A Critical Review of Supportive Interventions for Family Caregivers of Patients with Palliative-Stage Cancer

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ABSTRACT. The impact of supporting a dying family member has frequently been reported as extremely challenging. In addition, family members of dying cancer patients have consistently identified a need for additional guidance and support from health care professionals. Provision of high-quality palliative care services should include strategic support for families of patients confronted with a life-threatening diagnosis. To date, however, few published strategies clearly identify the most effective means of providing family support. The author seeks to provide a critical evaluation of past supportive interventions for family caregivers of dying cancer patients. The report confirms an urgent need for new supportive-care strategies for families to be tested. In addition, the review offers recommendations for designing and evaluating future family caregiver interventions. Psychoeducational interventions evaluated via randomized controlled trials are considered to be a priority. *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2004 by The Haworth Press, Inc. All rights reserved.]*

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The fundamental aim of palliative care is to achieve the best quality of life possible for dying patients and their families (Palliative Care Australia, 2000b; WHO, 1990). Holistic support for the patient and family underpins the philosophy of palliative care (Willard, 1999). Both patient and family should be recognized as the “unit of care” (Palliative Care Australia, 1998). From a sociological perspective, life-threatening illness may affect family roles and relationships (Willard, 1999). Therefore, involving the family unit as well as the patient in delivery of care is recommended.

Family caregivers play a crucial role in home care and commonly undertake complex care tasks, including assessment and management of symptoms, hygiene care, and administration of medications (Barg et al., 1998). Family caregivers not only assist in care alongside providers of palliative care services but also provide the bulk of support within the home (Decker & Young, 1991; Ferrell, 1998; Kurtz et al., 1995; Rhodes & Shaw, 1999). Without the input of family caregivers, the well-being of the majority of individuals with a life-threatening illness would be compromised (Stetz & Brown, 1997).

The physical, emotional, financial, and social impact of caring on family caregivers is considerable and often negative. The authors of several studies have reported that caring for a person dying of cancer may be associated with physical problems, such as exhaustion, fatigue, sleeplessness, weight loss, burnout, and general deterioration in health (Barg et al., 1998; Oberst et al., 1989; Ramirez, Addington-Hall, & Richards, 1998; Stajduhar & Davies, 1998).

For many family caregivers, caring for a dying relative is their first major confrontation with death (Andershed & Ternestedt, 1998). Those caregivers carry the dual responsibility of helping their dying relative to prepare for death, alongside their own emotional preparation for the impending death (Steinhauser et al., 2001). A variety of psychological sequelae may confront caregivers, including depression, reduced self-esteem, and feelings of isolation, fatigue, and anxiety (Kinsella et al., 1998). Also, caregivers are often confronted with social burdens resulting in restrictions on time, disturbance of routines, diminished opportunities for leisure activities, and loss of income (Stajduhar & Davies, 1998).

It is apparent, however, that the principle of family and patient as equals in provision of care may not always be upheld. Although family caregivers have identified a need for information and resources, they are not always recognized as legitimate “players.” In some circumstances, the health care system does not acknowledge the centrality of

the family caregiver's role (Stetz & Brown, 1997). Research has identified that caregivers of patients with advanced cancer report a variety of unmet needs despite input from health care services: Caregivers report unmet needs associated with social support (Grande, Todd, & Barclay, 1997), financial assistance (Stajduhar & Davies, 1998), emotional support (Wingate & Lackey, 1989), and assistance with managing the dying person's symptoms (Kristjanson, 1997).

Although caregivers' experiences and needs have been well researched, there is a dearth of literature related to intervention strategies (Barg et al., 1998). The effectiveness of psychosocial interventions in addressing caregivers' distress has received little systematic consideration (Blanchard, Toseland, & McCallion, 1996; Pasacrete & McCorkle, 2000). More caregiver intervention studies are advocated to conceptualize strategies aimed at minimizing caregiver burden and helping to plan ways to meet caregivers' needs (Pasacrete & McCorkle, 2000; Stajduhar & Davies, 1998). Interventions that incorporate supportive information-focused approaches are advocated (Given, Given, & Kozachik, 2001).

Given the recommendations for the development of supportive information-focused approaches for family caregivers, an examination of published interventions is warranted to avoid unnecessary duplication and to guide interventive approaches.

A CRITICAL REVIEW OF INTERVENTIONS

A review of interventions with family caregivers of cancer patients from the years 1985 to 2001 revealed few published interventions aimed at enhancing the knowledge, skills, and support of family caregivers of patients with palliative-stage cancer. Moreover, the interventions were compromised by poor methodological approaches or were awaiting evaluative outcome data. Several intervention studies involved caregivers of patients with cancer who were not receiving palliative care.

Studies with a Reasonable Evidence Base

Table 1 offers a summary of intervention studies conducted with reasonable methodological approaches. As shown, none focused exclusively on family caregivers of patients with palliative-stage disease.

Derdiarian's study (1989) identified the effects of treatment. However, the intervention was not described comprehensively, the measures

TABLE 1. Summary of Support- and Information-Focused Family Caregiver Interventions with Reasonable Methodological Approaches

Derdiarian, 1989

Intervention: Individualized information and counseling. *Cancer stage:* Nonpalliative. *Sample size:* 60. *Design:* Randomized controlled trial. *Framework:* Transactional model of stress and coping. *Outcome variables:* Informational needs assessment. Satisfaction with information. *Effect:* Caregivers gained more information and were more satisfied with it. *Comments:* Intervention not described well. Questionable construct validity of the measures.

Toseland, Blanchard, & McCallion, 1995

Intervention: Six individual sessions providing support and teaching problem-solving and coping skills. *Cancer stage:* Nonpalliative. *Sample size:* 78. *Design:* Randomized controlled trial. *Framework:* Not specified. *Outcome variables:* Health and marital status. Coping, depression, anxiety, burden, support, mastery, help seeking. *Effect:* None. *Comments:* Caregivers not overly burdened at baseline.

J. Pasacrete et al., 2000

Intervention: Three group sessions providing support and information. *Cancer stage:* Not specified. *Sample size:* 187. *Design:* Pre- and posttest; self-selected sample. *Framework:* Not specified. *Outcome variables:* Caregivers' reactions. Caregivers' demands. *Effect:* Higher levels of confidence regarding provision of care. *Comments:* High potential for social desirability. No control group.

Jepson, 1999

Intervention: Three home visits and six phone calls. *Cancer stage:* Nonpalliative. *Sample size:* 161. *Design:* Randomized controlled trial. *Framework:* Not specified. *Outcome variables:* Caregiver reactions, depression. *Effect:* None. *Comments:* Caregivers with physical problems were more burdened.

Ferrell et al., 1995

Intervention: Three home visits for pain education. *Cancer stage:* 35% "noncurative." *Sample size:* 50. *Design:* Quasi-experimental. *Framework:* Conceptual model: Impact of pain on quality of life. *Outcome variables:* Quality of life, family pain and burden. *Comments:* No control group.

did not have demonstrated construct validity, and it was not clear whether the same research assistants who collected the data also administered the intervention.

Toseland, Blanchard, and McCallion's intervention (1995) incorporated counseling sessions conducted by social workers, but whether the intervention was offered at home was not specified. Interviews were undertaken with caregivers two weeks before and two weeks after the intervention. Multivariate repeated measures and univariate ANOVAS revealed no differences between the experimental and control groups. The authors acknowledged that caregivers were not overtly stressed be-

fore the intervention and suggested that their baseline psychological status severely compromised the capacity to achieve an intervention effect.

Pasacrete et al.'s program (2000) incorporated symptom management, technical skills, and medication management. Group sessions with caregivers were conducted on three occasions, and the sessions lasted two hours. Data were collected before the program began and then four months after its completion. Higher levels of confidence to provide care were reported by caregivers after attending the support and education program. It was not clear from the published findings if this increase in "confidence" was in accordance with a single item or a subscale. The authors noted several limitations that may have had an impact on the results, such as the self-selected nature of the sample, which they suggested was healthier than might be found in the caregiving population at large. Also, Pasacrete et al. contended that social desirability affected caregivers' responses (the program instructor usually collected the data after the course ended) and advocated data collection by personnel not directly involved in the intervention.

In Jepson et al.'s study (1999), the treatment group received three home visits and six telephone calls from an oncology nurse specialist. The focus of the intervention was on problem solving, symptom management, and self-care strategies involving patient and caregivers. No significant differences were found between the intervention group and the caregivers who received standard care at three and six months after the patient was discharged from the hospital.

The intervention of Ferrell et al. (1995) consisted of three home visits, during which information regarding pain was offered to caregivers. Following the intervention, their quality-of-life scores were enhanced, their tasks of caring were perceived as being less burdensome, their knowledge about pain was enhanced, and their experience of caring for the person with pain was less confronting. The lack of a control group for comparison was a noteworthy limitation.

Studies with a Less Than Optimal Evidence Base or Published Outcome Data

As was stated earlier, other intervention studies have been conducted, but they have been compromised by poor methodological approaches or by insufficient published outcome data (these studies are not included in Table 1). Pickett, Barg, and Lynch (2001) developed a standardized educational program for home-based family caregivers of

patients receiving palliative care for cancer. The authors acknowledged a desire to evaluate the program formally with family caregivers but were unable to do so because of organizational and resource difficulties.

Kissane (2000) conducted research aimed at improving families' adjustment during palliative care with the aim of reducing bereavement morbidity. Although this intervention was the only well-conducted one with family caregivers of palliative-stage patients that was identified, the major focus was on strategies to enhance family cohesiveness and conflict resolution, not on preparing and educating caregivers for the day-to-day management of the patient and their own self-care. Furthermore, a comprehensive account of the outcome data collected from the randomized controlled trial in the study has not yet been published.

Cockayne and Hudson (2000) developed an educational program for family caregivers incorporating five weekly sessions focused on typical aspects associated with caring for a dying relative. Preliminary data based on a small sample size and descriptive statistics indicated increased knowledge as perceived by caregivers associated with the caregiver role. Although the qualitative feedback from participants regarding the program was positive, it was difficult for many caregivers to leave their homes to attend the program. The limited number of participants made it difficult to provide the course in a cost-effective manner.

Code and Paul (1999) provided a commentary on the advantages of a formalized support group for caregivers attending to the needs of patients confronted with a life-threatening illness. Although the authors did not provide a detailed analysis of the program's results, they implied that, on the whole, the courses were of benefit to caregivers who attended.

Horowitz, Passik, and Malkin (1996) developed a group intervention for spouses of patients with brain tumors of varying stages. Twenty spouses met twice monthly for 18 months (including after bereavement) for emotional support, information, and education. The authors reported that the group social support and interpersonal group processes, such as instilling hope, were enhanced. The authors' conclusions were based on the group leaders' impressions rather than on rigorous collection of data or on mechanisms of analysis.

Bucher et al. (1999) reviewed a group program incorporating three two-hour sessions and a full-day workshop. Sessions for caregivers of cancer patients (stage of disease not specified) covered basic problem-solving techniques, symptom management, and methods of obtaining community resources. The researchers undertook a preliminary evaluation with 36 caregivers. Many of the caregivers said they had

used some of the problem-solving techniques taught in the course. Because the sample was self-selected and specific outcomes were not set and measured, the results should be viewed with caution.

Robinson et al. (1998) reported on the impact of an educational program for caregivers of cancer patients (disease stage not specified). The six-hour course aimed to educate caregivers by providing information on three core areas: communication skills, symptom management, and use of resources. Caregivers (number not specified) were required to complete participant evaluations before the program began and again six to eight weeks after it ended. Curiously, the authors reported, without reference to statistics or analytic methods, that caregivers felt less overwhelmed and were better able to cope as a result of attending the course. Once again, the research findings are dubious, given the poor methodological approach.

Stetz and Brown (1997) undertook a qualitative study that examined the impact of caring via an eight-week telephone intervention. The study involved caregivers of 11 patients with cancer (disease stage not specified) and 15 patients with AIDS. The telephone contacts apparently lasted two hours, which, if correct, seems excessive. At the beginning of each contact, the investigator delivered content on the impact of caring, relationship issues, loss, death and dying, self-care strategies, symptom management, and formal and informal supports. Interviews also were conducted in the patients' homes at two specific times using the "Caregiver Outreach Interview Guide"—a set of questions about the experience of caregiving. The authors noted that their findings reflected information gathered only when data were collected and apparently were not related to the intervention. Unfortunately, Stetz and Brown did not clearly explain whether an analysis of the intervention results was offered in an alternative publication.

Additional intervention-type programs have been developed that aim to provide additional information and support to caregivers. These programs include such groups as "Living With Cancer Education Program" in Australia (Cancer Council of Victoria, 2002). In their review, Pasacrete and McCorkle (2000) identified two similarly focused programs in the United States and one in Sweden, all three of which had significant methodological flaws. These types of interventions appear to have admirable objectives but lack rigorous techniques to evaluate their effectiveness.

This review has identified a paucity of methodologically sound interventions to support family caregivers of dying cancer patients. Interventions conducted with family caregivers of non-palliative-stage patients

have been of a higher standard. For example, the sample sizes in several randomized controlled trials have appeared to be reasonable (see Table 1). Nonetheless, intervention effects have been rare. Studies in which effects occurred lacked a control group (Ferrell et al., 1995; Pasacrete et al., 2000), or the intervention was not well implemented and the construct validity of the outcome measures was not explicated (Derdarian, 1989). Furthermore, most interventions lacked a comprehensive theoretical or conceptual framework.

Other authors have confirmed the findings of the aforementioned review and have advocated the importance of the development and testing of interventions focused on support for family caregivers. Blanchard, Toseland, and McCallion (1996, p. 30) conceded that, "Overall, the literature indicates that cancer patients' family members are distressed and that there has been little systematic consideration of the effectiveness of psychosocial interventions in addressing this distress."

Following their review of interventions for family caregivers of cancer patients (including but not restricted to palliative-stage disease), Pasacrete and McCorkle (2000) argued that despite the documented importance of providing information to caregivers, there was a scarcity of rigorous interventions focused on enhancing caregiver support in this area. Furthermore, they contended that, given the paucity of intervention studies, there was a lack of guidance with regard to relevant outcome variables and that replication studies were inappropriate. The authors argued that intervention research initiatives had thus far not been well grounded theoretically. Although conducting family outcome studies poses many conceptual and methodological challenges, studies of this type are imperative (Feetham, 1991).

A substantial number of studies have identified caregivers' needs, but the development and evaluation of research-based interventions focused on reducing negative aspects of caregiving are required (Barg et al., 1998; Kelly et al., 1999; McCorkle & Pasacrete, 2001; Stajduhar & Davies, 1998; Yates, 1999). Furthermore, the literature sufficiently justifies the need for supportive educational interventions (Pickett, Barg, & Lynch, 2001). According to Given, Given, and Kozachik (2001), few documented, effective strategies are available to guide family members caring for patients with advanced cancer. Furthermore, these authors argued that strategies must be put in place to support family caregivers because their care will have a significant effect on health care costs. Moreover, they claimed that the burden placed on family caregivers may have a negative effect on the quality of life of cancer patients as well as on their caregivers.

National health care organizations also have identified the need for strategies to enhance outcomes for family caregivers of patients with palliative-stage cancer. In its national palliative-care strategy, the Commonwealth Department of Health and Aged Care (2000) recommended that the knowledge and skills of family caregivers needed to be improved. The department advocated the development of programs to provide support and information to lay caregivers of dying patients. When Palliative Care Australia (2000a) (the peak body representing national palliative-care agendas) conducted a review to determine the priority research areas for palliative care within Australia, it identified family research as a priority. Specifically, the organization recommended that research should be undertaken to develop interventions to improve family education and support.

Providers of palliative care seek to relieve the suffering and improve the quality of life of dying patients and their families (WHO, 1990). Yet providers are regularly unable to achieve this goal because evidence to support clinical interventions is lacking. Therefore, research that focuses on evidence-based practice is urgently needed (Casarett & Karlawish, 2000; Ferrell & Grant, 2000).

EVALUATION OF SUPPORT-FOCUSED INTERVENTIONS

Strategies that may guide the inception and evaluation of new support-focused interventions need to be explored. Research with family caregivers and cancer and palliative-care patients in this area has failed to provide sufficient direction. Thus, recommendations from intervention studies conducted with family members caring for patients with nonpalliative cancer will be incorporated. Lessons learned from these general family caregiver studies should assist in the development of interventions related to palliative care families.

For the most part, these general studies identify a small-to-moderate impact on caregivers' well-being (Sorenson et al., 2002; Toseland & McCallion, 1997). However, the lack of random assignment in these studies is a notable limitation (Sorenson et al., 2002). Therefore, interventions with palliative-care families, when pertinent, should be tested through randomized controlled trials with a large enough sample size to produce inferential statistics (Pasacreta & McCorkle, 2000).

Interventions that incorporate multiple rather than single approaches (e.g., support and education versus support alone) have been more successful in producing positive outcomes for caregivers (Ostwald et al.,

1999; Sorenson et al., 2002). Thus, multimodal approaches targeted toward palliative-care families may have a greater propensity for success. Furthermore, the measurement of multiple outcome variables will serve as a guide to future research (Sorenson et al., 2002).

Schultz et al. (1993) asserted that psychoeducational interventions are promoted as having potential merit, but few controlled studies have been conducted. Furthermore, the authors contended that there has been a tendency to focus support strategies toward task-oriented facets of care rather than toward minimizing its negative psychosocial impact. Consequently, the authors recommended psychoeducational approaches that measure psychosocial sequelae when designing interventions for families caring for a palliative-stage patient.

Acton and Kang (2001) conducted a meta-analysis of the intervention research focused on reducing burden in caregivers of patients with dementia and found that no treatments reduced caregiver burden. In fact, some interventions had a negative effect; in other cases, the control group improved more than the treatment group. The authors concluded that the burden may be too global and multidimensional for interventions to have a positive impact and that researchers should continue to focus on other variables. Furthermore, Acton and Kang acknowledged that few caregiver intervention researchers had screened participants for elements related to the intervention. As a result, interventions may have been delivered to caregivers who did not require them. Therefore, interventions for family caregivers of palliative-stage patients may benefit from measuring specific as well as global dependent variables and should be targeted toward caregivers who demonstrate a need for the intervention.

Group intervention strategies have the advantage of providing opportunities for individuals to interact with others who have gone through, or are going through, a similar experience (Bloom, 2000). However, it can be extremely difficult for caregivers to attend such classes because of caregiving responsibilities or transportation problems (Cockayne & Hudson, 2000; Code & Paul, 1999; Lovett & Gallagher, 1988; Pasacreta et al., 2000; Pickett, Barg, & Lynch, 2001). Moreover, caregivers who attend groups may represent those least in need of interventions because their attendance demonstrates their capacity to use social support or to gain access to respite care that allows them to attend group programs (Pasacreta & McCorkle, 2000). Meta-analyses of the effectiveness of caregiver interventions highlight findings indicating that individual interventions are more successful than group programs (Knight,

Lutzky, & Macofsky-Urban, 1993; Sorenson et al., 2002). Although group approaches with palliative-care families should continue to be evaluated, the priority should be the development and testing of individual interventions.

Consumer involvement in the process of enhancing care also is advocated. Such involvement is not only a consumer right but makes good sense in relation to improvement of services as well (Draper, 1997). Grobe (1996) recommended this participatory research strategy, whereby the groups that will be affected by the intervention are represented. Thus, the specific content of the new intervention requires direct input from caregivers and health care professionals. Engaging family members of palliative-stage patients at the design stage of interventions is promoted, and the use of focus group interviews as a vehicle to achieve their involvement has proved to be valuable (Hudson, Aranda, & McMurray, 2002).

Minimal palliative-care research to date has actually focused on the entire family. Instead, one family member, usually a spouse, is commonly selected. The barriers to involving the entire family in research include time, budgetary constraints, family availability, and data collection instruments applicable to children (McClement & Woodgate, 1998). Furthermore, in most cases, one relative or friend assumes the major responsibility for the patient (Gaugler, Kane, & Langlois, 2000). Consequently, targeting this person appears to be logical. Developing strategies for the primary family caregiver in the first instance may be more realistic. When possible, however, the impact of these interventions on other family members, including the patient, requires evaluation.

Future interventions may need to involve caregivers independently of patients because the caregivers' perception of need may be different (Grande, Todd, & Barclay, 1997; Kristjanson, 1997). Furthermore, caregivers may not wish to disclose issues with the patient present (Beaver, Luker, & Woods, 1999; Code & Paul, 1999). This reluctance was highlighted by a daughter of a palliative-stage patient who said (Keegan et al., 2001, p. 453):

[He] was starting to wet the bed and forget things. . . . I found it was very difficult to be specific about these things in front of him; I felt like I was being disloyal . . . in these interviews. There should be a separate part for the relative.

An appropriate way forward may be to consider giving the primary caregiver the option to have the patient present or not if the choice is deemed important to the caregiver.

Finally, the impact of health professional strategies aimed at enhancing caregiver support needs to be examined at different time periods (Laizner et al., 1993). Thus, longitudinal approaches are advocated (Pasacreta & McCorkle, 2000). Furthermore, there is support for the evaluation of interventions incorporating caregivers' bereavement outcomes (Lev & McCorkle, 1998). Nolan, Grant, and Keady (1996) also advocated interventions that are evaluated after a patient's death; they conceded that when caregivers stop their caregiving role because of the patient's death, they are not turned into noncaregivers within a matter of hours. Indeed, even after the friend or relative's death, caregivers may enter into a retrospective type of caring in which they reflect and evaluate their experience. Longitudinal evaluation of interventions with palliative-care families could occur, for example, through a baseline assessment when the patient is referred for palliative care and, again, after the intervention and during bereavement.

CONCLUSION

Most family caregivers of dying cancer patients report that their role is physically and emotionally demanding and that they require additional support and information from health professionals. There is a consistent request for support-focused family caregiver interventions from caregivers and researchers, supported by appeals from health care organizations. However, few supportive palliative-stage family interventions have been conducted, not to mention rigorously evaluated. It appears that psychoeducational approaches directed toward individual primary family caregivers, rather than groups, may be worth pursuing. New interventions should be evaluated over time and, ideally, by way of randomized controlled trials. Unless new evidence-based supportive strategies for families are realized, there is a real danger that health care professionals will not be meeting the core elements of family centered delivery of palliative care. Therefore, there is an urgent need for new strategies to be designed and tested; otherwise the principle of the family as the unit of care will not be upheld.

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