

Post-treatment support for patients with haematological malignancies: findings from regional, rural and remote Queensland

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Abstract

Social support is a significant factor in the cancer patient's psychosocial wellbeing. This paper presents the findings of recent Queensland-based research that explored the experience of families returning home to the regional, rural and remote sector after a family member completed specialist treatment for a haematological malignancy and related blood disorder in a major metropolitan centre.

Family and friends are the key resource persons providing support. To a large degree, this is because of the absence of alternative sources. Even support from health professionals can be problematic and for many the only source of support is the specialist centre many hundreds of kilometres away. The primary response to developing supportive services needs to be through person to person contact either via telephone or newsletter. If targeted appropriately, there is also evidence that educational programs, support groups and volunteers would be an effective medium for providing support. Educating the local health professionals (GPs and nurses) about haematological conditions is a logical extension of providing support to families.

Introduction

The nature of the problem addressed in this paper may be illustrated by noting the following two contrasting open-ended comments from participants:

The trauma went on for years while he was taking (Interferon) in large doses. We lived on an isolated property. He was against me talking to his doctor and I spoke to NO-ONE! On one visit to Brisbane (the specialist) invited me in from the waiting room, which was a help as at least I was in the picture with a few facts.

Because I have such great support from family, great friends, and neighbours, I've been luckier than most.

The importance of social support for families coping with cancer was acknowledged by early research in the field of psycho-oncology (Cassel 1974; Cobb 1976). Since this time, the role of social support for cancer patients has received a great deal of attention (Blanchard et al. 1995; Broadhead & Kaplan 1991; Hann et al 1995; Holland & Rowland 1989; Holland 1998; Kosasa et al. 1991; Krause 1991; Murray 1995).

It is now understood that social support is a significant factor in the cancer patient's psychosocial well being (Bottomley & Jones 1997; Carlsson & Hamrin 1994; Dow 1995). Unfortunately, however, studies show that cancer patients typically experience a loss in social relationship (Bottomley & Jones 1997; Dunkel-Schetter

1984) and even where relationships are maintained they may eventually have negative consequences (Galinsky & Schopler 1994; Sabo et al. 1986). This is at a time when there is a need for support to mobilise coping strategies as situational demands can come to exceed personal resources (Grahm 1996).

Patients treated for haematological malignancies and related blood disorders (HMRBD) are in a unique situation in regards to support. They face the challenge of coping with a life threatening illness, the treatments for which are usually prolonged, risky, and invasive (McGrath 2000a). Because of the need to relocate to a metropolitan hospital for the duration of specialist treatment, most of these patients and their families must deal with stresses during treatment away from the comfort of close contact with family and friends (McGrath 1998; 1999a; 1999b). To date, the psychosocial research that has been completed on the support systems for these patients and their families has focused mainly on the treatment experience and its sequelae (McGrath 2000a). There is scant work completed on the experience of returning home after specialist treatment. Such information is vital for understanding the long-term sequelae of treatment and for planning appropriate follow-up support services.

This discussion presents the findings of recent, Queensland based research that explored the experience of families returning home to regional, rural and remote areas after a family member completed specialist treatment for a HMRBD in a major metropolitan centre. The aims of the research were firstly, to describe the needs of patients and their families after returning home; secondly, to document the support they receive; and thirdly, to examine the role that their local general practitioner plays in following-up and supporting them. This discussion presents the findings on the support available to such families on returning home.

The research

The research was funded by Australian Mutual Providence (AMP) and was conducted in collaboration with the Leukaemia Foundation of Queensland (LFQ) and the Children's Leukaemia and Cancer Society (CLCS). The impetus for the research grew out of a concern by patient support staff at the LFQ as to the plight of families after they left the intensive and supportive health and allied health care services in the metropolitan area.

The treatment regimens for these patients (eg. high dose chemotherapy, bone marrow transplantation, and stem cell transplantation) are particularly demanding and require concentrated attention by the metropolitan specialist treating team. On completion of therapy patients must leave the close, supportive situation of the specialist hospital and return, often many hundreds of kilometres, to their home situation. In the absence of follow-up data it is impossible to know if such families are making a successful transition to returning home or if (and how) they need support. Thus, this research was conducted to provide the necessary information for planning support services. The hope and expectation is that the findings will make a contribution to stimulating research interest in this neglected area, whilst providing information to guide the development of appropriate services for regional, rural and remote families affected by a HMRBD.

Methodology

Suggestions for the development and design of this research project were obtained from support and hospital staff with long term experience in working with patients (both children and adult) with a HMRBD from LFQ, Wesley Hospital, Brisbane, and CLCS. After extensive discussion of feasibility and costs it was decided to target a state-wide (Queensland) sample of relevant families and a sample of the general practitioners who care for them. The methodological details of the general practitioner arm of the research, published elsewhere (McGrath 2000b) is not directly relevant to this article and so the following discussion will centre on the family questionnaire.

The names and addresses of the families were obtained from the admission lists of the LFQ accommodation centres and the patient mailing list of CLCS. Ethical clearance was obtained to contact these families through the QUT university ethics committee and the management committees of the organisations involved.

The admission sheets covered the years from 1997 to 1999. The data was entered onto an Excel spreadsheet and cleaned for duplicate entries. Patients not resident in Queensland were eliminated, as were temporary visitors. All families where the patient was known to have died were eliminated from the study. The first questionnaire was to 269 families. A second mail-out was completed two months later in an effort to involve

families who had not had time to complete the first questionnaire. There were in total 18 family questionnaires returned to sender from both mail outs and an additional 9 questionnaires were returned with a note that the patient had since died. Of the possible 242 families surveyed 115 responded providing a response rate of 47.5%. The questionnaires were developed through discussions with staff experienced in working with patients with a HMRBD and their families. The questionnaires were circulated for comment and piloted with a small number (n=8) of families prior to mailing out. There were no suggestions for changes to the questionnaire and the pilot responses have been included in the findings. The central concern in developing the family questionnaire was to provide as much opportunity as possible for open-ended comment so that the research could record as fully as possible the experience of returning home from the respondents' perspective. A blank page with the suggestion for further comment was added to the questionnaire and many participants took the opportunity to write about their experiences.

The open-ended comment was entered into Word 97 and analysed thematically using the exact words of the participants. All quantitative data was entered into SPSS and analysed with simple descriptive statistics.

Results

The questionnaire was sent out to families at residential addresses throughout regional, rural and remote Queensland with a family member diagnosed with a HMRBD, including, among others, acute (n=36) and chronic leukaemias (n=6), Lymphomas (n=21) and myelomas (n=11).

The majority (n=96; 83.5%) of questionnaires were filled out by either the patient or, in the case of a child, the patient's parent. There was a fairly equal distribution of male (n=54; 47%) and female (n=45; 39.1%) respondents. Just about half of the sample (n=58; 50.4%) estimated their total income as less than \$30,000 with equal sub-groups (n=12; 10.4%) at both extremes of the income scale of under \$10,000 and over \$60,000. The most common form of transport reported for these families was the family car (n=94; 81.8%). A minority of participants (n=11; 9.6%) indicated that they had difficulty accessing transport.

Table 1. Demographics

	Frequency & Percent
Questionnaire completed by	
Patient	N=59 (51.3%)* ¹
Parent	N=37 (32.2%)
Partner	N=8 (7%)
Carer	N=6 (5.2%)
Family Member	N=3 (2.6%)
Gender	
Female	N=45 (39.1%)* ²
Male	N=54 (47%)
Estimate of total family Income	
Less than \$10,000	N=12 (10.4%)* ³
\$11-20,000	N=23 (20%)
\$21-30,000	N=23 (20%)
\$31-40,000	N=12 (10.4%)
\$41-50,000	N=9 (7.8%)
\$51-60,000	N=6 (5.2%)
\$61+	N=12 (10.4%)

*Note: *¹Two, *² sixteen, *³ sixteen questionnaires missing data.

Although over a third of the patients had returned home after the completion of treatment within the previous three months, there was a wide variation of times since return from specialist treatment with some patients home for as long as six years.

The majority of patients (n=83; 72%) had returned for specialist follow-up within the last nine months.

Table 2. Time since patients return home from treatment (N=115) *

Number of Months	Frequency & Percent
3 months or less	N=45 (39.1%)
4-6 months	N=16 (13.9%)
7-9 months	N=6 (5.2%)
10-20 months	N=24 (20.8%)
21-30 months	N=9 (7.8%)
31-40 months	N=3 (3.7%)
41-72 months	N=2 (1.8%)

*Note: Ten (n=10; 8.7%) participants did not provide these details.

Patients returned to the metropolitan centre for specialist treatment after their return home for a number of visits ranging from under five times (n=31; 26.9%) to over forty times (n=17; 14.8%).

Participants were asked to rate on a scale of from one to ten how well they felt supported after returning home (1-3 no support; 4-7 sufficient; 8-10 excellent). There was a wide range of responses with twenty-nine respondents (25.2%) indicating they had no support, thirty-seven (32.2%) indicating sufficient support, and thirty-nine (33.9%) indicating excellent support.

When participants were asked to comment on the most important source of support they had received since returning home they indicated that family and friends (n=91) were clearly the most significant. Support from health professionals was also recorded as important (n=25). Other sources of support documented included the Leukaemia Foundation of Queensland (LFQ) (n=6), support from place of work (n=5), church support (n=5), Children's Leukaemia and Cancer Society (n=2), support groups (n=2), the local community (n=2), a Hospice service (n=1), home help (n=1), and the Queensland Cancer Fund (n=1).

Twelve respondents not only tick lack of support in the rating scale but also indicated in their comments that they had no sources of support, including lack of support from family and friends. One participant indicated that they didn't need support.

Participants were asked to describe how well they were able to maintain the supportive relationships that had been established at the metropolitan treatment centre, after returning home. Many (n=49) indicated that support was still satisfying and ongoing. Comments about this satisfying relationship indicated that patients have managed to 'stay in contact with patients and staff' at the metropolitan treating centre and can 'phone them any time (they) feel worried'. Metropolitan staff were described in positive terms such as 'a really nice bunch of people' who 'certainly wanted to know how things were going' for patients after they had returned home.

Others (n=34) indicated that contact was either broken or unsatisfactory. Descriptions of the lack of continuity include concerns such as 'You don't even get to speak to the same doctor as they change every 3 months or so'. Some participants indicated that they 'really miss' the previous closeness as can be seen by the statement, 'That is the one thing I really miss. When our child was sick we became very close to everyone. I really miss all the close friendships. I don't want to live in the past but I'd love to know how the other children went. Did they survive or what?' Respondents were philosophical about the difficulty of 'maintaining relationship as time goes on and (they) visit the hospital less'. This lack of contact, however, 'made (them) feel alone'.

A minority (n=7) indicate that relationships are 'fair' or only just adequate, providing the essential 'with no other support given'. Others (n=7) commented that they still see the metropolitan staff on a regular basis.

The on-going contact and support with LFQ was recorded by some (n=4) as providing an important element of continuity of care. Another (n=1) participant indicated that even this contact with LFQ had been lost. Three of the respondent commented that they did not need to continue contact.

When asked if there were any obstacles to accessing available support, thirty-six respondents (n=36) indicated that there was not. However, there were indications by others that there were barriers to support. Of these, distance was recorded (n=16) as one of the chief obstacles. Others (n=12) indicated that there was no support available to access, and some (n=7) participants made comments indicating that their problem was that they did not know what support was available. Practical obstacles (n=7) included lack of wheelchair access, financial restrictions, problems arranging childcare, and lack of time. Emotional barriers (n=2) included the lack of awareness of the disease by others and psychological distress.

Participants were asked to tick on a list of suggested health and allied health professionals those who had provided the most significant support on returning home after treatment. The responses are itemised in descending order of significance in Table 3.

Table 3. Most helpful health and allied health professionals

Professional	Frequency & Percent
General Practitioner	N=61 (53%)
Hospital Specialist/Haematologist	N=33 (28.7%)
Hospital Nurse	N=17 (14.8%)
Other	N=16 (13.9%)
None	N=14 (12.2%)
Community Nurse	N=10 (8.7%)
Social Worker	N=4 (3.5%)
Teacher	N=4 (3.5%)
Psychologist	N=0 (0%)

Participants were asked if they found upon returning home that the health and allied health professionals in their community had sufficient knowledge of the illness and associated concerns to provide appropriate assistance. Fifty-two (45.2%) participants indicated that the knowledge level was sufficient and forty-seven (40.9%) recorded that it was not. As the following summary shows, the respondents' open-ended comments on this issue were similarly divided.

Thirty-eight participants (n=38) made comments indicating that their general practitioner and/or local hospital were not informed about the illness. This observation was accompanied with statements understanding that because of the small number of patients with such a condition 'this would be expected' and that where the local general practitioner 'try hard.. that makes up for it to some degree'. Although some general practitioners 'knew nothing about treatment and after care' they helped by 'referring to the specialist in Brisbane for advice'. Some doctors were recorded as being honest about their lack of knowledge and 'admitted to not knowing about (the disease) or the medical procedures', particularly in areas such as the care of the Hickman line.

Other participants documented that their general practitioners were well informed and helpful (n=20). Comments from these participants were full of praise, 'My GP was very understanding and supportive and went out of his way to find out as much information as he could about the disease'. Typically these general practitioners fostered contact with the specialist at the metropolitan centre, as can be seen by the comments, 'the local GP ... never hesitated to contact specialist in Brisbane if he was unsure of something regarding (patient's) health' or 'my GP was very knowledgeable about my problem and very interested in what the specialist in Brisbane decides'.

Some (n=10) of the respondents indicated that they only rely on metropolitan treating team or specialist /haematologist. Such participants if needing medical advice travel to the metropolitan centre and only see their specialist, they 'never seek local advice'.

There were comments to indicate that some patients knew more about treatment issues than their general practitioner (n=6), such as, 'Without a doubt, I knew much more about Leukaemia than any GP I saw following transplant'.

Participants were asked the question of whether there were particular needs for support that were not met. Thirty-four (29.6%) participants answered yes. Respondents detailed problem areas such as the lack of emotional support (n=11), the lack of information about condition and/or side-effect of treatment (n=6), the absence of any support at all (n=4), the lack of physical support (n=4), no financial support (n=3), no follow-up social work support (n=2), inadequate school support (n=1), and the lack of organisational support (n=1).

Participants were asked to make suggestions about how they could be offered support most effectively. A list of choices were provided with the option for participants to tick as many as they thought suitable, and the results are summarised in Table 4.

Table 4. Most effective means of providing support

Name of Option	Frequency & Percent
Telephone Contact	N=57 (49.6%)
Newsletter	N=34 (29.6%)
Health Professional Follow-up	N=33 (28.7%)
Community Nurses	N=24 (20.9%)
Counselling	N=23 (20%)
Social Workers	N=20 (17.4%)
Physiotherapist	N=15 (13%)
Educational Program	N=31 (27%)
Practical Assistance	N=28 (24.3%)
Support Groups	N=26 (22.6%)
Volunteer Support	N=21 (18.3%)
Electronic Media	N=14 (12.2%)
Spiritual Support	N=14 (12.2%)
Local Community or Charity Support	N=12 (10.4%)
No Support Needed	N=16 (13.9%)

Discussion

The findings demonstrate that any discussion of support issues in the rural sector must take into account the disparate levels of support available to families. Over a third of this sample indicated excellent support networks, and their associated comment provided descriptions of satisfying relationships with family, friends, community organisations, health and allied health professionals.

A quarter of the sample, however, recorded a complete perceived absence of support, and many of their written anecdotes were indicative of considerable hardship. Participants recorded lack of emotional support, no information about the condition and/or side-effects of treatment, absence of physical or financial support as the important unmet support needs.

There is a wide range of people who can provide support to patients including family, friends, nurses, doctors and other staff (Suominen et al. 1995; Bottomley 1995). For the respondents in this research, the most important source of support was quite clearly that of family and friends. For a minority of families, community organisations play an important support role. Because of the complexities of HMRBD and their treatments, families must cope with many more issues over a longer period of time, and non-ill members must adapt to

taking on new responsibilities (Adams-Greenly 1986; Futterman & Wellish 1990). Taking into consideration the great inequities between the resources of different families it is unsatisfactory to leave the responsibility for post-specialist support solely up to this informal form of support. Families need assistance to effectively support their sick member, and some families need far more support than others.

One of the challenges of returning home after specialist treatment for HMRBD involves leaving the comfort of the supportive relationships built up with health and allied health professionals at the metropolitan treating hospitals. Indeed, because of the intense dependency created through high-technology treatment, both patients and their families often feel ambivalence when it is time to leave the protective atmosphere of the hospital and return home (Freund & Siegel 1986; Kellerman et al. 1976; Patenaude et al. 1979). The response to questioning about this aspect of returning home in the present study was mixed. Some participants reported that the positive connection had not been severed and remained satisfying and ongoing, with some still seeing staff regularly. Others reported the contact as only just sufficient or at worst, broken or unsatisfactory, thus, eliminating the hospital as a source of support.

Major obstacles to accessing the required support included distance, the non-availability of support, lack of information about the availability of support and practical obstacles: issues characteristic of rural and remote communities (Cheers 1990).

Health professionals, although rated as less important than the informal support of family and friends, were noted as key sources of support. By far, the health professional seen as providing the most support was the general practitioner. This finding parallels evidence elsewhere that indicates that general practitioners are key providers of health care in regional, rural and remote areas (Humphrey & Rolley 1991). Many patients however still rely on the specialist in the metropolitan hospital. Nurses, both hospital and community, were noted as an important source of support, a trend documented worldwide in rural communities (Marris 1992).

Hawkins and Curtiss (1997) document that rural residents with cancer face lack of localised medical expertise, with rural physicians, nurses, and pharmacists having limited resources to provide the necessary care for these patients. In this study, over forty percent of the participants registered concerns about the insufficient knowledge about HMRBD displayed by their local health professionals. This meant for some patients that they knew more than their general practitioner and were dependent on the support they received from the specialists at the distant treating hospitals. This situation must be balanced by the minority who wrote about the excellence of care they received from their GP who were supportive and actively sought information on the disease and its treatment. Thus, although there was a great deal of appreciation expressed about the support provided by general practitioners, this support was still problematic and requires constructive strategies for improvement such as doctor education about HMRBD and fostering of direct communication between local general practitioners and metropolitan specialists.

For patients, the preferred medium for receiving support was by telephone. This was followed by newsletter, health professional follow-up, educational programs, practical assistance, support groups, and volunteer support. Electronic media were among the least desired for follow-up. This information can be used by health care organisations and voluntary bodies to inform the development of strategies to improve support to these families.

Conclusion

The findings from this research have direct practical implications for any organisation seeking to provide post-treatment support for those with HMRBD in the rural sector. Firstly, the expectation should be that not all families will require intensive support after hospital discharge, and thus any program should devise strategies for targeting those in need of support. There will definitely be a significant sub-group that will be experiencing hardship from lack of support and hence will be in need of assistance, including practical assistance.

At present, family and friends are the key resource persons providing support. To a large degree this is because of the absence of alternative sources of support. Even support from health professionals can be problematic and for many the only source of support is the specialist centre many hundreds of kilometres away. For patients returning from the high-technology procedures associated with HMRBD, appropriately informed medical assistance is a key issue in allowing these patients to feel supported.

The response to developing supportive services needs to be through person to person contact either via telephone or newsletter. If targeted appropriately there is also evidence that educational programs, support groups and volunteers would be an effective medium for providing support. Strategies to educate the local health professionals (GPs and nurses) about HMRBD are a logical extension of providing support to families.

The information provided in this discussion not only documents the need families experience for support after they return home from specialist treatment, but also goes some way to defining how such support can be provided. It is the hope and expectation that such information will provide the groundwork for the development of strategies to assist those making the difficult journey of re-entering life after the intense experience of being away for treatment at a major metropolitan treatment centre.

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