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# Psycho-Educational Group Intervention for Family Caregivers of Hospitalized Palliative Care Patients: Pilot Study

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## Abstract

**Background:** Family caregivers of patients requiring palliative care commonly experience physical, social, and psychological burdens. Although family caregivers are acknowledged as valid service recipients of palliative care, many have unmet needs, and systematic reviews have shown there are limited evidence-based supportive interventions.

**Objectives:** This study aimed to develop and pilot test a psycho-educational group education program delivered in the inpatient specialist palliative care setting and designed to prepare primary family caregivers for the role of supporting a relative receiving hospital-based palliative care.

**Methods:** (1) Development of education session and delivery protocol by the research team and expert panel; (2) pilot the intervention in three clinical sites (five sessions in total); (3) evaluate its accessibility and acceptability; and (4) preliminary testing of outcome measures used to assess the intervention's effectiveness.

**Results and conclusion:** The results revealed that the intervention was appropriate and acceptable to caregivers. The intervention needs to be tested in a larger sample to determine the potential benefits for caregivers' sense of preparedness and competence, and testing needs to ascertain if the intervention is accessible.

## Introduction

CARING FOR A FAMILY MEMBER with life-threatening disease is commonly associated with negative physical and psychosocial outcomes.<sup>1</sup> The World Health Organization standards for palliative care highlight the importance of family caregivers.<sup>2,3</sup> A hallmark of palliative care is that patients have a choice related to the site of their care. Most people want to die at home, yet for many this is not achievable.<sup>4,5</sup> The likelihood of a home death is significantly increased if family caregivers receive comprehensive preparation and support. Information may help caregivers to solve caregiving problems, decrease their anxiety, and increase their sense of control.<sup>6,7</sup> The benefits of family involvement in discharge planning have been reported,<sup>8,9</sup> yet most family care-

givers lack preparatory information and may feel unable to make an informed choice about their role.<sup>10</sup> Family caregivers report a variety of unmet needs and have been referred to as 'hidden patients.'<sup>11</sup> Health professionals acknowledge that providing supportive information to family members as well as to patients presents an enormous challenge.<sup>12</sup> Although family caregivers are acknowledged as valid service recipients of palliative care, they continue to have largely unmet informational and psychological needs.<sup>13</sup> Given that a large proportion of patients will have received end-of-life care in hospital, research needs to focus on testing strategies for supporting family caregivers in the in-patient setting as well as in the home.<sup>10</sup> Addressing this gap in service provision is a priority, and evidence-based approaches to support and guide family caregivers are required to justify interventions and resource allocation.<sup>13</sup>

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Psycho-educational interventions delivered on a one-to-one basis (health professional to caregiver) have demonstrated a capacity to decrease caregiver burden, increase caregiver quality of life, and increase knowledge of patient symptoms.<sup>14,15</sup> Evidence from systematic reviews conducted in cancer populations demonstrate that structured information provision from health professionals can reduce anxiety.<sup>16</sup> Although one-to-one interventions are appropriate for some family caregivers, others may prefer a group context. The advantages of group interventions are that they allow for social comparison, the comparison of one's situation with a peer group who are experiencing similar circumstances; they provide social support and sharing of experiences; and they often require fewer resources.<sup>13,17</sup> Therefore, we aimed to develop a psycho-educational group education program to be delivered in the inpatient setting and to pilot test the developed program prior to undertaking a larger study to examine its effectiveness.

## Methods

The pilot study had four objectives: (1) to develop the specific education session content and delivery protocol; (2) to pilot the intervention in three clinical sites; (3) to evaluate its accessibility and acceptability; and (4) to undertake preliminary testing of outcome measures used to assess the intervention's effectiveness. Ethical approval to conduct the study was obtained from relevant human research ethics committees.

### Intervention development

Responses to the family caregiver role may be understood from a psychological perspective based on a transactional model of coping in which caregivers make cognitive appraisals to determine the possible impact of their circumstances.<sup>18,19</sup> In this way, family caregiving is seen not necessarily as stressful; it could vary, depending upon individuals' internal coping resources. Such resources include feelings of preparedness, competence, and having adequate information. Hence, strategies that target these factors may assist family caregivers to respond more favorably to their role.<sup>19</sup> This theoretical framework underpinned the intervention.

The intervention was developed by the research team based on the aforementioned theoretical framework and from other psycho-educational interventions for family caregivers of cancer patients that had a similar purpose.<sup>20,21</sup>

The intervention was subsequently reviewed by an expert panel on two occasions. The expert panel ( $n=8$ ) were recruited (via purposive sample) from several health and educational institutions in Melbourne, Australia. The panel was multidisciplinary and comprised of a palliative care medical consultant, educational psychologist, palliative care education specialist ( $n=2$ ), social worker, palliative care nurse, adult health education specialist, and a bereaved caregiver. The panel members were chosen based on their recognized expertise within the fields of palliative care or education. Following each meeting the research team reviewed the intervention in accordance with comments from the expert panel.

### The intervention

The single-session (1.5 hr) didactic group intervention consisted of five topics: (1) what is palliative care? (2) the

typical role of family caregivers; (3) support services available to assist caregivers; (4) preparing for the future; and (5) self-care strategies for caregivers. The rationale for a single-session intervention as opposed to multiple sessions was based on pragmatic grounds; the average stay in the participating clinical sites was estimated at 18 days, hence trying to offer more than one session during this relatively short time period was deemed unviable.

The main written resource, in addition to key handouts relevant to each topic area, was a guidebook that focused on preparing family caregivers for their role. This guidebook was developed with input from current and bereaved family caregivers and its utility was tested as part of a randomized controlled trial, which explored the effectiveness of a one-on-one psycho-educational intervention for cancer patients' family caregivers.<sup>21</sup> At the end of the program family caregivers were given the opportunity to meet individually with relevant members of the multidisciplinary team to discuss their needs. This also provided an opportunity to make formal referrals and to schedule family meetings.

At each of the three participating clinical sites an education facilitator and a research assistant were employed. The education facilitators, who were experienced palliative care nurses, and the research assistants all attended a one-day training course to promote an understanding of their roles and responsibilities, the education program objectives, content and format, and the research protocol. A detailed research protocol manual was developed for consistency across all sites.

All sites conducted a mock education session to ensure that they were confident with the format and content of the session. Additionally, all sites introduced the study to the clinical staff via a short presentation and discussion before proceeding with the pilot education sessions.

### Pilot testing

The program was pilot tested in three inpatient palliative care units (PCUs) in the states of Victoria, New South Wales, and Western Australia. Patients admitted (for the first time) to the participating inpatient palliative care unit and their primary family caregiver/s were approached to participate. While patients were not required to complete any measures, their informed consent was required to confirm access to the primary family caregiver and for access to their medical record.

*Patient eligibility criteria:* a diagnosis of cancer; at least 18 years of age; able to read and speak English; able to provide valid, informed consent; able to identify a relative or friend as their primary caregiver; and willing for that person to be invited to participate. Patients were excluded from the study if they exhibited signs of significant emotional distress that was likely to impact upon their capacity to provide informed consent, or if they were experiencing cognitive impairment, for example, delirium or dementia.

*Caregiver eligibility criteria:* at least 18 years of age; able to read and speak English; able to provide valid, informed consent; and willing to be recognized as the patient's primary lay caregiver.

*Exclusion criterion:* exhibiting signs of significant emotional distress that was likely to impact upon their capacity to provide informed consent, complete data, or participate in the intervention.

Following the patient's admission, eligible caregivers were sent a letter by the palliative care unit's manager informing

them of the study. A research assistant phoned the caregiver three days later and invited him or her to participate in the study. All participants were given a plain language information statement and were required to complete a consent form before participating in the study.

Participating family caregivers completed a brief post-program evaluation form (developed by the project team), which sought to determine caregivers' subjective perspectives of the program. This included 10 closed-response questions (yes/no), five open-ended questions addressing the benefits of attending and suggestions for improvement, and one question asking participants to rate the usefulness of the program on a 10-point Likert-type scale (10=very useful).

In addition to this, the education facilitators were invited to reflect on the program and identify aspects that might require modification. The research assistants completed a checklist for each of the sessions they attended to ensure that the session was delivered as planned and to note which sections in particular did not work well.

**Preliminary testing of effectiveness**

At the commencement of the education program, participants completed a set of self-report questionnaires, which were linked to the variables relevant to the objectives of the intervention and the aforementioned theoretical framework. The rationale for administering validated measures during the pilot phase was to explore family caregivers' capacity and willingness to complete these and to assess other data collection issues in preparation for a subsequent larger effectiveness study. The questionnaire included a sociodemographic questionnaire and the following validated self report measures: the Family Inventory of Needs,<sup>22</sup> the General Health Questionnaire,<sup>23</sup> Preparedness for Caregiving Scale,<sup>24</sup> and the Caregiver Competence Scale.<sup>25</sup> At completion of the education program, family caregivers were given a sealed envelope containing the same set of instruments administered at Time 1. Participants were asked to complete the questionnaire in three days, returning them in the enclosed reply-paid envelope. A reminder to complete was made by phone, where required. We chose three days in order to limit attrition due to patients' death.

**Analysis**

Refinement of the intervention was based on feedback from the caregivers' evaluation forms and suggestions provided by the education facilitators and assistants. Descriptive statistical approaches were conducted to describe and profile the sample of caregivers who attended the programs as well as the palliative care patients. Five paired *t*-tests were conducted to examine whether the intervention had an effect on psychological well-being, preparedness, competence, importance of needs, or needs being met.

**Results**

**Participants**

During the pilot testing phase there were 149 admissions to the sites. Of these, 85 participants were ineligible for the following reasons: patient imminently dying *n*=45, noncancer diagnosis *n*=11, no contact details *n*=10, non-English-speaking *n*=5, no caregiver *n*=4, and other *n*=10. Of the 64 caregivers who were eligible to participate, 35 declined participation,

citing too busy (*n*=16) and other reasons (*n*=19). Of the 28 who agreed to participate, 13 did not attend the program. Reasons for this included the patient dying or imminently dying prior to the session (*n*=3), caregiver unable to attend the program (*n*=3), caregiver unwilling to complete the paperwork (*n*=1), and no reason given (*n*=7). Of the 15 caregivers who attended one of the five programs conducted across the three sites, 13 completed both Time 1 and Time 2 questionnaires.

The majority of participants were older women caring for a partner. The majority of participants were retired or reported domestic duties, less than a quarter ceased paid work to be a caregiver. Demographic information of the participants is included in Table 1.

**Acceptability and applicability of the intervention**

Overall, participants were very positive about the education session. Results of the program evaluation are included in Table 2 and as shown, the overwhelming majority reported that the content was relevant, the length of the session appropriate, and it was offered at a suitable time.

Participants were invited to make comments regarding the content and presentation of the session. All comments

TABLE 1. SOCIODEMOGRAPHIC DETAILS

<i>Caregiver characteristics</i>	(n=15)
<b>Gender</b>	
Female	12
<b>Age</b>	
Mean	61.4
Range	46-76
<b>Marital status</b>	
Married	12
Single / never married	1
Widowed	1
<b>Country of birth - Australia</b>	13
<b>Religion</b>	
Christian	11
Other	3
None	1
<b>Education level</b>	
Professional/university degree	7
Technical/apprenticeship	2
High school completed	3
Did not complete high school	3
<b>Occupation</b>	
Full-time employment	1
Part-time employment	2
Retired	6
<i>Patient characteristics</i>	(n=15)
<b>Relation of person to caregiver</b>	
Spouse	9
Parent	3
Friend	2
Sibling	1
<b>Gender of patient</b>	
Male	10
Female	5
<b>Age of patient</b>	
Mean	70.3
Range	48-91
Level of dependency (ECOG) – Mean (1-5 scale, 1=low dependency / 5=total dependency)	4.1

TABLE 2. PARTICIPANT FEEDBACK ABOUT THE EDUCATION SESSION

Statement	Agreed with statement n=12
The venue and refreshments met expectations	12
The time of day of the program suited my needs	12
The length of the program was adequate	12
I experienced no difficulties attending the session	10
Facilitators presented information in an appropriate way	12
The content of the program met expectations	12
Opportunity to be with other caregivers was of value	12
I found the resources useful (caregiver kit)	12
There were no downsides from participating in the program	11
I would recommend program to others	12

received were favorable, as exemplified by the following statement:

*I felt completely engaged. . . . The topic brings all the emotions you try to contain on a daily basis to the surface, but I felt the presenters calmly dealt with each question raised in a helpful way.*

Participants were also asked to identify any benefits of attending the session, as well as the least helpful aspects of the session and suggest any improvements. The participants' feedback is outlined in Table 3. All participants reported at least one benefit (and most reported multiple benefits), and only three suggested improvements. The most common benefits of attending the program related to receiving information about palliative care support services, which was reported by approximately two thirds of participants. About a third of participants mentioned benefits related to preparation for the death of the patient, being with other caregivers, and increased skills and confidence. Among suggestions for improving the session, one caregiver suggested a follow-up session would be helpful. Another caregiver expressed a preference for more time for informal discussion.

TABLE 3. QUALITATIVE FEEDBACK RELATED TO THE PERCEIVED BENEFITS OR IMPACTS OF THE PROGRAM

Benefit/Impact
Services: <i>Where to find help/extra information/finding out what resources are available/that I can ask for help</i>
Prepared for death: <i>More knowledge of what to expect/signs of approaching death was really useful/useful information when it comes to the end</i>
Group benefit: <i>Opportunity to share with others in the same situation/being with other caregivers and listening to their stories/helped me feel less isolated</i>
Skills and confidence: <i>Talking about coping with problems/confidence that I'm doing okay/knowledge to make things easier for my relative/more ready to care than I was before</i>

Participants were asked to rate the overall usefulness of the session out of a possible score of 10, 10 indicating very useful; the average score was 8.9.

The feedback from the education facilitators and research assistants was also favorable. All education facilitators commented that the sessions had gone well. Encouraging questions and discussion was viewed as useful and it was deemed important to establish a relaxed and informal environment. Two facilitators reported that the length of the session was appropriate and allowed adequate time for discussion. However, one facilitator reported that she found it difficult to limit the group to the agreed-upon amount of time. It was acknowledged that the first topic (information about palliative care) may be redundant for some caregivers who have a good understanding of palliative care, as they already have been receiving palliative care for a while. Two research assistants reported that there were many questions from participants about practical issues related to finances, and funeral arrangements, thus reinforcing the need to routinely include this information.

#### Methods to test the effectiveness of the intervention

The research assistants and education facilitators reported no issues with the administration of the study measures. Compliance was reasonable with regard to completion of Time 2 data (13/15 caregivers). Results show that the intervention had no significant effect on competence, importance of information, unmet needs, or psychological distress, from Time 1 to Time 2. However, there was a significant improvement in the level of preparedness from Time 1 to Time 2,  $t(11) = -2.42, p < .05$  (Table 4).

#### Discussion and Conclusion

The results of the pilot study of a group psycho-educational intervention for family caregivers of hospitalized palliative care patients were favorable. Family caregivers, the education facilitators, and research assistants gave positive feedback about the content and facilitation of the sessions. The educational facilitators were for the most part able to deliver all the content within the time limit as well as answer questions and encourage discussion.

In light of the results of the pilot, no major modifications to the program were required. It was however acknowledged that some of the content, for example defining palliative care,

TABLE 4. MEANS AND STANDARD DEVIATIONS FOR MEASURES OF ADJUSTMENT FOR PALLIATIVE CARE PRE-INTERVENTION AND POST-INTERVENTION (N=12)

Measure	Time 1		Time 2		t-test (sig.)
	Mean	SD	Mean	SD	
GHQ	29.04	6.04	28.83	5.89	NS
Preparedness	16.83	4.95	18.67	5.47	$p < .05$
Competence	8.45	1.92	8.68	1.95	NS
FINA	67.69	9.85	68.75	10.57	NS
FINB	53.29	4.22	57.08	9.45	NS

GHQ, general health questionnaire; FINA, family inventory of need subscale A; FINB, family inventory of need subscale B; NS, not significant.

may be redundant for some family caregivers. Therefore, it is recommended that, where pertinent, the education facilitator summarize relevant content and allow more time for other topics.

Although the results indicate that the intervention seemed to be applicable and acceptable, it is not possible to conclude that it was accessible for family caregivers. On average, only three family caregivers attended the education sessions; the intervention was designed to accommodate approximately six family caregivers. While the feedback on the timing of the education session was favorable, perhaps the session needs to be offered more frequently to promote uptake.

The purpose of administering pre- and post-intervention measures for this pilot study was to explore potential administration and completion issues, and none were identified. The session did have a significant effect on family caregiver's sense of preparedness. No other significant effects were identified; however this was most likely attributable to the small sample size.

An additional limitation of this study was that only approximately one quarter of those eligible participated. This raises the possibility of selection bias and should be taken into account for future studies in order to minimize external validity issues.

In conclusion, the results of this pilot study of a psycho-educational single-session intervention for family caregivers of palliative care patients admitted to a palliative care unit revealed that the intervention appeared to be appropriate and acceptable. The intervention needs to be tested in a larger sample to determine potential benefits for caregivers' sense of preparedness, competence, needs, and to ascertain if it is accessible.

#### Author Disclosure Statement

No conflicting financial interests exist.

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