Family-Focused Palliative Care

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Contents

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Abstract

A family-focused care approach in palliative care recognizes the fundamental role of families in contributing to the care of people with life-limiting conditions. It is essential that healthcare providers develop understanding of families' needs and the skills to collaborate effectively with families caring for people at the end of their lives. This chapter introduces the concept and components of family-focused palliative care. It continues with a discussion of what patients and families perceive to be the most important aspects of end-of-life care. This chapter provides information to assist healthcare providers who work with people with life-limiting conditions and their families in providing family-focused care and identify the gaps and challenges to providing such care.

Keywords

Family · Carer · Caregiver · Palliative · End-of-life · Life-limiting condition

1 Introduction

The increasing reliance on informal family caregivers ("carers") in today's healthcare environment mandates families to be actively involved in patient care and advocate for best practice. The Institute for Patient- and Family-Centered Care defines family-centered care as an approach to planning, delivering, and evaluating healthcare in the context of mutually beneficial partnerships among healthcare providers, patients, and families. It emphasizes collaboration with families who define their own membership and roles in care and decision-making (Johnson et al. 2008). The aim of this chapter is to increase healthcare providers' awareness of the needs of families to optimize their current and future well-being, including their bereavement outcomes.

After reading this chapter, you will be able to

- Describe the components of family-focused care
- Discuss patient and family priorities for the end-of-life care
- Identify the opportunities to strengthen the provision of family-focused palliative care

2 Defining Family

The family is the basic unit of care and comes in all shapes and sizes, compositions, and origins. Contemporary connotations of family extend beyond just people related to one another by blood or marriage. Divorce, same-sex partners, cohabitation, and workforce globalization have ushered in a new era of family configurations that have superseded traditional nuclear family structures comprised of a husband, wife, and one or more children. Single-parent families are increasing, and many children live with a step-parent or grandparent(s) at some point in their lives. In addition to traditionally termed extended family, close friends, companions, and others may all be considered to be part of an individual's family. Family members may live in close proximity or at great geographic distances from one another and an increasing number of older people live alone. Global mobility and changing demographics mean that many family members may not be physically available to provide care and support in the context of a life-limiting illness and may have limited contact with one another. In this situation, neighbors and friends or distant relatives often step in to fill this void. As a result, who and what constitutes "family" has been evolving. While some people continue to define family as the group of people they were born into (family of origin), others will define family as the group of close friends they have chosen to surround themselves with (family of choice) (Lawton et al. 2014). In this chapter, "family" is defined as whomever the patient describes, considers, or chooses to be family (Fineberg 2022). This can include biological family, family via marriage or other relationships, friends, community members, or pets (Palliative Care Australia 2018). It can also include people who the patient identifies as important and who influences their care and well-being (Wright 2007) or people they agree can be involved in their care (Palliative Care Australia 2018).

3 Family's Needs Throughout the Care Trajectory and Across Life Stages

The World Health Organization (2018) has long championed the importance of assessing and addressing families' palliative care needs, as reflected in their current definition. This definition centers palliative care on providing relief from pain and distress, normalizing the dying process, providing holistic support using a team approach, and facilitating good quality of life and coping at all stages of the illness for the patient and their family (World Health Organisation 2018). By positioning families alongside patients, this definition highlights the needs of families as recipients of care, particularly in the provision of adjusting, coping, and bereavement support.

A progressive life-limiting illness diagnosis is a life-changing experience for not only patients but also their families. This type of diagnosis is associated with significant physical, emotional, financial, and social support needs as well as access to timely clinical support and information. Most patients will call upon various family members, often a partner/spouse, to assist them with their decision-making in relationship to treatment preferences, advance care planning, and legal and financial issues. The quality of life of people with palliative care needs and their families depends on various factors that can change over the course of the illness. These fluctuating needs often occur during the transitions from curative to comfort care as the disease progresses. With each transition, families will have different information needs, and if they are active carers, their contributions to various activities of daily living are likely to increase as the patient's disease progresses, and they become less able to maintain their activity. The care and support that families require may differ according to their varied life stages and relationship to the patient. In some cases, patients are also carers for offspring, siblings, or older parents, which have implications for the family as the patients' own care needs increase. There are also some different implications for the individual and their family depending on whether the patient or carer is of working age (under 65 years old), has young children and/or teenagers, or is post-working age (over 65 years) and living with in-home or more distant family support.

3.1 Factors Affecting Families' Needs

Both malignant and nonmalignant diseases pose a significant burden at the end of life. Some diseases, especially neurodegenerative conditions and/or primary or metastatic brain cancer, often cause more physical impairment and cognitive/personality changes. These devastating personality changes and disability also affect carers' capacity to manage (Pace et al. 2009; Arber et al. 2010; Gofton et al. 2012) and indicate significant support needs for carers.

Age can play a role in determining the type and level of needs of both patients and their families. Younger cancer patients have been shown to have higher levels of unmet psychosocial needs than older patients (Hamilton et al. 2018). These different needs can be attributed to the unexpectedness of a cancer diagnosis at a young age (Hamilton et al. 2018) and cancer and its treatment having more of a psychosocial impact on younger people (Barakat et al. 2016).

Younger carers of patients with advanced cancer have higher levels of unmet financial, social, and care-related needs than older carers (Wang et al. 2018). Older carers can experience physical and emotional needs in their caring role. Physical challenges to caring can be due to existing health problems (causing physical discomfort while caring) and fatigue. Emotional challenges can include experiencing distress (particularly if caring for a spouse), encountering ageism (e.g., healthcare professionals doubting caregiving abilities), and a loss of sense of self. Compared to older male carers, female carers are at greater risk of experiencing caregiver burden, role strain, and worsened physical health. In part, this may be due to the various roles many women undertake simultaneously, as daughters, daughters-in-law, wives, mothers, and grandmothers. However, many older carers experience positive caregiving. These can include positive spiritual well-being through meaning-making during caregiving and viewing caring as an act of love for their family members (Xue et al. 2022).

3.2 Needs of Younger Working-Age Families

Facing premature death during working age (ages 24–65 years) has its own inherent challenges related to life-stage commitments such as family, work, and financial responsibilities. A life-limiting illness has a profound impact on the family life of patients, their partners, and children. Family dynamics are often changed and normal life interrupted, which can be particularly burdensome for any dependent children, as their reality and day-to-day life often change as the illness of their parent progresses. Families of working-age patients have a range of needs at different time points across the illness trajectory (Kochovska et al. 2017), including

- Supportive care needs, which vary according to disease (malignant or nonmalignant) but typically for working-aged families, include assistance to effectively manage the patient's pain and other symptoms and dealing with feelings of loss (anticipatory grief), uncertainty, and fear of the patient and/or children suffering (Kochovska et al. 2017). The partner of a working-aged person facing a premature death often has increased input into clinical, household, and financial decision-making and difficulty juggling multiple roles such as parenting, household duties, and family finances. This is all in addition to navigating the healthcare system, transporting the patient to/from hospital and/or appointments, maintaining family schedules, and minimizing the impact on other family members.
- Information needs for families are also significant and include diagnostic and disease information, financial and legal information, as well as end-of-life and spirituality information (Kochovska et al. 2017). This information is required at different stages in the illness trajectory, and healthcare providers should be both aware and prepared to meet families' specific information needs in a timely manner.

  - Disease and prognosis information is most often sought at the initiation of treatment and transition from curative to palliative care but least wanted as death approaches.
  - Financial and legal information from the time of diagnosis can help to manage anticipated reduced employment capacity for both the patient and carer.
  - Financial advice is least wanted when completing treatment and when returning home from hospital. The need for financial/legal information related to death notification requirements and funerals is greatest immediately after the patient's death.
  - End-of-life and spirituality information is most desired during a final hospital or hospice admission and least desired at the commencement of treatment.
- Carers' needs are significant, as most will need access to support services (such as respite and daycare) and practical support (e.g., picking up children, preparing a meal, and other household tasks), especially in rural and remote areas (Kochovska et al. 2017). Balancing these competing demands while trying to maintain normality (especially when children are involved) is challenging, particularly for employed carers and/or those with young children.

Anticipatory grief and bereavement needs are experienced by patients, partners/spouses, and their children at various junctures and require an individualized and empathetic response that recognizes grief as normal but provides timely access to professional help for the minority who need it. Spending quality time with the deteriorating and/or dying person is important and can positively influence bereavement outcomes (Kochovska et al. 2017).

3.3 Maintaining Normality and Balancing Multiple Roles

For both the parent living with the terminal illness and their partner/spouse, maintaining normality is of paramount importance, as it acts as a coping mechanism that limits the adverse effects of the parent's illness on their children. Maintaining this delicate balance is challenging, and most families need practical advice about how best to describe in simple terms the patient's diagnosis, prognosis, and impending death; cope with their partner's/spouse's deterioration; and access practical help and resources, so as to minimize the impact on their children (Kochovska et al. 2017).

The interruption of family dynamics and the need to be able to maintain children's normal routines while managing escalating care demands is a frightening and stressful experience for many families (Kochovska et al. 2017). This is primarily because it requires the healthy parent to assume new roles within the family, deal with uncertainty and feelings of loneliness, balance everyone's needs (including the children, the patient, and themselves), and support their children. Access to specialist palliative care can mitigate many of these challenges and contribute to positive short-term and long-term effects, especially for carers of cancer patients (Kochovska et al. 2017).

Although dealing with a life-limiting illness is a demanding and stressful experience for everyone, there are some positive aspects for both parents with terminal illness and their children, which include strengthening the relationship and shifting perspectives on valuing the family and the important things in life (Kochovska et al. 2017). It is particularly important that children and dying parents remain connected during the terminal illness, and clinical care and support should be tailored to facilitate that (Kochovska et al. 2017).

3.4 Balancing Being Honest with Children, but Not Overburdening Them

Children of parents diagnosed with a life-limiting illness and/or who are dying need access to timely, age-appropriate information about their parents' disease that is sensitively communicated by people they trust both within and outside of the family (Kochovska et al. 2017). Children with parents living with a life-limiting illness (e.g., advanced cancer) display significant distress but also remarkable awareness and understanding of their parent's illness. While children of dying parents need support, they should not be protected from the truth of the situation, but rather, given accurate information as sensitively as possible (Kochovska et al. 2017).

Adopting a transparent approach helps children to make sense of their parent's impending death in their own way and grow through the experience. They also need an opportunity to spend quality time alone with their parent. While some children may welcome the opportunity to help care for a dying parent, they also need to have opportunities to engage in "normal" activities outside of their caring role both with their family and in contexts where they can temporarily "forget" their home situation (Kochovska et al. 2017).

Where children bear a significant caring responsibility, respite care may be required to enable them to take a break, while their parent is cared for by others. Adolescents and young adults, whilst not the primary carer, are often required to assume more household responsibilities and have decreased social activity outside the home (Beale et al. 2004; Kennedy and Lloyd Williams 2009), which can contribute to increased stress (Huizinga et al. 2003). Older children often take on more practical responsibilities, including picking up their younger siblings from school (Phillips and Lewis 2015). Adolescents, in a home where a family member (e.g., parent, grandparent, or sibling) is dying, also report feeling alone and alienated as family priorities shift and family roles are renegotiated within the family unit (Phillips and Lewis 2015) and rely on routines to maintain a semblance of normality (Dehlin and Reg 2009). For adolescents, self-management and managing emotions through talking, thinking positively, and creating distractions and social support are also important (Phillips and Lewis 2015). Most adolescents try to maintain a positive attitude and facilitate communication within the family (Phillips and Lewis 2015), viewing the experience as something that helps them mature and change their way of thinking about life, and reassess their values and relationship with other people (Dehlin and Reg 2009).

There are a growing number of adolescent and young adult carers, so considering their needs is crucial as they often have a significantly poor quality of physical health (Hanly et al. 2015) and could be considered to be doubly disadvantaged because their carer role impacts their educational opportunities and future earning capacity. Australian statistics show that the premature death of a parent can have a detrimental effect on the future wealth and employment of their children as adults (Australian Bureau of Statistics 2010).

4 Defining Family-Focused Care

A family-focused approach to care recognizes the fundamental role of families and includes the following core concepts, namely, dignity and respect, information sharing, participation, and collaboration (Johnson et al. 2008). This method of care delivery supports the family in their carer roles and includes them in treatment decision-making. It positions the family as key members of the care team and privileges collaboration as a vehicle that increases trust and promotes more open communication between patients, families, and healthcare providers. When individuals perceive open communication, they are more likely to perceive fair processes, cope, and feel less frustration and confusion. Through collaboration, care provided to patients and families can be tailored to their individual needs, thereby demonstrating recognition of the uniqueness of each patient and family. Furthermore, the family is a valuable source of support for a patient and source of information on their behavior and coping strategies (Bamm and Rosenbaum 2008). To help families feel supported and cared for, the palliative care team should adhere to families' preferences for communication, degree of involvement in caregiving activities, information provision and education, visiting, and counseling (Wright 2007).

5 The Most Important Elements of End-of-Life Care from the Family Perspective

The following section details the most important elements of end-of-life care for families from the perspectives of patients and family members.

5.1 Expert Care (Good Physical Care, Symptom Management, and Integrated Care)

Family-focused care for the domain of expert care centers around the concepts of excellent nursing care, excellent symptom assessment and management, holistic care delivered from a multidisciplinary team integrated into their care planning and delivery, and the need for healthcare providers to be knowledgeable about the patient they are caring for. To improve care practices, healthcare professionals are encouraged to systematically use patient-reported measures (PRMs), which are status updates directly from the patient regarding their health or experiences. PRMs include patient-reported experience measures (PREMs), which include patient views on their physical health, and patient-reported outcome measures (PROMs), which include patient views on their care experiences (NSW Agency for Clinical Innovation 2022).

While patients perceived many of these aspects of care provision as highly important for optimal end-of-life care, families specifically noted the importance of the following key aspects of care provision to enable quality end-of-life care:

- Careful attention to the personal hygiene and care needs of the patient both when family are and are not present in the hospital
- Excellence in core nursing as well as the ability to manage specialist patient requirements (e.g., colostomy care)
- Ensuring rapid and comprehensive assessment and management of symptoms with a particular focus on staff prioritizing the patient's description of their symptoms
- The specific need to manage pain and agitation well
- Multidisciplinary care to support the patient physically, emotionally, and/or spiritually
- Integrated care inclusive of effective discharge planning and ensuring the patient could die in their location of choice
- That healthcare providers were knowledgeable about the specific condition of the patient and that it was clear who was in charge of care (Virdun et al. 2015, 2017, 2021)

Families need expert care provision for the patient from healthcare professionals. When carers perceive the patient to be suffering from the presence and intensity of symptoms, this can decrease carer quality of life, increase carer strain, and promote the onset of sleep disorders and depression (Valero-Cantero et al. 2022). In addition to witnessing expert care of the patient from healthcare professionals, family carers also wish to provide quality care themselves. In recent reviews, families have expressed the need to be provided with information from healthcare professionals on how to provide better care for their loved one, particularly through the dying process (Cheng and Chen 2023). However, information provision is not always helpful as it is usually based on informing rather than involving family carers in care. Healthcare professionals should engage in capacity building of carers to promote empowerment, confidence, and self-efficacy in caring. Ultimately, family carers wish to be treated as part of the care team by healthcare providers (Vermorgen et al. 2021).

5.2 Effective Communication and Shared Decision-Making

Family-focused care requires healthcare providers to have effective communication skills to be able to engage multiple members in different aspects of care. The ability to interview or converse with family members together is important to understanding the interactions between family members (Denham 2016). Healthcare providers must clearly explain medical issues, ensure family understanding, and clarify any technical language used. Plain language materials and providing opportunities for discussion and questions are recommended to address health literacy needs (Wittenberg et al. 2017; Dittborn et al. 2021). Effective communication is necessary to ensure that the patient, family, and healthcare providers have a shared understanding, which is dependent upon the compassionate delivery of understandable and honest information (Virdun et al. 2015, 2017). The need for information from healthcare professionals is one of the most commonly reported needs of family carers according to recent systematic reviews (Cheng et al. 2023; Marco et al. 2022; Benites et al. 2021). Additionally, families expect to receive the same information (consistent) from all members of the care team (Dittborn et al. 2021). Being provided with the necessary information is important for families involved in end-of-life decision-making because they want to understand the medical complexity and the emotional and financial implications of any decisions and be provided with sufficient and timely information to make the decisions that best reflect the patient's preferences (Virdun et al. 2015, 2017). Being actively involved in day-to-day care planning and having regular planned discussions with the healthcare team, including discussions with physicians, are considered by families to be essential for effective communication and shared decision-making (Virdun et al. 2015, 2017; Gonella et al. 2019). One study showed that 78.9% of family caregivers wished to engage in shared decision-making with the healthcare team regarding palliative and end-of-life issues (Piña-Escudero et al. 2019).

Families are likewise responsible for providing accurate information to healthcare providers including medical and treatment history, patient preferences, and subtle changes in the patient that the provider may not see. That is, families have an important and active role within the healthcare team as they have experience, insights, and knowledge about the patient that can contribute to their overall health and well-being (Johnson et al. 2008). Further, the family, as the unit of care, provides information about group values, supportive interactions, decision-making, relationships, caregiving, and health habits.

The delivery, content, and timing of end-of-life prognostic communication have a significant impact on the quality of life of spousal carers of patients with palliative care needs who have dependent children (Park et al. 2015). Families' preferences for honest and clear information communicated using nonprofessional language and with compassion help to foster a shared understanding of the clinical situation. The provision of adequate information throughout the admission helps support decision-making, decreases family stress, and minimizes surprises (Virdun et al. 2015, 2017).

Healthcare providers should be aware, however, that there may be barriers to end-of-life communication in the family context. Family members may experience emotional barriers (such as the need to protect themselves or the patient from difficult emotions, fear of death), cognitive barriers (such as denial of illness, hope for a cure, lack of awareness of prognosis), relational barriers (such as family dynamics, differences in opinion), communicative barriers (such as lack of understanding on how to talk about death), and external barriers (such as caregiver characteristics). Healthcare professionals should be aware of these barriers, provide support, and hold conversations to address these barriers, where needed. Providing a safe space for families to discuss concerns can increase feelings of support and decrease feelings of isolation (Nagelschmidt et al. 2021).

An important outcome of family-focused care is patient and family coping, which can be facilitated by incorporating elements of family-focused care in practice (Wright 2007), such as

- Information sharing: The healthcare team communicate comprehensive, accurate, and balanced information for families in a timely, affirming, and useful manner to enable effective participation in both care planning and care provision.
- Collaboration: Valued collaboration with families in relation to policy and program design, implementation, and evaluation, the design of

health facilities, and professional education and planning and delivery of care.

- Participation: Valued and supported participation in care planning and provision, inclusive of decision-making, to the level of the family member's choosing.

DiGiacomo et al. (2013) reported an example of how communication gaps can lead to protracted grief in a qualitative study of recently widowed older women. In the following excerpt, one woman described missed opportunities for healthcare providers to communicate with her regarding her husband's prognosis (refer Box 1). This is further confirmed by data reported by Virdun et al. (2015), where families noted the importance of being able to receive straightforward information about tests, treatments, and prognoses, as well as stating that being sheltered from honest information did not contribute to quality end-of-life care.

Box 1: Unintended Consequence of Ineffective Communication: Julie's Story

Family carer quote:

> I definitely would have liked a realistic view. If somebody had said to me, "Julie, the end is nigh," you know? Nobody ever said that. The only thing was the young doctor and only about 3 weeks before he (my husband) died; he (the doctor) was in the room and he was always so lovely, and he said to me, "Julie, have you ever heard of sepsis?" And I said, "Yes, I have." End of conversation. Maybe if I'd answered no, he might have expanded. I remember thinking, "He hasn't got sepsis," but thinking, "Why did he ask me that question?" I thought about that as I drove home that night. I thought, did he know something more than I knew? Maybe I should have followed up on it. At that stage of an illness, I was waiting for them to give me information, not to have to solicit it. That's what I was waiting for. I actually really did think, why wasn't I given more information? All these doctors were coming around and nursing staff, but nobody was telling me anything. To go through the same thing again, I'd be asking a lot, lot more questions. I think I was a bit reticent to ask. I'd keep thinking, they'll tell me if there's something that I should know. I would have liked somebody to have come to me who knew the situation wasn't going to be good and sort of alerting me to what I was going to face. I think that would have been helpful to me...
>
> I was coloured by what happened. I thought, what if I'd said more? I don't know in my case whether it would have altered the outcome, but I think I could have made things a little bit better for him. (Julie, age 71, wife and carer of patient who had cancer and died 12 months prior to interview)

Box 1: (continued)

Commentary: These excerpts reflect the interactions and the inner dialogue Julie experienced during her husband's final days in the hospital. Although her carer role had partially acclimated her to her husband's condition, she did not have enough knowledge to understand his illness trajectory. Julie was left ruminating over the experience after her husband's death with feelings of guilt and anger that culminated in a formal complaint to the health service. She had an expectation that information would be provided without necessarily having to seek it out. She wondered whether emphasizing her lack of understanding would have facilitated more and better information provision. This excerpt from an interview with a bereaved spouse depicts an example of the damage inflicted on family caregivers when they perceive that their loved ones have not received adequate care. Self-blame and sorrow for her husband's experience persisted.

Reprinted from DiGiacomo et al. (2013), Copyright 2013 with permission from Elsevier.

5.3 Respectful and Compassionate Care

Families have identified that respectful, compassionate care that preserves the patient's dignity and supports both the patient and family is vital. Family-focused care enables a welcoming environment where healthcare providers deliver tailored care for the unique needs of each patient and their family unit. Families desire helpful, optimistic, empathic, affectionate, appreciative, comforting, gentle, considerate, and capable staff who are approachable and reliable (Virdun et al. 2015, 2017; Dittborn et al. 2021). Provision of compassionate and humanized care has been described as a positive aspect of care by families. When this care is not provided, families feel disappointed and concerned (Dittborn et al. 2021). Where possible, healthcare professionals should be available and accessible to families (Vermorgen et al. 2021).

Families also spoke of the fact they want to be able to have physical contact with their loved one (Virdun et al. 2015). Finally, individualized care provision is hugely important in enabling quality care with families noting the need for patients to remain a person and not become a number or illness within the healthcare system (Virdun et al. 2015, 2017).

5.4 Trust and Confidence in Healthcare Providers

Families consistently ranked trust and confidence in their healthcare providers as highly important. Therefore, family-focused care needs to explicitly focus on developing trust and confidence for both patients and families with their treating team. An explicit focus on the principles of person-centered care provision will support this aspect of care (McCormack and McCance 2016).

5.5 Adequate Environmental and Organizational Characteristics

Family-focused care respects the integral role of the family in care provision for patients with end-of-life care needs. In doing so, care providers should ensure hospital rules and processes both make sense and support optimal patient care. For example, families have described being asked to move their car while they were visibly distressed, patients not being given symptom relief while waiting for formal admission, and visiting hour restrictions for dying patients (Virdun et al. 2017). Families also note the importance of privacy, cleanliness, and quiet within the care environment. Indeed, families noted that lack of privacy led them to feel disconnected from their loved one, unable to talk openly, and like they were simply observing. Family-focused end-of-life care ought to ensure these environmental and organizational characteristics are explicitly reviewed for each patient's care to identify which family members may require alterations to usual care practices. Some examples include

- Changed visiting hour allowances (Virdun et al. 2017).
- Access to chairs and beds to allow families to sit or lie beside the patient's bed overnight (Virdun et al. 2021).
- Quarantined time for privacy where staff do not disturb the patient/family member. Likewise, a place for families to have private conversations at end of life (Virdun et al. 2021).
- Innovative thinking for enabling privacy in open-plan environments such as the intensive care unit (Virdun et al. 2017).
- Access to a space or room for the family to hold private discussions or spend time together away from the patient's bed (Virdun et al. 2021).
- Availability of space to support cultural practices such as congregating family, chanting, or other rituals (Virdun et al. 2017).
- Access to affordable meals within the hospital, as well as access to basic kitchen facilities or items (microwave, water) (Virdun et al. 2021).

5.6 Recognizing and Supporting the Family Role in Care Including Valuing Their Expert Knowledge of the Patient and Advocating for Patient Needs

Families have outlined the importance of being recognized and respected as having expertise in the care of their loved one. It is essential that healthcare providers understand and respect that many families have been providing expert care to their dying family member long before palliative care is involved, so we need to draw upon their expertise and include them as authentic partners in care. Valuing and honoring families' contribution to care would ensure families were included as equal partners in care planning and provision and would enable their role as patient advocates to succeed. Failing to do this leads to family's feeling they are simply being an observer to care and their contribution is not valued. This challenges healthcare providers to consider approaches to communication and care both within usual care and also at times where care may be distressing with some data showing that removal of family members at times of distress may cause long-term harm in bereavement (Virdun et al. 2015, 2017).

5.7 Financial Affairs

Ensuring that the patients'/families' financial needs are identified and addressed in a timely manner is an often-overlooked element of care. Families desire and need healthcare providers to proactively provide them with information about available financial supports, which helps to enhance comfort and decrease stress. Upon admission, this can include information about managing parking costs, access to the Internet, supported accommodation options, carer payments, and access to subsidies for clinical equipment purchases for provision of home care (Virdun et al. 2021).

Families also want healthcare providers to create opportunities for financial issue discussions, at all stages of the patient's illness trajectory, not just during the final days of life (Kochovska et al. 2017). Taking the lead to initiate these conversations is important, as many patients avoid starting these conversations during the early stages of the illness, as they focus on understanding their diagnosis, treatment, and planning their recovery.

For most working-aged patients, an advanced cancer diagnosis is associated with loss of employment and/or their working partner/spouse also having to reduce their working hours. Studies consistently reveal few patients diagnosed with advanced cancer return to work after active treatment and consequently experience significant economic disadvantages, especially in the absence of universal healthcare or health insurance coverage (Kochovska et al. 2017). Cancer-related financial burden has adverse psychological consequences for both patients and their families, increasing the risk of depression, anxiety, and distress (Kochovska et al. 2017). Healthcare costs and out-of-pocket expenses add to financial stress, sometimes forcing families to reduce their discretionary spending and often affecting their medical treatment (Kochovska et al. 2017).

Taking on a caring role adversely impacts employment with many carers having to reduce their work hours and/or having to stop work. In working-aged families, the spouses/partners are often also caring for an aging parent and/or a young family. In this situation, taking on an additional carer role often impacts adversely on childcare costs (Kochovska et al. 2017). Patient care cost and limited access to financial assistance are additional concerns of Australian carers, while unexpected costs, bereavement costs, and legal expenses also contribute to the financial burden (Kochovska et al. 2017). As well as imposing a significant financial strain (Gott et al. 2015), a carer role is associated with a significant negative impact on quality of life (Williams et al. 2014). Younger patients and those with larger families are at greater risk of financial burden, while those without income seem to have a significantly lower quality of physical health (Hanly et al. 2015).

5.8 Maintenance of Patient Safety and Prevention of Harm

Families identified the need for optimal end-of-life care to prevent harm and a feeling of being unsafe within a clinical environment. Aspects of care perceived to lead to a lack of safety included poor communication, lack of person-centered care, lack of identification of unique needs of people at the end-of-life, poor nursing care, lack of timely attention, and families feeling unsure of how to be involved in their loved one's care (Virdun et al. 2017). A recent study articulates that concepts of patient safety for those who are dying, and their family members, continue to focus on correct treatment, timely interventions, and appropriate infection control, just as would be the case for any patient, and therefore, careful attention to this is important for all patients (Collier et al. 2016). However, this same study asserts that patients with palliative care needs and their families also define patient safety quite broadly, inclusive of approaches to care, interpersonal communication, and the sociocultural context of care. Therefore, consideration of patients at the end of life and their families within usual patient safety parameters is required (as this patient population is not routinely considered within this forum) as well as consideration of broader contexts of safety, as articulated above. Finally, family-focused care also works to enable support and a feeling of safety for family carers to speak up without repercussions, as required (Virdun et al. 2015, 2017; Kochovska et al. 2017).

5.9 Preparation for Death

Family-focused care ought to ensure optimal communication and, in doing so, ensure families are aware of and prepared for a patient's imminent death so that they are able to say goodbye, fulfill last wishes (Cheng and Chen 2023), and assist their bereavement outcomes. Honest communication, delivered compassionately, is imperative as several family members described not understanding the extent of their loved one's illness or that they were imminently dying (Virdun et al. 2017). As healthcare providers, we need to ensure such conversations have been held and understood by families and to plan for and/or facilitate their support throughout this time. At the time of death, healthcare providers should treat and care for the body with respect, allow the family to have unrushed time with the body, and ensure accurate completion of the death certificate. Information about immediate processes, such as removal of the body and death certification, should be provided both verbally and in written form. Finally, a clinician involved in the decedent's care should follow up with the family via phone or email to provide grief and bereavement information and support (Virdun et al. 2021).

5.10 Duty of Care Extending to the Family After Patient Death

Families have described their need for follow-up after a family member's death to avoid feeling disconnected and abruptly rushed away from the hospital at such an important time (Virdun et al. 2017; Vermorgen et al. 2021). Follow-up after death and into bereavement has been highlighted as an urgent and neglected issue (Llop-Medina et al. 2022). If the healthcare provider team truly partners with family members in care provision, then it stands to reason that the duty of care would extend to them, following the patient's death. Systems and processes may hinder this aspect of care, and therefore, needs should be considered within a policy and quality improvement framework.

While the majority of palliative care services focus on contacting the decedents' family, usually their documented next of kin, this approach may fail to identify informal caregivers, who, despite their intensive caregiving role, are not listed as the patient's next of kin because their relationship falls outside of these parameters. Given the complexities and nuances of modern relationships, an important area of inquiry is to develop the evidence base for palliative care services to systematically determine more broadly the patients' kinship network (Phillips et al. 2018).

Grief is a normal response to loss during a period of bereavement. Spousal bereavement has been associated with increased mortality and longer hospital stays and negative effects on employment (Stephen et al. 2015). Psychological or social support (e.g., talking to family members and friends during the grieving process) and practical support (e.g., with funeral arrangements, legal and financial help) are commonly identified needs of bereaved persons (Stephen et al. 2015). When the bereaved prefers to speak to others or when family networks are dysfunctional, help is sought from professionals closer to the time of death and shortly after (Benkel et al. 2009). Children and teenagers who experienced the death of a parent due to cancer have a range of psychosocial anticipatory grief and bereavement needs (Macpherson and Emeleus 2007a, b). These include maintaining contact with the dying parent; being prepared for their death; holding on to meaningful memories; maintaining privacy, normality, and continuity in family and school life; escaping the intensity and stressfulness of the home situation; being understood and supported by others; and better understanding death (Macpherson and Emeleus 2007a, b). Children and teenagers desire support and understanding from others to help them cope with feelings of grief, anger, and depression and need access to information and opportunities to talk with others who have had a similar experience (Patterson and Rangganadhan 2010).

Although grief is a normal response to loss, a subset of bereaved individuals may experience "persistent complex bereavement disorder." It affects approximately 10–20% of bereaved people and causes significant functional impairment and symptoms that last 6 months or longer (Lobb et al. 2010; Shear et al. 2011). Complicated grief requires early intervention (Lobb et al. 2010).

5.11 Enabling Patient Choice at the End of Life

Family-focused care requires healthcare providers to be aware of and follow the patient's advance care directive. Advance care planning shared decision-making tools may improve goals of care documentation and care recipient satisfaction with communication (Sloan et al. 2021). Given recent debates about legalized euthanasia for people with advanced and critical illnesses, legal support in relation to enabling patient choice (both in relation to advance care planning/directives and legalized euthanasia) needs to be understood within each care jurisdiction with global variances notable within this aspect of care. However, the principle of care ought to remain focused on supporting patient choices, within legal parameters, which is fundamentally important and forms an important aspect of family-focused end-of-life care.

5.12 Caring at Home

Families may choose to provide care at home toward the end of life to maximize time spent together as a family. Patients may also want to receive care at home to stay at home and continue their daily lives for as long as possible. However, when providing end-of-life care within the home for their loved ones, family carers can experience feelings of fear, uncertainty, frustration, helplessness, and a lack of control (Bureau of Health Information 2022). As the majority of caregiving takes place at home, support in the provision of end-of-life care should be a priority (Dittborn et al. 2021). Families have expressed various needs in terms of provision of care at home, some of which include

- To receive information, education, training, and clinician support to provide home care (Dittborn et al. 2021; Bureau of Health Information 2022).
- Carers report feeling insufficiently skilled, trained, and supported to provide care and comfort to their loved one, particularly if symptoms worsen or are exacerbated, or as death approaches (Dittborn et al. 2021). They would like help with these physical aspects of caring but also need someone to talk to about the challenges of providing care (Bureau of Health Information 2022).
- For home care providers to be empathetic, sensitive, and reliable; take time to address the patient's needs; visit during a time that is appropriate for the family, and to forward plan and anticipate next events.
- For the healthcare team to value communication and shared decision-making, which includes providing careful explanations, being available to answer questions, and providing assistance with decision-making. Families also need transparency and honesty during transitions into active dying to assist with preparation for death.
- For connection to community social services that provide practical support such as food or transport.
- To receive continuity of care with their home care team.

- To have access to formal 24 h support services, particularly for rural or isolated families, and to have the contact details of the clinical team.
- To receive respite from their caring role.
- Accessibility of appropriate medication for effective symptom management from General Practitioners (Bureau of Health Information 2022).

Providing appropriate support for caring at home may be even more important post-pandemic, where shifts in place of death may occur due to restrictions or limited resources in acute settings (Payne et al. 2022).

5.13 Caring During Pandemics

The COVID-19 pandemic (commencing in 2020) impacted the ways in which family carers were able to provide care to family members. Carers described experiencing severely restricted access to their family member and the healthcare team due to public health measures implemented in hospitals and residential aged-care facilities. As a result, family carers needs went unmet. These include the need for access to their family member to provide care, involvement in decision-making, receiving adequate communication from the healthcare team (such as information about their family member's well-being, information about approaching death), and receiving practical (e.g., funeral) support and emotional support at the end of life (Hanna et al. 2021; Selman et al. 2022). Carers were not always able to say goodbye to their loved one in ways that they would have liked at the end of life. Support following death and into grief was a major concern for family carers, who felt that they were inadequately supported by healthcare providers at this time (Harrop and Selman 2022).

During the COVID-19 pandemic, family carers experienced helplessness and guilt when they were not able to care for their family members as they would have liked due to hospital restrictions (Dhavale et al. 2020). Families who provided care at home during the pandemic were less supported by healthcare professionals than carers in hospitals (Lobb et al. 2023). Following the death of their family member, families were at higher risk of experiencing prolonged grief disorder and increased levels of social isolation and loneliness (Selman et al. 2022). Those who had a home death experienced high level of grief-related distress and psychological impairment after death (Lobb et al. 2023).

Some ways in which healthcare teams can provide support to family carers during pandemics are by

- Ensuring family carers are adequately prepared for a home death and receive appropriate support (Lobb et al. 2023)
- Providing frequent and detailed updates about the care recipient and their well-being (Hanna et al. 2021) and implementing follow-up calls to answer lingering questions (Bakar et al. 2020)
- Facilitating video calls between patients and families (Bakar et al. 2020), but prioritizing in-person visiting whenever possible
- Facilitating opportunities for family members to say goodbye in person where possible (Hanna et al. 2021)
- Providing information about bereavement support after death, including professional services and self-help resources (Selman et al. 2022)

5.14 Care in Residential Aged-Care Facilities

The needs and experiences of family carers of people with dementia are varied when their relative transitions into a residential aged-care facility. Some family carers experience less burden once their loved one moves due to a decrease in caring responsibilities; however, many continue to experience caregiver burden after admission and increased strain as end-of-life approaches. Having a family member move into a residential aged-care facility does not always mean the caring role has ended, but rather, they have transitioned into a new phase and setting. Family carers should receive information from healthcare providers about the illness trajectory and treatment options, as well as support for their social, emotional, psychosocial, and spiritual well-being. Due to the declining capacity of the person with dementia, family carers often undertake the role of surrogate decision-maker. Therefore, supporting family carers with decision-making must be a priority for healthcare professionals (Gonella et al. 2022).

Family carers describe good end-of-life care in residential aged-care facilities to be similar to other settings. In terms of care for the patient, family carers describe good end-of-life care as quality physical, psychosocial, and spiritual care; symptom management; continuity of care; and respect for wishes at the end of life. Good end-of-life care for families involves ensuring family understanding of the disease trajectory, being kept updated about their relative's conditions, and receiving support for decision-making (Gonella et al. 2019).

5.15 Summary

Many of the above domains of care have been consistently reported by families as contributing to optimal end-of-life care for more than 30 years, yet few healthcare systems and services have been able to effectively address these priorities (Virdun et al. 2017). Services currently lack the ability to measure the quality of such care provision that hinders careful and targeted quality improvement strategies. Strategies focused on education, quality improvement, policy development, and research are required to truly see family-focused care realized for all patients with end-of-life care needs, irrespective of care setting (Virdun et al. 2017).

6 Strategies to Optimize Outcomes for Families

There are a number of important and cost-effective strategies that healthcare providers can implement to optimize palliative care outcomes for families, as detailed below.

6.1 Need for Healthcare Provider Self-Awareness

It is important for healthcare providers to be aware of assumptions they may have about families. Common assumptions may involve the perceived altruistic nature of family members, such that they always have the best interests of the patient at heart, when this may not be the case and/or that the family is close, supportive, and loving. Another assumption is the belief that children, particularly female children, are obligated to care for chronically ill or older family members. We all bring our own assumptions about the structure and function of families, but not all families are the same, and they all bring their experiences from the past when provision of care is required. Activities to facilitate self-awareness can help healthcare providers acknowledge and reflect on their own assumptions and biases to facilitate their ability to provide family-focused care (Acquaviva 2017).

6.2 Interdisciplinary Team

A key strategy underpinning the provision of family-focused interventions is the active engagement of a cohesive team of healthcare providers who are able to respond to the needs of patients and their families during the palliative phase of the patient's illness. To improve family experiences, the interdisciplinary team should have education and training in palliative care (Quigley and McCleskey 2021). It is important to recognize that the focus of care should be on an interdisciplinary approach that enables and supports shared decision-making that includes the family as a core team member. Using this approach, all members of the team are able to contribute and share their expertise in providing care to the patient's family and in making decisions that are responsive to family issues and concerns (Haugen et al. 2015). The team's focus should be on responding to the family's needs, issues, and care, rather than basing their decisions on the imperatives of healthcare providers (Speck 2006).

6.3 Effectively Engaging and Supporting Families

One of the most important aspects of engaging and supporting families is to respond to them with respect and compassion, in a manner that is nonjudgmental and preserves the dignity of their personhood. It is important to recognize the unique qualities of each individual and their unique ways of behaving and responding in the palliative care phase. Chochinov (2007) outlined key elements of preserving dignity for the patient, which could equally be used in the care of families. He emphasized the importance of attitude, behavior, compassion, and dialogue. Attitude focuses on the healthcare providers' attitudes and assumptions so that they do not adversely affect the rapport that needs to be created and maintained with the patient. Behavior can include the necessity for honest, open, and easily understood communication, and making time to answer questions and clarify information provided. Dialogue encompasses the individuality of a person and gaining an understanding of the person beyond their disease or circumstances. As part of this dignity approach, Chochinov has developed a key question to ask the patient and has reported benefits to patients, families, and healthcare professionals resulting from the use of this question

> "What should I know about you as a person to help me take the best care of you that I can?" (Chochinov et al. 2015)

This same question and the key components of the dignity-preserving model can be equally considered for engaging and supporting the family. These principles can provide the foundation for engaging in a relationship with the family to provide effective support during the palliative care phase. Effective engagement of the family using this framework will guide the support that families require. Information about the patient's condition, what to expect at this time, explanations of how the condition may evolve, and information about the dying process are vital to facilitate coping, particularly at the end of life (Benites et al. 2021). Explanations of what a service provides and the roles of the different healthcare providers are also fundamental to families. Information needs to be tailored to the needs, language, and culture of the family. It is important to understand the family's current understanding of the patient's condition and their degree of acceptance or denial of the situation, so that information can be provided in a nonthreatening and empathic manner. Information that may seem self-evident to healthcare providers concerning dying and death may be totally foreign to a family who has never previously experienced the death of someone (Kristjanson and Aoun 2004).

Acknowledgment of the physical demands and caregiving roles of families is important in providing adequate support. Practical issues such as ensuring that families have access to sustenance can be provided with overnight facilities toward the terminal phase of the patient's illness; gentle reminders to take "time-out" or obtain some relief for their caring roles are also important. Families may need psychosocial support to manage the strain of caregiving and have an opportunity to discuss their feelings (Cheng and Chen 2023).

At the end of life, spirituality can provide family caregivers comfort, strength, and support to deal with worsening of their loved one's condition and approaching death by placing hope and trust in a higher power. Spirituality provides family members with hope, relief, and acceptance, whilst also providing opportunities for meaning-making, self-reflection, and re-prioritization. However, family members may also experience existential and spiritual suffering with regard to their loved one as they approach death. Family carers can feel overwhelmed, frustrated, and anxious when their loved one deteriorates. They can also feel uncertain about the future and feel a loss of control when their loved one enters the terminal phase (Benites et al. 2021). Therefore, support for the emotional needs of the family members is critical. The witnessing of a relative's deterioration, the impending loss, and a sense that they may be relatively alone in confronting this existential challenge require careful assessment and appropriate emotional, psychosocial support, and spiritual support. Family caregivers wish to receive compassionate care from healthcare providers, which involves providers demonstrating respect for and genuine interest in carers' religious and spiritual beliefs (Benites et al. 2021; Gonella et al.

2019; Dittborn et al. 2021). Attending to these needs and preparing the family for the impending loss may alleviate some of the distress of bereavement (Fineberg 2022). It should also be noted that the COVID-19 pandemic altered the end-of-life experience for many families and caregivers and may have implications such as prolonged grief disorder for grieving family members (Fineberg 2022). Engaging the family in preparatory grieving can be ultimately therapeutic for individual family members and the family unit as a whole.

In an increasingly digital society, availability of digital health interventions or telehealth is growing, which may offer new forms of support for family caregivers. However, it is yet to be determined whether accessing support online leads to increased isolation (Payne et al. 2022).

6.4 Specific Needs of Family Carers

In a recent overview, Marco et al. (2022) identified the most commonly expressed needs of family carers and their preferred sources of support to meet these needs. The top five needs were emotional (e.g., managing emotions, coping), disease-specific information (e.g., what to expect), role responsibilities (e.g., education and training for carer role), self-care (e.g., improving quality of life), and practical (e.g., assistance with daily living tasks). Family members most often prefer to have their needs met through professional services and interactions with their healthcare providers.

Family carers want healthcare providers to recognize that they have unmet needs (Vermorgen et al. 2021). Healthcare providers should ask carers about their unmet needs and/or use established assessment tools to identify carer needs, such as the Carer Support Needs Assessment Tool (Marco et al. 2022; Ewing and Grande 2013).

6.5 Undertaking a Family Assessment

A thorough understanding of the patient's family is fundamental to providing family-focused interventions. To ensure that this occurs, a comprehensive assessment of the family should be undertaken (Fineberg 2022). Use of instruments or tools is one method of assessing carer needs. The Carer Support Needs Assessment Tool is a screening tool that allows healthcare providers to identify carer support needs (Ewing and Grande 2013). Other needs assessment tools are specific to family caregivers of cancer patients receiving palliative care. These include the Family Inventory of Needs (Kristjanson et al. 1995), Home Caregiver Need Survey (Hileman et al. 1992), Questionnaire about the Needs of the Dependents of Advanced Cancer Patients (Cui et al. 2014), and the Spiritual Needs Inventory (Hermann 2006).

This assessment will involve both psychosocial and other healthcare providers on the team. The assessment should include the identification of key family members and any other people considered "family" by the patient. To ascertain the important family member(s) to a patient, a healthcare provider can ask the patient who is important to them or who they consider their family to be and who they want at the bedside or to have present at a meeting about care. The way a healthcare provider asks this question can convey the provider's openness to different family configurations. To normalize this phenomenon of bringing an accompanying person, the healthcare provider can explain that patients often find it helpful to invite one or more people to participate in the meeting with healthcare providers (Acquaviva 2017).

The role of family members in relation to the patient's illness and his/her care should also be delineated, for example, caregiving duties. Identifying all the people who constitute the patient's family ensures that no family member is excluded from the support needed during the palliative care phase (Kristjanson and Aoun 2004). It is also prudent to obtain information about any estrangements in the family and identify the family members who are not readily available to the patient or for the important interactions that need to take place. Documenting the family structure in the form of a genogram may help to ensure that this information is easily accessible to the entire interdisciplinary team. In the course of the patient's care, different family members will often encounter different members of the interdisciplinary team. Recognition by the team of all family member(s) provides a context that is most likely to enhance communication and good relationships between the family and team members. It is also important to gain an understanding of the patient's current illness and its impact on the family as a whole and on individual family members (Lethborg and Kissane 2015). Previous significant life events, as well as important events likely to occur in the future (e.g., the birth of a child), should be documented. Particular note should be made of any history of mental illness, substance abuse, or any intra-family abuse (Fineberg 2022). In addition, the possible impact of the patient's illness, according to the life stage of individual family members, should be considered. Social aspects of the family unit such as culture, language, financial, and employment issues should also be recorded (Lethborg and Kissane 2015). Religious practices and an understanding of spiritual beliefs should be assessed. The particular sources of meaning and purpose for family members will be relevant, given the context of dying and death of their family member.

6.6 Identifying and Understanding Family Patterns of Communication and Cohesion

A specific area for family assessment relates to an understanding of how family relationships work, the sources of strength within the family structure, and the family members' preferred communication style(s). Previous ways of relating to each other, and managing challenging family situations, may influence and provide the team with guidance as to how the family might respond and confront the life-limiting illness of their family member (Lethborg and Kissane 2015). Any previous or current issues that have provoked conflict should be identified, particularly those affecting the patient at this final phase of his or her illness. This information and any major concerns articulated by individual family members, or by the family in its entirety, will assist the interdisciplinary team to respond with suitably family-focused interventions (Lethborg and Kissane 2015). The resolution of family conflict may not be possible. However, appropriate family-focused interventions and support may improve family relationships. Such interventions may also foster more open communication and enhance decision-making so that the family's cohesiveness is optimized at this time (King and Quill 2006).

6.7 Engaging Families in Decision-Making

Decision-making in the palliative care context will be influenced by the communication styles of the family and the family's previous ability in making decisions. It may be that the family do not routinely make joint decisions or they may have a preference for one family member to make decisions on their behalf (Wellisch 2000). In addition to understanding previous decision-making patterns, the interdisciplinary team requires an understanding of the degree to which the family unit and individual family members wish to be involved in this process. Some families are content to forego input into decision-making and allow all decisions to be made by the healthcare team. Alternatively, other families and family members require regular information, consultation, and involvement in decision-making (Isaac and Curtis 2016). It is important to elicit from the family where they are placed on this continuum of decision-making and which decisions are of particular concern to them. For instance, the family may be comfortable for the interdisciplinary team alone to make decisions about the patient's care. However, they may require the team to consult with them about all decisions that affect both the patient and the family. Families may often have a preference to engage with specific team members in the decision-making process. This preference should be shared with other team members. It is essential to establish and document to what degree family members are surrogate decision-makers for the patient or if one particular family member is the primary spokesperson and surrogate decision-maker (Isaac and Curtis 2016). Patients and families also value the naming of a decision-maker as a contingency plan for situations in which the patient may be unable to make decisions (Steinhauser et al. 2000). Recognition of these key factors will guide the team to respond effectively and will enable the provision of family-focused care in relation to decision-making.

The processes required for decision-making are likely to involve sharing of information with families and individual family members, in either one-on-one conversations, informal consultations around the patient's bedside or at home, or during a family meeting. Decision-making is likely to be an iterative process, and although it is time-consuming, it is integral to family-centered care. In the era of enhanced communication, telephone and electronic devices can facilitate discussions and decision-making when family members are not physically available (Fineberg 2022).

Evidence supports the importance of decision-making by family members in the palliative care setting not only from the family perspective but also for the patient (Steinhauser et al. 2000). It should be recognized that decision-making may not only focus on clinical issues. Decisions about everyday activities such as going to the hospice garden or having a pet visit may be just as vital for the patient and family. This type of decision-making enables the patient and family to experience some degree of control in their life at a time when this may be limited. Preparation for the end of life with patients and their families is also valued, and it is incumbent on the interdisciplinary team to recognize and support such decision-making and preparation to ensure family-centered care (Steinhauser et al., 2000).

6.8 Undertaking a Family Meeting: Purpose, Roles, and Responsibilities

Effective communication in palliative care is central to adequately addressing patient and family needs, and concerns at the end of life (Wittenberg et al. 2016; Virdun et al. 2017; LeBlanc and Tulsky 2022). Bringing patients, families, and clinicians together for purposeful discussion has been recognized as a means of strengthening patient–family–team communication in palliative care populations (Fineberg 2022; Hudson et al. 2008; Powazki and Walsh 2014). These formalized conversations are usually referred to as a "family meeting" or a "family conference," and these terms are often used interchangeably in clinical and research settings. In the palliative care context, a family meeting may be defined as

> . . . a one-time meeting including the patient (when possible), family members of the patient, and relevant healthcare staff to discuss a topic related to the health and care of the patient and family. (Fineberg 2022, p. 544)

The evidence informing models of family meetings is largely descriptive and has only been a focus of research since 2008, other than a preliminary study in 1991 (Cahill et al. 2021). Nevertheless, the reasons for convening a family meeting in palliative care have been variously documented (Altilio et al. 2008; Hudson et al. 2008; Fineberg 2022; Hudson et al. 2009; Kissane and Zaider 2022) and include

(i) Discussing symptoms, goals of care, and current treatment with the healthcare team and the patients and their family
(ii) Building consensus about goals of care and management plans with the healthcare team and the patients and their family
(iii) Promoting a shared understanding of the current clinical situation between the patient, family, and healthcare team
(iv) Supporting the expression of emotion, concerns, and issues by patients and their families

Family meetings also provide an opportunity for family carers to collaborate with healthcare professionals, which is significant considering that they feel that they frequently miss opportunities to do so (Vermorgen et al. 2021).

There has been support for family meetings as best practice in the palliative care setting

(Glajchen et al. 2022). The literature has also described that family meetings provide a critical means of optimizing communication between patients, families, and the care team, while simultaneously enhancing family outcomes such as clarifying goals of care and addressing misunderstandings or concerns (Sullivan et al. 2015; Kissane and Zaider 2022; Fineberg 2022).

Guidelines for Conducting Family Meetings in Palliative Care were developed in Australia (Hudson et al. 2008) based on available literature, various theoretical models, expert opinion, and the results of focus groups. These consensus guidelines provide a planned approach for preparing, conducting, and documenting the agreed decisions resulting from a family meeting. An evaluation to assess the effectiveness of these guidelines demonstrated a significant increase in families' unmet needs being satisfied as a result of participating in such meetings. Family members also reported that the meetings were useful because they gained a better understanding of the patient's illness and what to expect in the immediate future (Hudson et al. 2009).

More recent evidence has indicated that family meetings have resulted in a significant decrease in participating family member's distress measures post-meeting (Powazki et al. 2018) and care needs (Hannon et al. 2012). The most recent study concluded that family meetings undertaken in an inpatient setting appear to assist in the reduction of family caregiver distress and enhance the preparedness of the family for the caregiving role (Hudson et al. 2021). For these reasons, palliative care services should consider inviting patients and families to participate in a family meeting following admission to the service if there are no contraindications such as the terminal phase of the illness trajectory or significant family conflict. This aligns with guidelines for family support and the concept of early palliative care. Data also suggests that meetings can occur without increased healthcare utilization costs as hospitals can deploy existing resources to facilitate family meetings (Hudson et al. 2021).

The adoption of an open style of communication by the interdisciplinary team members during the family meeting can help build consensus about the goals of care and management plans and promote a shared understanding of the current clinical situation and its uncertainties. These meetings can also increase the patient's and family's involvement in decision-making. Facilitating the expression of family concerns, issues, and needs provides the family with a sense that their concerns are being heard and addressed, that they have a voice and may feel more empowered in the current situation (Altilio et al. 2008; Hudson et al. 2009; Powazki and Walsh 2014; Kissane and Zaider 2022).

Discussion at these meetings will inevitably include clinical issues; however, psychosocial issues and spiritual concerns may also be addressed (Tan et al. 2011), as well as other key areas of importance for that patient and family. In a recent family meeting study of a model that required patients to set the agenda for the meeting, families expressed that having this type of family meeting helped them address sensitive topics with the patient; clarify approaches to current end-of-life issues and plans for the future; understand the roles of the interdisciplinary team caring for the patient; and ensure the family is on "the same page" (Cahill et al. 2021).

Conflicting perspectives may emerge between the patient and family members, especially when certain family members are not able to be present. Family participants (or significant others) may also raise contentious issues and unresolved concerns or indicate preexisting family conflict. In all cases, it is important to address the specific issues (if possible) or to give voice to concerns as expeditiously as possible so that the meeting's focus remains on the patient and the family. In some cases, it may be prudent to acknowledge these concerns but to offer an alternative time to deal with them more fully, either with both patient and family present or with the family in the absence of the patient. Significant conflict between the patient and a family member, such as the existence of an abusive relationship, is not conducive to the patient or family member (s) being able to honestly discuss their concerns and issues. In such situations, a family meeting may not be possible or may even be contraindicated and the principles of trauma-informed care should be used in progressing interactions between patients and families (Fineberg 2022).

The practical aspects of arranging, organizing, and convening a family meeting are important if one is to achieve the maximum benefits for all participants in terms of communication, information sharing, and decision-making (Kissane and Hempton 2017). Key components include who will participate and where and how the family meeting will be conducted. The patient and the primary family support person including any additional family members who wish to participate or whom the patient requests to attend. The patient's palliative care consultant and/or registrar and social worker should routinely attend the meeting. Other members of the team, including pastoral care, nursing, and allied health staff, should attend according to the agenda or the specific issues and concerns that are to be discussed and previous healthcare providers may be also appropriate to attend to foster continuity of care (Fineberg 2022). Patients and families may also request the presence of particular team members during the preparation phase of the meeting. Prior to the meeting being convened, one of the attending healthcare providers should be designated to facilitate the meeting based on mutual agreement with other team members. A co-facilitator of the meeting may also be considered (Kissane and Hempton 2017; Fineberg 2022). Ideally, the lead healthcare provider should have had prior experience in facilitating family meetings in the palliative care setting. All participants should be informed in advance of the date, time, and place for the meeting and commit to being present for the entire meeting, with the exception of unanticipated crises. This will ensure that the flow of conversation and discussion is not disrupted nor are participants distracted.

Given that the agenda will influence the goals of the meeting, it is important to recognize that the process by which the agenda is set varies considerably in the reported literature. Some authors suggest that healthcare providers set the agenda. However, the Australian Guidelines for Conducting Family Meetings in Palliative Care (Hudson et al. 2008) recommend that the primary family carer should be the one to identify the main issues and concerns; if the patient attends, he/she also should attempt to identify key issues. Whichever method is used, a prearranged agenda shared with all participants is preferable to an ad hoc arrangement, although it is likely that the patient and/or their family may raise additional issues or concerns as the meeting progresses. An alternative to the clinical team setting the agenda is the model of a patient-centered family meeting, which supports the patient setting the agenda with input from the family as desired by the patient (Sanderson et al. 2017; Cahill et al. 2021). This strategy may increase their sense of agency by providing them with the opportunity to identify and prioritize topics for the meeting (Cahill et al. 2021). Whichever form the agenda should guide the family meeting, it is likely that the patient and/or their family may raise additional issues or concerns.

A private, comfortable space with adequate seating and ventilation is preferred for the meeting. Meetings should not be held in a shared room within inpatient units unless there is no other option physically possible. The space for the meeting should be prepared in advance so that the meeting can commence in a timely and unrushed fashion. The family meeting begins with the facilitator ensuring that all participants introduce themselves and indicate their relationship to the patient and to each other. The participating healthcare providers are reminded of the importance of open listening and to refrain from interrupting the patient and family discussion or directing the discussion away from those issues raised by the patient and family members. Occasionally, however, clarification of an issue or point will need to be made to provide information requested by the patient and/or the family. Kissane and Hempton (2017) describe specific details of communication skills required in the context of family meetings. These include the use of circular questions to support the expression of family members' needs and issues, reflexive questions so that families may reflect on what is happening in their lives as a result of the patient's life-limiting illness and strategic questions to identify the possible solutions to current issues (Kissane and Hempton 2017). Fineberg (2022) has also described key elements required for facilitating the discussion at family meetings.

It is important that the facilitator acknowledges and facilitates discussion about the issues raised. However, clarification of information about the patient's illness, prognosis, goals of care, and management plans will usually be required (Kissane and Hempton 2017; Kissane and Zaider 2022). Patients and family members should be supported when raising anxieties or fears so that these can be heard by all present and addressed in a timely manner.

Once the discussion has been completed, the facilitator provides a summary of the views expressed by the family and summarizes the agreed goals of care. Other key points that have been discussed or agreed to, any matters of disagreement, and any actions required to be undertaken following the meeting are confirmed (Kissane and Hempton 2017; Kissane and Zaider 2022). Endorsement for the decisions made and the actions to be undertaken is sought from the patient, family, and healthcare providers (Hudson et al. 2008; Kissane and Hempton 2017). The facilitator concludes the meeting by emphasizing the positive results from the meeting; acknowledging the patient, family, and clinical contributions to the meeting; and thanking all the participants.

For families from different cultural backgrounds or speaking a language that differs from the healthcare professionals caring for the patient and family, family meetings may be more challenging. Sharma and Dy (2011) have acknowledged this issue by proposing a framework for use in diverse populations. It is vital that the healthcare professionals are mindful of the need for these families to participate in a family meeting in a constructive manner.

During the COVID-19 pandemic, the usual family face-to-face meetings in palliative care were problematic and often not possible. However, a study undertaken in the United States demonstrated positive outcomes for virtual family meetings (i.e., E-Family Meetings). A total of 97% of scheduled family meetings were completed and families reported the benefits of being able to ask questions, express their thoughts, and understand their family member's care. In addition, the E-Meeting assisted the family in trusting the treating team (Kuntz et al. 2020).

Despite the many benefits of conducting family meetings, there are some barriers to implementation. These include lack of clinician confidence regarding communication skills (particularly surrounding bad news), lack of time, costs, insufficient infrastructure, and insufficient administrative support (Glajchen et al. 2022). Therefore, there is a need for innovative strategies to better support healthcare systems in the implementation of family meetings.

6.9 Family Carer Contributions to Health Service Improvement

Families may be open to providing feedback to health services with regard to quality improvement initiatives. Families have various preferences in terms of their engagement in improvement work, which should be respected and integrated into engagement initiatives. Based on family carer feedback:

- Carers desire supportive and individualized ways to provide feedback on care quality. This includes having a key person to speak with, provision of contact details of the clinical teams, a dedicated clinician to "check in" on needs regularly.
- Carers find it difficult to provide real-time feedback to clinicians due to fear of repercussions. They preferred being contacted after discharge but only if the patient was in a stable condition. Carers also would appreciate an authentic conversation where providers check in and ask about needs, rather than focus explicitly on feedback.
- Willingness to contribute to improvement work depended on the timing (whether they were a current carer or bereaved former carer) and diagnosis (malignant or nonmalignant). Bereaved former carers were often eager to contribute; however, they needed health services to be mindful of time commitments and be able to promise that their time would incite real change.

- Carers prefer to provide face-to-face feedback; however, if rurally located or unable to attend, they appreciate the option to participate online (Virdun et al. 2022).

6.10 Future Research on Family Carers

Currently, most family carer research focuses on carers of patients with cancer; therefore, there is less known about the support needs of carers of patients with other conditions. There is a need for greater research on carer characteristics that may impact caring, carers with concurrent roles and responsibilities, carer access to and use of resources, carer health literacy, and carers from diverse and marginalized groups. There is a need for more research that develops feasible interventions that support carers and their needs (Payne et al. 2022).

7 Conclusion and Summary

While caring for a family member with a life-limiting condition can be distressing, it can also be a positive and rewarding experience. Carers have reported positive experiences from caregiving to include a strengthened relationship between carer and care recipient, personal growth, increased self-efficacy, and recognition of personal strength through adversity, acceptance, and necessity (Hudson 2004; Wong et al. 2009). However, family-focused care is critical in supporting positive care experiences and more healthy adjustments to grief and bereavement, where possible. Challenges to family-focused care include individual healthcare provider practice that fails to prioritize working in partnership, a lack of policy and infrastructure support with often-exclusive focus on patient needs, and a lack of open, innovative, and creative thinking to facilitate and partner with families caring for people at the end of their lives. Meeting these challenges through education, policy reform, quality improvement initiatives, and research provides enormous opportunity for improved family-focused end-of-life care in the future.

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