

Couples Intervention: Promoting communication between patients and their partner

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Background

- The progression of cancer impacts on both quality of life and on relationships as the burden of care increases.
- Evidence of significant distress arising from the impact of terminal illness on relationships (McLean & Jones 2007)
- Brings about difficult conversations about plans for the future, changes in prior roles and responsibilities.
- Varying levels of adjustment as they respond to the increasing demands of the disease and ultimately to the death of one partner and the bereavement of the other.
- Coping with cancer can test the couple's usual communication pattern resulting in decreased communication, increased uncertainty and increased avoidance of talking about illness-related distress. (Carlson et al 2000; Manne & Badr 2010)

Background

- Patients identify their partner as their most important source of support (Pistrang & Barker 1998).
- However, may avoid discussing fears and concerns to protect the other person. (Hinton 1998)
- By avoidance spouses can harbor guilt, remorse and regret, leading to poorer bereavement outcomes. (Kuijer et al 2000).
- Providing specific assistance to couples at the end of life can help identify gaps in their communication about end-of-life issues (Badr & Krebs 2012)
- Facilitate a sharing of new understandings, provide an opportunity for relational growth and result in a greater sense of well-being. (Song et al 2012)

Bereavement outcomes and communication

- 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 better adapt to their loss following the death.
- Mohr et al 2003; Porter et al 2012; Northouse et al 2007; McWilliams 2004; Metzger & Grat 2008; Baik and Adams 2011.



Couple-based interventions

- Systematic Review shows:
 - Beneficial in improving couple communication, psychological distress and relationship functioning
 - Limited impact on physical distress and social adjustment
 - No evidence on efficacy of mode of delivery e.g. telephone, face-to-face
 - Couples uptake related to symptom severity, available time and willingness to travel
 - Most interventions delivered by Masters level nurses or clinical psychologists face-to-face (Regan et al 2012 BMC Cancer)

Barrier to couples interventions in palliative care

- Whilst Systematic Review showed couples based interventions are at least as good as patient-only or caregiver-only
 - Interventions require a commitment of time and energy which may not be appropriate for palliative care because of the on-going and increasing demands of their disease.



Pilot: Clinical interview

- 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.
- This model emerged from qualitative studies that identified a broad range of issues that can be subsumed under the heading of dignity related distress
- Chochinov et al. 2002, 2005, 2008, 2009

Patient Dignity Inventory (PDI)

- The Patient Dignity Inventory, is a 25-item self report instrument. (Chochinov et al 2008)
- The PDI addresses five areas:
 - Symptom Distress,
 - Existential Distress,
 - Dependency,
 - Peace of Mind, and
 - Social Support.
- Chochinov et al. The Patient Dignity Inventory: A Novel Way of Measuring Dignity-Related Distress in Palliative Care. *J Pain & Sympmt Mgt.* 2008;36(6):559 - 71.

Concept

- A study that determined how psychosocial oncology professionals (e.g. social workers, psychologists, psychiatrists) would use the PDI with their practice and what benefit it might have across the broad spectrum of cancer (Chochinov et al., 2012).
- 90% clinicians 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, H. M., McClement, S. E., Hack, T. F., et al (2012). The Patient Dignity Inventory: applications in the oncology setting. *Journal of Palliative Medicine, 15(9), 998-1005.* doi: 10.1089/jpm.2012.0066

Scoring

- 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

1	2	3	4	5
Not a Problem	A slight problem	A problem	A major problem	An overwhelming problem

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
- Feeling like I am no longer who I was

The pilot

- 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 clinician 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

Understanding each other

- 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 95% 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)



Not understanding each other

- 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 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 4 wife)



Acceptable to Australian men

- 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)



Clarify differences

- A few couples noted that the intervention assisted in clarifying differences between them, actually changing awareness and behaviour
- "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)



Skilled clinician

- Nearly all the couples felt the intervention benefitted by the skills of the clinical psychologist in facilitating discussion of similarities and differences in an enlightening, compassionate way

"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)



Clinician feedback

- 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".

Potential changes

- One of the gaps identified by one of the couples was the lack of questions about sexuality.
- 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 additional exemplar 'intimate partner' to question 12 'not being able to carry out important roles' (e.g. parent, spouse, intimate partner).

Challenges in the pilot

- Use of language
- Time to fit in between medical appointments
- Patients being unwell
- Reluctance to seek "psychological" help
- Potential for interview to be delivered by other health professionals

Clinician implementation

- The interview works as a stand-alone, one off clinical interview and was reported as straight forward and easy to administer.
- The manual includes a step by step guide and complements existing clinical skills to allow the clinician to engage each couple easily in the intervention .
- An hour is sufficient time for each couple and it is not necessary to do a detailed history or genogram prior to moving into the interview.

• Mowl, J., Lobb, EA, Lane, L., Lacey, J., Chochinov, HM, Kelly, B., Aggr, M., Links, M., Kearsley, JH, Brock, C., Lauw, W. A preliminary study to develop an intervention to facilitate communication between couples in advanced cancer. *Palliative & Supportive Care*. 2015 Published Online: DOI 10.1017/S1478951514001333

Who is not suitable?

- 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 in interview.

Process

- The PDI is delivered in a single 1 hour session (approx.) and is comprised of the following steps:
- The patient completes the Patient Dignity Inventory;
- The patient's identified partner completes the PDI as they perceive the patient is feeling;
- The clinician reviews the results with the couple, summarising areas of concurrence and of discordance;

Process

- The clinician uses additional clinical time, to discuss and determine the extent to which completion of the PDI, identified distress;
- Reviews couples' concurrence or discordance on this distress to enable communication and/or a better mutual understanding for both parties.

Timing

- Part One: Assessment and orientation to using the PDI to enhance communication:
- Assessment (5 – 10 minutes)
- Understanding the PDI and its use in couple communication (5-10 minutes)
- Completing the PDI (about 10 minutes)

Timing

- Part Two: Facilitating a discussion using the PDI scores to facilitate
- Comparing answers (5 – 10 minutes)
- Facilitating discussion with couples (25 – 30 minutes)
- Conclusion and wrap-up (5 – 10 mins)

Understanding the PDI and its use in couple communication

- Gaining a shared understanding of the PDI and its rationale for use in the present session is an important component of the intervention.
- It will also enhance the motivation and investment of the couple to the session.
- Likewise it is important to acknowledging the normalcy of difficulties in communication around cancer in couples.
- Imparting information from other studies, that many couples reflect the need for them to communicate effectively together about how the cancer is affecting the person with cancer, may also be useful.

Understanding the PDI and its use in couple communication

- It is important for the therapist to focus the session on the couple's communication together about the issues that arise from the PDI,
- RATHER than focussing on the issues themselves.
- Thus the session is not based on problem solving areas of concern (where the patient has high scores).
- Rather the focus is on what the couples know about each other's perceptions of areas of concern for the patient; whether the couple have talked about areas of concern together and facilitating communication about these areas in the session.

Session Goals

- Facilitate a discussion to share each area of concordance, discordance and high scores with the couple
- Continue to explore areas of difference or concern with the couple together to begin to identify ways to acknowledge each other's perspective
- Acknowledge and reflect back on strengths observed in couple
- Summarise and close (**Important:** Advise follow up available)

Introducing the session

- It is common that couples where one has cancer may experience difficulty in talking together about the issues around the cancer that are concerning for them and in sharing their concerns with each other.
- The question sheets we will be using today asks you to rate how much of a problem issues to do with your illness are for you, these include distress about your current symptoms, concerns about the future, worry about being dependent on others; peace of mind and the availability of support of family and friends.
- We also want your partner to fill out the same questions to see how your partner thinks you are going as well.
- The first aim of the session today is to find out from each of you what your responses are to the questions so that we get a sense of both your perspectives on how (name couple member) is going.

Introducing the session

- Next we will review both your answers together so we can see where you have similar answers and where you have different answers. It will also show us which areas are particularly concerning or difficult from each of your point of view.
- We will then spend some time talking your answers through together; concentrating on the areas where you each think differently and / or areas which are distressing.
- Remember there are no right and wrong answers, getting very different answers from each other doesn't mean that you are doing anything wrong, rather these areas highlight issues you may wish to talk about together.

Introducing the session

- It may be that when we have identified areas where you think differently and / or areas which are distressing – you may not want to discuss them (and that is fine).
- Do you have any questions or concerns before we go on?

Facilitating discussion

- What are the surprises for you in your partner's answers?
- How much and in what way have you talked together about these issues?
- Which is the area of most concern for you each? (Are these different/the same?)



Trouble shooting

One partner not wanting to talk about issues

Strategies

- The main questions to consider when one partner doesn't wish to talk; is this usual pattern of communication in the couple?
- Is the couple satisfied with one partner not talking or is it causing any distress or perceived difficulties for one or both?
- If 'not wanting to talk about issue' is the norm and this is working for both the partners in the couple, then this should not be challenged by the intervention session.
- It may thus be a process of 'checking in' and finding out from the couple how their communication works for them.

Strategies

- Psycho education about benefits of communication about cancer issues and/or exploration of safe ways to talk together about issues.
- Exploring the reasons why there is reluctance which can then be explored and addressed
- Asking about a past example of unsuccessful communication about sensitive issue may also allow difficulties with communication to be aired

Trouble shooting

Little or no difference between scores

Strategies

- This may reflect that the couple are communicating well about issues and have a close understanding. This can be reflected back to the couple.
- Exploring the way the couple communicate together, what and how communication happens may both validate for the couple what they are doing and give us insight into what successful communication around end-of-life issues can look like.

Strategies

- It may also be useful to check out if there is indeed any area that they think may need some further attention between them both.
- It can be useful to ask them to reflect on any overarching question/s

Trouble shooting

Questions not answered by one or both

Strategies

- These can be identified by the therapist to the couple directly, again with the aim of drawing out communication together.
- Unanswered questions similarly to divergent responses are valuable to highlight areas of communication issues for the couple.
- Opening discussion will both allow issues to do with communication to be identified and provide 'permission to speak' about difficult topics together.

Trouble shooting

Focusing on 'problem solving' the issues of high concern rather than on communicating about them

Strategy

- Exploring the issue may assist the couple in communicating together about the issue
- Reflect on how the couple are sharing the information and feelings about the issue together to model communication about the issue together in the session
- Keep reflecting back to how the couple are talking about the issue, by asking questions about communication, understanding, points of difference and similarity.

Conclusion and Wrap-Up

- Provide a brief summary of the session. If there are major unresolved issues make a plan to address these in either a future session or referral to a suitable service.
- It may be appropriate to provide strengths based feedback to the couple commenting on their success in communicating as a couple, reflecting on the time ahead and acknowledging the difficulties they are facing.
- It would be useful to include a summary which gives permission to the couple to continue to communicate together after the session. **Give copy to couple?**

Discussion points

- 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.

Important

- The health care professional delivering the intervention needs to allow time to focus discussion on differences and similarities in a supportive way that ensures each person in the dyad is 'heard'.



Manual

- The manual has been produced to provide appropriately trained and accredited counsellors, social workers and psychologists with information about a couple's communication tool. It is not a replacement for careful assessment and treatment of any condition

Investigators

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