

# **“It’s horrendous - but really, what can you do?” Preliminary findings on financial impact of relocation for specialist treatment**

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## **Abstract**

*There has been little analysis of the process of relocation for specialist treatment for patients with haematological malignancies. Existing work does not cover the financial impact on families of such an experience. This paper describes seminal work in this area by presenting findings from research based on interviews with patients and families affected by relocation. The two-fold intent informing this discussion is to provide data to initiate research in the area, whilst fostering a consideration of epistemological issues at the interface of qualitative and quantitative research. The results show that there are very significant financial problems. In planning psychosocial support for such families, serious consideration must be given to both their short and long-term economic plight.*

## **Background to the research**

Patients diagnosed with haematological malignancies and their families face a unique set of challenges associated with lengthy, potentially life-threatening, aggressive, and invasive treatments, which have distressing short- and long-term side effects (Baker, Curbow & Wingard, 1991; Grant *et al.*, 1992; Leigh *et al.*, 1995; McGrath 1999a; Whedon & Farrell, 1994;). Because of the high technology and specialist nature of such medical interventions, the treatments are predominantly carried out at major metropolitan hospital centres. The non-availability of regional or rural specialist treatment in this area means that a great number of patients and their families must cope with the additional stress of relocating from their homes to the metropolitan centres for lengthy periods of treatment (McGrath 1998; 1999b).

There has been little work on the process of relocation (Langlands, 1993; McGrath, 1998; 1999b) and that work does not cover the important issue of the financial impact on families that need to relocate for specialist treatment. Indeed, there is a disquieting absence of data on how the financial costs associated with specific cancers and their treatments actually affect the economic security of families. This is in spite of the studies to indicate that taking socio-economic factors into consideration is important in understanding the cancer experience (Cella *et al.*, 1991; Ell & Nishimoto, 1989; Freeman, 1989; Kogevinas & Porta, 1997; Leake, 1995; Schulz *et al.*, 1995; Tomatis, 1997). In the area of haematological malignancies, the existing work focuses on the costs to the treating institutions rather than the patients (Stalfelt & Brodin, 1994; Stalfelt, 1994; Waters *et al.*, 1998). In terms of health policy planning and the provision of support services for patients with haematological malignancies, this silence is a concern because it is known that this subgroup struggles with extraordinary difficulties of coping with lengthy and expensive treatments, often away from their own homes. In short, there are significant provisional reasons to believe that financial impact could be a major issue of concern.

This paper presents seminal work in exploring the financial impact of relocation for haematological malignancies by presenting preliminary findings based on interviews with patients and their families. The two-fold intent informing this discussion is to provide data to initiate research in the area, whilst fostering a consideration of epistemological issues at the interface of qualitative and quantitative research.

As there is no data available in the area of the financial impact of relocation for haematological malignancies, the rationale for this project needed to be exploratory. Although it is acknowledged that research focusing on financial data would traditionally be seen as purely numerical, and hence quantitative, the decision was made to tackle the problem from a qualitative perspective.

Qualitative methodologies are seen as particularly valuable in early exploratory work where minimal information exists (Grbich, 1999; Halvorson *et al.*, 1993; Herbert, 1998; Waxler-Morrison *et al.*, 1995). Qualitative work is not only able to provide in-depth insights into an emergent area, it also avoids, to a large degree, the trap of allowing preconceived ideas to dominate. In short, the researcher is able to "enter the field without over-direction, enabling him (sic) to see the evolving issues more clearly" (Grbich, 1999). The strength of a qualitative perspective is that it seeks to capture data from the 'insiders' perspective, rather than imposing an 'outsiders' framework that has been preconceived without the informants voice to guide the study (Holloway, 1997). This process is particularly valuable in seminal work where the variables of greatest concern are unclear (Black, 1994). It has been noted that researchers often start measuring in areas before they fully understand the underlying issues, and thus may not target the appropriate factors: the risk is of pursuing the measurable rather than the relevant (Black, 1994). Qualitative research is a process of analytic induction, where the researcher does not start with a set of questions to impose, but generates ideas from the data (Greenhalgh & Taylor, 1997; Waxler-Morrison *et al.*, 1995).

The qualitative process for gathering data on the financial impact of relocation was founded on four assumptions. Firstly, it was considered that too little work had been done in the area to start with a quantitative, author-designed questionnaire that imposed preformed assumptions about variables that needed to be explored. Secondly, it was considered important to consult with those who had first hand experience with relocation. Thirdly, this consultation process needed to be open-ended, non-structured and receptive in order to facilitate as full an understanding as possible from those who actually had the life experience to know the details of what was involved. Fourthly, as this work is an extension of a psycho-social research agenda, the opportunity to gain phenomenological insights into the emotional and social aspects of the financial impact were also greatly valued. A qualitative approach using open-ended interviews met all of these criteria and proved effective in gaining insight into a multitude of factors associated with the financial impact of relocation.

## Method

The research described here is part of a larger project that examined issues associated with the administration of the Patient Transit Assistance Scheme (PTAS). PTAS is a Queensland government initiative designed to assist patients and their carers financially during relocation for specialist medical treatment. As a full discussion of both PTAS and the research project associated with the scheme has already been provided in an earlier edition of this journal (McGrath, 1998), the full details will not be repeated here. Attention will focus on the specific arm of the research (Arm D) that examined the financial impact on families of relocation through interviews with patients and their carers.

Participants were recruited from the accommodation centres of the Leukaemia Foundation of Queensland (LFQ). LFQ has three accommodation centres (ESA Village, Herston Accommodation Centre, & Holydene) that have been developed as a response to a perceived need for support for out-of-town visitors who need to come to Brisbane for treatment. As the name suggests, LFQ cares for families facing a diagnosis of leukaemia or an associated haematological disorder. With the exception of hostel accommodation associated with the Royal Children's Hospital, LFQ is now the predominant provider of accommodation to this diagnostic group of patients and their carers in Queensland. Families who stay at the LFQ accommodation centres are relocated from all over Queensland, as well as from interstate and overseas (McGrath, 1998). A full description of LFQ accommodation centres is provided elsewhere (McGrath, 1998; 1999b).

Ten patients and their carers were recruited. The participants were approached by the patient support staff at the centres and asked if they wished to be involved in the research. If they agreed then contact was made by the researcher through a preliminary telephone call during which a time was set for the interview. Participants were engaged in a detailed discussion of what was involved in the research process and given a full written description of the project before being asked to participate. Informed consent was obtained in writing and ethical clearance was given by both LFQ and the QUT university ethics committee. All families were enthusiastic about participating, and expressed the altruistic hope that by contributing to the research it may help to improve the administration of this very important scheme. The only person who declined to participate did so because the family was undergoing an acute medical crisis.

The expectation was that by recruiting participants from the LFQ accommodation centres that there would be a definite sampling bias toward more positive stories about relocation. LFQ provides excellent services for its clients, for example, contact with patient support staff, support courses, transport to and from the hospital, social gatherings, and practical assistance with PTAS applications. Accommodation at the centres is free, and is subsidised by the PTAS scheme. The patients arriving at the centres are considered to be those fortunate enough to have been referred for accommodation and assistance. As these 'fortunate' patients have real stories of hardship it is worrying to consider what is happening to patients who do not find out about such accommodation services. The patients who fall through the referral net are surveyed in a different arm of this research (Arm B).

Qualitative analysis is based on the principle of saturation of data, where common or reliable themes emerge when a number of participants say the same thing. The number of participants enrolled was determined by this criterion. Even after six interviews, participants were starting to communicate remarkably similar stories. By the tenth interview very little additional information was obtained.

Participants filled out a short questionnaire that provided descriptive demographic information as well as basic information on their financial situation. Open-ended interviews were then conducted about the experience of relocation. Although a number of prompt questions were used to make sure important areas were covered, the interviews were primarily designed to capture the emic or 'insiders' perspective (Harris, 1976), and hence were as non-directive as possible. One of the prompt questions specifically asked respondents about the financial effect of having to relocate.

These interviews were audio-recorded and transcribed verbatim. The qualitative analysis was conducted through a computer-assisted qualitative data analysis software, the NUD\*IST program. During the initial stage of the thematic analysis, all comments by participants were prioritised and used to build categories of commonality. The democratic nature of qualitative analysis is valued in this research as it allows for the privileging of all the insights and observations recorded by participants. The text units for each category were printed out and checked for internal consistency. For significant categories, checks were made against the full transcriptions to make sure that all possible text units had been included. The four themes that emerged from the texts were the additional costs incurred during relocation, factors associated with decrease in income, factors that buffered the financial impact, and long-term financial problems.

Talking about personal finances can be considered a taboo in our society, and yet participants were very generous in their discussion of their financial situations. In the presentation of the findings all identifying information has been removed and only core statements from participants' exact words will be recorded (in *italics*) in the text of the discussion to further eliminate any risk of identification.

## Results

### \* Demographics

The patients were predominantly female (80%), aged from 17 to 53 years, and diagnosed with a haematological malignancy (AML, n=3; Lymphoma, n=2; ALL, n=1; CML, n=1; Hodgkin's disease, n=1; PNH, n=1; ALL/Lymphoma, n=1). The majority (80%) were on social security benefits (Disability Pension, n=4; Sickness Benefit, n=3; Invalid Pension, n=1). Only 30% had health care cover.

The carers were mainly female (90%), aged between 25-57 years and either the mother (n=5) or partner (wife, n=4; husband, n=1) of the patient. The majority (80%) of these carers had other dependents for which they were responsible (4 dependents, n=1; 2 dependents, n=3; 1 dependent, n=4). Four carers were on social security benefits (Carer's Pension, n=2; Parenting Allowance, n=2). One had work cover. These families had been relocated from 44 to 1717 kms from their home.

### \* Additional costs incurred during relocation

Participants made reference to seven areas where the process of relocation directly added costs to their budget. These areas are outlined in detail in Table 1.

Of these, the areas mentioned by most participants are listed in descending order as follows. Five (n=5) interviewees spoke about the increased medical costs associated with hospital expenses, pharmaceuticals, doctor's fees, and diagnostic technology. It is interesting to note that participants with private insurance made strong statements indicating stress, including the following:

*"We had to pay our accounts after the end of each week and it sort of drained our funds like that, it'll be a thousand or \$1500 every week we were paying out. We didn't really have that much money, but we had to try and find it somewhere to keep us going."*

*"The fees, the fees, the doctors fees are so much higher than what the schedule fee is."*

*"Like all the time, if you got private health ... you still got to pay. There's always little things that's gonna come out of your pocket all the time."*

*"Some of the scans and some of the things he had done when he wasn't very well, you know, you don't get much back at all."*

It was not only the financial demands of treatment that stressed participants, but also the sheer practical challenges of meeting the bureaucratic requirements in the alien world of a new city environment.

*"And Medicare was hard because it's hard to find in Brisbane ... we had to do a lot of running around."*

Four of the participants (n=4) directly mentioned concerns about the increased cost of the weekly shop. The need to eat properly in spite of the costs was important to participants during this time of medical crisis. One participant stated that *"... we have one goal that we shouldn't have to keep cutting back, especially on food."* Distress was registered at the loss of freedom to shop around for the less costly food.

The extra visitors, friends, and family, that call to offer support also add costs to the already limited budget. This creates problems, even though the caring is appreciated. *"We just get by, buying double food, I suppose, or extra food. I mean, friends come down here for me, but that is not to worry."* The additional cost associated with groceries was one area where participants saw that they were *"... getting into money (that they) shouldn't have to just (to) keep going and trying to keep everything good."*

The cost of accommodation was mentioned by four participants. It is important to restate that these comments were made by those fortunate enough to have found free accommodation at the metropolitan centre. In an attempt to emphasise the severity of the cost of accommodation for such lengthy treatments away from home, one participant indicated that without the free accommodation provided this person would have had to probably sell my house to afford it. Another noted that *"... without the free accommodation here, we would have been in deep, deep trouble."* An indication of the accommodation costs can be seen from one participant's statement that *"... before finding the free accommodation, it was costing us \$60 or more a day, just for a room."*

Four participants talked about the costs associated with extra telephone calls and the reasons for this (outlined in Table 1). Three noted the incidental costs, and two mentioned that it costs *"... an awful lot of money"* to maintain two households.

**Table 1. Additional costs Incurred During Relocation.**

Additional Costs Incurred During Relocation	
Extra Expense	Associated Issues
Increased cost of shopping	<ul style="list-style-type: none"> <li>• Cannot "shop around" for bargains</li> <li>• Need to buy special foods for patient</li> <li>• High costs of healthy foods such as fresh fruit and vegetables</li> <li>• Double grocery bill (for family at home and family at metropolitan centre)</li> </ul>
Telephone Calls	<ul style="list-style-type: none"> <li>• The medical emergency increases the need to communicate news and gain support</li> <li>• Because of relocation calls are long-distant not local</li> <li>• Increased family concern means more calls to overseas relatives</li> <li>• Telephone calls seen as an essential not a luxury</li> </ul>
Loss of support of local voluntary organisation	<ul style="list-style-type: none"> <li>• During relocation families lose previously established links with voluntary organisations that provide financial assistance (eg. Endeavour Foundation).</li> </ul>
Additional medical costs	<ul style="list-style-type: none"> <li>• Hospital costs</li> <li>• Drug/pharmaceutical costs</li> <li>• For private patients costs of "gap" between scheduled fee and doctor's charges</li> <li>• Costs of diagnostic and assessment technology eg. scans</li> <li>• Treatments for haematological disorders are very lengthy, high-tech and expensive</li> </ul>
Accommodation Costs	<ul style="list-style-type: none"> <li>• Many families are not aware of PTAS or accommodation centres in the metropolitan centre and hence spend considerable amounts on private hostels/motels during initial stages of relocation.</li> <li>• This target group does not include those who never find out about accommodation assistance</li> </ul>
Cost of maintaining home in absence after pets etc in caretakers absence	<ul style="list-style-type: none"> <li>• Extra costs of paying someone to carry out maintenance such as lawn mowing, repairs, looking</li> </ul>
Incidental costs	<ul style="list-style-type: none"> <li>• Additional airfares for family members</li> <li>• Wear and tear on car</li> <li>• Return trips home not paid for by PTAS eg. for business or family reasons</li> </ul>

### Factors associated with decrease in finances available

The process of relocation is not only associated with the stress of an increase in expenses, but also with a simultaneous decrease in the income available to meet these expenses. Table 2 provides an outline of the three problem areas that participants suggest are associated with erosion of available finances during relocation.

Four participants (n=4) mentioned the negative impact of having to leave employment. This impact ranged from being on leave for seven months without pay, having to take sick leave and eventual retirement, losing part-time work that supplemented the family income, and the difficult problems of coping with the disruption to self-employment. Even where patients considered themselves lucky because they had sick leave to cover their absence, the forced retirement was seen as "... sort of stressful just leaving the job." This economic hardship was described as a big struggle, and particularly so for the participant who was self-employed, as can be seen by the following text.

*"Because I was self employed it was a bit hard because you have to walk away from your business. Really we didn't get much support whatever for a while. Like we live on really nothing, we had no money. Because we were self-employed we sort of asked about some benefits. They wanted everything we owned, our financial statements. I would have taken me a month to get it together from the accountant...but I couldn't bear to be away (from the patient to get the necessary financial statements)."*

Two participants mentioned the problem of providing large outlays needed for up front payments of medical bills and travel and accommodation expenses when on low income. This situation is exacerbated by the long waiting time before reimbursement.

**Table 2. Factors Associated with Decrease in Finances Available.**

Factors Associated with Decrease in Finances Available	
Factor	Associated Issues
Loss of employment	<ul style="list-style-type: none"> <li>• Crisis if the patient is the sole/chief provider</li> <li>• Difficult adjustment if it is the second income that is lost as family must readjust to reduced income</li> </ul>
Self-employment	<ul style="list-style-type: none"> <li>• If the family relies on an income from self-employment this is disrupted even if the patient is not the breadwinner as such businesses are difficult to run during relocation</li> <li>• Even accessing appropriate business files in order to apply for Centrelink assistance is difficult without returning home to the place of the business</li> <li>• Periods of financial non-support as self-employment does not provide sickness or recreation leave</li> </ul>
Money needed 'upfront'	<ul style="list-style-type: none"> <li>• Participants spoke of the difficult of having to pay out of pocket for medical and travel expenses before being able to claim</li> <li>• There can be a delay of a couple of months before payments are refunded</li> </ul>

### Factors that buffered the financial impact in the short term

For those fortunate enough to have access to them, there were a number of resources used by families to buffer the immediate impact of the rising costs and decreasing incomes. Participants outlined ten of these resources and they are listed in detail in Table 3.

All of the participants spoke in praise and gratitude of the assistance provided by the Leukaemia Foundation of Queensland. In terms of lessening the financial impact, participants made mention of how the foundation not only provides free accommodation, but also free transport to and from the hospital, taxi vouchers for special occasions, as well as assistance in obtaining financial assistance for travel and accommodation through the PTAS scheme.

Two participants were in the fortunate position of having a 'nest egg', either through savings from a double-income family or from a retirement package. Although one participant did speak in detail about the buffer in income insurance, this was not an unqualified good, as the following text reveals.

*"Yeah, we were lucky in a lot of cases, but in other ways it has been a little bit of a pain. We couldn't actually get (Social Security) because we had this income insurance. But if we got the social security, we'd actually get more benefits. You get a health care card, you get all this other bits and pieces. Health care cards don't just apply only for health care ... you get a lot of other benefits. I suppose we are lucky, but when this is over we're gonna look at it (income insurance) and see whether we should have had it."*

**Table 3. Factors that Buffer the Financial Impact in the Short Term.**

Factors that Buffered the Financial Impact in Short Term	
Factor	Associated Issues
Accommodation at Leukaemia	<ul style="list-style-type: none"> <li>• Free accommodation</li> </ul>
Foundation of Queensland's Centres	<ul style="list-style-type: none"> <li>• Assistance with transport</li> </ul>
Employer support	<ul style="list-style-type: none"> <li>• Job is being held ie. able to take leave without pay and retain job security</li> <li>• Assists if allowed to take accumulated sick /recreation leave</li> <li>• One employer actually fund-raised to provide financial assistance to the family</li> </ul>
Retirement	<ul style="list-style-type: none"> <li>• Superannuation provides financial assistant</li> <li>• The diagnosis/treatment can force early retirement for financial reasons</li> </ul>
"Bread winner" not affected	<ul style="list-style-type: none"> <li>• Usually in this situation the patient is the child in a traditional family structure where the carer is the mother leaving the father to bring in the income</li> </ul>
Credit Cards	<ul style="list-style-type: none"> <li>• Families take out credit cards to provide the cash flow for payments of bills that can later be claimed back</li> </ul>
Prescribed drugs on PBS	<ul style="list-style-type: none"> <li>• Cytotoxics used in treatment for haematological malignancies are expensive and this can be prohibitive unless the drugs are scheduled on PBS</li> </ul>
Part-time income	<ul style="list-style-type: none"> <li>• If one family member is still able to bring in part-time income this acts as a buffer against subsistence income of security benefits</li> </ul>
'Nest-egg' available	<ul style="list-style-type: none"> <li>• Some families who had double incomes had managed to save extra money to use in such a medical emergency</li> </ul>
Home Owner	<ul style="list-style-type: none"> <li>• Eliminated extra cost of rent or home repayments</li> <li>• Financial asset is buffer</li> </ul>
Income Insurance	<ul style="list-style-type: none"> <li>• The down-side to income insurance is that the families who receive it cannot get benefits and claim on health care card</li> </ul>

### Factors associated with long-term financial problems

Treatments for haematological malignancies are lengthy, with many treatment protocols extending over two years. The long term erosion of family finances can be devastating, particularly if the patient is the breadwinner. Participants outlined seven factors that could be implicated in a long-term financial crisis for families. They are outlined in detail in Table 4. Commitments that could be met in the short-term because of extra family resources could not be sustained over a prolonged period.

**Table 4. Factors Associated with Long-term Financial Problems.**

Factors Associated with Long-term Financial Problems	
Factor	Associated Issues
Threat of selling family home	<ul style="list-style-type: none"> <li>• For many families the only assets they can call on during the crises is the family home</li> <li>• Mortgage loan on home helps with short-term expenses but creates long-term difficulties</li> </ul>
Home and Car Re-payments	<ul style="list-style-type: none"> <li>• Families could not meet high home and car re-payment commitments during the medical crisis and suspended payments which led to long-term financial distress</li> </ul>
Erode 'buffer zone'	<ul style="list-style-type: none"> <li>• Where families had extra money from insurance policies or savings this was eroded by the medical experience leaving them with no capital to call upon as a buffer to extra expenses</li> </ul>
No savings to start with	<ul style="list-style-type: none"> <li>• Some families did not have a 'buffer zone' of savings to start with.</li> </ul>
Long-term on social security benefits	<ul style="list-style-type: none"> <li>• Social security benefits are not seen as adequate to cover the long-term medical crisis</li> <li>• Erodes savings, insurance pay-outs and superannuation eventually leaving the family without a financial buffer</li> </ul>
Credit Cards	<ul style="list-style-type: none"> <li>• Although credit card meet the short-term requirement of cash flow to provide payment for bills the long-term addition of interest can create problems for families</li> </ul>
Self-employed	<ul style="list-style-type: none"> <li>• Businesses run by the self-employed can be severely and permanently damaged by the long-term disruption created by the absence of the caretaker</li> <li>• This is particularly so if the patient is the self-employed and are required to take extensive time of because of treatment or are unable to get back to work because of long-periods of recovery</li> </ul>

## Existential Insights

Although participants were descriptive of the hardship involved, they made many statements indicative of a positive philosophical outlook, as follows.

*"At least we can say (patient) is still with us. We can pay off the mortgage for ever."*

*"We tried not to worry financially. I mean, nothing's too much trouble for (patient). We just do it."*

*"We have learned to live day by day and not have any expectations of anything."*

*"As far as I am concerned all of my priorities go toward (patient) so mostly other things just don't really come into it".*

*"As I have said on a lot of occasions, the almighty or whatever you like to call him, never handles you anything you can't handle. We just get on with it don't we (patient's name)."*

They also expressed compassion towards others in similar situations.

*"I mean, I don't know how other people would get on if they were both on pensions. I don't know, I suppose it's just something that you just think, well you have to do it."*

*"It's frightening, I do not know how people without work or live on the dole or with 3 or 4 kids (could manage). I don't know how they could do it."*

*"A lot of people would be a lot worse off financially than we were."*

There were, however, descriptive statements providing insight into the hardship, as follows.

*"Well, it's horrendous - but really, what can you do?"*

*"Well, basically, you just don't live your life (on such limited finances)."*

*"If you haven't had the experience the average person wouldn't know."*



## Discussion

One of the purposes of this preliminary work is to isolate factors to be explored through further research. The focus of the qualitative process is descriptive - that is, to outline a range of factors associated with relocation for specialist treatment for haematological malignancies. The factors isolated are presented as foundational information to inform further comprehensive quantitative study.

Participants provided information on seven areas where substantial additional costs were incurred during relocation: the increased cost of shopping, additional telephone calls, loss of local support, extra medical expenses, accommodation costs, the financial strain of maintaining two households and the incidental costs of relocating. Although these additional costs would be common to the experience of relocation, the actual impact on the specific family would be dependent on a number of factors, not the least of which would be their pre-diagnosis financial situation and ongoing income during the medical crisis. A caveat to these findings, however, is that the interviewees were in the fortunate position of having access to free accommodation. Their comments indicated that families without such benefits might face critical financial dilemmas.

Not only are additional costs incurred during relocation, but the family can also have a decrease in the actual income available. This will mainly be through loss of employment, or disruption to self-employment. Having to pay 'up front' for services and then wait for long periods before repayment adds to this reduction in available finances.

For fortunate families, there can be a number of buffers that protect them from immediate financial crises. They include support from LFQ, sympathetic employers, superannuation from retirement, a family member remaining in full time work, short term credit, PBS, part-time income, family savings, home ownership, and income insurance.

For the less fortunate, and those who have endured a long term medical crises, there can be a spiral into poverty caused by an inability to repay mortgages, failure to meet home and car re-payments, an erosion of savings, or an excessive build up of credit. Some families will be vulnerable from the start if they have scant savings at the beginning of the medical drama, are long-term recipients of social security, or are self-employed.

## Conclusion

In general, the findings indicate that, in planning psychosocial support for such families, serious consideration needs to be given to both their short and long-term economic plight. These families are vulnerable to a long-term poverty trap, where their financial reserves are depleted and welfare dependence erodes their quality of life. Hopefully by furthering such work, the time will come when there will be sufficient knowledge that, if accompanied by the political will, the plight of these families may begin to be addressed.

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