

SURVIVING THE CRISIS OF RELOCATION FOR SPECIALIST TREATMENT IN HAEMATOLOGY: INSIGHTS FROM NEW ZEALAND*

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ABSTRACT

Patients diagnosed with haematological malignancies require specialist treatments provided by major metropolitan hospitals. Those living outside the cities where the specialist care is located have to relocate for this specialist treatment. The findings presented in this article are from a program of research that documents the psychosocial impact of relocation on patients and their families. Prior Australian-based research conducted as part of the program indicates that the process of relocation exacerbates the stress of treatment and creates significant practical, emotional, social, and financial disruption to the families involved. The Australian findings provided the basis for a recent comparative study conducted by the program that explores the experience of relocation for haematology from the perspective of patients and their carers in New Zealand. The findings from the comparative study indicate that whilst there is evidence of similar psycho-social distress associated with relocation, there are a number of factors specific to living in New Zealand that ameliorate the impact, including smaller distances, strong community connections, and the participants' personal determination to retain the focus on living.

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INTRODUCTION

Patients diagnosed with haematological malignancies require specialist treatments provided by hospitals in major cities. Australian and American research indicates that those living in areas distant from treating hospitals have to relocate for specialist care (Rohlf, Gerber, Lacey, Richard, & Dett, 2007) and, thus, deal with the crisis of diagnosis and treatment away from the comfort of home and family (Andrykowski, 1994; McGrath, 1999a). Australian research indicates that the process of relocation exacerbates the stress of treatment and creates significant practical, emotional, social, and financial disruption to the families involved (Davis, Williams, Redman, White, & King, 2003; McGrath, 1999b; McGrath & Rogers, 2003). Individuals are forced to put "life on hold" and negotiate the unfamiliar world of the metropolitan hospital at a time when they are experiencing the shock of dealing with invasive treatments and the loss of close contact with their supportive network (McGrath, 1999b).

Across diagnostic groups, relocation is also documented as having direct clinical implications. For example, there is now published evidence that issues of relocation for specialist care can have a significant and direct impact on the pattern of uptake of cancer treatments. The work of Jones and associates (2008) in the United Kingdom indicate that there is an effect of geographical access to treatment services on cancer treatment patterns with treatment at specialised centres involving longer than average patient journeys, resulting in an inverse association between travel time and treatment take-up. In terms of breast cancer, Meden and associates (2002) in the United States demonstrated that those patients who lived at greater distances from a radiation oncology facility were more likely to undergo a mastectomy, in light of travel burdens which include expenses and duration of travel. Similarly, Moist and associates (2008) in Canada reported, in relation to kidney disease, that longer travel time is significantly associated with greater mortality risk and decreased health-related quality of life. Thus, relocation for specialist care is an important issue that impacts not only on the psycho-social experience of patients and their families, but also has serious relevance to treatment outcomes.

To date, most of the research on the psycho-social impact of relocation has been conducted in Australia where the dispersed population across a broad geographical area means most rural and regional patients have to travel vast distances to specialist centres. This article presents comparative insights on the experience of relocation for haematology from a recent study conducted in 2010 based in New Zealand.

THE RESEARCH

The study conducted by the International Program of Psycho-Social Health Research was funded by the Leukaemia & Blood Foundation of New Zealand

(LBF). The aim of the study was to extend an Australian-based program of research that examined issues associated with relocation for specialist treatment to include an understanding of the experience of relocation in relation to patients diagnosed with a haematological malignancy and their carers who reside in New Zealand.

The participants were a purposive sample selected from a database of clients maintained by LBF which contained details of name, geographical location, diagnosis, and contact details. The participants were enrolled for the study through two project officers who were under contract with the University and, thus, independent of LBF. The potential participants had all received a letter from LBF informing them of the study and stating that if the person did not want to participate in the study they could contact the Foundation to opt out. To ensure confidentiality, any individual not wanting to be involved in the research was deleted from the list prior to the list being transferred to the project officers. At this stage, the database of patient and carer contacts, excluding the details of those who chose to withdraw from the study, was provided to the research program for the selection of participants. Thus, the actual identity of those who did participate remained confidential as LBF was not involved in the actual selection.

The participants were enrolled from a purposive sample from this list through an initial telephone call, followed by one of the project officers providing a written Project Description and inviting voluntary participation in the research. Prior to interviewing, participants were again informed of their ethical rights (e.g., informed consent, confidentiality, right to withdraw) and individual consent obtained. The University ethics committee and the Health Research Council of New Zealand approved the study.

Purposive Sample of Participants

A list of potential participants for the study was selected from the LBF list based on a number of criteria, including ensuring both a representation of all major haematological diagnostic groups (leukaemia, lymphoma, myeloma) and the corresponding catchment areas of primary specialist haematological centres in New Zealand (Auckland, Christchurch, Dunedin, Palmerston North, Wellington). Once identified, potential participants were consecutively enrolled based upon the declining largest distance between the identified primary specialist treating centre and the participant's primary residence. A secondary sub-group was also chosen to address concerns relating to geographical distances that did not accurately reflect travel time by land, such as participants residing in a location which required travel by ferry to obtain treatment at a primary specialist haematological centre.

All patients had to meet the criteria for relocation in that they did not live in the city where the treating centre is located and for some of their treatment, they were forced to live for a period of time away from home at the location of the treating centre. One hundred and forty-two potential participants were contacted

to participate in the research, with 28 declining to participate and 52 being un-contactable (due to change in contact details). In total, there were 62 participants, of which 46 were patients and 16 were carers. The demographics are outlined in Table 1.

There were significant ethical concerns about avoiding identification of participants as individuals who were not only clients of LBF, but were also part of a small sub-group of cancers (haematological malignancies which represent 5-7% of total cancers) and were treated by a small number of treating centres ($n = 5$) in a country where the research indicates there is a high level of familiarity and interconnectedness in the population. Thus, the consent procedures emphasised confidentiality. For this reason, only broad demographics will be provided on the participants. The participants resided in all district health boards across New Zealand.

Research Design

An open-ended, exploratory qualitative design was utilised for the study (Holloway, 2008; Patton, 2002). Qualitative research is important for work with a consumer focus where the intent of the study is to record the experience from the consumer's perspective (Kratwohl, 1993; Polit & Hungler, 1995). A list of topic areas to explore during the study was developed from the findings of the program's prior research on relocation and included issues that explored the emotional, social, financial, and practical aspects of relocation. However, in accordance with the iterative principle of qualitative research (Holloway, 2008), the issues being explored evolved with the study with early insights informing the discussions in subsequent interviews.

Interviews

The exploration of the experience of relocation from the consumer's perspective was conducted through an iterative, qualitative research methodology using open-ended interviews conducted by speaker-phone at the time and location of each participant's choice. In order to establish a solid baseline for subsequent interviews, the initial five interviews were conducted by an experienced psycho-social researcher—the chief investigator for the study who has a background in cross-cultural research and is employed by the University and, thus, independent of the LBF. Subsequent interviews were conducted by two project officers who also had extensive experience in conducting qualitative interviews. As the interviewing progressed, there were regular meetings between the chief investigator and the project officers involved in the interviewing to compare notes and revise or add questions based on the iterative approach of qualitative research.

The haematology patients and their carers were encouraged to talk about their experience with relocation from the point of diagnosis until the present. The line of questioning included the techniques of probing, clarification, paraphrasing, and

Table 1. Demographics Including Details of Primary Treating Centres, Diagnostic Groups, Distance Traveled, and Age

	(km)	Distance traveled				Age			
		Ave	Min	Max	St. Dev.	Ave	Min	Max	St. Dev.
Primary Treating Centres									
Auckland	<i>n</i> = 6	217	147	281	49	50	35	60	9
Christchurch	<i>n</i> = 15	112	32	182	51	58	40	68	9
Dunedin	<i>n</i> = 15	187	17	566	121	46	23	63	14
Hamilton	<i>n</i> = 9	160	143	220	23	45	23	61	11
Wellington	<i>n</i> = 16	131	43	333	106	62	41	73	8
Diagnostic Groups									
Leukaemia	<i>n</i> = 22	137	18	281	71	50	23	73	16
Lymphoma	<i>n</i> = 18	163	58	249	68	47	27	65	11
Myeloma	<i>n</i> = 14	133	43	566	136	55	50	67	7
Other	<i>n</i> = 7	179	85	333	109	55	42	68	9

summarising to explore each participant's experience (Gaskill, Henderson, & Fraser, 1997). The interviews lasted for approximately 1 hour and were audio-recorded. The interviews were transcribed verbatim by a research assistant independent of LBF.

Analysis

The language texts were then entered into the QSR NUD*IST (N5 1995) computer program and analysed thematically. All of the participants' comments were coded into "free nodes" which are category files that have not been pre-organised, but are "freely" created from the data. The list of codes were then transported into Microsoft Word (Word 2007) and organized under thematic headings. The coding was established by an experienced qualitative researcher and completed by a project officer who has extensive experience with coding qualitative data. There was complete agreement on the coding and emergent themes. There were 406 free nodes created from the transcriptions. The themes and codes that related to significant differences between the experience of relocation as presently documented in the literature and New Zealand insights are presented here.

FINDINGS

The findings indicate that whilst there is evidence of psycho-social distress usually associated with relocation for specialist treatment, there are a number of factors specific to living in New Zealand that ameliorate the impact. The detail on the stresses and challenges of relocation for specialist treatment from the study will be published in full elsewhere. The focus of this article is on the factors that highlight the different experience for New Zealanders as compared to other countries, such as Australia, where published insights on relocation are available.

In relation to the detail in parenthesis in the front of the participants' statements, the first two letters indicate if the participant quoted is a patient (Pt) or carer (Cr). The second set of letters indicate the diagnostic group of which the corresponding diagnostic abbreviations are: AML, Acute Myeloid Leukaemia; ALL, Acute Lymphoblastic Leukaemia; HD, Hodgkins' Disease; NHL, Non-Hodgkins' Lymphoma; BrkL, Burkitt's Lymphoma; MF, Myelofibrosis; and MM, Multiple Myeloma. The location of the participant or further identifying information could not be included for reasons of confidentiality.

The Desire to Deal with Treatment from Home

The patients interviewed expressed a strong desire to return home, as can be seen by the following examples of typical statements on the issue:

(PtAML) Well they did say to [participant's husband] he could've stayed in the house they had for the patient's family but he just found he wanted home.

(PtNHL) I was quite happy to get out as soon as I possibly could. I'm not a great fan of the hospital [laughs]. If they say you want to stay, if I can go I'll go, don't worry about that.

There is a wide range of benefits to returning to the comfort of one's own home, as demonstrated by the following statement:

(PtAML) Yeah, it's definitely lonely and isolating and like I feel, when I came home, just your energy and everything's so much better just cause of where you are, you're in your own house, you're eating your own food, you're sleeping in your own bed. It just feels so much better whereas being stuck in [specialist centre] every day you eat rubbish food and you're stuck in bed.

Able to Return Home

The important point in relation to the New Zealand findings is that most of the patients and carers interviewed did indeed find a way to return home as regularly as possible. Apart from times of intense hospitalisation, such as during bone marrow transplantation, most of the participants managed to return home regularly during the treatment period. Many of the participants indicated that when they were able to, they chose to do the round trip daily even though it may take several hours of driving, so they could complete their treatment from the comfort of their own home.

(PtNHL) I didn't stay in hospital for my first treatment. I avoided being away from home and just went down to get the chemo and returned home.

It was noted that driving the round trip from home to hospital and back again became easier over time, for example:

(PtBrkL) Attitude is the biggest, most important thing of the lot, going there. Well you get used to it, I was counting the days near the end though, I was saying "aw, one more trip," you know?

This is in direct contrast to other countries where research on relocation for specialist treatment has been completed, such as Australia. Because of the vast distances in other countries, people are simply unable to return home on a regular basis once they have relocated to the specialist treatment centre. In comparison, as can be seen by the following statements, the trade off in New Zealand of traveling 2 hours for treatment is considered doable and not a significant issue for many of the participants:

(PtNHL) It's just the journey you take and it's got to be fine and not be an issue so it's not—two and a half hours drive, it's not a biggie really.

In addition, many of the participants actually lived within an hour's drive from the specialist hospital, as one carer reflected:

(CrHD) Well when [patient] was first diagnosed we had six months of chemo in [name of specialist centre] which was 50 minutes away from here, that's our nearest hospital, that wasn't a big drama.

One patient participant similarly stated:

(PtMF) It was okay, yes. It's only an hour into Christchurch and it's a good road so there wasn't really that much of a problem.

Where the distances were very long, some patients did return home by government-funded flights, for example:

(CrMF) When we first came home he was going back once a week to Wellington flying down, they flew him down from [name of town near home] to Wellington; they supplied the plane flights down and up.

There was evidence that the specialist treating staff understood the desire for people to stay at home and made flexible arrangements to assist this process, for example:

(PtAML) So we flew to [name of specialist centre] and had stayed there for five days and then flew back again and that was a boost as well and they tried to get you out and so you can go home for a few days you know. If anything goes wrong they said just get back in here quickly.

In understanding such a finding, it is important not to reduce appreciation for the hardship of those who have to relocate, nor to trivialise the challenge of traveling during serious illness to access treatment. Patients were prepared to travel long hours and endure some hardship in order to return home, as one participant explained:

(PtNHL) You know you're basically on the road for nearly seven hours, seven to eight hours so it does take it out of you.

Throughout the findings were statements from participants that highlighted a positive attitude to life that helped both patients and carers to deal with the traveling to and from the hospital from a constructive perspective, for example:

(PtAML) Anyway we went home for a couple of days and then we went back, my temperature shot up again so they. . . . [Interviewer: Is it hard coming home and then having to go back as you're sort of not sure how long you're going to be able to stay at home?] I made it an adventure.

Not Having to Put "Life on Hold"

The important point is that it is possible to access treatment whilst returning home and maintaining the connection with home and community in New Zealand.

There was evidence that for some participants there was little interruption to life, for example:

(CrNHL) I think it didn't [interrupt life] to a degree, the times when we had to go to Auckland came at a time when my social life was at a standstill over the holiday period so that actually fitted in quite well. Didn't bother me unduly.

The assistance of friends and family was very important to both patients and carers in helping them to keep connected to life as normal, as can be seen by the following statement:

(CrNHL) We just kept it as normal as possible and it didn't affect us in every way, no. No difference, and friends were helpful.

Importantly, many participants described how even when they were in hospital the distances meant that family could visit and so they were able to maintain strong connections. This is exemplified by the following participant insights:

(PtAML) My grandkids were up every day, couple of days sort of style, the middle of the week and then on the weekend and all that sort of stuff. [Interviewer: Okay so they did the round trip a fair bit?] Yes, quite a bit.

(PTNHL) My sister-in-law in [name of place], which is two, three hours away from Christchurch, she had to actually come up to Christchurch. I still had people around me.

This was so even when family had to drive long hours, for example:

(PtMM) Between seven and a half and eight hours. I drove with my mother. The family did the long travel even though I said no one was to visit. That's the hardest thing, my brother and his family came down from [name of town] so four hours for them, they came down and stayed a couple of days.

There were indications that the patients interviewed made every effort to continue to attend significant family events, such as weddings:

(PtAML) They let me go home, they were really good because my niece got married and they weren't going to let me go but right at the last minute they said, "your counts [are] moving so you can go."

Participants indicated that they greatly valued the opportunity to stay connected with their home and community, for example:

(CrMF) It [life] sort of wasn't [on hold]. I could only come home in the weekends, every second weekend I did. But because I was able to come home, my treatment was very good. I was one of the lucky ones with my treatment, I could drive and do all sorts of things, and I had family support and it was just very lucky.

The opportunity to return home reinforced their positive attitude to dealing with the diagnosis and treatment, for example:

(PtALL) Sometimes if I got home and I'd been home a wee while we'd go shopping over at [name of city] which is an hour's drive and that was quite good fun. As I say to a lot of people you know "alright I've got cancer blah, blah, blah," I said that the journey that I have had from what I did have prior I said, "I quite enjoy it really."

The area of work or employment is a significant area of life which is usually impacted upon by relocation. Some of the participants indicated that as they could return home each day (even if that involved lengthy drives), there was limited disruption to their work. One participant explained:

(PtMM) Well I was still working all that time while I was having the treatment so everything kind of carried on as normal and I would go in and have chemo and sometimes I even just went back to work or else I would go home. I'd do it so it would be later in the day and then I would go home and things would carry on as normal.

Likely Familiarity with Location of Metropolitan Hospital

A major issue documented in the literature on relocation is the significant challenge of adjusting to an unfamiliar major metropolitan city and treating hospital. It is very common for those who relocate to have not visited or have any familiarity with the metropolitan hospital or the city in which it is located. This adds a range of stresses during the difficult time of adjusting to diagnosis and treatment.

In New Zealand it was noted that people are familiar with the towns where the specialist treating centres are established, for example:

(CrNHL) Well I think we're not such a big country and we used to perhaps go into these places.

It was noted that, although the situation differs depending on location, overall New Zealand is a country where people are likely to have contacts in the metropolitan areas where the specialist centres are located.

(PtAML) I mean this is the advantage in New Zealand, like my brother who's the donor lives in [name of major city] and an aunt and uncle and my cousins live there and friends that shifted from here live there and I caught up with an old friend I hadn't seen for years, a couple of old friends.

Even in relation to the experience of familiarising themselves with the hospital, the participants used words like "comfortable" and "easy" rather than the descriptions more common to relocation, such as feeling lost and alienated. Many participants were already familiar with the hospital, as the following statements exemplify:

(PtNHL) I had been to the hospital to visit other people who had cancer.

(CrHD) No, not foreign at all—you see my mum had had cancer and she was in the hospital, we just got over my brother's death from cancer and we're sort of at the hospital.

DISCUSSION

The findings indicate that the smaller distances to be negotiated in New Zealand, the strong community connections, and the participants' personal determination to retain the focus on living, translated into positive outcomes. Although there are considerable individual variations, overall patients and their carers in this study who relocated for haematological malignancies were more able to remain engaged in normal life, return home, and access family and community support than participants in Australian studies.

It is a common theme in Australian relocation research that the desire to return home is strong for patients and their families (McGrath, 2006). The participants in this study shared that desire and spoke enthusiastically of the benefits of returning home. However, in comparison to Australian evidence of relocation (McGrath & Rogers, 2003), most of the participants accepted as a given, the choice to return home and were practically able to do so, even though for many this involved the hardship and inconvenience of hours of daily travel to the hospital. The relatively small geographical size of New Zealand translated into a "do-ability," in terms of patients being able to return home with the support of the hospital staff. By way of contrast, in Australia individuals often have to travel long distances to access specialist services (Keleher & Ellis, 1996). Similar research on relocation conducted in Queensland, Australia (McGrath, 1999a), indicated that many patients and their families were unable to return home as the distances they have to travel to the treatment centre can include: 1700 km or over 24-hour drive from Cairns; 972 km or 12-hour drive from Mackay; 649 km or 9-hour drive from Rockhampton; and 362 km or 5-hour drive from Bundaberg. In countries with vast areas such as Australia, some rural patients have to travel up to 2,500 kilometres to receive specialist care like radiation (Davis et al., 2003).

These insights do not trivialise the sheer hardship associated with daily travel to and from the hospital for the New Zealand participants and the findings from the study affirm the difficulties faced by families in this regard. The preparedness of New Zealand patients and their families to negotiate the distances associated with specialist care may also have additional clinical advantages if consideration is given to the work of Jones and associates (2008), which link shorter distances to specialist care with greater treatment uptake. The present findings that highlight the importance of shorter distances as a factor in relocation certainly indicate that exploring the connection between geographical access and treatment uptake in the New Zealand context may be a worthwhile research direction. To

date, the work that does exist on the topic of travel for treatment has been completed in: Australia on the financial impact of travel for treatment (Davis et al., 2003); the United Kingdom on the long distances traveled by child cancer patients for treatment (George, 2009; Jones et al., 2008); the United States on the fact that some breast cancer patients chose mastectomies rather than travel long distances (Meden, St John-Larkin, Hermes, & Sommerschild, 2002; Rodriguez, Baz, Jawde, Rybicki, Kalaycio, & Advani, 2008); in Canada where travel distances and transportation problems are shown to encourage inpatient treatment (Shapiro & Roos, 1984); and Honduras where, for childhood patients with leukaemia, abandonment of treatment is associated with long distances of travel to hospital (Metzger, Howard, Fu, Pena, Stefan, & Hancock, 2003).

An important outcome of the pragmatic possibility of returning home where possible is that patients and their families were, to a large degree, not forced to put life on hold as noted in Australia (McGrath, 1998). Indeed, some reported little disruption to their normal life. It must be noted that further findings from the study indicated that a minority of participants did experience a distressing interruption to their life. For many, however, contact with family and friends remained strong, special family occasions were celebrated, work was maintained and the opportunity to return home provided the emotional nurturing that helped to buffer the impact of diagnosis and treatment. This is in direct contrast to Australian research that indicates that relocation for specialist care detrimentally disrupts the lives of patients and their families (Davis et al., 2003; McGrath, 1999b).

Another important difference in the New Zealand study when compared to the Australian study was that most of the individuals who had to relocate were already familiar with the metropolitan towns and hospitals. Indeed, it was common for individuals to have personal contacts at the town where the treating hospital was situated. This familiarity acted as a buffer against the documented experience of alienation and disorientation that is associated with relocation in the Australian context (McGrath, 1999a).

Although the representation of participants from the LBF list is extensive in that it includes both patients and carers from a diversity of geographic locations, diagnostic groups, and treating centres, the insights are restricted to individuals who were in contact with the organisation. A limitation to the findings is that it is not inclusive of individuals who did not have contact with LBF and cannot be generalised to diagnostic groups other than haematology.

CONCLUSION

Although the focus of this article is on difference, the broad findings from the study affirmed a wide range of similarities in the relocation experience for those living in New Zealand as compared to elsewhere. It is important to note that New Zealanders, as with those in other countries, are deeply challenged by the stress of relocation. Furthermore, such relocation adds considerable psycho-social

burdens at a time when they are dealing with the distress of diagnosis and treatment. In no way do the findings reported in this article aim to trivialise or understate the hardships involved for any individual coping with specialist treatment away from home.

However, these findings are a strong reminder that geographical and cultural differences need to be taken into account when applying insights on any health care issue from one country to another. The geographical size of New Zealand and the familiarity and the pre-existing links with the towns and hospitals where specialist care occurs allows connections with family and friends to be maintained, reduces the impact on normal life, and minimises the interruption to work and community life. The strong message from this research is that, where patients are able to return home, albeit with considerable hardship, there are innumerable psycho-social advantages in relation to maintaining their sense of normality and connection with family and community. The findings indicate that those able to return home were clearly appreciative of the opportunity and the perceived benefits this afforded, with regards to coping with their diagnosis and treatment. Thus, where possible, the provision of support for individuals to return home during specialist treatment for a haematological malignancy is recorded as a positive and worthwhile approach to address the crises and loss associated with relocation for such specialist treatment.

AUTHORS' BIOGRAPHIES

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committed to improving the quality of life for patients and their families living with these conditions. The core services are patient support, research, information, awareness, and advocacy.

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