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Editorial

Helping the Relatives of Patients with Cancer

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THE DIAGNOSIS and treatment of cancer inevitably affects not only patients but also their relatives. Few people inhabit a social vacuum, so the primary sources of social support for patients are likely to be family members. Furthermore, changes in the delivery of cancer services, as well as cost containment issues, mean that a considerable burden of complex physical treatment, after-care and terminal-care may also become part of the families' responsibilities. McCorkle and associates [1] have pointed out that, with patients being discharged from acute care settings so much earlier than in the past, there has been a dramatic shift in the role of care-giving from "one of promoting convalescence to actively providing high technology care in the home". It is not that unusual for patients to be receiving chemotherapy through intravenous lines at home and seriously ill patients with cancer having parenteral nutrition. Although some families become adept at administering treatments, many find it an intolerable strain [2].

It is gratifying that, in contrast to the situation which existed in the past, much more emphasis is now placed on helping patients with cancer deal with their many psychosocial concerns. However, if counsellors and others focus too narrowly on the patients' feelings, thoughts and concerns, it is too easy to overlook the major needs of the family. A failure to acknowledge and then help alleviate the families' predominant emotional needs, will ultimately deprive patients of the comfort, love, support and companionship that they will need throughout the course of their disease. As many studies have reported the importance of appropriate social support in mediating the effects of a serious stressor such as cancer, e.g. [3,4] and others have shown that the psychological status and coping styles of patients with their closest family care-giver are closely matched [5], assessment of both patients and their carers may be crucial for long-term adaptation.

The article by Harrison and colleagues in this issue (pages 1736–1740) identifies the significant levels of psychological distress and major concerns experienced by the key relatives of patients with newly diagnosed cancer. Using a standardised psychiatric screening tool, Harrison and colleagues found that almost half the relatives had scores above threshold, which suggests that rates of anxiety and depression were probably higher amongst relatives than those found in patients. It seems unlikely that the relatives they surveyed, who had this level of psychological distress, would be able to provide sufficient support for their suffering partners. Coping with the many physical and emotional demands and conflicts provoked by caring for a sick relative may challenge profoundly a relative's own emotional health and sense of wellbeing. The study by Harrison and associates was at an early stage of diagnosis and treatment; consequently, some of the more practical (but not necessarily less stressful) concerns were not mentioned by relatives. The chronic stress of dealing with a sick patient for some time may increase the difficulties for even those carers with well-developed coping strategies. For example, some recent research by Hinton [6] on 77 terminally ill patients and their relatives, showed that grief and strain on the carers' own health influence their ability to enjoy life. Serious depression and anxiety were considerably less in patients than in their relatives.

Not addressed directly in the article by Harrison and colleagues is the wider impact that cancer may have on the functioning of a whole family, although 34% of relatives felt that "effect of illness on others" was of major concern. Caring for a partner, child, parent or relative clearly has implications for other family members. The primary care-giver, who may already be experiencing a myriad of difficulties, may also have to be supportive to other family members. At an individual level, relatives may feel inadequate and confused about how to help. In particular, children may feel guilty that they are not sick themselves, or guilt that they sometimes find themselves impatient or angry at the changes coping with a sick relative has imposed upon the family. Many feel extremely fearful about what lies ahead. For example, several studies have highlighted the high levels of anxiety, depression and fear of death and separation found in the siblings of children with cancer [7–9]. Children who were 'protected' by their parents by exclusion from involvement in the care of terminally ill patients with cancer, were at particular risk of adjustment problems and psychological morbidity [10]. Positive adjustment is found amongst those families who are able to allow children to express their anxiety and concerns about a sick relative and encourage their active participation in some of the care-giving [9].

Those of us involved in the hospital care of patients with cancer need to consider the many different stressors that impact on a family dealing with a relative at home. When the cancer is at an advanced stage or if patients have had mutilating treatments, all family members have to find some means of coping

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with their distress at the changed appearance, physical and sometimes intellectual functioning of a loved one. Witnessing the steady mental, as well as physical, deterioration of someone with a cerebral tumour or brain metastases is particularly stressful.

Many people have difficulty adjusting to very new relationship roles, especially those families in which, prior to illness, the role boundaries were very closely observed. For some, this challenge permits individuals to identify hidden strengths and resources, whilst others find such adjustment very hard or they may resent the changed roles. The demands of caring for someone whilst also trying to work can impose an intolerable strain, especially on those relatives with stressful jobs or on families with somewhat fragile financial circumstances. The exhaustion makes it impossible for some carers to balance the needs of well members of the family with those of the sick person. Spinetta and Deasy Spinetta [11] have pointed out the difficulty of "walking the narrow line between time spent focusing on disease and its treatment, and time spent on one's spouse and other children, on the continuation of life and living".

The manner in which families adapt to cancer in one of its members will be a reflection of the intimate relationship, history and culture of that family. Therefore it is difficult to be certain about the impact that different concerns may exert, and prescriptive about interventions that might ameliorate the difficulties. Some problems may have their origin in deep-rooted family processes that pre-dated cancer and are difficult to challenge, but others may be quite amenable to change. After the initial trauma and sadness associated with the diagnosis and treatment of cancer, many families do reach a degree of acceptance, manage to cope with uncertainty and the changing family dynamics. It is easy to overlook the pressures created by organisational issues, such as cancer centres being far from the family home, housing conditions that make the home-care of a relative very difficult to achieve. Some of these challenges can be surmounted with minimal help and support and some families develop and report that their relationships are improved by the challenges, but what of those who cannot adjust satisfactorily? Harrison and associates suggest that relatives could be screened for psychiatric disorders, although it is not clear whose reponsibility their care would then be—the already hard-pressed hospital-based psychology or psychiatric services, the general practitioner, the specialist nurse or social workers? Wellisch and Cohen [12] go one step further and have suggested that as dysfunctional families may disrupt the quality of a patient's life and interfere with treatment goals, identification and help at an early stage is important. A recent report by Kissane and associates [13] has demonstrated the clinical utility in cancer of the 12 item Family Relationships Index (FRI). This is a sensitive global measure of family interaction assessing cohesion, expressiveness and conflict. Kissane and associates argue that the FRI could be used to identify 'at risk' or dysfunctional families on whom to target interventions. This still leaves the problem as to who would then provide the specialist counselling and support needed. The dearth of such psychological service provision for patients with cancer does not give cause for much optimism that resources will be readily available for families. However, with the increasing care-burden imposed on families, the level of distress they experience and their importance for a patient's well-being, non-provision of support services may be short-sighted.

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