately by two of the research team (JM and EL) to identify cogent themes (Corbin & Strauss, 2008). Broad themes were elucidated to determine within a qualitative framework the benefits or otherwise of the intervention from the standpoint of the participants.

RESULTS

Some 34 couples were referred, 12 of whom consented and 9 of whom completed the intervention and the

Table 2. Demographics of couples (N = 9)

Gender	
Male patient/female partner	4
Female patient/male partner	5
Total participants	18
Age	
Range	52–76
Mean	64
Education	
Year 10	7
Year 12	3
Technical & further (TAFE)	5
University	3
Employment	
Full-time	2
Part-time	2
Retired	11

follow-up interview with the research assistant, yielding a 25% response rate. There were four male patients with female partners and five female patients with male partners (see Table 2). The reasons for nonparticipation (when given) included: not being available at the time when psychology appointments were offered; time restraints due to work commitments; one member of a couple being interested but the other not; the patient being too sick or hospitalized; the study focus was not acceptable as a patient did not consider that their cancer was advanced or that they were at the end of life, so the study was not appropriate for them (despite a clinician-confirmed prognosis of 2–12 months); and another couple said it was too difficult to attend the hospital appointment with the clinical psychologist, though they would consider a home-based meeting. Issues regarding recruitment are further explored in the discussion of feasibility and limitations.

Overall, both patients and their partners found the PDI–CI to be useful and reported that they appreciated the opportunity to have a guided discussion focusing on their understanding of the issues facing the patient. For the most part, couples were satisfied with the length of the interview and that it was a one off deal, though one couple felt that an hour was not long enough. Couples reported a number of benefits of the PDI–CI, which are now described under the following themes.

Structure Allowed Men to Talk

Both men and women in couples expressed that the structure of the PDI–CI is particularly helpful for men to discuss issues. For example,

(. . .) because I'm not a great verbalizer, the questions are kind of a bit better and bit more [helpful]

for me to use. (. . .) Yeah, it's somewhere to go, it's somewhere to start. (couple 10b, male partner)

It was very good, for that I think— Yeah, because, because it was like doing exams. You put this little thing over there, and you went, no you're different there, you're different here and sort of (. . .) “are we?” You know, yeah. (. . .) Yeah, the questioning was well framed. (couple 2a, husband patient)

In a general conversation, [my husband] may not have come out and said that. He may have just kept quiet. (couple 9b, female partner)

Insight into Each Other's Feelings

A number of couples reported that the intervention highlighted areas of differences between them, which then facilitated clarifying communication at that time or subsequently:

As a couple, it's important to understand [that] the carer and the patient might look at things in a different way, and sometimes that doesn't help. (. . .) So it's good to sort of know. (couple 5b, male partner)

I can see the benefit from the questions in that we both have exactly the same [questions]. When you're having a chat, one might be leading the other in a conversation. (. . .) When you've actually got questions to focus on and then you compare each other's answers— It's quite revealing because you get to see which part that might be the other person's thinking when you didn't, you know. (. . .) Yeah. I did find that it was very— yeah, enlightening, really, to see what— what was really going on. (couple 9b, female partner)

Facilitated Changed Behavior Toward Each Other

Importantly, one couple expressed that discussing the questions on the PDI allowed the patient to acknowledge her deteriorating health and accept more help from her husband:

[The intervention] was to me an eye-opener, and what I answered then has actually— made me more aware. (. . .) I wasn't being realistic, which was making it more dangerous and more worrying for [him], so that to me was a big change. Yeah, that I had to be a bit more realistic about what I was doing and about how I was coping with it. (couple 12a, wife patient)

A patient in another couple noticed some changes in how her husband cared for her:

Yeah. [to husband] I noticed that you acted a bit differently after we'd done [the interview]. With some things that happened at home, you were a little bit more thoughtful, I thought, and I don't know whether it was because it was discussed there maybe. (couple 10a, wife patient)

The importance of the intervention in assisting in preparation for the end of life was also noted:

People do need time to perhaps resolve things, perhaps to explore their relationship a little bit more, and to make it better— not easier but better for both of you, right? Because you know (. . .) if the ending is a positive one, it makes it easier for the other to go on. (couple 2b, female partner)

Validated Communication

A number of couples felt that the intervention provided an enhancement of their already good communications, which elicited positive feelings:

We came away from that [interview], and we patted each other on the back. We felt, oh, the gold star, you know. (couple 11a, male patient)

There was nothing that we were markedly different on at all. (. . .) It made me feel good. It made me feel good. I think (. . .) it showed I listen. (couple 10b, male partner)

Eased Access to Counseling Services in the Future

More than half of the participating couples expressed a sense of reassurance that they could go back and see the psychologist:

Well, that's what [name] said to us, you know. Even though we saw [name] on that occasion, we can still go back and talk with her, you know. I said, well, had I not seen my other counselor, I probably would have done that [gone back to the clinical psychologist] (. . .) because I think it's harder on the carer, sometimes, because, yes, I can see what he's going through, but you don't know how they feel, really. (couple 6b, female partner)

Yeah, if we need her services, like she's always there. I mean if we (. . .) see her together or [the wife] wants to see her, or I want to see her by myself. (couple 1a, male patient)

Overall, most participants liked using the PDI–CI and found some benefit in discussing the similarities and differences in their answers with the clinical psychologist. However, one patient felt that the intervention was not particularly helpful, in that the psychologist did not initiate enough discussion of differences:

In fact, [I found it] quite confronting (. . .) Some of it I'm not quite sure was helpful or not (. . .) Some of the things that my husband had said and compared with what I had said surprised me (. . .) He seems to think that I'm unsure of myself and that I hadn't achieved enough in life, I never felt that. And I was quite upset about it (. . .) [There wasn't a lot of discussion] to resolve the whole thing. It— Well, it just sort of hung there, you know—the elephant in the room. (. . .) It probably cleared a few things up. On the whole, I don't really think it was deep enough. (couple 4a, female patient)

Feedback from the Clinical Psychologist

The clinical psychologist reported that the PDI–CI intervention worked as a standalone, one-off clinical interview, one that was straightforward and easy to administer:

I think [the PDI] asked some really good questions about loss of role and becoming more dependent, and I thought the questions were very meaningful and gave people the opportunity to talk about those issues. (. . .) I thought [using the PDI] was fantastic. It was essential. (. . .) I think it made the study much less scary for people as well.

The use of the manual along with the step-by-step guide complimented existing clinical skills to allow the psychologist to engage each couple in the intervention. Overall, an hour was sufficient for each couple, and it was not necessary to do a detailed history or genogram prior to moving to the intervention. Crucially, it was reported that from a clinical point of view the intervention was useful in assisting the couple to identify and talk about areas of difference between them and about issues related to physical and emotional care and dependence more easily than would have been the case without using the PDI. Further, the clinical psychologist felt that the PDI–CI could be delivered in a clinical setting by other health professionals (e.g., social workers, psychologists, or nurses), after receiving appropriate training, in order to support cancer patients.

DISCUSSION

The aims of this preliminary study—to operationalize and test the feasibility of the PDI–CI, an intervention using the Patient Dignity Inventory as the basis of a clinical interview with couples—were achieved. The PDI–CI is able to succinctly tap into both the patient and their partner’s perceptions of challenges related to patients’ advanced cancer.

In particular, identifying differing perceptions of physical and emotional issues for the patient on the PDI provided an accessible way for the couple to confirm each other’s understanding of how these issues were affecting the patient. Couples were then able to talk through and resolve these differences, if any, in their perceptions and, for some, then make behavioral changes—for example, accepting more help in day-to-day tasks from a partner (couple 12) or experiencing more thoughtful interactions (couple 11). Couples felt that the intervention helped men in particular to talk, as the structure of the questionnaire and the guided discussion gave permission for men to identify and respond to such issues. The couples in our study felt that the intervention enhanced their communication skills, which allowed for issues to be resolved and potentially drew couples closer together, something that most likely had a positive impact on their quality of life (Northouse et al., 2012a; Waldron et al., 2013).

While a one-off intervention is not expected to change longstanding communication patterns, couples felt that the intervention did assist them, and the follow-up interview some weeks post-intervention confirmed that this change had been sustained. Given that research in this area is relatively new, testing short interventions that may assist couples suffering the challenges of a terminal disease is an important activity (Hudson et al., 2010; Hudson & Payne, 2011). A randomized controlled trial comparing three brief information and support sessions (two 90-minute home visits and one 30-minute phone session) to six extensive sessions (four 90-minute home visits and two 30-minute phone sessions) with usual care found similar short-term benefits for both (Northouse et al., 2012b). At the same time, regardless of the length of the intervention, studies to date suggest that sustained effects may not be achieved, are limited or only occur for carers, and are often not measured (Northouse et al., 2007; Candy et al., 2011; Northouse et al., 2012b), and longitudinal studies are rare.

Clinical Implications

The finding of our study that the intervention was perceived as helpful is important. Perceptions of closer communication and connection may enhance a

couple’s own coping resources, and this intervention is a relatively simple means of providing an opportunity for such connection and may be an important adjunct in helping to prepare the couple for the challenges inherent in advanced cancer toward the end of life.

One of the challenges of working with couples is to ensure that those who experience disparities or difficulties in communication have a chance to resolve their difficulties. There was a suggestion from one participant that the disparities made evident during the session were not properly resolved, and this had left some residual distress for her. Thus, it is most important when dealing with both the manual and any training needs that the healthcare professional delivering the intervention allow enough time and focus the discussion on differences and similarities in a supportive manner that ensures that each person in the dyad is “heard.”

A further issue is determining which couples would most benefit from the intervention. Couples admitted into this study were not screened for initial distress or conflict; as such, it is less clear how couples with fractured communication or those in conflict would benefit. Targeting at-risk couples and identifying effective ways to help them is challenging for this and other couples studies in end-of-life cancer (Candy et al., 2011; Northouse et al., 2012b). Nevertheless, the PDI–CI may be useful as a starting point in identifying which couples would benefit from further assistance from clinically appropriate follow-up.

One of the gaps in the PDI–CI identified by one of our couples is a lack of questions about sex or sexuality, which they saw as a significant illness-related loss worthy of discussion. Milbury and Badr (2013) noted the lack of studies looking at sexuality at the end of life and further found in their study of women with metastatic breast cancer that the way a couple talked about cancer-related issues influenced the association between depression and sexual problems. Communication and intimacy are closely linked for couples, and it is worth considering how to explore this in future development and testing of the PDI–CI. For example, adding an exemplar “intimate partner” to question 12 “not being able to carry out important roles” (e.g., parent, spouse, intimate partner).

Feasibility

Notwithstanding the numerous inherent methodological difficulties in delivering well-designed, robust randomized controlled trials (RCTs) in psychological intervention studies (Ost, 2008), our preliminary study has identified specific challenges to couples interventions at the end of life. Low recruitment was an issue, with only 25% of referred couples completing

the inventory. While this is in line with other couples studies in cancer and particularly for communication-focused studies with couples, it remains a significant challenge for future trials of this intervention (Regan et al., 2013).

A challenge to recruitment arose from the language used in study documents. The title of the study on the documents initially included the words “end-of-life issues.” Feedback to the researcher from other referred couples, who declined consent, indicated that this wording was problematic. The partner wife in one couple who participated also felt “confronted” by the words “end-of-life” and “advanced cancer” in study documents, and, while poignantly noting that a previous experience of loss from cancer of her first husband meant that she would rather have this honesty in the research documents, she did feel that it may be too confronting for many couples. Once that terminology was removed, with approval from the ethics committee, and the study renamed “communication about advanced cancer,” the recruitment rate seemed to improve. Nevertheless, some referred couples indicated that they did not believe they fit the study criteria. It is important for future studies to balance the sensitivity of using such terms with the need to be ethically transparent about the purpose and aims of a study, a situation that mirrors the dilemma of physicians in discussing end-of-life issues with their patients.

Some of the physical barriers to recruitment found in this study are common to other studies and include accessibility, difficulty in securing appointments for a research study in a busy clinic, competing priorities with medical appointments and paid work, and increasing illness severity (Regan et al., 2013). The limited availability of appointment times with just one clinical psychologist and having to attend the hospital, in combination with the day-to-day demands on couples, were some of the major factors limiting recruitment. Assessment from the clinical psychologist indicated that this intervention can be delivered by clinicians from a range of health disciplines who are experienced in working with vulnerable populations after undertaking manual-based training.

An important consideration is that, while most couples in the study experienced benefit, not all may require communication facilitation. At the same time as addressing the barriers to recruitment uncovered by our study, including more appointment times from a broader range of professionals, nuanced language in both study documents and in introducing the study to participants, consideration of community-based as well as hospital-based delivery, and multiple recruitment sites would perhaps mean improved recruitment, making the intervention available to more couples.

CONCLUSION AND FUTURE DIRECTIONS

We have learned from this preliminary study that the majority of couples approached do not necessarily identify themselves in need of couples intervention. Importantly, for those who did participate, the intervention seemed to help, whether or not they were in distress and whether or not they shared similar perceptions regarding dignity-related distress. It may be that the language of a “couples intervention” is offputting to prospective participants. A future design needs to ensure that the study is not emphasised as an intervention for couples about communication problems. Rather, the focus should be to enroll patients and their significant others in a one-off structured counseling/support session (the PDI–CI) to allow them to identify and discuss areas of concern, thus enhancing mutual understanding and allowing gaps in understanding to be shared within a supportive environment. These aspects have been found to be important in enhancing relational growth and well-being by other investigators (Mohr et al., 2003; Murillo & Holland, 2004; Hodges et al., 2005). The innovative approach of the PDI–CI is a promising new addition to existing interventions that assist couples communication when one partner is facing the end of life. Further research is needed to test the feasibility and helpfulness of this intervention for patients and their partner or significant other in a larger, more representative sample. Consideration should also be given to testing the intervention in a patient-preference RCT, tailoring the intervention to couples’ expressed communication needs and testing to what extent the PDI–CI makes a difference on measures of communication, anxiety, and quality of life, among other domains.

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