

Predictors of Bereavement Outcomes in Families of Patients with Cancer: A Literature Review

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Le but de cet article est d'examiner la littérature consacrée aux prédicteurs des conséquences du deuil chez les familles ayant prodigué des soins à un proche décédé du cancer. Cette littérature a été divisée selon des thèmes communs de prédicteurs, soit les caractéristiques de la personne décédée, les caractéristiques de la personne endeuillée, les comparaisons entre les personnes endeuillées et des groupes de personnes non endeuillées, le bien-être de la personne endeuillée avant le décès, les relations interpersonnelles antérieures, les caractéristiques de la maladie, les caractéristiques de l'expérience de soins et les caractéristiques des soins donnés lors de la phase terminale.

Un certain nombre de comportements récurrents permettent d'identifier les personnes courant un risque plus élevé de mal s'ajuster au cours du deuil. Il est manifeste que les hommes et les femmes expriment leur chagrin quelque peu différemment. Cependant, il reste encore à déterminer qui, des hommes ou des femmes, coure le plus grand risque d'un mauvais ajustement. Des preuves empiriques suggèrent qu'un statut socio-économique inférieur et les barrières linguistiques interfèrent avec l'ajustement au cours du deuil. Fournir des services adaptés aux besoins particuliers des différentes communautés culturelles est important si l'on veut aider les patients recevant des soins palliatifs et les membres de leur famille à faire les ajustements requis. La nécessité de prendre pleinement conscience de l'imminence du décès et de planifier avec attention le moment et le lieu de la mort est apparente dans la littérature. La présence régulière et fréquente de soignants professionnels rehausse le degré de satisfaction à l'endroit des soins offerts en milieu familial. Les résultats divergents des études indiquent la nécessité d'explorer davantage les questions sous-jacentes qui expliquent ces contradictions. Les personnes plus âgées qui ont pris soin d'un proche semblent avoir certains avantages par rapport aux plus jeunes au moment du deuil, mais cette conclusion ne se retrouve pas dans les résultats de toutes les études. Les problèmes méthodologiques rencontrés incluent la taille réduite des échantillons et de grandes variations entre les conséquences particulières des deuils étudiés.

The purpose of this paper is to review the literature on predictors of bereavement outcomes in family caregivers of persons who have died of cancer. The literature has been divided into common themes of predictors: characteristics of the deceased person, characteristics of the bereaved person, comparisons of bereaved and non-bereaved persons, well-being of the bereaved person prior to the death, prior interpersonal relationships,

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characteristics of the illness, characteristics of the caregiving experience, and characteristics of terminal care. A number of recurring patterns point the way to identifying persons who may be at increased risk for poor adjustment during bereavement. It is apparent that men and women express their grief somewhat differently. Whether men or women are at greater risk for poor adjustment, however, remains to be determined. There is some empirical evidence to suggest that lower socioeconomic status and linguistic barriers interfere with adjustment during bereavement. There is a dearth of culturally relevant services to help palliative-care patients and their family members make the required adjustments. The literature makes apparent the need for open awareness of the impending death and for careful and thoughtful planning for where and how the death ought to occur. The regular and frequent presence of professional caregivers contributes to family caregivers' satisfaction with care. Discrepant findings point to the need to explore the issues that underlie them. Older bereaved caregivers appear to have some advantages over younger ones, but this finding is not universally found in the results of these studies. Methodological problems include small sample sizes and large variations in the particular bereavement outcomes studied.

It has been estimated that by the year 2000 cancer will surpass heart disease as the primary cause of death in North America (Greenwald & Sondek, 1986). Approximately 75% of cancer patients will inevitably require some form of palliative care (Diehl, 1994). According to the World Health Organization, the principles of palliative care include the availability of a support system to help the family cope during the patient's illness as well as during the period of bereavement (World Health Organization Expert Committee, 1990). Thus the focus of palliative care goes beyond the patient to include the family.

Family members as well as the patient experience the trajectory of cancer, and following the death of the patient the family members carry the memories of their experiences into the bereavement stage. Thus palliative care not only relieves the suffering of the patient and the family during the terminal phase of the illness, but also helps to ease the suffering of family members after the patient's death.

The purpose of this paper is to review the literature on predictors of bereavement outcomes following the death of a family member from cancer, focusing in particular on the identification and examination of those characteristics of caregiving during the terminal phase that affect bereavement outcomes.

Selection of the Literature

To be included in the review, a paper had to focus on outcomes following the cancer death of a family member *and* say something about pre-bereavement conditions and variables that would allow predictive statements to be made. Furthermore, the paper had to describe empirical work published since 1980. Only papers written in English were

included in the review. The majority of the patients in the study had to have died of cancer and its respondents had to have had a close, committed relationship with the deceased person. This limitation, while somewhat arbitrary, allows us to draw conclusions about "family" relationships that might go beyond blood or legal ties but are committed and caring ones nonetheless. If qualitative papers met these criteria they were included, along with studies that had used quantitative methods. The papers that describe qualitative method hold a special place in this analysis because they add to our understanding in a way that even a very high correlation coefficient fails to accomplish.

The literature will be reviewed according to categories of predictors: characteristics of the deceased person, characteristics of the bereaved person, comparisons of bereaved and non-bereaved persons, well-being of the bereaved person prior to the death, prior interpersonal relationships, characteristics of the illness, characteristics of the caregiving experience, and characteristics of terminal care.

Characteristics of the Deceased Person

Only two studies were found to focus on specific characteristics of the deceased person as affecting bereavement outcomes. Hoekstra-Weebers, Littlewood, Boon, Postma, and Humphrey (1991) focused on the age of the deceased child, while Shanfield, Benjamin, and Swain (1984) focused on gender. Neither study has been replicated, nor were studies found that explore the nature of the relationships between these demographic variables and bereavement outcomes.

Hoekstra-Weebers et al. (1991), in a Dutch study, examined the age of the deceased child as a potential predictor of grief responses. They compared the parental coping styles and psychological well-being of parents who had lost younger children (age 3–9) and parents who had lost older children (age 13–19). Parents of younger children were found to be more likely to use a problem-focused coping style. This study included 33 parents of 19 bereaved children. It did not acknowledge the potential for non-independence of data from the mothers and the fathers. Shanfield et al. (1984) found the gender of the deceased adult child to be a factor in parents' post-bereavement anger scores as well as in the closeness of family relationships during the bereavement period. Both scores were elevated when the deceased child was a daughter. Further research might determine whether these findings can be replicated, and could also explore the relationships between characteristics of the deceased person and bereavement outcomes.

Characteristics of the Bereaved Person

A number of studies focused on a range of characteristics of the bereaved persons and the outcomes associated with bereavement. Gender is among the most commonly studied predictors of bereavement outcomes. Some studies found that females tended to score higher on measures of distress, whether they were parents of deceased adult children (Shanfield et al., 1984), young-adult children of deceased parents (Galloway, 1990), or spouses (Gilbar & Dagan, 1995). Other researchers, however, found no association between gender and depression during the bereavement period (Kurtz, Kurtz, Given, & Given, 1997; McHorney & Mor, 1988), emotional distress (Houts, Lipton, Harvey, Simmonds, & Bartholomew, 1989; Yancey, Greger, & Coburn, 1990), or satisfaction with care (Beck-Friis & Strang, 1993).

Gilbar and Dagan (1995) explored possible reasons for their findings of gender-based differences in a study with Israeli widows and widowers. Among their explanations were the potential for reduced caregiving stress associated with lower expectations among male caregivers, financial problems that might result from a husband's prolonged illness, and the loneliness experienced by older women who have become highly dependent on their husbands.

Cook (1983) examined the influence of gender on spousal relationships in the year following the death of a child from cancer or a blood disorder. This study featured both qualitative and quantitative aspects. Cook found important differences as well as similarities in the ways in which fathers and mothers grieved for their child and articulated their grief. The quantitative data confirmed the qualitative findings. Mothers were found to be significantly more likely to experience difficulties at anniversaries and on special days, and more likely to report distance in the marital relationship, but less likely to report that they and their spouses were able to comfort each other.

The extent to which the conflicting findings regarding gender are a result of cultural or cohort differences in the experiences or expressions of grief, or a result of pre-bereavement relationships or other variables, remains to be determined. The role of gender in bereavement outcomes is not likely to go away, and we will benefit from the debate.

Age is commonly tested as a predictor in bereaved or potentially bereaved groups. The results to date are contradictory and bear further exploration. Beck-Friis and Strang (1993) found an association between advanced age of bereaved spouse and greater satisfaction with care, and Houts et al. (1989) found that younger bereaved spouses were

likely to experience greater distress during bereavement. However, Jurk, Ekert, and Jones (1981), in an Australian study of parents of children who had died of cancer, found older parental age to be associated with greater family dysfunction during the bereavement period. Kurtz et al. (1997) did not find age to be a significant predictor of depression during the bereavement period. McHorney and Mor (1988), in a study of 1,447 bereaved caregivers, found that caregivers under age 65 were 1.8 times more likely to be depressed during bereavement. Vachon et al. (1982) found younger age of bereaved widows ($n=162$) to be associated with lower scores on a general-health questionnaire.

Socioeconomic variables have also been studied as potential predictors of bereavement outcomes. Jurk et al. (1981) found lower educational achievement to be related to greater family dysfunction after the loss of a child to cancer. This finding is supported by that of McHorney and Mor (1988): caregivers who had not completed high school were found to be 1.9 times more likely to experience post-bereavement depression than those who had completed some post-secondary education. Similarly, Vachon et al. (1982) found that lower socioeconomic status predicted higher distress scores among widows at two months post-death.

Cultural and linguistic characteristics of bereaved persons can potentially affect grief resolution. Access to informal support systems can be limited for those whose cultural group is limited, and formal support services for bereaved persons are of limited benefit in the face of linguistic and cultural barriers. Only the Vachon et al. (1982) study included ethnicity as a potential predictor of bereavement outcomes. It found that having a primary language other than English or being Jewish were associated with higher distress scores in bereaved widows at one month post-death.

One of the few studies to focus on measures specifically designed to predict bereavement outcomes was that of Robinson, Nuamah, Lev, and McCorkle (1995), who adapted the Parkes and Weiss (1983) Bereavement Risk Index (BRI) for identifying spouses at risk for psychological distress. Eight items, each using an ordinal scale, focus on age, occupation, length of preparation for the patient's death, clinging or pining, anger, self-reproach, availability of family support, and clinician's overall prediction of the respondent's bereavement outcome. Robinson et al. found that low-risk and high-risk groups (based on BRI scores) demonstrated similar patterns of change in their distress scores over the course of the study. The high-risk group scored significantly higher on somatization, interpersonal sensitivity, depression, and

anxiety than the low-risk group at all time points except the 25-month point.

Comparisons of Bereaved and Non-Bereaved Persons

A number of studies compared bereavement outcomes to norms for non-bereaved populations as well as to scores of psychiatric patients. Researchers have been particularly interested in measures of physical and emotional health. Widely discrepant measures and varying methods of operationalizing variables account for a number of the conflicting results of these studies.

Family members of deceased children (Moore, Gilliss, & Martinson, 1988), offspring of deceased parents (Shanfield et al., 1984), and bereaved family members in general (Kristjanson, Sloan, Dudgeon, & Adaskin, 1996) were found to score low on a number of measures of psychological health when compared to normative scores from a non-bereaved population.

Birenbaum, Robinson, Phillips, Stewart, and McCown (1989–90) found that the siblings of children who had died of cancer exhibited more behavioural problems and scored lower on measures of social competence than children who had not been bereaved. In contrast, Siegel, Karus, and Raveis (1996) found that while children whose parent had died of cancer scored higher than matched controls on measures of depression and anxiety prior to the death, their scores on both variables were not statistically different from those of matched controls at seven to 12 months after the death.

Birenbaum, Stewart, and Phillips (1996) found that parents of children who had died of cancer were not significantly less healthy than a normative sample of adults and that they concluded their health was not adversely affected by the death of their child. Hoekstra-Weebers et al. (1991), however, found bereaved parents to be less emotionally expressive when compared to normative data for The Netherlands. The authors speculate that everyday occurrences may no longer be sufficient to elicit an emotional response for parents who have experienced the death of a child.

There is growing interest in the effects of stressful events, such as bereavement, on immune function. Irwin, Daniels, Smith, Bloom, and Weiner (1987) compared Natural Killer (NK) cell activity and depression scores in widows ($n=10$) and age-matched control women ($n=8$) with healthy husbands. They also compared the NK activity and

depressive symptoms in women ($n=6$) before and one month after the death of their husbands from cancer. Bereaved women had lower NK activity and higher depression scores than the controls. In the longitudinal study, neither mean NK activity nor mean depression scores differed significantly from before the death to bereavement. However, for respondents whose depressive symptoms increased during this time, NK activity was found to be likely to decrease. These findings suggest that immune responses may be related to depression rather than to the process of bereavement itself.

Well-Being of the Bereaved Person Prior to the Death

There is increasing evidence to suggest that the greatest predictor of well-being during bereavement is well-being prior to the death. In general, these studies suggest that caregivers be especially vigilant regarding poor bereavement outcomes when family members are unwell prior to the death. Kristjanson et al. (1996) studied 64 family members of advanced-cancer patients before and after the death. They found the strongest predictor of health (using the symptoms-of-stress scale) during the bereavement period to be the health score during the terminal phase of the illness. In a similar vein, Houts et al. (1989) found that bereaved spouses who had been in distress just prior to the death experienced greater distress during bereavement, and Jurk et al. (1981) found previous social and psychological disturbances to be predictive of family dysfunction in the bereavement period. Kurtz et al. (1997), in a study with family caregivers of cancer patients, found two critical factors associated with increased post-bereavement depression: decreased caregiver optimism and high levels of pre-bereavement depression. Furthermore, these two factors predicted whether or not the depression would lessen during the bereavement period.

McHorney and Mor (1988) analyzed data from the National Hospice Study and found poor prior physical and mental health to be predictive of post-bereavement depression. Their study included 1,754 bereaved caregivers for whom they had complete data, including interview data from the bereavement period. They found the odds of experiencing post-bereavement depression to be twice as great in caregivers who had been depressed prior to the death. Shanfield et al. (1984) found no significant differences in parents' health complaints before and after the cancer death of an adult child, and Vachon et al. (1982) found prior poor health to be predictive of greater post-bereavement distress.

Awareness of Impending Death

Interest in the potential value of anticipatory grief has generated studies of links between awareness of the impending death and bereavement outcomes. Houts et al. (1989) found that bereaved spouses who had avoided thinking about the possibility of the death were likely to experience higher levels of distress during bereavement than spouses who had thought about the death. In the study by Jurk et al. (1981) the children had not generally been informed of their impending death. The investigators found that when the bereaved parents perceived that their child knew s/he was dying there was a significantly higher incidence of family dysfunction in the bereavement period. These studies would support the value of open awareness for healthy grieving.

Prior Interpersonal Relationships

There is considerable interest in the effects of prior interpersonal relationships on the bereavement process. Kissane, Bloch, and McKenzie (1997) studied bereavement with 670 family members of 115 adults who had died of cancer. They found family coping to be the most consistent correlate of the bereavement outcomes (grief, distress, depression, and social adjustment). Another important interpersonal characteristic appears to be social support during the terminal phase of the illness. Kurtz et al. (1997) found family caregivers who reported higher levels of social support from friends during the terminal period to be at higher risk for depression during the bereavement period. This finding seems to be contrary to expectations. The authors relate it to other findings (Kurtz, Given, Kurtz, & Given, 1994; Sankar, 1991; Vachon et al., 1977) that as the terminal illness progresses members of the social network gradually disappear, leaving the caregiver to manage alone. Perhaps the variable of interest is not the amount of social support, but the degree of change over time. If the support system dwindles during the terminal phase of cancer it may not be available during bereavement. Given the value of social support in general, this issue bears further exploration. McHorney and Mor (1988) also found that social support was not significantly related to post-bereavement depression. They did find the odds of experiencing post-bereavement depression to be 1.4 times greater for caregivers who reported family tension than for those who did not. Yancey et al. (1990), however, found social support from family and friends to be positively associated with post-bereavement function. Their study included family members and friends who had had some "involvement" (physical care, emotional support, and/or

instrumental support) with the deceased person during the week prior to death. The depth of involvement was not defined.

In her study with siblings of children who had died of cancer, Davies (1988) examined the degree to which the closeness of the sibling relationship prior to the death influenced behavioural responses during bereavement. The interview data suggested that social withdrawal during the bereavement period was related to the closeness of the sibling relationships. The quantitative results, although not statistically significant, supported these findings. Shanfield et al. (1984) found that bereaved parents who perceived closeness during the illness of their adult child were more likely to feel that the loss of the child had been the most painful experience of their lives and were less likely to feel guilt or sense that business had been left unfinished. These findings are confirmed by those of McHorney and Mor (1988): for spouses the odds of being depressed are 1.5 times greater than for bereaved offspring and 3.6 times greater than for persons who have lost secondary kin or a non-family member. However, spouses did not differ significantly in their odds of being depressed when compared to bereaved parents or siblings. Jurk et al. (1981) found poor family communication and lack of support within the family by one of the parents to be associated with family dysfunction during the bereavement period. These findings suggest that the closeness of the relationship is an important predictor of bereavement outcomes.

Fakhoury, McCarthy, and Addington-Hall (1996), in a large British study with bereaved family caregivers, found the presence of living children to be associated with greater satisfaction with care delivered by district nurses. Houts et al. (1989) found living alone to be predictive of emotional distress following spousal bereavement.

Characteristics of the Illness

Researchers are recognizing the benefits of a good caregiving experience for bereavement outcomes. Caregiving experience moves beyond the characteristics of patient and caregiver to include the contributions of professional caregivers to the quality of the experience for family members. Another important aspect is the perceived value of the caregiving role.

A number of researchers looked at the effects of the cancer trajectory on bereavement outcomes. Of particular interest is the effect of duration of illness on the grieving process. Beck-Friis and Strang (1993), in a study with 87 primary caregivers of patients who had died of

cancer, found the length of time from diagnosis to death to be unrelated to satisfaction with care. However, they found a greater length of time (> 60 days) in terminal care to be associated with greater satisfaction. All patients had been part of a hospital-based home-care program and died at home. These findings suggest that family members need time to adjust to programs of care and to the personnel who deliver the care. Fakhoury et al. (1996) found caregivers whose deceased family member had experienced lengthy functional limitations, but short durations of incontinence and respiratory symptoms, to be more satisfied with their general practitioner (GP). McHorney and Mor (1988), like Beck-Friis and Strang, found length of illness to be unrelated to post-bereavement depression in family caregivers of cancer patients. However, Shanfield et al. (1984), in a study with parents of adult children who had died of cancer, found a relationship between length of illness and frustration with the patient. Steele (1990) found an illness of less than six months to be associated with increased social isolation, anger, and hostility, as well as greater dependency, among bereaved caregivers.

Characteristics of the Caregiving Experience

Fakhoury et al. (1996), in their large study ($n=1,858$), found that caregivers who perceived their role as rewarding and had not required additional help in caring at home were more likely to be satisfied with the district nurse and the GP. On the other hand, caregivers who had found home-based caregiving a burden reported greater satisfaction with the hospital physicians.

Häggmark, Theorell, and Ek (1987) conducted a quasi-experimental study to evaluate the results of increased participation in care of cancer patients by family members. They interviewed family caregivers over the course of the illness and at one and two months following the death. The experimental treatment consisted of an invitation to participate in the care of the family member while in hospital as well as to meet regularly with staff. Caregivers in the experimental group had increased the number of their own activities at one month following the death, which suggests that participation in caregiving activities facilitates recovery from the experience.

Kurtz et al. (1997) found no relationship between perceived esteem associated with caregiving and post-bereavement depression. McHorney and Mor (1988), however, found that caregivers who expressed dissatisfaction with their caregiving abilities were twice as likely to experience post-bereavement depression as caregivers who

did not. These findings are supported by those of Shanfield et al. (1984), who found that bereaved parents who reported frustration with their adult child during the illness had higher scores on obsessive-compulsiveness and hostility.

Stetz and Hanson (1992) conducted a longitudinal study of perceptions of the caregiving experience and found that these changed somewhat after the death. During the illness experience, the top three perceived demands on caregivers were ranked as managing physical care, managing household finances, and standing by. Retrospectively, standing by was ranked first, followed by managing physical care and alterations in the caregiver's well-being. These findings suggest that while nurses should be aware of the demands placed on family caregivers, they should keep in mind that these perceptions might change following the death. Significantly, caregivers wished, in retrospect, that they had sought out more resources to help them in their caregiving experience. Further research might explore the degree to which fatigue prevents caregivers from recognizing the need for rest. Perhaps only in retrospect, after the death has occurred and they have had time to sleep and reflect, do caregivers realize how fatigued they were. Another possible reason for the finding is that caregivers see the death as too imminent to justify their taking a respite; as a result, when the death occurs they find themselves too fatigued to fulfil the social responsibilities that accompany bereavement.

Levy (1991) reported on the development of a measure of anticipatory grief. He found a correlation between anticipatory grief and depression and subjective stress, and suggested that anticipatory grief might not be as helpful to positive bereavement outcomes as had previously been thought.

Characteristics of Terminal Care

A number of studies compared the care of cancer patients in hospital versus at home, and in specialized (palliative-care, hospice) units versus in general medical in-patient units. Many of these studies focused on the satisfaction of family caregivers. Generally, caregivers of patients cared for in hospices were found to be more satisfied than caregivers of patients cared for elsewhere (Cameron & Parkes, 1983; Dawson, 1991; Godkin, Krant, & Doster, 1983-84; Steele, 1990). Furthermore, Dawson found overall satisfaction with the program of care to be very positively correlated with the psychosocial support of the nurse and with the satisfactory fulfilment of basic needs.

Fakhoury et al. (1996), in their survey of 1,858 bereaved caregivers in 20 health-care districts in England, used a range of service and non-service variables as predictors in measuring satisfaction with the district nurse, the GP, and hospital physicians. Service variables produced higher odds ratios than non-service variables. Among the service variables that predicted greater satisfaction with the district nurse were: higher frequency of home visits, contacting other services, helping at night, and visiting the bereaved caregiver. Satisfaction with the GP was predicted by higher frequency of visits and telling the caregiver about the diagnosis. Caregivers were more likely to be satisfied with hospital physicians if they thought the deceased person had been given a choice about treatment and had been allowed sufficient privacy while in hospital and if they thought the doctor had treated the patient's respiratory symptoms. In addition, if the patient had died at home, caregivers were more likely to have reported satisfaction with the district nurse. Similarly, Yancey et al. (1990) found that survivors of cancer patients reported higher levels of perceived social support from nurses and greater satisfaction with care when the deceased person had participated in a hospice program than when the patient had been cared for in hospital.

Ferrell (1985) used the Grief Experience Inventory (GEI) to examine the place of death as predictive of grief experiences, including feelings, symptoms, and behaviours associated with grief. Her study with spouses of cancer patients who had died at home ($n=22$) and in hospital ($n=38$) found that the home-based spouses experienced less guilt, ruminated less, and experienced less depersonalization during bereavement. Scores on other clinical scales (despair, anger, social isolation, loss of control, somatization, and death anxiety) were not significantly different for the two groups of respondents. Similarly, Steele (1990) found home deaths to be associated with lower scores on denial, guilt, and rumination, as well as on social isolation and death anxiety. These findings suggest that home-based deaths can have beneficial bereavement outcomes for family caregivers. They also suggest that caregivers whose loved one dies in an institutional setting might experience a sense of failure, which can complicate the bereavement process. Nurses who provide care to patients with advanced cancer might do well to explore this issue with family members.

Lauer, Mulhern, Bohne, and Camitta (1985) and Lauer, Mulhern, Schell, and Camitta (1989) studied the effects of home and hospital death on the adjustment of siblings and parents. In both studies, multiple family members participated and no accounting for non-independence was explicated. Both reports suggest that home deaths are asso-

ciated with positive outcomes, including stronger family relationships and fewer psychological and interpersonal problems. The siblings of patients who died at home (Lauer et al., 1985) reported that they had been involved in their care and had been kept informed, whereas the siblings of those who died in hospital felt useless in terms of their involvement with the ill child and ill prepared for the death.

These findings are not supported by those of Houts et al. (1989), who found home death to be associated with greater distress among bereaved spouses. In this study with 112 respondents, distress scores were calculated by summing the scores of the three measures used: CES-D, selected questions from the GEI, and respondents' self-reports of their distress concerning the death. Thus the distress score is likely a somewhat different measurement of attributes of distress (e.g., depression) than that of the GEI alone. Furthermore, the respondents in both the Ferrell (1985) study and the Steele (1990) study had arranged for a home death. Since the children studied by Lauer et al. (1985) had been part of a home-care program, one might assume that a home death was favoured in those cases as well, although this is not explicitly stated in their findings. Houts et al. do not state whether the deaths studied in their investigation occurred as planned. Also, we do not know the degree to which the services in the two studies were comparable. Kurtz et al. (1997) did not find a relationship between the setting of death and post-death depression. These findings would suggest that caregivers are likely to experience less distress when the death has occurred as planned.

Methodological Concerns

A major and recurring methodological problem in the research on palliative care and bereavement outcomes is small sample size, resulting in limited ability to find meaningful relationships among variables of interest. The primary reason for small sample size is perceived vulnerability in family members of terminally ill or recently deceased persons. Also, both clinicians and family members often act as gatekeepers, preventing access to patients as potential respondents. Protector of vulnerable subjects is a role that clinicians and family members take seriously, as they should. The vulnerability of bereaved persons must also be acknowledged and respected. However, there are times when patients and family members might welcome the opportunity to participate in research. Protecting potential respondents from intrusion must be balanced by offering them an opportunity to participate in studies that are conducted in an ethical and compassionate manner.

Another way to solve the problem of small sample sizes is to develop research networks. Investigators can increase sample size by broadening the base of clinical settings from which they accrue respondents. Networks can be developed informally across settings or across a country. An excellent example of cross-Canada networking is the Sociobehavioural Network developed by the National Cancer Institute (Advisory Committee, 1994).

Another recurring issue for researchers relates to the collection of data from multiple family members. Collecting information from more than one family member allows for richness of the data. However, precautions must be taken for the sake of statistical analysis, because data collected from one family member cannot be assumed to be independent of that collected from another. This problem of non-independence can be handled in a number of ways. Moore et al. (1988) collected data from bereaved mothers and fathers but analyzed the two sets of data separately. Davies (1988) reported separately for data collected from single siblings and data representing multiple family members. Birenbaum et al. (1996) tested their data for non-independence and then analyzed appropriately. Siegel et al. (1996) weighted the scores to account for multiple family participants. Each of these methods is appropriate and each facilitates valid statistical analysis of the data.

Differences in predictors, outcome variables, and measures used make it difficult to compare results. This problem, which is a common one in psychosocial research, is caused by many factors, several of which are intertwined. Researchers who conduct studies into palliative care and bereavement outcomes represent a variety of disciplines, each with its own way of approaching psychosocial phenomena. The concepts being examined are complex and often multidimensional, requiring multiple measures within a single study, which in turn requires that the measures be valid, reliable, and short, so that respondents with limited time and energy can answer questions without becoming unduly fatigued. These problems are balanced, however, by the richness that accrues from research projects conducted in this way. It is of paramount importance that researchers build on each other's work and use scales that are valid and reliable and that fit conceptually with the variables of interest.

Conclusion

A number of recurring patterns point the way to identifying persons who may be at increased risk for poor adjustment during bereavement.

It is apparent that men and women express their grief somewhat differently and that women generally report greater distress. Whether either gender is at greater risk for poor adjustment, however, remains to be determined. Age is one area in which findings conflict, depending on the particular bereavement outcome measured and the age range included in the study. There is some empirical evidence to suggest that lower socioeconomic status and linguistic barriers interfere with adjustment during bereavement. There is a need for culturally relevant services in helping palliative-care patients and their family members make the required adjustments.

A recurring theme in the literature on palliative care and associated bereavement outcomes is the need for open awareness of the impending death and for careful and thoughtful planning of the location and circumstances of the death. The presence of professional caregivers contributes to the satisfaction of family caregivers with the care being provided. This professional presence is especially important for patients being cared for in their own home.

Discrepant findings point to the need for further exploration of the issues that lie at the source of these discrepancies. Older bereaved caregivers appear to have some advantages over younger ones, but this finding is not universal to the results of these studies. Perhaps some sort of curvilinear relationship exists between age and bereavement outcomes. Older bereaved caregivers may also fare better on some variables and worse on others. Some of the specific outcomes investigated vary from study to study.

Methodological problems point to the need for strategies to accrue samples large enough to allow for meaningful interpretation of results. Two such strategies were suggested in the studies reviewed. Although the diversity of variables and their measures renders it difficult to compare findings, it makes for a richness that in the long run might benefit the development of a strong knowledge base.

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Acknowledgements

The authors would like to acknowledge the assistance of Pamela Berry, R.N., B.Sc.N., with the accrual of papers. They would also like to thank the reviewers of this manuscript for their thoughtful comments.

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