

The development and evaluation of a multimedia resource for family carers of patients receiving palliative care: A consumer-led project

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ABSTRACT

Objective: Previous intervention research has shown that group education sessions for carers are effective but not always feasible due to the demands of the caregiving role and the difficulty in getting carers to attend. This project was a consumer-led research initiative to develop and evaluate a multimedia resource (DVD) providing information and support for carers of people receiving palliative care.

Method: Eight carers were recruited from a community palliative care service to form a steering committee for the project. In collaboration with two researchers, the committee discussed the topics that would be included in the resource, developed an interview guide, participated in the filmed interviews, and developed the evaluation program. The steering committee participated in a focus group as part of the evaluation to elicit their experiences of the project. An evaluation was conducted that included the following: questionnaires for 29 carers and 17 palliative care health professionals; follow-up telephone interviews with carers; a focus group with health professionals; and a focus group with the Carer Steering Committee.

Results: The carers and health professionals reported that the DVD was informative (93 and 94%, respectively), realistic (96 and 88%), supportive (93 and 88%), and helpful (83 and 100%). All health professionals and carers reported that they would recommend the resource to carers. Carers on the steering committee reported substantial benefits that involved the opportunity to help others and to openly discuss and reflect on their experiences.

Significance of Results: This is an important resource that can be utilized to support family carers and introduce palliative care. Currently, 1500 copies have been distributed to palliative care services and professionals nationwide and is available online at centreforpallcare.org/index.php/resources/carers_dvd/. Development of this DVD represents a strong collaboration between carers and researchers to produce a resource that is informative, supportive, and meaningful.

KEYWORDS: Family carers, Caregivers, Palliative care, Resource, Education

INTRODUCTION

International and Australian standards explicitly acknowledge that the needs of primary caregivers and family members should be considered as an integral

component in the provision of specialist palliative care services (WHO, 2002; PCA, 2005a; 2005b). Family carers within the context of palliative care have been defined as a relative, friend, or partner who has a significant relationship and provides assistance (physical, social, and/or psychological) to a person with a life-threatening, incurable illness. Family carers of palliative care patients shoulder many responsibilities, including personal hygiene, medical care, emotional

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support, financial and legal tasks, household duties, patient advocacy, and consultation with health professionals (Hudson et al., 2009). Several studies have shown that caring for terminally ill patients is associated with depression, anxiety, burnout, fatigue, and sleep problems (Thomas et al., 2002; Barg et al., 1998; Schulz et al., 2004; Payne et al., 1999).

Research has demonstrated that the role of a family carer is typically burdensome and can have psychological, physical, social, and financial repercussions (Rossi Ferrario et al., 2004). Depression rates between 12 and 59% (Hauser & Kramer, 2004; Grunfeld et al., 2004) and anxiety rates of 30–50% (Grunfeld et al., 2004) have been reported. A recent study involving 300 family carers following admission to palliative care reported that nearly 50% had moderate to high levels of psychological distress on at least one of four measures, which included depression, anxiety, demoralization, and pre-loss grief (Hudson et al., 2013).

Unmet needs are also consistently cited in the literature that relate to a lack of psychological support and information provision for family caregivers (Harding, 2005). The information that family caregivers have stated they need to support a dying relative includes: (a) how to provide for patient comfort, (b) practical care needs, and (c) strategies to minimize their own psychological burden (Kristjanson et al., 2003).

Hudson and colleagues (Hudson et al., 2008; 2009) have published evidence that carers who attend a carers' group education program report: (1) feeling more prepared, (2) feeling more competent, (3) having fewer unmet needs, and (4) experiencing the more positive aspects of the caring role. Furthermore, carers report that hearing about the experiences of other carers and being supported by other carers was a benefit of attending the group program. However, recruitment to the programs was hampered by carers' work and family commitments. Another method of delivering this information, such as by DVD, was required for the large proportion of carers who are unable to attend group programs.

While there are many sources of information for carers and/or health professionals available—including fact sheets, booklets, books, webinars, online learning modules, and helplines—there are only a few DVDs available that focus on the carer's rather than the patient's experience. The weaknesses of the DVDs that are available include the fact that they usually focus on one aspect of care such as the practical aspects of caregiving (e.g., bed baths, managing medication) or decision making about stopping treatment, while other DVDs available for carers are disease specific (e.g., Alzheimer's). While dis-

ease-specific information is very useful, it is only useful for certain subgroups of carers. There are many disease types, and it would be impractical to provide a separate resource for every disease. There is one DVD produced by the Canadian Partnership Against Cancer entitled "The Truth of It" that provides both information and support for carers of patients at the end of life. However, this is still produced for carers of people with cancer and therefore would not be relevant for many other carers.

The aim of our study was to develop and evaluate a multimedia resource (DVD) for family carers of someone receiving palliative care in order to meet carers' informational needs and provide peer support. A secondary aim was to set up a steering group of current and former family carers to develop the specific contents of the DVD and to be involved in its evaluation. We also wanted to explore the carers' experience of being involved in the project.

METHOD

We recruited a Victorian community-based palliative care service to be involved in this project. Ethics approval was received for all its aspects.

Establishing a Carer Steering Committee

To establish the carer steering committee (CSC), a letter of invitation was sent from the service manager. Those carers who contacted the project officer were given more detail, and a Plain Language Information and Consent Form was posted to those carers who wished to participate. Carers were required to attend five meetings and received honorarium payments for their time to cover time and travel. Eight carers agreed to be involved in the CSC and assisted in the development of the DVD for carers.

Development of the DVD

The DVD was developed with direct input from the CSC. This was a committee that included eight current or bereaved carers. They met on five occasions with the project team to discuss the objectives and content of the DVD and to assist in its development, including being interviewed and filmed for the DVD. Using information from previous research and written resources for carers of patients receiving palliative care, the CSC developed the content around the following themes.

1. **Becoming a carer (and the role of a carer):** This section explores both positive and negative feelings about becoming a carer and provides information on the types of support that carers provide to their relatives.

2. **Looking after yourself and your relationship:** This section explores the stress of caregiving and provides examples of ways a carer can look after their own physical and mental health as well as their relationships.
3. **Family and social support:** In this section, carers speak openly about how some of their social relationships changed over this time and who they sought support from.
4. **The palliative care team:** This section provides information on the services provided by the palliative care team and the types of support a carer can expect.
5. **Practical issues:** This section explores some of the generic practical issues that carers will need to consider when they are caring for someone at the end of their life.
6. **End-of-life discussions and care:** In this section, carers speak openly about what happens during the last few days of life, including the death itself.
7. **Bereavement:** The final section provides information on where to seek support and includes carers talking about their own experiences of bereavement.

An interview guide was developed based on the key content areas that were to be included in the DVD. Each CSC member was asked to write their answers to the questions in the interview guide. The written answers were then shared with the other members of the CSC to promote further discussion and consensus about what should go into the DVD. The filmed interviews formed the basis of the DVD and were based on the carers' responses to the seven themes listed above. The CSC was also involved in the editing process and approved the final version of the DVD.

Evaluation

A list of 20 bereaved carers and 26 current carers was accessed from the participating palliative care service, and 15 (75%) bereaved carers and 15 (58%) current carers agreed to review the DVD. Recently bereaved carers (less than six months), carers who were younger than 18 years, and carers who did not speak English were excluded from the study.

Carers were sent a letter from the manager of the service informing them of the project within one week of admission. Carers then received a telephone call from the project officer to outline the project and invite them to be involved in the evaluation. Carers were sent a copy of the DVD to watch and a question-

naire to complete and return. Once questionnaires were returned, the project officer followed up with a phone call to get additional qualitative information from the carers. The telephone interviews were transcribed directly by the project officer.

All palliative care health professionals from the participating palliative care service were sent an email inviting them to participate in the study. Health professionals were invited to attend a group viewing of the DVD and to then complete a questionnaire and participate in a focus group. Seventeen health professionals agreed to participate. The focus group was recorded and later transcribed.

The questionnaire included some basic demographic information as well as a number of questions with rating scales measuring whether participants found the film helpful, interesting, informative, realistic, inspiring, supportive, or upsetting. They were also asked to rate their satisfaction with the film and evaluate how well they related to the carers in the film. The questions on the questionnaire were all specifically designed for this study. Semistructured interview questions and focus group questions included the positives and negatives of the DVD, the usefulness of the DVD, and general satisfaction with the DVD.

Qualitative content analyses of the interviews and focus groups were conducted by the project officer to identify key themes and content. The evaluation questionnaires were collated and analyzed using descriptive statistics.

RESULTS

Carers and Health Professionals

The 29 carers who participated in the evaluation were predominantly female ($n = 21$; 72%) and ranged in age from 29 to 84 years (median age = 49 years). The carers were caring for either a spouse ($n = 21$; 72%) or a parent ($n = 8$; 28%) for between 2 months and 20 years. The majority lived with the person for whom they were caring ($n = 25$; 86%).

The 17 health professionals who participated in the evaluation were multidisciplinary and included nurses, allied health professionals, a bereavement coordinator, a social worker, and a volunteer coordinator.

The results showed that all carers would recommend the DVD to others, and 27 (93%) carers stated that they were satisfied or very satisfied with the DVD. Further, all of the health professionals would recommend the film to others and reported that they were either satisfied or very satisfied with the DVD.

Table 1. Carer and health professional ratings of the DVD

Item	Mean Score (0–4 Scale*)		% Responding with a 3 (Quite) or 4 (Very)*	
	Carer (n = 29)	Health Professional (n = 17)	Carer (n = 29)	Health Professional (n = 17)
How helpful was this short film?	3.17	3.41	83%	100%
How interesting was this short film?	3.45	3.35	90%	100%
How informative was this short film?	3.55	3.35	93%	94%
How realistic was this short film?	3.83	3.18	97%	88%
How inspiring was this short film?	3.55	3.06	86%	76%
How supportive was this short film?	3.38	3.47	93%	88%
How upsetting was this short film?	1.97	1.24	24%	6%
How well did you relate to the carers presented in this short film?	3.55	3.71	82%	94%
Overall satisfaction in this short film?	3.66	3.18	93%	100%
How much did this short film enhance your ability to care for your relative?	2.73	N/A	65%	N/A
Recommend this short film to others?	N/A	N/A	100%	100%

*0–4 Likert scale, where 0 = not at all, 1 = a little, 2 = somewhat, 3 = quite, and 4 = very.

Table 1 shows the mean response to each item for both carers and health professionals. Carers rated the DVD highest for being realistic, informative, interesting, and inspiring. Health professionals rated the DVD highest for being supportive and helpful. Both groups related well to the carers in the film and were overall very satisfied with the film. On average, the carers and health professionals found the DVD only “a little” to “somewhat” upsetting, and, given the content of the film, this was viewed positively by the research team. Finally, the results showed that 65% of carers reported that the DVD had enhanced their ability to care for their relative “quite a lot” or “very much.”

The qualitative data showed that the overall response to the DVD was positive, and many carers reported that they wished they had seen it earlier, when first referred to palliative care:

Excellent, I received it too late. It would have been good when we were first referred to palliative care. I can relate to everything the people said. So much was word for word what happened to us. [bereaved carer]

I was disappointed that we were not told by the hospital about palliative care. It is important to get the word out there, and this DVD would do that. [carer]

I really think it is a valuable and worthwhile project which would be helpful to see, if you were caring. Timing is tricky as to when it is appropriate and how one introduces this appropriately. [health professional]

Carers commented that they liked that the people were real and that they could relate to the carers in the film: “One older lady had my sense of humor, it was sad but heartfelt”:

(. . .) with the lady, how it was beautiful when her husband died and this happened when my mother died, and I felt at peace and spent some time with her. [bereaved carer]

Participants reported that the film had assisted them in their role as a carer in that “It helped me to know what to expect.” One carer stated, “I have a journey ahead of me, and it is good to know that palliative care is there.” Others reported that the DVD had empowered them “not to be scared and ask more questions and ring the nurse.” Health professionals liked that it also presented caring in a positive light and was “a positive film showing you can come out the other side. You can survive and be enriched by the experience which is doable.”

Many participants commented that the DVD offered insight and helpful advice:

Good advice; there is no “should-do”; do what is right for you; if there are offers of help accept it; plan for when the loved one is gone. [carer]

“Walk away, just walk away” was one point that stood out for me. You do get very frustrated and it is a good point. You need time for yourself and looking after yourself. [carer]

Refreshing honesty from the Australian point of view, dealing well with difficulties and discussing

some difficult aspects; for example, injections, medications, beds, wheelchairs, 24 hours phone call, power of attorney, wills, volunteers, and feeling safe and secure at end of life. [health professional]

Good to hear the actual specifics of how the carers do their self-caring activities. [health professional]

In addition, carers commented that the DVD provided a sense of support by showing that others were having similar experiences. One carer stated, “The comment about friends disappearing helped me feel connected and not alone. You don’t feel singled out and alone.” Another carer reported, “The other people’s views were really good. Thought we were alone, but can see that others had the same experiences and help is out there.”

The bereavement section of the DVD was also commented on by participants:

I had a “double take” at the bereavement section but found it heartfelt and real. [bereaved carer]

I am more at peace. You are never ready for these things, and you know you are going to get old but you are not ready. The bereavement section was hard to watch but true. Glad I looked at it, made me feel stronger and ready to get on with it. [carer]

Demystifies death and refers to the patient remaining with the carer for a number of hours after the patient dies, very helpful to talk about this. [health professional]

While carers did not have any negative feedback about the film, two health professionals suggested that the film could include: (1) cultural diversity, (2) financial issues, and (3) ambivalent relationships, as in “Relationships were very loving, but a lot of people have very difficult relationships—ambivalent.”

Carer Steering Committee

The results of the focus group with the CSC showed that involvement in the project was overall highly valued by committee members. Carers reported that they had chosen to be involved in the project to help others and share what they had learned:

I thought our experience could assist others to realize that palliative care means comfort and support.

It has been an opportunity to contribute and help others as well as learn and talk about it.

Carers commented that they had really valued having another opportunity to talk about their experiences in a supportive environment:

It helps enormously to talk about the experience. It is important to be part of a group that has a common link, and especially when it is so incredibly deep and emotional. My future well-being has been seriously enriched by this, and not everyone gets this opportunity.

It has allowed me to think in depth about the experience, and I have enjoyed that.

Carers also commented on the importance of the researchers providing a safe environment during meetings and regular communication between meetings:

Relationships of trust have been built through regular meetings. The project leaders actively ensured no “pressure” to participate or contribute with such an emotional topic. At every stage participants were reassured of free choice.

The support was consistently high. Project staff guided the group superbly without any pressure. They showed deep respect and unconditional care and consideration.

Always felt in the loop, with emails, communications, and phone calls.

Carers also felt that they learned new skills or gained new knowledge by being involved in this project:

I had never given the role of an editor a great deal of thought and to see what she has done with those hours and hours of filming and the incredible intuitive decisions she has made. It has given the DVD great depth; it is so moving.

To me the experience has been one of growth. I have learned so much from the other participants.

Distribution and Feedback

One thousand copies of the DVD were distributed to 234 relevant agencies, including (approximately): 700 copies to palliative care services in Victoria, 200 copies to palliative care services across the remainder of Australia, and 100 copies to other relevant agencies and individuals. A further 500 copies of the DVD were kept at the Centre for Palliative Care and have been mailed out on request. The DVD is also available to download chapter by chapter from the Centre for Palliative Care’s website centreforpalliative.org/index.php/resources/carers_dvd/.

Brief feedback forms were sent out with copies of the DVDs to assess level of interest and satisfaction with the resource and to gauge how the resource would be utilized. Of the 26 agencies that returned the feedback form, all would recommend the DVD to others. On a scale from 1 to 5, where 1 was “not satisfied” and 5 “very satisfied,” 85% of respondents rated the DVD as a 5 and the remaining 15% rated the DVD as a 4.

The majority of respondents said that the DVD would be very useful in their work with families/carers to: introduce palliative care, educate people about the services palliative care can offer, assist in decision making, highlight the benefits of caring, provide information on the role of a carer, normalize feelings related to being a carer, and use during carer education sessions.

Some respondents also reported that the DVD could be employed to promote discussion in bereavement support groups. Respondents also highlighted that the DVD would be very useful for staff education, including student and volunteer training. Two respondents did state a concern that not all palliative care services across Australia would be able to offer all aspects of the services discussed in the DVD.

DISCUSSION

Previous intervention research has shown that, while effective, group education sessions for carers are not always feasible due to: (1) the demands of the caregiving role and (2) the difficulty in getting carers to attend (Hudson et al., 2008; 2009). The aim of our study was to develop a resource for carers that could be accessed at a carer’s convenience and that would provide some of the same information and support received from a group education session. Furthermore, we were committed to having strong consumer involvement in all aspects of the project.

A completed resource for carers of patients receiving palliative care was developed with strong input from a group of past and current carers. The resource was then evaluated by 29 carers and 17 health professionals. The results of the evaluation were very positive, with all participants reporting they would recommend the resource to others. A number of benefits of the resource were described as: (1) providing useful information and advice, (2) being able to relate to the carers in the DVD, (3) helping to understand the caring role, (4) feeling supported/connected (not alone), and (5) demystifying death. Overall, it was considered a positive tool and a good introduction to palliative care that would be useful early on during admission to palliative care.

The research was limited to one community palliative care service, but the themes developed for the

DVD included broader issues highlighted in the international literature. The eight carers filmed in the DVD were a self-selected group, articulate and insightful, with a strong desire to help others by sharing their experiences. Further research is required to evaluate the DVD using a pre- and post-test methodology or in different contexts and with different samples. Further, an important extension of the application of the DVD would be to evaluate it as part of the palliative care referral process.

It is also noteworthy that the consumer involvement in this project was a strong contributor to the success of the final resource. The project demonstrates the benefit of genuine collaboration between researchers and consumers, which in this case resulted in development of an informative and meaningful resource that consumers could relate to and that can assist in improving carers’ understanding of palliative care and their role as a carer.

The DVD is available to download a chapter at a time from the Centre for Palliative Care’s website, http://centreforpallcare.org/index.php/resources/carers_dvd/.

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