

An explorative study of a new intervention for couples to facilitate communication around end of life issues



Investigators

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Background

- There is evidence of significant distress arising from the impact of terminal illness on relationships
- Providing specific assistance to couples at the end of life can
 - help identify gaps in communication about end-of-life issues
 - facilitate a sharing of new understandings,
 - provide opportunity for relational growth
 - result in a greater sense of well-being



Background

- Studies on pre-loss communication suggest that those who discuss aspects of death and dying with a loved one:
 - Maintain a more positive relationship with the individual.
 - Are able to adapt to their loss following the death better than individuals who do not discuss the impending death of their loved one.
- However, these interventions require a commitment of time and energy; not appropriate for this population because of the on-going and increasing demands of their disease.



Aims

- To evaluate the feasibility of developing a relatively simple intervention to facilitate communication about end-of-life issues and improve well-being for couples, using the Patient Dignity Inventory (PDI) as the focus of a 1 hour clinical interview.
- To operationalise and optimise the intervention, establish acceptability and confirm the suitability of outcome measures and inform final design of a future phase II trial.

Concept

- A study that determined how psychosocial oncology professionals (e.g. social workers, psychologists, psychiatrists) would use the PDI with their practice and what utility it might have across the broad spectrum of cancer (Chochinov et al., 2012).
- 90% participants used the PDI and reported that in 76% of instances the PDI revealed one or more previously unreported concerns; in 81% of instances, clinicians reported that the PDI facilitated their work (Chochinov et al., 2012).

Intervention

- The intervention uses the Patient Dignity Inventory, a 25-item self report instrument. (Chochinov et al 2008)
- Each PDI item is rated to indicate the degree to which the patient experiences various kinds of end-of-life distress such as symptom distress, existential distress or lack of social support.

Examples of PDI items

- 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 important roles
- Feeling I have “unfinished business”
- Not being treated with respect or understanding by others
- Feeling that care needs have reduced my privacy
- Feeling I have not made a meaningful contribution
- Feeling I am a burden to others

Design: Intervention

- The PDI protocol was delivered by a clinical psychologist to the patient and their identified partner and comprised of the following:
 - The patient completed the Patient Dignity Inventory (PDI);
 - The patient's partner completed the PDI as they perceive the patient is feeling; and
- The psychologist explored those items on the PDI in which the patient and/or partner scored ≥ 3 (an indicator that a particular area of distress is problematic), focussing on areas concurrence and discordance between them to assist communication and mutual understanding

Methodology

- Develop Manual for Intervention
- Train clinicians (n = 2)
- Pilot with couples (n = 9)
- Interviewed couples and clinician
- Provide feedback about its usefulness, benefits and drawbacks



Patient eligibility

- The patient must be at least 21 years of age;
- English speaking;
- Oncologist or palliative clinician's opinion that patient has a diagnosis of cancer and a life expectancy of 2-12 months
- Receiving ambulatory or out-patient care.
- Have partner (i.e. spouse or spouse equivalent).

Exclusion criteria

- Significant psychiatric disturbance e.g. presence of psychotic disorder or severe major depressive disorder
- Presence of cognitive impairment disorder, such as delirium or dementia
- Functional impairment such as hearing loss or speech deficit; or
- Physical limitations or illness severity (e.g. extreme fatigue) sufficient to preclude participation.

Study Measures: Patient

- Socio-demographics
- The Quality of Life Scale (QLS) (Graham & Longman 1987)
- Spielberger State-Trait Anxiety Inventory (Marteau & Bekker 1992)
- Beck Depression Inventory (Beck et al 1961, 1988)
- FACIT-PAL (Lyons et al 2009)
- Couples Illness Communication Scale (CICS) Arden-Close et al 2010)
- Interview

Study Measures: Partner

- Socio-demographic Questionnaire
- Caregiver Quality of Life (CQOLC) (Weitzner et al 1999)
- Spielberger State-Trait Anxiety Inventory (Marteau & Bekker 1992)
- Beck Depression Inventory (Beck et al 1961, 1988)
- Couples Illness Communication Scale (CICS) Arden-Close et al 2010)
- Interview

Results

- 34 couples were referred; 12 consented and 9 completed the clinical interview.
- The intervention was well-received by couples.
- Reported benefits included enabling couples to express their concerns together, identifying differences in understandings and giving 'permission to speak' with each other, particularly for men.
- Importantly it allowed the couple to be in control of the issues and be part of the resolution by enhancing mutual understanding of the challenges in managing advanced cancer in a supportive context.
- For the clinician the tool was helpful in facilitating these communications and provided a gateway for couples seeking further support.

Couples Illness Communication Scale

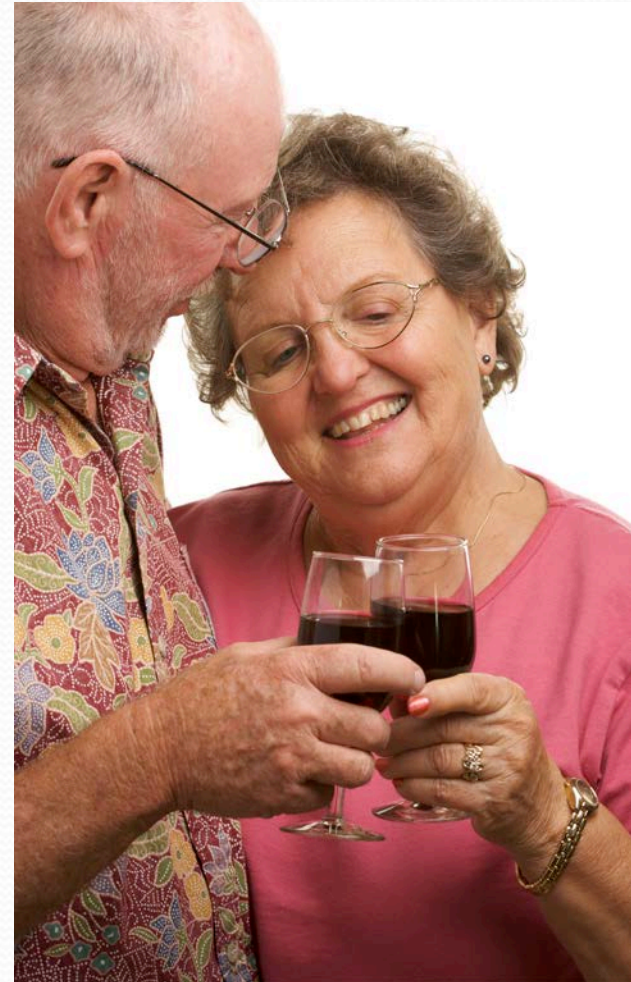
- It is hard for me to express feelings about my illness to my partner.
- I feel comfortable discussing issues related to my illness with my partner.
- My partner is reluctant to talk about my illness.
- My partner is willing to share his/her feelings about my illness with me.

Likert scale 1 – 4 disagree strongly – Agree strongly

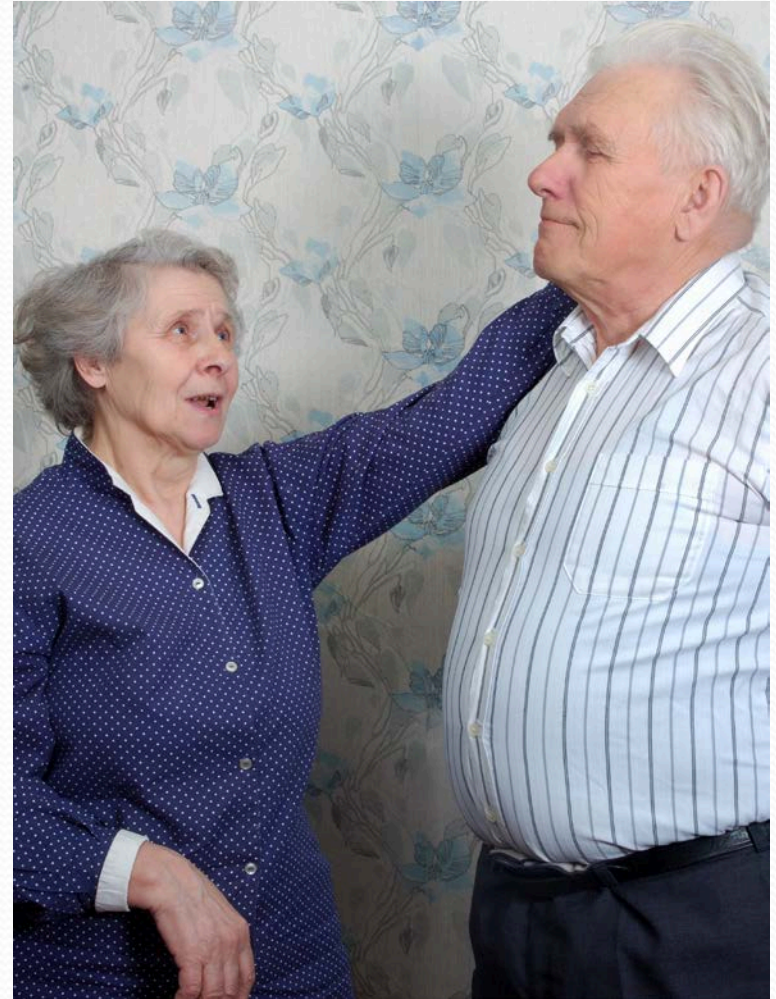
Communication (CICS) 5 couples (n = 10)

- The mean for responses to questions asking about *comfort in discussing issues and willingness to share feelings* increased from M 6.75 (sd 2.2) prior to the intervention to M 7.1 (sd 2.6) post intervention.
- *difficulties in expressing feelings and reluctance to talk* had decreased from M 5.4 (sd 2.2) before the intervention to M 3.8 (sd 1.3) after the intervention.
- This positive direction of the means points toward a potential improvement in communication as indicated by participant's perceptions on the CICS.

- For most couples the PDI confirmed that they were “*on the same page*” and where differences were identified it provided a forum for discussion and enhanced closeness.
- “*you know I don’t think we have an issue with communications although it’s a challenge for us but we work at it you know, and the fact that I think we’re on the same page with 99% of the stuff we do almost all the time is a testament to that...We came away from that (Interview) and we patted each other on the back, we felt oh the gold star you know*” (Couple 11)



- The focus of the interview around the Patient Dignity Inventory (PDI) provided a structure which was particularly acceptable for men.
- *“yeah I suppose for me because I’m not a great verbaliser the questions are kind of a bit better and bit more for me to use....Yeah, it’s somewhere to go, it’s somewhere to start”* (male partner Couple 10)



- Nearly all the couples felt the intervention benefitted by the skills of the clinical psychologist

“A very easy meeting. She was a very sensitive lady. I think it was good to speak – or have someone more or less point out issues that perhaps ...I hadn’t recognised (had) just taken for granted, yet once you start looking at the answers that were on the questionnaire, it was – yeah I found it very useful and she was very good and professional in the way she did it all, very sensitive I thought”.(009 female partner)

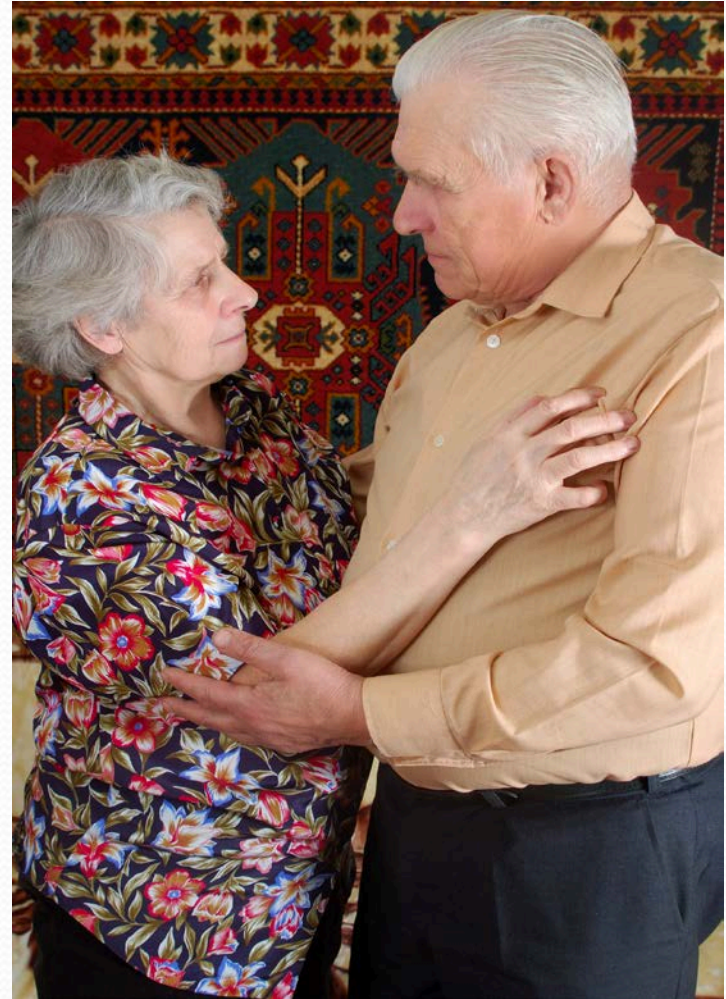


- A few couples noted that the intervention assisted in clarifying differences between them, actually changing awareness and behaviour- thus bringing them closer and assisting them in preparing for the future.

“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, do you know what I mean?” (couple 10)



- A patient in one couple felt that the intervention was not particularly helpful, in that the psychologist did not initiate enough discussion of differences
- *In fact quite confronting... Some of it I'm not quite sure was helpful or not...some of the things that [my husband said] had said and compared with what I had said, surprised mehe 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 4 wife)*



Feedback from clinician

- The intervention worked as a stand-alone, one off clinical interview; straight forward and easy to administer.
- Development of the manual including the step by step guide complimented existing clinical skills to allow the psychologist to engage each couple easily in the intervention.
- An hour was sufficient time for each couple and it was not necessary to do a detailed history or genogram prior to moving into the intervention.

Feedback from clinician

- 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.
- *“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 and it gave the - I think it made the study much less scary for people as well”.*

Feasibility

- Addressing the barriers to recruitment
 - 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 mean improved recruitment, making the intervention available for more couples

Feasibility

- Addressing the physical barriers
 - 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 the sole clinical psychologist and
 - Having to attend the hospital, in combination with the day to day demands on couples.

Conclusion

- It may be that couples who are already fairly close benefit from the intervention
- It is less clear that couples where communication is fractured or conflictual would benefit.
- It is not expected that any one off intervention can change a long standing pattern of communication in a couple.
- The manual and any training needs to allow time and to focus discussion on differences and similarities in a supportive way that ensures each person in the dyad is 'heard'.

Conclusion

- The majority of couples approached do not necessarily identify themselves in need of a couple intervention
- Those who did participate - the intervention seemed to help couples, whether or not they were in distress and whether or not they share similar perceptions regarding dignity related distress.
- It may be that the language of a “couples intervention” may be off putting to prospective participants.

Conclusion

- These preliminary findings suggest that a brief clinical interview has the potential to improve communication between couples.



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