Importance of Family-Centred Care to Palliative Medicine

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The family is inevitably involved in care-provision when one of its number suffers from a progressive and life-threatening illness such as advanced cancer. Distress reverberates throughout the family, with moderate rates of psycho-social morbidity, including up to one third of partners and one quarter of adult children (1–3). There has been growing awareness over recent years of the importance of a family-centred model of care to fully meet the needs of patients and families involved with palliative care services and, moreover, maintain continuity of support into bereavement (4).

To achieve this, we need both conceptual and pragmatic methods of classifying families to guide our efforts at intervention. Historically, one approach has been to conceptualize families in terms of the phase of illness they must negotiate (5); another stressed the family’s needs or the associated burdens it experienced (6); a third focused on the family’s developmental stage (7). Yet none of these approaches proved predictive of psycho-social outcome over time. It was not until attention turned to family functioning that a clinically useful method of predicting psychosocial outcome emerged (8,9).

Through these longitudinal studies of families during palliative care and bereavement, we were able to classify families using the following dimensions of their functioning: (i) cohesiveness, the family’s sense of togetherness; (ii) expressiveness, their sharing of both thoughts and feelings; and (iii) conflict resolution. These dimensions form a simple screening instrument, the 12 item Family Relationships Index (10).

USE OF FAMILY FUNCTIONING AS A CLINICAL APPROACH

Using these dimensions of family functioning, we have been able to define 5 classes of adult families when one parent suffers from terminal cancer (8,9). Two classes appear well functioning: one third were named supportive, characterised by high levels of cohesiveness, and one fifth conflict resolvers, in whom effective communication provided the wherewithal to tolerate difference of opinion and resolve conflict constructively.

In contrast, two classes of families were clearly dysfunctional: hostile families (6%) were distinguished by low levels of cohesiveness, expressiveness and much conflict, while sullen families (9%) had more muted levels of anger and also carried the highest rates of clinical depression among members. The final class of family was termed intermediate (one third in number) because its characteristics lay somewhere between the well functioning and dysfunctional families, yet considerable morbidity still occurred for its members. Furthermore, intermediate families tended to become more dysfunctional under the stress of bereavement (9).

SCREENING PERMITS RECOGNITION OF FAMILIES AT GREATER RISK

It would be labour intensive, costly and unnecessarily intrusive to seek to intervene with all families. We should have confidence that well functioning families are able to effectively support their membership and cope adaptively with the grief of bereavement. However, a preventive model of care that enhanced functioning in families at risk of maladaptive outcome would do much to reduce psycho-social morbidity in the community. Screening families to define their functioning would enable such a model of palliative care.

Families could then be invited to meet as a family group to discuss care of their ill relative and consider how we might further help them. This model is a focused brief intervention, whose primary goal is to enhance family functioning, with the aim of reducing psycho-social morbidity both during palliative care and across the later phase of bereavement (11). The dimensions of family functioning that are targeted include promotion of cohesiveness, reduction of conflict and encouragement to share thoughts and feelings with each other. Integral to this process is the sharing together of family grief, while the family’s strengths and successful ways of coping together are affirmed.

Attendance at a family meeting is open to all interested, including the dying patient. However, if a family member chose not to attend, one should respect their wishes, having confidence in the principle that change in one part of a system will inevitably influence other aspects of the system.

The model is a flexible one that seeks to engage families during palliative care and continue the support during early bereavement, once the cancer patient has died. Initially, two weekly sessions are conducted as part of an assessment process. Then with more focused treatment, sessions tend to occur fortnightly to monthly, dependent upon the issues at hand. Generally some 4 to

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6 focused treatment sessions occur, before moving to less frequent consolidation sessions, occurring 2 to 3 months later, before therapy is terminated.

A number of common themes arise during this family work: concern about death and the dying process; any unfinished business which may be present; the process of saying goodbye; the material or instrumental care provision tasks that are there for the family; any question of suffering; the existential issue of uncertainty; intimacy and closeness; the role of culture and religion; the needs of younger children; past losses; and eventually, whether the death proved peaceful, or one which brought disappointment. Eventually the family moves to the dominant issues of grief and loss.

As the family progresses to the point of termination, review of the work that the family has done is appropriate. Success is affirmed, but the family is reminded that old patterns will occur, and that they need to continue their efforts to pull together more closely, communicate well and avoid conflict. The therapist endeavours to look to their future with confidence and wishes them the very best in concluding this therapy.

TRUTH TELLING ABOUT CANCER AND THE FAMILY

Despite the recommendations of the Japanese Ministry of Health and Welfare task force on the terminally ill in 1989 (12), full disclosure of the diagnosis has progressed slowly (13). However, suspicion about the diagnosis had been present in over half those not informed. Our experience of family meetings is that they empower frank and easy discussion of the predicament as anxious relatives discover that their parent can courageously accept the truth. Clinicians can readily clarify family ideas by asking directly about their expectations and fears (14). Family meetings model direct and open communication about cancer and palliative care and bring considerable relief and peace of mind to family members.

CHALLENGES IN WORKING WITH CANCER FAMILIES

Some particular challenges occur in doing this work. One of these is the engagement of families who are especially avoidant. The hostile type of family proves the hardest to bring together. This, if it can occur, needs to be on neutral territory, such as in the doctor’s office. However, for better functioning families, particularly intermediate families, as the illness progresses, the need is often there for family meetings to occur in the home.

The doctor or therapist needs to establish clear guidelines for the safe conduct of family sessions within the home, clarifying seating, time, processes and ensuring that the family won’t be interrupted by visitors or the telephone. Sometimes if the dying patient is too ill, the family may move from the bedside back into a family room, separate from the patient.

It is always important in this therapy that achievable goals are targeted, sometimes modest ones for poorly functioning families, as the work is, of necessity, time-limited. Nonetheless, consider-