

THE SOCIAL SUPPORT REQUIREMENTS OF FAMILY CAREGIVERS OF TERMINAL CANCER PATIENTS

Linda S. Nugent

The family, not just the patient, experiences the impact of cancer (Gray-Price and Szczesny, 1985; Lewis, 1983). When the cancer patient becomes terminally ill and is cared for at home, the family bears a considerable burden for the care. The need for support for the family is apparent; yet, limited documentation describing the nature of that support is available. This study examined the social support required by caregivers in the families of terminal cancer patients.

Literature Review

Family caregivers of terminal cancer patients face considerable physical and emotional demands in their caregiving role (Holing, 1986). Although they assume responsibility for the patient's physical care, they often lack knowledge about patient care (Rose, 1976; Welch, 1981; and Wilson, 1975). They experience difficulty obtaining the equipment necessary for the job (Rose, 1976; Wilkes, 1984), and confinement to the home as a result of their duties (Stetz, 1987; Welch, 1981). Enacting family roles also pose demands; for example, child care problems and difficulties with transportation may be experienced (Rose, 1976; and Welch, 1981). Other problems include household help, shopping and finances (Googe and Varricchio, 1981; Stetz, 1987).

Studies (Evernden, 1984; Wilkes, 1984; and Wilson, 1975) suggest that the health of caregivers may be adversely affected by the demands of their situations. In fact, there is evidence that health problems encountered by spouses of terminally-ill patients persist after the death of the cancer victim (Hampe, 1975; Parkes, 1964 and Vachon, 1976).

Social Support is helpful in meeting the demands of various stressful events (Carveith and Gottlieb, 1979; Lin, Ensel, Simone and Kuo, 1979; and Norbeck and Sheiner, 1982). However, no study has actually measured the effect

Linda S. Nugent, R.N., M.Sc.N. is Assistant Professor of Nursing, in the Division of Sciences, at the University of New Brunswick, in Saint John.

of social support in relation to caregivers in families of terminal cancer patients. Some of the gap in this body of knowledge can be attributed to the lack of a consensual definition of social support (Dimatteo and Hays, 1981).

However, there are studies (Evernden, 1984; Ward, 1974) that report on some dimensions of social support with this population. Ward (1974) determined that, amongst chief carers who had regular and substantial help from network members, it was more likely that the terminal cancer patients would be kept at home than in the hospital. One-third of the caregivers in Evernden's (1984) study who perceived themselves as managing the care of the terminal patient well, attributed their success to the availability of support systems.

Before exploring the potential buffering effect of social support on caregivers in families of terminal cancer patients at home, we need to describe the concept of social support more precisely with this population. The purpose of this study was to determine the social support that caregivers in families of terminal cancer patients who are at home require.

Method

Sample

The convenience sample of 24 caregivers in families was obtained with the assistance of visiting nurses in a large metropolitan area and a smaller urban area. Potential subjects were initially contacted by the nurse for permission to release their names and telephone numbers to the investigator. The investigator then contacted them by phone, explained the research protocol as well as the subjects' rights and invited them to participate. Written consent was obtained prior to the interviews which took place in the family caregivers' homes.

Instrument

The Social Support Questionnaire (SSQ), the main instrument for the study, was adapted from Norbeck's Social Support Questionnaire (NSSQ) (Norbeck, Lindsey and Carrieri, 1981) with permission from Dr. Norbeck. The format of NSSQ and the items pertaining to affect, affirmation, aid and loss formed part of the SSQ. Adaptations to NSSQ included changes in the instructions on the face sheet, and the addition of items on the provision of information, additional helpful support, gain in support and changes in the support network. These adaptations were substantiated in clinical practice, and by the literature review and conceptual framework. They were made to reflect the uniqueness of the clinical population under study. Precisely, NSSQ and the SSQ are based on Kahn's conceptualization of social support

(Khan and Antonucci, 1980). These authors suggest that family caregivers' needs for social support may be heightened because of their situations. However, there is no guarantee that their additional needs for support will be met.

An 11-item structured questionnaire, the SSQ is designed to obtain information about the number of people, range (e.g. spouse, friend, health care provider, etc.), and type of network the caregiver is currently involved in and the network she or he would desire. Type of support refers to affect, affirmation and aid. Affect is an expression of liking, admiration, respect or love. Affirmation is an expression of agreement or acknowledgement of the appropriateness of some act or statement by another person. Aid describes a situation in which direct assistance is given, including things, money, information, time and entitlements (Kahn and Antonucci, 1980, pp 267-268).

Most questions measuring type of support ask caregivers to rate (Likert scale with 5 categories) the importance of the help that each network member provides. For example, one item measuring affirmation is, "How much can you confide in this person?" With other, more open-ended questions, the type of support is determined through content analysis. For example, with regard to additional helpful support, caregivers were instructed, "Please tell me the type of support you need and who you feel could provide that support."

The Family Caregiver Profile and the Situational Profile, which were developed by the investigator for the purposes of this study, were composed of caregiver and situational variables that could influence the family caregivers' requirements for social support.

Reliability and validity of the SSQ

Responses to the open-ended questions on the SSQ were content analyzed and assigned to one or more of the categories (affect, affirmation and aid). To increase specificity in the analysis, the components of aid outlined in Kahn's definition (time, things, money, information and entitlement), were also used. A nursing colleague with research and clinical experience in palliative care also categorized the responses. Interrater reliability was established at 100%. In choosing the items for the SSQ, content validity was addressed in that Kahn's social support theory, the literature review and clinical practice guided the selection.

Results

Characteristics of caregivers in families

The family caregivers' sex, marital status, age, household income and sociability are represented in Table 1. The mean age of the subjects was 51.3 years (S.D. 13.9, r 21-71). Of the 13 households with incomes less than \$20,000, four had male cancer patients of working age who obviously could not work. Caregivers in three of the other households had resigned full-time jobs because of the patient care demands.

Table 1

Properties of the Family Caregivers

Properties	Categories	Frequency	Percent
Sex	M	4	16.7
	F	20	83.3
Marital Status	married	18	75.0
	divorced or separated	3	12.5
	single	2	8.3
	widowed	1	4.2
Age	18-35 years	4	16.7
	36-65 years	17	70.8
	65 years	3	12.5
Education	1-8 years	2	8.3
	9-12 years	14	58.3
	13-16 years	5	20.8
	17+ years	3	12.5
*Household Income	<\$20,000	13	54.2
	\$20,000-\$39,999	3	12.5
	\$40,000+	5	20.8
Sociability	very social	9	37.5
	rather social	13	54.2
	keep pretty much to myself	2	8.3

*3 subjects were uncertain of their household income and did not respond.

All caregivers were related to the cancer patients. Of the 18 married subjects, 16 were spouses of the patient. Caregivers that were not spouses were most often children of the cancer patients (n=6). Caregivers had spent varying lengths of time in their caregiving roles (\bar{x} 7.4 months, S.D. 6.9 months, r 2 weeks - 2.5 years). For one-half of them (n=12), the time did not exceed six months. Most of the family caregivers (n=21) had not had as much previous experience providing patient care at home.

Table 2

Properties of the Situation

Properties	Categories	Frequency	Percent
Sex of patient	M	17	70.8
	F	7	29.2
Age of Patient	<18 years	1	4.2
	18-35 years	0	0.0
	36-65 years	14	58.3
	>65 years	9	37.5
Type of Cancer	digestive	7	29.2
	lung	5	20.8
	central nervous system	4	16.7
	breast	3	12.5
	genito-urinary	3	12.5
	other	2	8.3
Number of other people in household*	0	10	41.6
	1	7	29.2
	2	2	8.3
	3	3	12.5
	4	1	4.2
	5	1	4.2
Dysfunctional score**	0-2	4	16.7
	3-5	12	50.0
	6-8	5	20.8
	9-10	3	12.5

*Besides cancer patient and caregiver

**Calculated by summing the individual ratings on 5 A.D.L. scored as dependent (2), needs assistance (1), independent (0).

Characteristics of the situation

Data for the age and sex of the cancer patient, type of cancer, number of other people residing in the household and measure of dysfunction of the patient are presented in Table 2. Mean age for the cancer patients was 61.5 years (S.D. 16.1, R 5- 91). The dysfunctional score reflected the degree to which the patient depended on his or her caregiver for the performance of five activities of daily living (ADL): bathing, dressing, mobility, toileting and feeding. These scores ranged from 0-10 (\bar{x} 4.9, S.D. 2.6); the higher the score, the more dependent the patient. Patient care demands for family caregivers are obvious in that slightly more than one-half (n=13) of the patients required assistance from or were completely dependent upon their family caregivers for bathing, dressing and at least two of toileting, mobility and feeding.

In ten households, the family caregiver were living alone with the patient. Seven of these caregivers were older female spouses (\bar{x} age 62.3, S.D. 5.12, r 56-70). When other people lived in the household, age seemed to be the critical factor for whether or not they were reported as supportive. Of the seven situations in which they were not considered supportive, most were situations involving children (n=5). Family caregivers in these situations seemed concerned about having enough time to perform both parenting and caregiving roles. One mother commented: "My oldest daughter seems to get the least attention. By the time I look after my husband (patient), the baby and my other daughter, there is little time left for her."

Social support

Social support requirements included the support caregivers were receiving at the time of the interview (current social support), and their expressed need for additional support (desired social support). Since caregivers were selective in their reports of current support, the investigator assumes the support they reported was necessary.

Current social support. Each family caregiver reported 1-15 network members (\bar{x} 7.96, S.D. 3.83) from several range categories: spouse, family, friend, neighbor, (primary group), work/school/church associate, health care provider, clergy, homemaker and other (secondary group). As evident from Figure 1, collectively, more support was provided by the primary group than the secondary group.

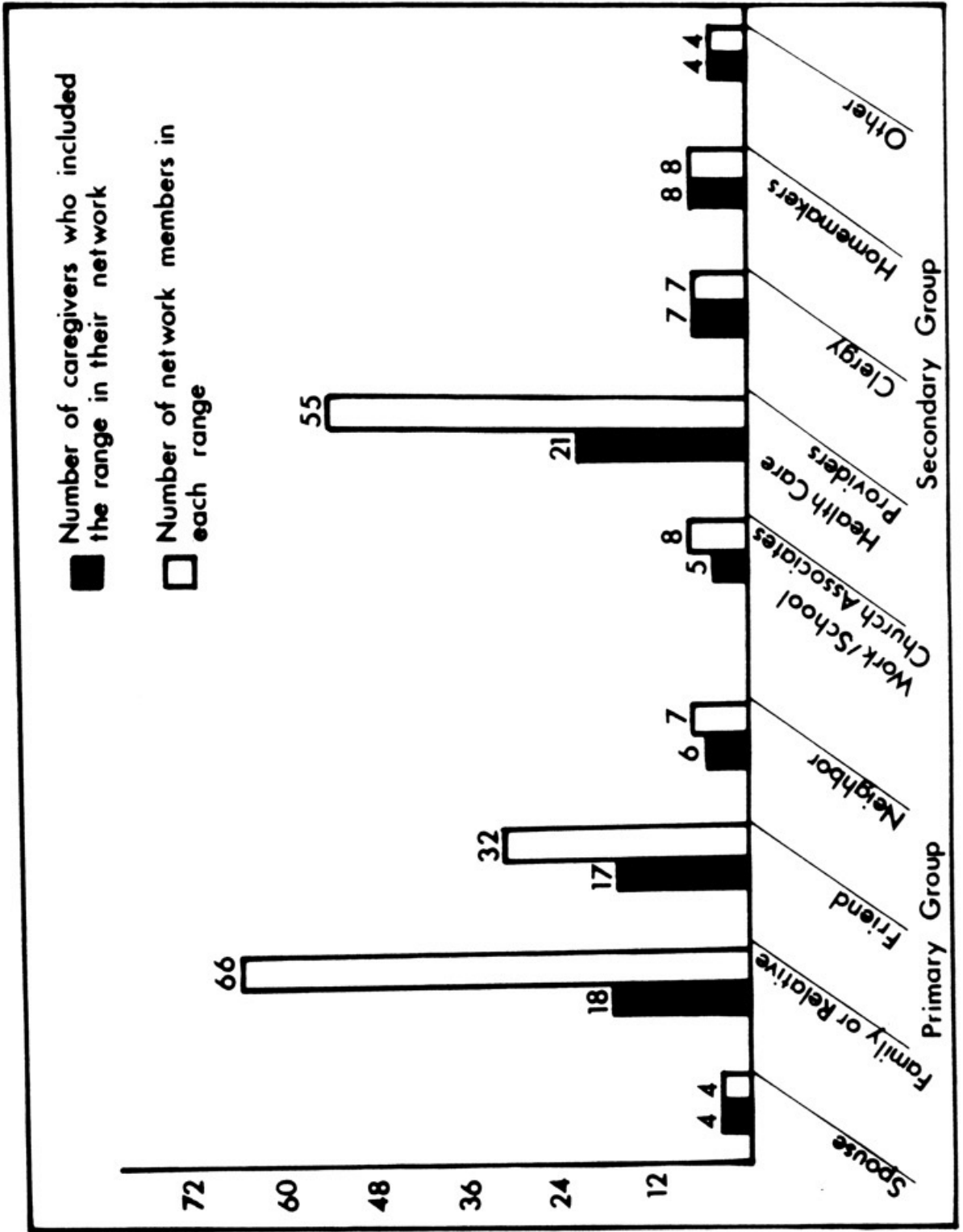


Figure 1
Frequency of the caregivers who identified each range and the network members in each range

The type of support that network members provided varied with the range. Families, health care providers and friends were the major sources of support. When compared to other ranges, the data suggest that families are good confidants; friends support family caregivers' actions or thoughts; and health care providers provide information about the patients' condition or care.

Nurses were the largest subgroup of health care providers. They earned the caregivers' highest score for supporting their actions or thoughts. In praising the nursing services they were receiving, family caregivers' comments (n=9) indicated that the nurse seemed to understand their concerns and behaviours. As one family caregiver commented: "They make me feel that they are as concerned about me as they are about my husband. I can tell them about my feelings, fears, even cry in front of them and that's okay. They are coming in and seeing the day to day situation. I can't say enough about the nurses who come into your home - they are a God-send."

Desired social support. One-third of the sample (n=8) desired more support and collectively identified 11 needs for aid. Five of these caregivers were looking for time; for example, someone to "patient-sit", so that they could get out to bank or shop. Each subject was specific about the time required, their needs ranging from one day every two weeks to an "on call" service. They also recommended that professional nurses, allied nursing personnel or homemakers (secondary group) should provide the service.

Worthy of note is that five caregivers who did not require additional support described the arrangements they had made for time for themselves. Some were taking advantage of the time the homemaker was available; others were relying on friends and relatives. One caregiver identified the purpose of this time: "I need to get out myself, otherwise I get frustrated. When I get frustrated I sometimes take it out on my mom (cancer patient), and that doesn't make me feel very good."

Change in social support

Most caregivers (n=21) had experienced changes in their social support since assuming the caregiving role. Positive changes - situations in which caregivers received more support from known network members, a gain of a new network member or both - were reported by 19 caregivers. Nearly one-half (n=11) of the caregivers described network members who had become more supportive. Most commonly, families and friends were providing more aid, in terms of time, by calling or visiting more often. Families were also responsible for an increase in the caring or concern (affect) they demonstrated toward the caregivers (n=7).

Nearly two-thirds (n=15) of the sample had gained supportive relationships, ranging from 1 - 7 (\bar{x} 3.4, S.D. 1.72). Aid was the type of support most often

realized from the gain. From the secondary group, the aid was in the form of nursing care, equipment, homemaking services and the provision of information regarding the patient's condition and care. The primary group, generally friends, provided caregivers with time and things: they were available to do "anything", spent time with the caregivers and brought food to their homes. Through their understanding nature, nurses accounted for the greatest gain in affirmation. Most of the 15 caregivers (n=9) attributed "a great deal" of their support to the new network members.

Five caregivers reported a loss of network members (negative change) predominately from the primary group and involving people not visiting, calling or spending time with them (aid). In addition, three caregivers identified network members who were less supportive. The magnitude of these losses was considered to be low. As one caregiver commented: "If they aren't available to you now, then you probably weren't getting that much support from them in the first place."

Discussion

The profile of most caregivers is consistent with that reported by Evernden (1984), Holding (1986) and Stetz (1987): middle-aged female spouses of an older mate. Davis (1980) suggests that females assume the caregiving role more easily than men because it is highly associated with the mothering role, and is consistent with female self-expectations. Female caregivers in this study, and also in Holing's (1986) study, seemed to fit traditional female roles in that most were not working outside the home prior to the patient's illness. The investigator suspects that this profile may change in the future, as younger women today are more career-oriented and may be reluctant to assume full-time caregiving responsibilities.

Caregivers faced considerable demands. Consistent with other studies (Googe & Varricchio, 1981; and Stetz, 1987), the terminal patients in this study required assistance with many of their ADL, yet, 87.5% (n=21) of the caregivers had not had as much previous experience in this role. As indicated earlier, 41.7% (n=10) of the caregivers were living alone with the cancer patient. Fifty percent of the caregivers in Holing's (1986) study also lived alone with the terminal cancer patient. Seven caregivers dealt with parenting responsibilities as well as caregiving responsibilities. Goldstein, Regnery and Wellin (1981) suggest that, for young caregivers, the time and energy demands of caretaking tend to generate conflicts with other family, occupational or social roles and obligations (p.25).

Enabling factors for caregivers

The investigator suspects that several factors influenced the caregivers' abilities to manage the demands of their situations. First, the majority (n=16)

of the caregivers had the support they required. Investigators (Evernden, 1984; and Ward, 1974) have reported that the presence of "supportive others" was helpful in the overall management of terminal cancer patient care at home.

A second influencing factor may be that all families in the study were the recipients of home nursing services. Nurses provided information about the patients' conditions and care; affirmation, through their understanding approach; and nursing care for the terminal cancer patient. Other investigators (Kristjanson, 1986; and Skorupka & Bohnet, 1982) report nurses being helpful to caregivers of terminal patients because of the information they provide. Glaser and Strauss, cited in Hampe (1975), and Wright and Dyck (1984) identify information as being a need in families of terminal patients. The suggestion that visiting nurses provide affirmation to caregivers is supported by findings of Evernden (1984) and of Googe and Varricchio (1981).

A third factor influencing the caregivers' ability to manage may be related to experience in the caregiving role. Mean time in the role was 7.4 months; the caregivers had undoubtedly acquired some degree of caregiving skill over this period, and had had the opportunity to mobilize necessary resources. Five of the eight caregivers who needed additional support were below the mean - in four instances for less than two months. Petrosino (1985), in stressing the need for rapid referrals and well coordinated resources for these families, reports that 76% of the families in her study received hospice services for 2.7 months or less.

Finally, keeping the patient at home allows caregivers to meet some of their own needs. Being with the dying patient and being helpful to him or her are among the needs of grieving spouses which have been identified by Hampe (1975), and supported by Dyck & Wright (1985).

Focus on social support

There were more primary group members than secondary group members among caregivers. MacElveen (1978) and Mitchell and Trickett (1980) have suggested that primary groups are preferred sources of support during stressful situations. In the present study, the unsolicited comments of the caregivers would not lead one to conclude that they had a preference for a particular range category. Each group offered caregivers a different type of support. The value of support from secondary network members is suggested by its importance in meeting additional support needs of caregivers.

Caregivers perceived strong support for their actions and thoughts, particularly from friends and health care providers. It is possible that the significance of support from nurses and other health care providers would be

more important to caregivers because they are professionals who have knowledge and experience in the situation. Results in this study suggest that health care providers were perceived by caregivers to be knowledgeable about the patients' conditions and care.

All reports of desired social support involved aid - usually, a need for time. This fact, coupled with the unsolicited comments of caregivers, gave the investigator an overriding sense of the caregivers' need for time out. In keeping with this finding, one-third of the families of cancer patients in Welch's (1981) study indicated that having no one to patient-sit in the home setting was a problem. In contrast, Evernden (1984) reported that caregivers of terminal cancer patients at home were reluctant to leave the patient alone, even when network members offered to "patient-sit".

Change in support system

Caregivers were receiving more support than they had received prior to assuming the role. No doubt this was a direct response to the heightened need for support that has been identified by Kahn and Antonucci (1980). These authors suggest that most members of a person's convoy are initially connected to that person through the performance of related roles. In fact, new members of the secondary group filled role-related needs - nursing care, equipment, homemaking services and information.

Those caregivers experiencing negative support attributed little significance to the change. It is likely that changes in the circumstances in caregivers' lives had been a motivator in reorganizing their values and priorities. As one subject stated: "It is situations like these that really separate friends from acquaintances. I've found out who is really in my life."

Limitations

Generalization of the findings of this study is limited by the selection of subjects from a convenience sample and by the small sample size. Subjects were interviewed on only one occasion and, therefore, their responses are not representative of the entire terminal stage. Finally, the reliability and validity of the instruments used in the study have not been well established.

Recommendations

Nursing practice

Most caregivers who expressed additional support needs had been in the caregiving role for a shorter time than the total sample. This suggests that nurses should assess caregivers' needs for aid at the onset of their relation-

ships with these families. In particular, nurses should be attentive to what opportunities, if any, the caregivers occasionally have to get out of the home.

Second, nurses should maintain contact with these families, in spite of the fact that caregivers may be managing very well. The nurses in this study were serving a valuable purpose by providing information and affirmation to the caregivers in the home. Caregivers are likely to experience different concerns over time; they might readily share these with a nurse with whom they had established a good relationship.

Nursing research

A tool with dimensions more sensitive to the social support concept should be developed for this population. For example, the aspects of love and admiration, used by Kahn (1979) to describe affect, had little meaning in describing relationships with secondary group members. To facilitate this development, a research design that is more qualitative in nature should be used. Rather than using a structured interview schedule, more open-ended questions, which would afford caregivers the opportunity to describe relevant support indicators, is warranted. As well, a longitudinal study to identify the social support requirements of family caregivers over the course of the cancer patients' terminal illness would be useful. Such a study would provide insight about changes in social support requirements over time and about how these requirements are met.

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The author wishes to acknowledge the contribution to this study of Kathleen Arpin, University of Toronto.

RÉSUMÉ

Demandes de soutien social formulées par les aides-familiales qui interviennent auprès des cancéreux en phase terminale

L'objet de cette étude descriptive est de cerner le soutien social que sollicitent les aides-familiales qui interviennent au domicile des cancéreux en phase terminale. Le concept pluridimensionnel du soutien social de Kahn (1979) sert de base au principal instrument utilisé dans le cadre de cette étude.

La plupart des aides-familiales admettent que des changements positifs sont intervenus au chapitre du soutien dont elles bénéficient depuis la date de leur entrée en fonctions. Au moment où s'est déroulée l'entrevue, deux tiers des aides-familiales affirmaient obtenir le soutien social dont elles avaient besoin. Ce soutien provient de diverses sources et revêt des dimensions aussi tangibles qu'émotives. Les aides-familiales qui souhaitaient obtenir un soutien plus étoffé cherchaient, la plupart du temps, à obtenir un répit.

Des recommandations en matière de soins infirmiers et de recherche sont également formulées.