

integration of supportive care services and programs into everyday clinical practice in a tertiary oncology setting. Nurses were key players in the changes at both the organisational level, as well as in leading systematic change to help routinely identify patient need and facilitate a process that enhances access by the patient to supportive care services and programs. Using a systematic approach to care provision, nurses can intervene more effectively and efficiently by targeting services to differing levels of need in a timely manner across the care continuum.

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CARING FOR FAMILIES OF PEOPLE WITH CANCER: EVIDENCE AND INTERVENTIONS

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Each year approximately 495,000 Australians are diagnosed with cancer¹. If each of those individuals has two or three family members, the number of Australians facing the challenges of cancer care is notable. Given the fact that cancer is, for the most part a disease of the older person, it is anticipated that the number of people with cancer will continue to increase as the proportion of the population in the older aged groups expands. The needs of families who support these people are therefore expected to burgeon.

When an individual is diagnosed with cancer, the impact reverberates through the family, touching all members. Family members confront uncertainties about the meaning of the diagnosis, the prognosis of the patient and the patient's needs for care and support. Family members are often required to manage physical care changes and arrangements and practical difficulties with daily living, while they handle their own emotional distress about the patient's care and concerns about the future².

Families bring with them diverse histories and different approaches to coping. Some may experience the cancer illness as a prompt for greater closeness in relationships, a time for reflection about goals and values and enhanced family interactions. Others may bend under the burden of the illness and communication difficulties and dysfunctional family patterns may emerge. Memories about the cancer illness linger during the bereavement period, sometimes complicating their grief reactions and leaving them with feelings of regret³. A family's perceptions of the care experience may also affect their health and family functioning⁴. This article provides a synthesis of empirical work that offers direction about how to provide support to families of people with cancer.

Defining the Family

A discussion about caring for families requires clarification about what is meant by the term, "family". Care of the family

of a person with cancer is best served by an open and inclusive definition. Families are comprised of different individuals who may or may not be related through blood or legal ties. A family may be one couple, or may be made up of a large network of relatives, close friends and neighbours. Individuals within families will have various needs, commitments, personal histories and personal resources.

Failure to recognise the distinct characteristics or membership of families may exclude some family members who may be in need of support⁵. This error may be more common when families do not fit a traditional definition of family. Individuals who are in homosexual relationships, blended families, families who live geographically apart and those without apparent formal ties may be neglected in the family care approach if their relationship to the patient is not understood and respected^{6,7}. Therefore, supportive care to families begins with a careful consideration of who constitutes the family.

A useful definition of the term, family, is "those closest to the patient in knowledge, care and affection. This includes the biological family, the family of acquisition (related by marriage/contract) and the family of choice and friends (not related biologically, by marriage/contract)"⁸.

From a clinical perspective, the most functional approach to defining and knowing the family who is affected by an illness such as cancer, is to allow the patient and his/her family members to self-define the family, so that the unique structure and dynamics of the family can be acknowledged.

Impact on the Health of Family Members

Families of cancer patients experience a number of health changes both during the patient's illness and in the bereavement period^{10,11}. Family members may experience exacerbations of chronic illnesses (eg. hypertension). There is also evidence to indicate that children may experience more illnesses and accidents during a terminal illness of a family member¹². Kristjanson and colleagues¹⁰ revealed that family members experienced deterioration in health during the patient's illness and in the bereavement period. The health status of these individuals was much poorer when compared to a 'normal healthy' population. Health deterioration was most evident in the form of mental health changes (eg. difficulty

concentrating, depressed mood, anxiety states). The extent to which these changes were indicators or precursors of more serious clinical depression or anxiety disorders was not determined. However, findings suggested that referral of these family members for further assessment was warranted. Family members who experienced deterioration in health in the palliative care phase also reported similar deterioration in the bereavement period three months following the death of the patient. Other researchers have also described these types of mental health changes^{13,14}. Health changes most frequently present in the form of psychological health difficulties (eg. depression, sleep disorders) and cognitive changes (eg. difficulty concentrating)^{15,16}. Therefore, attention must be paid to the health needs of family members.

Impact on Family Functioning

The health of the family as a unit may also be affected by the cancer illness experience. Changes in family structure, roles, relationships, communication and conflict may be evident. Central to the health of the family as a unit is the ability of family members to communicate with each other, the patient and health professionals. It has been documented that poor communication causes more suffering to cancer patients and their families than any other problems, with the exception of unrelieved pain¹⁷.

Communication is essential to healthy family functioning and families who have limited communication skills are less able to manage stressful situations¹⁸. The family's previous patterns of communication determine to a large extent the degree of communication that occurs within the family at the time of the cancer illness. Some family members may be open and clear in their exchanges about the illness, treatment decisions, fears and doubts. Others may be reserved in their expressions of feelings, holding back worries, regrets, and uncertainties.

Relationship strains may occur as both the patient and family members endeavour to protect each other from worries and concerns about the illness. Patients may serve as a type of gatekeeper of information, as it is usually the patient who has primary contact with the health care team. This is particularly common when parents have cancer and are cautious about sharing information about their illness with their children^{19,20}. Family members often rely on the patient to convey important information about the illness to help them know how to cope with the treatment or subsequent phases of the disease and may feel uncertain or frustrated if they lack information. These protective approaches to communication can contribute to conflict, anxiety and poor communication within the family¹⁸.

Care Interventions to Support the Family

Family members provide support to the patient and have needs for support from health professionals. Family members whose own needs for support and assistance are not met are less able to maintain their supportive roles and are more likely to experience mental and physical health problems themselves^{21,22}.

In a review of cancer care literature specific to family interventions, Pasacreta and McCorkle²³ reported limited research on evidence based interventions aimed at family caregivers. They point out that identifying caregivers who are at risk for problems and tailoring interventions to their special needs seems to be an important direction for future research. This more recent review confirms that most of the research on families' experiences of cancer care has been descriptive. However, a number of recently reported care interventions directed toward the family have potential to be therapeutic. The results of these studies can be classified into four

categories: information giving, practical assistance with physical care requirements, emotional support and family communication, and assistance to manage the financial burdens associated with treatment and care.

Information Giving

The literature consistently documents difficulties that family members of cancer patients report regarding access to information²⁴⁻²⁶. Family members describe difficulties obtaining specific, straightforward information in a way that they can understand. Use of medical jargon is frequently mentioned as a barrier to adequate communication about the plan of care²⁷. Language barriers may also be a problem if patients and family members do not share the same language and cultural background as the health care professional²⁸. As well, differences in educational levels between health professionals and patients/families can create problems with exchange of content²⁹.

Health professionals may overload family members with large amounts of information or may provide information in small amounts in an effort to not overwhelm them with too much detail³⁰. This can create difficulties as family members vary in the extent to which they may be able to assimilate and integrate the shared information³¹.

Family members report a hesitancy to bother busy health professionals with questions about care because they believe that the health care providers are primarily responsible to the patient and that their needs and concerns are tangential⁴. The perceived unimportance of communication with the family is partly represented by the lack of time and space created or allotted for this communication exchange. The apparent lack of space for discussion about care plans and goals conveys a message that this interchange is not too important. It is not unusual for patients and families to report communication about treatment and care in the hallways of busy hospitals, over the phone or in small clinic rooms with little privacy or time for discussion³². Health professionals may also limit their information sharing with patients and families because of the pace of their busy work schedules, an assumption that the patient/family has understood the information conveyed and a discomfort in knowing how to communicate difficult/bad news^{33,34}.

Attention to these factors that limit effective communication exchanges between family members and health care providers may assist families to fill this information vacuum and feel more confident about coping with the patient's illness. Families who are well informed are better able to function in a supportive role and experience less illness-related anxiety⁷.

One of the most effective ways of assisting families is to empower them to provide care by giving them liberal amounts of well timed, simple information that helps them cope with the care challenges they face³⁵. Families will require information about how to provide comfort care, how to communicate within the family, how to pace their own energies and when to call for assistance. The desire for open and honest information from health care professionals is consistently reported^{28,36,37}.

Home care nurses are reported to be a valuable source of information^{38,39} and families value 24-hour access to information³⁷. In rural communities, the role of the nurse has also been found to be particularly important to families, as this health professional is often the most accessible and specific in providing information regarding how to provide care and support⁴⁰. Use of a family conference has also been reported by family members to be especially helpful in allowing them access to information and an opportunity to clarify questions³⁷.

Families need to be made aware of the typical demands associated with supporting a relative who may progress to a terminal phase of illness so they can prepare themselves⁴¹⁻⁴⁴. Families should be informed that they have a choice with regard to the amount and type of care they offer their relative⁴⁵. Family members should be advised not only about the resources and services available, but also about how to access them^{45,46}.

Provision of practical information that will help families anticipate the next steps of the patient's illness is especially helpful⁴⁵. This allows family members to "stay in front" of symptoms, know what to expect and not be caught in a moment of crisis, unprepared for deterioration in the patient's condition. Several authors have promoted the importance of advising family members about the common signs that death may be approaching^{44,47}. Families value this information because it helps them to prepare psychologically for the patient's death and have time to call family members who may wish to be present⁴⁵.

A recent study by Kirk, Kirk and Kristjanson⁴⁸ involved interviews with 38 palliative cancer patients and 36 family members to ascertain their experiences of the information disclosure process and their satisfaction with information sharing during the duration of the cancer illness. The results indicated that the process of information sharing was as important as the content. The timing, management and delivery of information by health care providers need to be carefully considered. The most important content areas were information about prognosis and hope. All patients in the study, regardless of ethnic/cultural background, wanted information about their illness and almost all were willing to share this fully with their families. All family members thought it important that the patient be aware of the diagnosis. As the illness progressed both patients and family members reported that information needs changed and there was greater divergence between patient and family needs. At the palliative phase of an illness many patients reported not wanting as much detail as they had asked for initially and some requested that their family member speak with health care professionals on their own.

Findings from this study provide a useful framework for understanding the process of communication between health professionals and patients and families in the context of a cancer illness. The way in which messages are conveyed is extremely important and is mediated by the six attributes that patients and families identified as critical to good communication: playing it straight; staying the course; giving time; showing you care; making it clear; and pacing information⁴⁹. These attributes point to the importance of the quality of the relationship between health professionals and patients and families and the need for sensitive and individualised information exchange.

Practical Assistance with Physical Care Requirements

The physical care demands of the patient can create specific needs for the family and the practical needs of families may be underestimated^{49,50}. For example, Buehler⁵¹ undertook a longitudinal study of the caregiving role of families in rural communities. This work revealed a lack of available resources for rural families caring for advanced cancer patients. This lack of support may occur, in part, because family caregivers are viewed as resources rather than as recipients of care themselves⁵.

In instances when the family caregiver is elderly and has health problems of his/her own, the demands of caregiving can be extremely taxing^{52,53}. Therefore, involvement of family members as carers must take into account the finite resources of these individuals, which they may be stretching beyond their usual limits because of a sense of duty to care for the patient. The

additive effect of these burdens and strains may be notable⁴. The outcome of this type of over-functioning may be caregiver fatigue⁵⁴. However, signs of caregiver fatigue may be missed or underestimated by health care providers, who observe family members briefly and intermittently⁴.

The assumptions of caregiving roles is usually gradual and the family member's feelings of responsibility for care of the ill person may prevent him/her from seeing alternative ways of receiving help with care. Families may require help to problem solve the demands created by the illness, which often begin with an acknowledgment that the health of family members must also be maintained. Instances of deterioration of the family caregiver's health while caring for an ill member are not uncommon⁷.

Caregiver fatigue may also occur because caregivers are unaware of the availability of resources that could be called upon to decrease the strain on the family. Others may experience fatigue because there is an underlying feeling of duty or guilt that is satisfied through an endless devotion to caring⁴.

Caregiver fatigue is not limited to small isolated families. Family caregivers that are members of large families can experience this fatigue as well because one person may be singled out as the primary caregiver. As well, an uncertain time trajectory for the illness may make the demands more difficult, as family members are unsure of how long they may be required to undertake the additional physical tasks, limiting their abilities to pace and metre their energies⁷.

If the illness progresses to a palliative stage, most patients identify home as their preferred place of death^{55,56}. For many families, practical assistance is essential for them to maintain home-based care. Although the level and type of practical assistance may vary according to need and available resources, there are several common services that should be offered to families⁵⁶. Oldham and Kristjanson⁵⁷ have developed and tested a pain education program for families of cancer patients. This simple intervention has demonstrated promising results in improving family members' attitudes toward pain management, knowledge of pain assessment and management and capacity to improve the comfort of their ill relative. This type of practical education may provide a useful model for other types of educational assistance that families of cancer patients require and warrants further research.

Respite services can be helpful to families in sustaining their caregiving energies. Respite might take the form of external (hospital/hospice based) services whereby the patient may be admitted if they have intractable symptoms, they are imminently dying and home is not the desired place of death and/or to allow the family to rest⁵⁸. In other instances, provision of home respite may allow families time to be relieved of caregiving duties for a short period of time.

Bramwell et al⁵⁹ conducted a survey to assess the caregivers' appraisal of the need for overnight respite. They found that 73% of caregivers received less than four hours of sleep and as a result were more vulnerable to exhaustion. Further, 70% of all caregivers in the sample indicated that they would use an overnight respite service. These findings point to a need for health care providers to monitor the primary family caregiver for hours of sleep, disturbances in sleep patterns and fatigue and then plan with the caregiver for respite. The researchers recommended further investigation of the relationship between carer exhaustion and early hospital admission and whether or not overnight respite would prevent hospital admission.

A more recent study to evaluate a community-based night

respite service for terminally ill cancer patients reported encouraging findings⁵⁹. An assessment tool to determine those patients and families most likely in need of night respite support was developed and tested. Results indicated that the assessment tool was reliable and feasible for use in practice. Care aides were then specifically trained to provide night respite support and 53 patients received this support over an 11-month time period. Results from this study demonstrated the benefits to patients and carers of a community palliative night respite service. Families who indicated moderate to severe levels of carer fatigue were identified as urgent candidates for night respite support⁵⁹.

Almost 70% of patients who died were able to die at home, compared with baseline data that showed that only 50% of patients die at home without this service. Family carers reported appreciation for the service and acknowledged that this assistance helped them to manage the patient at home. The costs associated with home deaths and the night respite service were much less than was the case for patients admitted to an in-patient facility for end-stage care⁵⁹.

The practical, physical challenges associated with providing care and support have notable effects on the physical, mental and social wellbeing of family caregivers^{60,61}. Without adequate family interventions and targeted support, the burden placed on family caregivers may limit their abilities to provide good quality care to the patient²³.

Facilitating Emotional Support and Family Communication

Families' abilities to provide support to the patient and manage home care depend to a large extent on the amount and quality of social and health professional support they themselves receive⁵⁰. Therefore, attention to the emotional needs of the family as a whole and as individual family members is essential to ensure that their caring efforts are sustainable. Emotional needs of family members include a need for support to help them cope with issues of loss, uncertainty about the patient's illness, the possible death of their relative, communication issues within the family and their own psychological distress⁶².

Provision of emotional support to families involves identifying ways they can manage the illness and the uncertainties they may face. Research to delineate the coping strategies found most helpful to families revealed that the strategy labelled, "taking one day at a time", was used to manage uncertainty⁶³. Acceptance, rationalisation and social support were also identified as useful coping strategies that family members used to cope with changes in the patient's condition⁶³. Offering families some of these approaches can be helpful in reminding them of how to cope, how to reach out for assistance and how to compartmentalise the stresses they face into more manageable pieces³⁵.

Families should be advised of the importance of accepting their own emotional needs as legitimate and valid. Furthermore, family members may not want to seek or access support because they believe that health care workers operate in a system where resources are limited and a health professional's time is constrained^{64,65}. Therefore, family members need to be advised that the health team considers the family's needs to be important. This approach may encourage family members to mention their emotional issues and seek support³⁵.

Communication is essential to healthy family functioning and families who have limited communication skills are less able to manage stressful situations¹⁸. The family's previous patterns of communication determine to a large extent the degree of communication that occurs within the family at the time of the cancer illness. Some family members may be open and clear in

their exchanges about the illness, treatment decisions, fears and doubts. Others may be reserved in their expressions of feelings, holding back worries, regrets and uncertainties.

Helping families to communicate among themselves is a particular challenge and one that may require specific focus. Families who communicated effectively prior to the illness have been found to cope more effectively during the illness than those with histories of less functional communication⁶⁶. Questions to explore early with the family about how they communicate may allow the health professional to be alert to difficulties and help the family to talk through how they are going to share information, as well as discuss concerns in a way that may avoid conflict and communication mistakes.

Family members who experience a traumatic illness or death may be at risk of a more complicated bereavement reaction^{67,68}. Therefore, caring for the family during the palliative phase of a cancer illness is a preventive health strategy that may place them in a better position to cope with this crisis and integrate the loss in a way that maintains their own health⁶⁹. Family members who have experienced a difficult death or witnessed unrelieved suffering of the patient may be in particular need of help to cope with the memories and regret associated with these experiences⁴.

Assistance with the Financial Burdens of Care

Given and colleagues⁷⁰ have documented the financial concerns that family members experience when a member has cancer. Children in the family, spouses and other dependent members may share these worries. Costs of care may be an issue. For example, family members may worry about the ongoing costs of medications and treatment. Indirect costs associated with providing care, or taking time from work to attend appointments, or providing assistance to the patient may also be a source of concern⁷⁰. Family members may be reluctant to disclose these concerns, or feel guilty about having worries about financial matters when the patient is ill and may be suffering. Family members who are preoccupied with financial concerns may be distracted and less attentive to the patient's care needs⁷¹.

The role of family carer may also impose additional financial burdens. Schofield and colleagues⁷² have reported that family caregiving commitments mean that some family caregivers are unable to work or have to work fewer hours, or work in a lower paid job with negative financial consequences. Children in the family, spouses and other dependent members may share these worries¹⁹.

With a shift in care towards home-based community care, the home is a more frequent care setting for the person with cancer. Addington-Hall and colleagues⁷³ studied 118 family carers who were providing care in the terminal phases of the patient's cancer illness. They found that half of the caregivers they studied reported having to take time off work to care for the patient at home. Another study revealed that the cost of family labour and family out-of-pocket expenditures for a three-month period for women with breast cancer was significantly less for families in which the patient was still alive, compared with families of patients who had died⁷⁰. Total cost for families with recently deceased patients was more than twice that of families where the patient survived. These results suggest that the financial demands on families may be significant and may be a serious, additional source of family stress.

A simple question about how families might be coping with the financial changes or pressures as a consequence of the illness may elicit these fears and allow health professionals to make appropriate referrals or help family members identify resources to help them to manage. The opportunity to discuss these

concerns may also ease the strain for family members who may be reluctant to discuss these matters with the patient or others⁴.

Conclusion

Notwithstanding the demands of caregiving, family caregivers report benefits and rewards from the caring role²⁴. There is also evidence that family caregivers may feel a strong sense of duty to provide good quality care to a loved one. A recent survey revealed that the most common reasons for being a family caregiver were a feeling of responsibility, believing that the family could provide better care than would otherwise be available, a sense of emotional obligation and an absence of other family or friends²⁵. Helping family members to assume the caregiving role in a way that is sustainable and fulfilling should be the aim²⁵.

To date, the role of health professionals in supporting families of people facing a cancer illness has been underdeveloped and poorly researched. The psychological distress of families during the patient's illness and in the bereavement period is clearly reported. However, the extent to which these families have access to supportive health services, are receptive to receiving these services during the patient's illness and might benefit from this input warrants further empirical investigation. Of particular concern are family members who may be particularly vulnerable to deteriorations in their own health or families with histories of poor functioning, who may cope poorly under the additional strains imposed by the cancer illness. If we do not care for these families during the illness, they may well become our patients later.

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CANCER CARE COORDINATORS: REALISING THE POTENTIAL FOR IMPROVING THE PATIENT JOURNEY

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A person diagnosed with cancer can receive multiple treatments in a variety of different health care settings over extended periods of time¹. During this time, they come into contact with multiple health care providers. For example, one recent UK study reported that cancer patients with a diagnosis of less than one year had met 28 doctors on average since their diagnosis². Add to this the many other health professionals with whom the patient will come into contact during their illness and the complex maze that can characterise the patient's cancer journey is obvious.

The *Optimising Cancer Care in Australia* report³ published in 2003 by the peak cancer organisations in Australia concluded that there are many places for the person with cancer to get lost in the system, causing unnecessary morbidity and undue distress. The lack of an integrated care system for people with cancer was identified as a major failing of today's health system⁴.

A number of states in Australia have moved to appoint cancer care coordinators as a strategy to address such problems. In Queensland, cancer coordination positions have been established in a number of Health Service Districts in the Southern and Central Zone of the State, initially to scope patterns of care, referral pathways and to define a cancer coordination model for their regions that is consistent across the state, but able to meet the local needs of the population. To support its Cancer Clinical Service Framework, the NSW Health Department plans to recruit up to 50 cancer nurse coordinators. Cancer nurse coordinators in NSW will work through Lead Clinicians and Directors of Area Cancer Services to support oncology team meetings, develop care pathways and protocols, and provide a direct source of contact for patients and primary care physicians accessing cancer services⁴. In Victoria, a number of program coordinators and regional nurse coordinators have been introduced as part of the breast services enhancement program. Individual institutions have also established nurse coordinator roles for specific tumour streams.

The cancer care coordinator role is a rapidly emerging one with a mandate to achieve some potentially far-reaching reforms to systems of care. To ensure these developments realise their potential, it is timely to consider the most effective ways to design and implement models of care coordination that