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Evaluation of a psycho-educational group programme for family caregivers in home-based palliative care

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Background: Family caregivers are often responsible for providing significant support to relatives who require palliative care at home. However, evidence suggests that family caregivers have limited information, resources or support to prepare them for such a role. Furthermore, family caregiving can be associated with negative physical, financial and psychosocial outcomes. **Purpose:** This project sought to examine the utility of a group family caregiver psycho-educational programme focused on preparing primary family caregivers for the role of supporting a relative with advanced cancer at home. **Method:** The education programme consisted of three consecutive weekly sessions presented in a group format, conducted at six home-based palliative care services across metropolitan and regional Victoria (Australia). Participating caregivers were required to complete a set of self-report questionnaires measuring caregiver competence, preparedness, optimism, rewards, social support, burden and information needs, at three time points: commencement of the programme (T1), upon completion (T2) and 2 weeks later (T3). Caregivers were also asked to report on the relevance, acceptability and content of the programme, as well as any barriers to access. **Results:** Sixteen education programmes were conducted, with 74 caregivers attending the first session. Forty-four caregivers completed all three data collection sets. Following the intervention, a significant positive effect was found for the following outcomes: preparedness for the caring role, caregiving competence, caregiving rewards and having information needs met from T1 to T2. These improvements were maintained at follow-up (T3). Feedback on the individual sessions and entire programme was favourable and the overwhelming majority of participants reported that the programme had a positive impact on their lives. **Conclusions:** This study demonstrated that a group education programme to prepare family caregivers for the role of supporting a dying relative at home was accessible, applicable and effective. *Palliative Medicine* (2008); **22**: 270–280

Key words: caregiver; education; family; intervention; palliative

Introduction

Family caregivers of individuals requiring palliative care may experience negative physical and psychosocial outcomes. Accordingly, the World Health Organisation highlights the importance of meeting the supportive care needs of family caregivers and palliative care patients.[1] Despite professional input offered by palliative care services, a family member or friend is usually relied upon to provide major assistance with care provision in the home.[2,3] Family caregivers play a critical role and commonly undertake complex care tasks including symptom assessment and management, hygiene care and medication administration.[4,5] Consequently, care in the community is usually only feasible if a family caregiver takes responsibility for the fundamental care of the person who is dying.[6] However, the physical, emotional, financial and social impact of caring on families is considerable. Caring for someone with a terminal condition presents unique challenges even for the experienced caregiver. Particular issues can include exhaustion, fatigue, anxiety, sleeplessness, weight loss, depression, burn out and general deterioration in health.[3,4,7]

An additional hallmark of palliative care is that patients have a choice related to the site of their care.

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Although most people want to die at home, only approximately 25% of patients in developed countries have a home death.[8,9] 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.[10,11] However, most family caregivers lack preparatory information and so feel unable to make an informed choice about their role.[12] Caregivers have been referred to as 'hidden patients'.[13] Typical unmet needs are associated with social support, financial assistance, emotional support and assistance with managing the dying person's symptoms.[14] Health professionals also acknowledge that providing supportive information to the family members and to the patient presents an enormous challenge.[15]

Caregiver experiences and needs have been well researched, but there is a dearth of evidence-based approaches aimed at meeting the supportive needs of palliative care families.[16–19] Group education programmes have been widely recommended as a valuable strategy to deliver support and information to palliative care families.[20] However, these programmes are currently underdeveloped, and those that exist have not been rigorously evaluated.[21] Psycho-educational interventions delivered on a one-to-one basis (health professional to caregiver) have showed their capacity to decrease caregiver burden, to increase caregiver quality of life and to increase knowledge of patient symptoms.[22,23] Evidence from systematic reviews of randomised controlled trials conducted in cancer populations also shows that structured information provision from health professionals can reduce patients' anxiety.[24] Although one-to-one interventions are appropriate for some family caregivers, others may prefer a group context. One advantage of group interventions is that they allow for discussions among caregivers that may help to normalise their experiences. Other advantages include opportunities for modelling adaptive coping behaviours and strategies, expression and validation of feelings, reduced isolation and increased social support, resulting in the need for fewer resources.[25,26]

In summary, although family caregivers are acknowledged as valid service recipients of palliative care, they continue to have largely unmet informational and psychosocial needs. Addressing this gap in service provision is a priority and evidence-based approaches to support and guide family caregivers are urgently required to justify interventions and resource allocation.[18,26]

Research purpose and questions

The purpose of the research project was to develop, deliver and evaluate a group education programme aimed at preparing primary family caregivers for the role of supporting a relative/friend receiving home-based palliative care.

Two research questions related to phase one (described herewith) of the project were: (1) Family caregivers who attend a group education programme will report that the programme was applicable, useful and accessible and (2) Family caregivers who attend a group education programme will show increased levels of preparedness, competence, optimism, social support, rewards and fewer unmet needs and burden.

Development of the group education programme

Theoretical framework

The diversity of responses related to end-of-life issues from patient and family caregivers can 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 a potentially stressful event.[27,28] The more capable the caregiver is, or the greater the number of resources at their disposal to manage an event, the more likely the individual will display adaptive behaviours. In this way, family caregiving need not necessarily be seen as stressful; it can vary, depending upon the person's internal resources for coping. Such resources include feelings of preparedness, competence, having adequate information and focusing on positive aspects of the role. Hence, strategies that targeted these domains were included in the education programme.[28]

Main studies informing the design of the programme

The main research that informed the development of the group education programme primarily arose from two projects. The first project conducted by Hudson, *et al.*[29] showed in a randomised controlled trial that a home-based one-to-one (nurse to caregiver) psycho-educational intervention focused on preparing family caregivers ($n = 106$) for the role of supporting a dying relative at home had positive caregiver psychological outcomes. Current and bereaved family caregivers were involved in designing the content of the intervention.[30] The project confirmed that the overwhelming majority of family caregivers wanted preparatory information early in the caregiving experience. It was also recommended that group education formats be tested.

The second study, by Harding, *et al.*,[31] evaluated the utility of a group education programme (comprising six sessions) for family caregivers of people receiving palliative care at home. Although the study found that the programme was acceptable and accessible, effects on psychological variables could not be assessed because of sample attrition. It was recommended that future studies be conducted with larger sample sizes and mixed method data collection approaches. Our research group decided that six sessions was not feasible (because of increased likelihood of attrition) as patients spend an average of 11 weeks in palliative home-care programmes in Australia.

Facilitation and ingredients for the group education programme

The main content of the education programme (including the number and duration of sessions) was based upon the aforementioned psycho-educational intervention[29] with additional refinement from the research team. The Caregiver Group Education Programme was conducted via three sessions (1.5 h each) over a 3-week period. Suitably, qualified health care professionals (Education Programme Facilitators) employed from within the participating palliative care services facilitated the programme. Facilitators undertook a short-training programme commensurate with an education programme manual developed by the project team.[32] In addition to the facilitators, the programme content was delivered by members of the multi-disciplinary team (e.g., palliative care doctor, counsellor, social worker, palliative care nurse). Participants were encouraged to attend each of the three sessions. The education sessions were semi-structured in a format including a mix of presentation and group work (didactic approaches were employed sparingly). Sufficient time for participants' questions, comments, clarification and dialogue was an essential feature of each session.

The title and objective(s) of the three education sessions are outlined in Box 1. All caregivers who attended the group education programme received a copy of a Caregiver Guidebook designed specifically for preparing family caregivers for the role of supporting a dying relative.[33] The guidebook provided information including problem solving, positive thinking and relaxation strategies that caregivers could refer to while attending the course, and afterwards.

Methods to evaluate the group education programme

Sample, setting and recruitment

Caregivers of patients admitted to six home-based palliative care services (mix of metropolitan and rural) in Victoria, Australia, were approached for potential participation in the study. The target population was the primary caregiver of patients requiring palliative care because of malignant disease. Inclusion criteria required that the caregiver was over 18 years, could speak and understand English (necessary for group cohesiveness and discussions) and was caring for a person receiving home-based palliative care. Primary family caregivers who were demonstrating pronounced psychological distress (as judged by the research assistant as potentially impacting upon their capacity to give informed consent) were not recruited. It was anticipated that a minimum of four and a maximum of eight caregivers would complete each programme. Ethics approval was obtained from each of the participating clinical sites.

Data collection

Quantitative data collection incorporated the following:

1) Session evaluation (collected before and after each session) and programme evaluation (completed at the end of the programme and 2 weeks later by mail) were designed by the research team to explore the applicability and acceptance of the programme to the participants. In addition, the programme evaluation form included a measure of the impact that participation in the programme had on participants lives. Item responses were formatted as a four-point Likert scale with '1' indicating no impact and '4' indicating significant impact.
2) Administration of demographic questionnaire and seven validated self-report instruments to assess the effectiveness of the programme: Time 1 = just before commencement of the caregiver education programme, Time 2 = just after completion of the care-

Box 1 Title and objectives of the education sessions

Session number	Session title	Objectives
1	What is involved in being a family caregiver?	(a) To provide education on the typical role of a caregiver in the palliative care context. (b) To outline the services available from the palliative care team, local doctor and other support services.
2	Caring for your relative/friend and taking care of yourself.	(a) To present key strategies relating to responding to a patient's physical and psychosocial issues. (b) Strategies to maintain family caregivers' well-being.
3	Caring for a person when death is approaching.	To deliver information about what to expect when: (a) Someone seems to be approaching death. (b) A person dies (including common emotional reactions). (c) Health professional supports (including bereavement).

Table 1 Measures administered to family caregivers to test effectiveness of the programme

Variable	Instruments and author(s)	References to support psychometric suitability
Perceived competence	Caregiver competence scale[35]	34,35
Perceived preparedness for the caregiver role	Preparedness for caregiving scale[36]	34,36
Unmet informational needs	Family inventory of need[37]	37
Positive aspects of the role	Rewards for caregiving scale[38]	34,38
Social support	Social Support Questionnaire[39]	34,39
Burden	Brief assessment scale for caregivers	40
Optimism	Life orientation test[41]	34,41

giver education programme and Time 3 = 2 weeks later (via mail). To test the hypothesis that the intervention would improve internal resources of coping such as preparedness, competence, adequate information, positive aspects of the role, optimism and social support, measures of each of these factors were included at all three time periods. To examine whether the intervention would result in lower levels of carer burden, a measure of carer burden was also included at all three time periods. Table 2 provides an overview of the seven measures included in the study. The psychometric properties of most instruments used to measure the dependent variables have been tested in family caregiver palliative care populations and described elsewhere.[34]

Qualitative programme evaluation was conducted via semi-structured interviews and facilitators' journals. Semi-structured interviews were conducted by phone at least 2 weeks after completion of the programme with at least one caregiver from each programme. These interviews were conducted by a research assistant who was independent from the participants and the delivery of the programme. Questions were developed by the project team, and these are outlined in Box 2.

Each of the programme facilitators was asked to keep a journal of experiences related to the programme. They were provided with some open-ended prompts, which guided the facilitators to provide feedback on particular aspects of their role and perceptions of the programme.

Analysis

Data were collected and presented using both descriptive and inferential statistics using the Statistical Package for the Social Sciences (SPSS version 12). Descriptive statistics were used to describe the basic features of the sample population. A number of variables were examined across three time periods (Time 1 = commencement of the caregiver education programme, Time 2 = following the caregiver education programme and Time 3 = 2 weeks following the last caregiver education session), and therefore repeated measures ANOVAs were employed. The main independent variable was time, and the dependent variables included were competence, preparedness, optimism, social support, rewards, burden and needs.

Results

Sixteen programmes were completed with 74 people completing Time 1 questionnaires (56 females, 18 males). Retention rates were moderate with 44 completed questionnaires at Time 2 and 45 complete questionnaires at Time 3. Of the original 74 participants, 44 completed all three time periods (59%). Ninety-six individuals declined to participate. Reasons for refusal were: caregiver coping and supported (17), not interested (14), working (10) and relative too unwell to leave alone (9).

To determine whether those who participated in all three time periods differed from participants who did not complete all three time periods, a multivariate analysis of variance was performed on all nine Time 1 variables.

Box 2 Semi structured interview questions

1. Thinking back to the education programme, which aspects of the programme did you find most beneficial in your experience of caring for your family member?
2. Have you been able to implement any of the strategies mentioned in the programme, and if so, please comment?
3. Again thinking about the training and your caregiver role, is there any information or topic areas that you feel should have been explored in greater depth to help you more in your caregiver role?
4. Do you have any thoughts as to how the programme could be improved or things that should have been done differently to assist you more in your caregiver role?
5. How did you get to the sessions (e.g., drove self, walked, volunteer drove, etc.)?
6. Do you have any further comments about the education programme?

These variables were: social support (amount and type of support), satisfaction, preparedness, competence, brief assessment scale for caregivers, rewards, outlook on life and family information needs partial or full participation was entered as a between group factor. There was no multivariate effect for incomplete participation.

Checks for the violations of the assumptions of normality were conducted on all variables. Significant skewness was associated with some measures; however, transformations were not undertaken because the skewness was assumed to reflect the inherent nature of the variables.[42] In particular, both social support variables were highly skewed because most participants reported not having anyone (specific individual) around to help support them. However, most reported high levels of satisfaction with their overall levels of support.

Socio-demographic profile

Socio-demographic information for the total sample regardless of whether they completed all time periods or not are reported in Table 3. No significant variations in the demographic information were found between participants who completed all time periods compared to those that had incomplete data sets.

Quantitative results

Session and programme evaluations

Sixty-nine participants completed session one evaluation forms, 61 participants completed session two evaluation forms, and 56 participants completed session three evaluations forms. The mean for each item at each session is reported in Table 4. All question responses were in the form of a 5 or 7 point Likert-type scale, with a low score indicating a positive response and a high score indicating a negative response.

Fifty-four participants completed a programme evaluation form, which included a number of yes/no questions further to assess the programme. The responses are shown in Table 5. The programme evaluation form also included a scale to assess the impact of the programme. Table 6 shows the mean response for each item, where a score of 1 reflects no impact and a score of 4 reflects significant impact. The mean for the total impact score has a possible score range from 11 to 44, with a high score reflecting a high significant impact.

A repeated measures analysis of variance was performed on all nine Time 1 variables: social support – amount (support-amt), social support – satisfaction (support-sat), preparedness (PREP), competence (COMPET), brief assessment scale for caregivers (BAS), rewards (REW), outlook on life (OOL), family inventory of needs – importance (need importance) and family inventory of needs – needs met (needs met). Three time periods were compared for 44 participants: pre-intervention, post-intervention and at follow-up. The within group factor was time, and there was no between group factor.

Using Pillai's criterion, multivariate effects within groups was found for time, $F(18,142) = 4.37$, $P < 0.001$. The results showed moderate associations between time and the combined-dependent variables, $\eta^2 = 0.36$. Univariate analyses showed significant difference between time periods on PREP, $F(2,78) = 10.64$, $P < 0.001$; COMPET, $F(2,78) = 7.77$, $P = 0.001$; BAS, $F(2,78) = 19.04$, $P < .001$; REW, $F(2,78) = 3.87$, $P < 0.05$, and needs met, $F(2,78) = 3.95$, $P < 0.01$.

As shown in Table 7, the intervention had a positive effect on preparedness, competence, rewards and having needs met from Time 1 to Time 2, which was maintained at follow-up (Time 3). Distress as measured by the BAS increased significantly from Time 2 to Time 3, which may be a result of patient deterioration rather than an effect of the intervention. Social support levels and optimism levels remained stable over time.

Qualitative results

Post-programme interviews

A total of 25 caregiver-participants were interviewed. Of the 14 females interviewed, four were bereaved. Of the 11 males interviewed, one was bereaved. All but two caregivers drove themselves or walked to the programme venue and found it to be an acceptable distance from their home. The remaining two caregivers were transported to and from each session by the programme facilitator or a volunteer.

Overall, the feedback about the programme was extremely favourable. Participants valued the opportunity to meet with other caregivers and to share their experiences with people confronting a similar situation. Participants also appreciated being provided with resources about available services, learning about symptom management and strategies for responding to their relative's needs. Eight participants commented on the practical advice provided in the programme, with one participant saying: *'It gave me courage to carry on…and is affirming to know you're doing the right thing…increased my confidence'*. Another participant, who actually cried during the interview, commented: *'I found it* (the programme*) very confrontational and felt very overwhelmed during most of the sessions, but didn't regret going'*.

Although caregivers were not asked during the interview whether they were employed, one male participant who was employed made the following comment: *'My employer was supportive and paid for time to attend* (the programme) *and gave me the rest of the day off with pay'*.

Occasionally, the patient was admitted to, and then died in, hospital while the caregiver was enrolled in the

Table 2 Frequency and percentages of participant's demographic information for incomplete cases, complete cases and total cases

	Incomplete cases (*n* = 30)	Complete cases (*n* = 44)	Total Time 1 participants (*n* = 74)
Caregiver characteristics			
Gender			
Male	23%	25%	24%
Female	77%	75%	76%
Age			
Mean	56.2	59.8	58.4
Range	23–79	39–84	23–84
Region			
Urban	50%	39%	43%
Regional	50%	61%	57%
Country of birth – Australia	77%	82%	80%
Religion			
Christian	79%	77%	78%
Other	4%	14%	10%
None	18%	9%	13%
Education level			
Professional/University degree	18%	24%	21%
Technical/apprenticeship	14%	19%	17%
High school completed	25%	21%	23%
Did not complete high school	43%	36%	39%
Occupation			
Retired	21%	29%	25%
Domestic	20%	7%	13%
Full-time employment	28%	29%	28%
Part-time employment	31%	31%	31%
Stopped work to be a caregiver – yes	10%	19%	15%
Reduced work to be a caregiver – yes	17%	28%	23%
Current health – mean (1-5 scale, 1 = very poor / 5 = very good)	3.67	3.93	3.82
Financial pressure – mean (1-4 scale, 1 = no financial pressure / 4 = a great deal of worry)	2.05	2.14	2.11
Previous caregiver – yes	43%	18%	33%
Care for others as well – yes	14% 7% children	21% 12% children	20% 10% children
Length of time caring for patient			
Mean (months)	24.57	29.58	27.69
Range (months)	2–120	1–240	1–240
Assistance – mean number of friends and family assisting	1.93	1.59	1.73
Community assistance			
None	46%	53%	47%
Home help	20%	25%	23%
Meals on wheels	7%	7%	7%
Nursing	40%	32%	35%
Reason you choose to care			
I wanted to	83%	93%	89%
I felt I should	17%	9%	12%
I have no choice	23%	5%	12%
Patient characteristics			
Relation of person to caregiver			
Spouse	59%	59%	59%
Parent	17%	27%	23%
Child	0%	2%	1%
Friend	7%	2%	4%
Sibling	10%	5%	7%
Other relative	3%	5%	4%
Gender of patient			
Male	59%	52%	55%
Female	41%	48%	45%
Age of patient			
Mean	66.2	70.4	68.7
Range	38–86	19–93	19–93
Patient lives with Caregiver – yes	83%	79%	80%
Level of dependency – mean	3.46	3.12	3.26
Illness of person – cancer	91%	96%	94%
Recent hospitalization – yes	40%	30%	34%

Table 3 Session evaluation questionnaires – means for each item

Question (scale)	Session 1 (*n* = 69)	Session 2 (*n* = 61)	Session 3 (*n* = 56)
	Mean	Mean	Mean
How interesting? (1–5)	1.61	1.39	1.41
New information? (1–5)	1.97	1.74	1.68
How useful? (1–5)	1.94	1.62	1.61
Sources of support? (1–7)	1.71	1.57	1.40
Roles of others? (1–7)	1.67	1.56	1.54
Identify symptoms? (1–7)	2.27	2.07	1.80
Identify needs? (1–7)	2.23	1.83	1.73
Identify emotions? (1–7)	2.24	2.07	2.00
Cope with death? (1–7)	3.53	2.90	2.52
Cope with bereavement?(1–7)	3.50	2.90	2.60

programme (i.e., the patient was not at home during or after the group education programme). Participants in these circumstances still reported receiving benefit from attending the programme (e.g., knowing how the syringe driver worked, and why it was used; suggestions for assisting the patient at meal times, etc.).

Although the majority of participants suggested they were very satisfied with the conduct of the programme, two participants emphasised the importance of ensuring the venue is well signposted, and time is allowed to welcome and introduce each other. Two participants reported that groups should consist of caregivers whose patients are at a similar stage (particularly with reference to the time from diagnosis). One male participant made the following recommendation: '*Have Caregivers in the group more similar in terms of experience. I felt he (*relative) *was at a more advanced stage and could have put others off as I was the "worst off" in the group)'*. However, three participants noted that they benefited from the reflections of a caregiver who had been involved in the patient's dying and imminent death even though their own relatives were not at that stage.

Table 4 Programme evaluation questionnaires – percentages agreeing with each item (*n* = 54)

Question	Percentage
	Responding 'Yes' (%)
Venue and refreshments met expectations?	100
Time of day suitable?	98
Length of session adequate?	92
Three sessions sufficient?	86
Forms easy to understand and complete?	88
Too many forms?	30
Facilitators presented information in an appropriate way?	100
Content met expectations?	100
Opportunity to be with other caregivers was of value?	98
Formed a friendship with someone attending sessions?	59
Any downsides from participating in the programme?	15
Would you recommend programme to others?	100

Three participants reflected they would have appreciated more information regarding medications. One participant described the responsibility for giving medications as *'overwhelming, scary to give so many medications'*. Six participants said that they would have liked more information regarding what to expect as someone is dying and the actual process after death.

Facilitator's journals

All the programme facilitators found the position description (as provided in the project manual[32]) valuable to guide their role and responsibilities. All programme facilitators acknowledged the multi-faceted nature of the role, and that it required a multitude of skills, particularly with regard to time management, flexibility in working hours, communication and group work. One facilitator wrote: '*It was tricky at times to juggle with my other role within the organisation but there was also real value in having this resource…'*. Programme facilitators suggested time required to manage the project varied from 16 h/week when initially setting up the programme to 8 h/week once systems were established.

Table 5 Programme evaluation questionnaires – mean score for 'impact' items (*n* = 54)

Question	Mean
Made me feel prepared to care	3.41
Made me feel more able to care	3.40
Made me feel more competent to care	3.43
Made me feel less isolated and alone	3.45
Improved how I may cope	3.44
Increased my awareness of medical symptoms	3.30
Improved my confidence to care	3.38
Equipped me with new strategies to help me care	3.38
Improved my knowledge of services that are available	3.76
Addressed practical issues I may face	3.56
I feel I can support my friend/relative	3.42
Total impact score	37.35

Table 6 Means and standard deviations for measures of adjustment for palliative care pre-intervention, post-intervention and follow-up ($n = 44$)

Measure	Time 1 ($n = 44$)		Time 2 ($n = 44$)		Time 3 ($n = 44$)		η^2 (sig.)
	Mean	SD	Mean	SD	Mean	SD	
Support-amt	6.82	1.53	6.73	1.48	6.95	1.89	0.02
Support-SAT	28.58	8.62	28.93	9.05	25.88	10.49	0.06
PREP	20.59	6.34	24.48	5.21	23.33	5.11	0.21***
COMPET	8.85	2.04	9.90	1.99	9.50	2.09	0.17**
BAS	16.52	5.58	16.23	6.70	22.93	7.61	0.33***
REW	23.11	11.04	26.00	10.05	25.41	11.41	0.09*
OOL	30.16	5.38	31.45	5.74	30.93	6.32	0.03
Need information	69.04	8.41	68.43	11.15	67.15	11.68	0.02
Needs met	60.67	12.18	64.41	12.09	62.08	11.48	0.09*

*$P < 0.05$; **$P < 0.01$; ***$P < 0.001$.

All programme facilitators strongly emphasised the importance of taking the time to develop relationships and to communicate with both the respective organisations and nursing staff on clinical sites, ensuring they are correctly informed about the project, and would result in positive benefits for recruitment to project and general cooperation. Clinical site staff benefited from explanations as to their role and the purpose of the project.

With regard to recommendations to the programme, the facilitators all agreed that making time at the beginning of session 1 to allow for adequate introductions was very important and assisted in *'setting the tone for the programme'*. All facilitators promoted a flexible presentation style for each session, tailoring the content to meet the needs of the participants, while ensuring the core content was covered. The inclusion of refreshments/meal provided opportunity for conversation between participants. Facilitators recommended increasing the minimum number of three participants to four for each programme. A minimum of three did not allow for the rate of participants who were not able to attend (primarily because of the deteriorating medical condition of their relative). Facilitators also highlighted the importance of providing a formal conclusion of the final session (session 3). Participants appreciated the opportunity to share personal details for ongoing contact beyond the life of the programme.

Discussion

The overwhelming majority of family caregivers who attended the psycho-educational group education programme reported that the programme was applicable, useful and accessible. This finding supports Harding, *et al.*[31] earlier work in this area. The utility of the programme was also reinforced via feedback from the programme facilitators.

The second hypothesis that family caregivers who attend a group education programme will demonstrate increased levels of preparedness, competence, social support, rewards, optimism and less unmet needs and burden was partially supported. There were positive improvements in participants' levels of preparedness, competence, rewards and unmet needs.

The favourable improvements in several domains offer further support to the relevance of the transactional framework of caregiver stress and coping, which underpinned the intervention. Additionally, this study supports earlier work, which also demonstrated that psycho-educational type interventions could increase positive perceptions of the caregiver role.[29] This finding is important as these positive perceptions may well act as a buffer against negative psychological factors influencing caregivers' experience.

However, improvements in optimism, social support, and burden were not detected. Given that optimism is considered to be a reasonably stable construct, perhaps it was overly ambitious to expect an intervention effect. In hindsight, the instrument chosen to measure social support for this study may not have been the optimal fit for the purposes of this research. Furthermore, attempting to improve levels of social support may have been unrealistic for this intervention and may require specific targeted strategies. Similar reasoning might apply to caregiver burden. Increases in caregiver burden remind us that caring for a dying relative is usually very stressful, and no matter how much support is offered, it may not lessen the demanding nature of the role. Findings from Walsh's[43] recent randomised control involving family caregivers demonstrates this.

Ensuring facilitators are skilled and experienced with group work was critical to the perceived success of the programmes. The delivery of the sessions was, therefore, enhanced by being provided in a safe and informal atmosphere, with capacity for the sessions to be guided by the needs of the participants while still ensuring the delivery of the key components of each session.

It appears that the programme could be readily incorporated into practice with minimal extra resources. Many specialist palliative care home-based services comprise multi-disciplinary staff, and as demonstrated in this study, suitably qualified programme facilitators were recruited from within the participating palliative care teams. From our evaluation, the approximate time commitment for the facilitator for each programme is 1 day/week for 5 weeks (from commencement of recruiting caregivers to completion of the programme).

For most caregivers, the experience of caring for a relative in the terminal phase of their illness is an unfamiliar one. The qualitative and quantitative results indicated that the group structure of the sessions provided participants with an opportunity to have their anxieties and experiences normalised and validated. The sharing of information assisted to demystify the role and to allow them to develop realistic expectations. The content allowed participants the opportunity to ask questions and acquire knowledge.

Limitations

The absence of a control group is an important limitation. The moderate sample size coupled with poor take-up of Time 2 and 3 data collection is a significant shortcoming. An additional post-intervention data collection point would have been advantageous to test retention of the knowledge gained from the programme. It would have been helpful to have the same facilitator facilitating all the 12 groups. However, given the positive feedback, it may indicate the session structure and content is sufficiently robust to absorb individual facilitator differences that may impact upon people's experience. Nonetheless, independent observer assessments to ensure facilitators adhere to the intervention protocol is recommended.

The fact that caregivers were looking after people at different stages of terminal illness may have hindered some caregiver engagement. Caregivers who were non-English speaking were excluded from study because of limited resources for translation. A comprehensive cost/benefit analysis was not undertaken. The course-evaluation surveys were developed by the research team specifically for this study and did not undergo rigorous psychometric testing.

Finally, testing of the intervention focused on caregiver perceptions. Knowledge and skills were not formally assessed.

Implications for practice and research

In addition to addressing the aforementioned limitations, future research studies might consider exploring other aspects related to the intervention. It would be useful to see how the programme impacts upon a family member's decision-making in relation to caring for their relative at home. For example, does improving caregivers preparedness, competence and unmet needs translate into increased or decreased resource utilisation and more or less home deaths?

Evaluating the intervention dose would be prudent. Might some caregivers only need one session rather than three? If so, how might this be determined? It would also be helpful to know if there were any indirect benefits for the patient. For example, were they now less concerned about their relative, knowing they had attended a programme aimed at helping them?

Given the interest from participants in resources related to specific areas including medications and the actual dying process, specific information packages could be developed to address these and other issues. Hence, consideration could be given to developing a range of resources, including multi-media, to complement the guidebook.

A key strength of this programme was the input of multi-disciplinary palliative care staff into the delivery of the education. It would be useful to ascertain how many referrals arose from the programme, and whether this may routinely be a useful mechanism for assessing caregiver needs.

The findings from this study and earlier work that comprised a one-on-one (nurse to caregiver) intervention[29] offers an enhanced evidence base to guide clinical practice. Although further testing and refinement is always useful, there are now psycho-educational programmes that can be implemented in practice that provide caregivers with a choice. That is, ideally, caregivers can elect to receive no care, usual care, one-on-one educational support or attend a group.

It is encouraging that other home-based caregiver studies are emerging such as those targeting reduction of patient symptoms,[44] and patient depression.[45] Additional recent studies have focused on reducing emotional distress in the carer[43] and increasing caregivers' comfort with their role.[46] Ideally, in the near future, a suite of interventions can be made available not only to those family caregivers involved in home-based care but also to those family caregivers involved in inpatient and aged care settings. If this is achieved then family caregivers can have greater confidence that the care they receive will be based on their needs.

Conclusion

The overwhelming majority of family caregivers of patients with advanced cancer consistently report a desire for information, resources and opportunity for discussion related to their caregiving role. The three-session caregiver education programme for home-based caregivers described in this study showed its effectiveness in meeting the informational needs of caregivers and enhanced their competence and preparedness for the role. Caregivers also reported increased positive feelings related to their role. Nonetheless, the programme would benefit from refinement and further evaluation with more participants.

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