

The challenge of family-centered care in palliative medicine

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Palliative care has long aspired to the competent delivery of family-centered care alongside outstanding person-centered care. While the rhetoric has been strong, models of effective family-centered care have proved challenging, leaving this as one of the key domains warranting the sustained focus of our discipline in the twenty-first century. Yet there is clear consensus that the unit of care is the patient and family.

Fortunately, recent studies have emerged that continue to throw light on the unmet need (1,2), effects of psychoeducation (3), and interventions to support difficult families from palliative care into bereavement (4). As we seek to learn from these developments, key questions include, “Who is the family?” “When to intervene with families?” and “Which model to apply in what circumstances?”

Firstly, who is the family? One helpful definition is the notion of ‘psychological family’ as a cluster of like-minded people who hold a shared history and will support each other in the future (5). Most importantly, they are those folk that the patient will want to invite to meet together when the clinician asks for a family meeting.

When is the family in need? While all families have educational needs to prepare for and provide caregiving, many are resilient and need not tax clinical services heavily. A routine psychoeducational model should meet their needs. However, one quarter of families have extra needs that demand specialist psychosocial care (6). The classic times that families struggle include when (I) families with young children have a parent with advanced cancer, including the single parent; (II) couple conflict affects the whole family; (III) a depressed parent has limited coping; (IV) a disabled child will become bereaved; and (V) a dysfunctional family with poor communication, unbridled conflict or reduced cohesion has limited coping and support mechanisms for the family.

Perspectives on family caregiving challenges

In a series of studies of family caregivers for patients with colorectal and lung cancer, Mosher and colleagues identified four consistent challenges experienced by caregivers: (I) emotionally coming to terms with disease progression towards end-of-life; (II) managing caregiving; (III) dealing with uncertainty; and (IV) responding to symptom-related suffering (1,7,8). These issues echo those addressed in psychoeducational and supportive interventions, where in a meta-analysis, Northouse and colleagues confirmed benefits in reducing the burden of caregivers, enhancing their ability to cope, and improving both caregivers’ self-efficacy and quality of life (9).

Psycho-educational interventions to prepare caregivers

A Swedish collaboration across ten services showed in a randomized controlled trial that a program of three family group educational sessions by physician, nurse and social worker/chaplain significantly increased family caregivers preparedness for and competence in caregiving (3). However, no effects were found on emotional issues including anxiety and depression. A structured review of family meetings at the end of life synthesized findings from 24 studies and noted that family satisfaction increased when the clinician allowed time for family speaking, provided assurance to alleviate patient suffering and not abandon the patient, while also supporting family decisions (10). The biomedical model at family meetings educates about prognosis, medical and pharmacological care needs and decisions about end-of-life care. When agenda setting was not purposeful at the start of the meeting, families reported feeling rushed and

emotionally unprepared for what occurred. As the family meeting becomes routine for all inpatient palliative care admissions, adoption of a structured model has been seen as crucial to adequately address family needs (10).

Identification of and intervention with difficult families

Most challenging to support are those families in conflict who block easy communication and where family ruptures and separations lead to unavailability for care provision and support. A routine screening model of family functioning was developed in Australia and replicated in the USA to use the 12-item Family Relationships Index (FRI) with good sensitivity to detect families with low communication, low involvement and high conflict (6). These families are at risk and in need for psychosocial support. Clinicians in individual consultations or family meetings can also ask three simple questions about family relational life to discern the presence of any dysfunctionality: (I) communication—how openly do you communicate as a family? (II) cohesion—how strong is family teamwork and mutual support? (III) conflict—how well do you resolve arguments and differences of opinion?

A recent randomized controlled trial of 170 palliative care families (620 individual members) stratified families selected by the FRI to be at risk for dysfunction and compared six *vs.* ten sessions of family therapy with usual palliative care (4). Ten sessions of family therapy, commenced in palliative care with the ill patient present and continued into bereavement over 12–18 months, delivered significantly better outcomes for both low communicating and high conflict families with reduced severity of complicated grief and prevention of the development of prolonged grief disorder. These challenging families can not only be engaged in a program of care provision but also helped to reduce conflict and begin to work constructively together.

The category of family that did not gain from family-focused therapy was the low involvement type of family, where relatives used distance to not only avoid conflict but also empower them to get on with life (4). These families quickly declare the barriers to availability for support and caregiving. Children might live interstate or overseas and the level of contact is infrequent. Clinical services do well to recognize that these patterns of family relationship are entrenched and predicative of limited capacity to support.

Special family needs

Clinicians do well to recognize the particular predicaments that challenge even resilient families, for instance, the expected death of a parent with younger children (11), the dying parent of a disabled child (12), and when a conflictual marriage strains relationships for the rest of the family (13). Fortunately, clear programs have emerged with structured models to support families in these circumstances and a clinical resource section is provided below to guide clinicians to read more about these excellent programs.

Structured models of family-centred care

The future of competently-delivered family-centred care depends on services adopting a structured approach to family care. A two-tiered approach is needed. At the first level, routine family psycho-education is needed for all, and should be accompanied by routine family screening for the quality of relational life with the FRI. A routine family meeting is a desirable standard of care for all inpatient palliative care delivery. At the second level, those 20% of families whose FRI scores suggest greater risk should be invited for an outpatient assessment family meeting where their concerns and needs are identified in an effort to provide them with the rationale to continue family-focused therapy. Here the ongoing goal of enhancing their emotional support for one another would be agreed upon during both palliative care and extended into bereavement. The continuity of psychosocial care that is delivered by the latter model proves a source of extraordinary support for families.

There is much still to do to embed comprehensive family-centred models of care with hospice and palliative care programs. More family trials will enrich the evidence-base, but dissemination and implementation of what has been learnt across recent decades is a crucial developmental agenda for all clinical services.

Recommended clinical resources

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