

Information provision for palliative care families

Peter Hudson, Sanchia Aranda and Linda Kristjanson suggest key strategies for meeting the supportive information needs of family carers of palliative cancer patients

Caring for a family member who is dying of cancer can have negative physical and psychological implications for the carer.¹⁻³ One means of alleviating this distress for family carers is to ensure that they are supported by healthcare professionals knowledgeable about palliative care.⁴ Access to palliative care supports varies greatly. However, the empirical literature confirms that many carers have needs that remain unmet despite input from healthcare professionals, suggesting that usual approaches to family care may not be sufficient.⁵⁻⁷ Carers consistently request additional information to assist them in preparing for and managing the care of a relative in need of palliative support.⁸⁻¹²

Information provision may empower carers by aiding them to solve caring problems and providing them with an increased sense of control.¹³ It may also assist family carers of dying patients to cope and lessen anxiety.¹⁴ Lack of adequate information forces carers to manage their roles in a speculative or uncertain manner. In this scenario, the carer will probably either be overprepared or underprepared for future demands.¹⁵ The stress associated with this uncertainty may be extreme.

Need for further research

Although information-focused interventions for family carers have been consistently advocated, they remain untested, pointing to the need for intervention studies in this area.^{16,17} The aim of this paper is to provide an overview of key recommendations that focus on enhancing information support for carers of palliative care patients. The paper will include empirically based recommendations advising how to deliver this information to family carers. The intent of this overview is to offer healthcare professionals a synthesis of 'best practice' guidelines and provide a template that might be used by researchers to structure future studies aimed at

developing and testing information-based interventions. Evidence-based approaches in palliative care are urgently required to justify interventions and resource allocation.¹⁸

What information?

There has been a substantial body of literature regarding the information needs of family carers and strategies recommended to meet those needs. Our literature review included the search terms: palliative, family carer, cancer, information, support, intervention and needs and the following databases were accessed: CINAHL, Medline, Psychlit, and Current Contents for the period 1980–2001. The search involved a comprehensive evaluation of the literature, but is not classified as a systematic review. Table 1 (overleaf) provides an overview of the recommendations for carer information provision, identified from the literature, incorporating studies where key information needs were identified by family carers.^{11,13-15,17,19-38} The list of references acknowledged is not intended to be all encompassing; instead it seeks to exemplify the evidence base in this area.

Lack of adequate information forces carers to manage their roles in a speculative or uncertain manner

Strategies for optimal information provision

The delivery of information interventions is guided not only by the type of information, but

Key points

- Caring for a family member who is dying of cancer can have negative physical and psychological implications for the carer.
- Information provision may empower carers by aiding them to solve caring problems and providing them with an increased sense of control.
- If healthcare professionals are to address the information needs of carers comprehensively, it is paramount that the assessed needs are documented in the plan of care.

Table 1. Recommended information and supporting empirical rationale as identified in the literature

Type of information	Supporting empirical rationale	References
Preparatory information regarding typical aspects of the role	Helps carers to anticipate the course of the patient's illness and provides carers with an outline of what to expect	11,17,19–23
Carer rights	Ensures that carers are aware that they have a choice with regard to the level and type of care they provide	17,24,25
Patient's medical condition and treatment plan (upon patient approval)	Helps carers to have realistic expectations and to be able to plan for the future	24,26–29
Acknowledging the difficulties of responding to a relative's palliative diagnosis	Recognition that some people find it difficult to accept that a relative is dying	30
Assessment and management of patient symptoms	Reduces trial and error approaches that may be detrimental to the patient's wellbeing	19,29,31
Hygiene and ambulatory care	Promotes safety	32,33
Financial implications of caring and potential reimbursements	Provides carers with realistic insight into the costs associated with supporting a dying relative	32
Coping skills	Helps carers to respond to the emotional implications of caring for a dying relative	24,32
Potential impact of relationships with the patient and with family members	Carers need to be made aware that the patient's illness can put a strain on the entire family	24,26,31
How to access resources	Carers not only need to be told about resources that are available but also how to access them	24,29
Problem-solving skills	Helps carers to assess and respond to issues	13,34
Potential carer rewards and satisfaction	Carers are often advised of the challenges of caring but not of the potential personal gains and rewards	15,17
Enhancing carer competence	In order to gain satisfaction from caring, family members usually need to feel confident about their skills	25,34
Respite	Carers need to be provided with ways of taking a break from the role	15,32
Signs that death may be approaching	Helps carers to prepare for impending death	14,30,35,36
Responding to the dying process; the death and bereavement	Provides carers with an opportunity to 'say goodbye', prepare for the funeral and raises awareness of common bereavement issues and resources	26,31,37,38

also the approach to delivery. The following outlines some of the key factors that are important to consider when providing information to family carers. To complement the information provision strategies, key questions that may assist healthcare professionals to meet such information needs are offered. The questions have been developed based on our clinical and research experience. These approaches require testing for their effectiveness by future researchers and are not intended to be prescriptive, but rather to serve as cues for consideration when interacting with carers.

Promoting a conducive environment

Carers often consider their personal needs as less important than those of the person who is dying.¹⁹ It is, therefore, important that healthcare professionals reinforce the importance of carer needs and create an opportunity to address specifically carer needs.

The key questions suggested to assess carer information needs are less effective if an optimal environment for communication exchange between the healthcare professional and carer is not fostered. Provision of a private time and location for this exchange enhances attention to a family's needs. Furthermore, carers require time to make sense of the information that they receive.¹⁹ Healthcare professionals cannot assume that provision of information is only suitable at one point in time. Carers need advice, recognition of their circumstances, endorsement of their worth and above all, an opportunity to talk.¹⁵ Family members' needs for open and honest information from healthcare professionals is consistently reported in literature spanning more than a decade.^{28,39–41} It appears that this need endures as a priority.^{12,14}

To provide an optimal environment for discussion it is important to incorporate principles of therapeutic communication. Time

alone with the carer(s) to discuss issues, without their ill relative present, may be beneficial.

It may be difficult to attempt to meet the needs of all significant family members. Hence, an appropriate starting point for family information support may begin with the primary family carer, who could also be asked to communicate relevant information to other family members.³² In some instances, however, this will not be suitable and communication with different family members at various time points or as a group may be necessary to address the specific concerns of individuals.

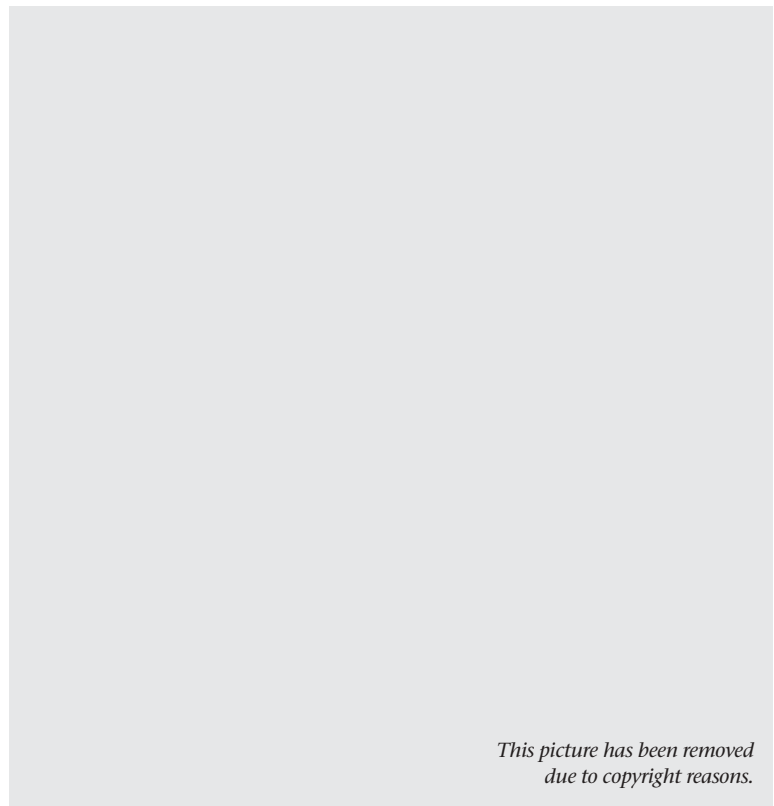
Carers needs should be assessed regularly. Carers appreciate having continuity of information and regular contact with the same healthcare professionals as they may not want to ask questions or raise issues with strangers.^{42,43} The optimal situation would incorporate care provision where continuity and consistency are provided.⁴⁴ Key questions to promote an optimal environment for assessing needs include:

- I would like to ask you a few questions to learn more about what sort of information you might need to help you
- When and where would be a convenient time for you to discuss the situation?
- Would you like to have your unwell relative/friend or any other family/friends present during our discussion?

Family meetings can be an extremely valuable means of assessing and delivering information, but must be sensitively used and well co-ordinated.⁴⁵ Family meetings can be held in any setting and are most useful at times when important decisions are required (for example, determining the site of care or considering the need for additional support). Clear aims and objectives help healthcare professionals to achieve positive family outcomes. In addition, when one person chairs or leads the meeting, this helps to ensure that the views and needs of all are heard and attended to. Consideration should be given to who attends the meeting; if too many healthcare professionals are present, this may not allow all parties to contribute effectively and may be overwhelming. Healthcare professionals must also be attentive to emerging family concerns that may arise in the meeting and flexible enough to adapt the meeting to respond to individual family needs.

Information according to individual carer's needs

Understanding the carer's perspective of the caring situation enhances intervention success.



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Family meetings can be an extremely valuable means of assessing and delivering information

Assessment of the carer's needs for information is a key starting point.^{15,46} Rose *et al* also acknowledge the importance of an individualised carer assessment, arguing that healthcare professionals should not assume that family needs will be similar within a family unit.⁴⁷ Grbich *et al* found that, although the majority of carers wanted clear information, a few family members they studied preferred not to know specific details about the patient's illness all at once.¹⁴ Healthcare professionals must be careful not to assume that if some information is good, more is better. A 'bigger dose' of information may not necessarily correlate with enhanced carer adjustment.⁴⁸ Information interventions should be provided in accordance with assessed need, provided at the pace and in the amount that the individual family member is able to receive. Key questions to ask include:

- What do you find most challenging at the moment?
- What information do you need now to help you with the situation(s)?
- What information might you need later to assist you to care for your relative/friend?
- What are some of the resources from the palliative care service that you are aware of?
- How would you access these resources? Do you need help to do so?

- How might you respond if your relative had an increase in pain or nausea?
- Do you have any questions at all about your relative's care; yourself or the palliative care service?

Providing a variety of resources

Once an understanding of the carers' information needs is established, it is important to offer resources that can reinforce the information provided verbally. People who are anxious or in crisis often find it difficult to filter and retain verbal information.²⁴ Moreover, adults learn in different ways and thus, carers need a variety of formats from which to choose information pertinent to their role.^{17,22} Written brochures are useful and, if available, audio or video tapes may reinforce or extend information provided.^{43,49} Carers have also recommended that home videos in a range of languages be developed, explaining palliative care and the implications of supporting a person with advanced cancer. Personalised information packages for carers have been recommended and may be an ideal approach, with provision for additional tailored information supplements according to individual family carer needs.¹⁴ Key questions to ask include:

- Have you been made aware of some of the written information resources (for example, brochures) with regard to supporting someone with palliative care needs?
- Would you be able to access these resources easily or would you like some help to know how to go about finding more?
- Some people find it helpful if I write down any information that arises from our discussion that might be useful to you. Would you like me to do this for you?

Providing appropriate information

Information, that is easy for carers to understand, also aids learning.¹⁹ The content should be provided at a level that is relevant to the carer's educational background and experience.¹³ Payne *et al's* survey⁵⁰ of the written information provided to patients and carers in palliative care units in the UK revealed that the quality of these publications was mostly suboptimal. More than 1,000 different types of leaflets were being used, 89% of which were internally produced, with most relating to specific information about the respective palliative care unit. The documents were evaluated for readability and it was estimated

that 64% were difficult to read. The authors concluded that many patients and their families might be unable to find adequate information about palliative care services and treatment options and called for urgent improvements in the standard of written information. Key questions to promote information provision according to educational level include:

- Can you think about your own way of learning new information, and let me know what are the best ways for you to receive information?
- Would it help if we went over again, some things we have spoken about in the past?
- Would you like me to demonstrate a task for you or I can watch you undertake the task and provide feedback?
- It is very common for people to forget new information, so I am quite willing to repeat information. So please let me know if this would be helpful.

Provision of information at critical points

Comprehensive supportive information is particularly important at critical transition points, especially at the start of caring or at the end of a period of active care. The preparedness of a carer at the start of caring is a major factor influencing the future burdens of care.¹⁵ Carers have expressed a need for information to be offered early in the caring role. Adam³⁶ sought to identify whether carers of dying patients at home had received enough information in the acute hospital, before discharge, to help them to prepare for their caring role. The qualitative study revealed that one-third of carers (n=12) were dissatisfied with the information received. Few carers were offered a role in care within the hospital setting, half the carers found administering medications stressful and believed that they had not received adequate information to prepare them for this role. Other examples of critical caring points include: when the patient requires hospitalisation; when the carer is finding the role particularly difficult to manage; and when it appears that the patient's death may be imminent.

Documenting, planning and evaluating information issues

If healthcare professionals are to address comprehensively the information needs of carers, it is paramount that the assessed needs are documented in the plan of care.⁴⁶ The plan needs to incorporate who the information is

It is important to offer resources that can reinforce the information provided verbally

for, precisely what information is required, how the information has been delivered (and via what means) and what information is still required, when, by what means and by whom. Furthermore, strategies need to be put in place that allow for evaluation of information-focused interventions. Interdisciplinary team meetings may assist in this process.

Conclusion

These guidelines provide a vehicle for moving closer to evidence-based practice in the provision of carer information. The strategies outlined for improving approaches to information provision are drawn from the literature and our experiences. In response to immediate family care needs, we propose that these guidelines will assist healthcare professionals in being more effective in providing the type of information carers require in a manner that is most helpful to them.

In the longer term, it is desirable that these best practice suggestions translate into evidence-based strategies. Without achieving the latter goal, we may not be meeting the needs of family carers of palliative care patients. Therefore, future research in this area must move beyond the assessing of information needs, to the testing of structured approaches to information delivery.

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