

# The long haul: Caring for bone marrow transplant patients in regional Australia

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## KEYWORDS

Bone marrow transplant, rural, quality of life, cancer, isolation, survivorship

## ABSTRACT

### Objective

To evaluate the experience of, and services to, patients from rural and regional Australia referred to a large urban tertiary referral hospital for allogeneic haematopoietic cell transplantation (allo-HCT) and to compare their quality of life with similar populations.

### Design and setting

A cross-sectional survey of allo-HCT recipients referred from the Calvary Mater Newcastle to Westmead Hospital, Sydney, NSW.

### Subjects

Thirty-seven of forty adult survivors of allo-HCT (92.5%) who underwent transplant between 1999 and 2008 and were at least three months post transplant.

### Intervention

All subjects completed a validated measure of quality-of-life (QoL) in bone marrow transplant recipients (*FACT-BMT* Version 4) and the Regional/Rural BMT Needs Assessment Survey.

### Results

Most patients (79%) were between one and five years post transplant. Almost all reported having been sufficiently prepared for transplant and received most information and support from the Nurse Coordinator. Despite the fact that 89% of patients reported significant adverse effects of allo-HCT, >60% still reported an acceptable quality of life. Importantly, however, about a third of patients experienced financial difficulties associated with transplantation and felt pressure to return to work.

### Conclusion

Patients referred for allo-HCT should be advised about the arduousness of transplant but also reassured that most survivors will experience acceptable levels of functioning and QoL one to two years after transplant. With sufficient local support and with appropriate nursing care and coordination the experiences of regional/rural patients is comparable with other allo-HCT patient populations. Further investigation into vocational rehabilitation is warranted due to the significant financial and occupational pressures reported by survivors of allo-HCT.

## INTRODUCTION

Allogeneic hematopoietic cell transplantation (Allo-HCT or BMT) is a complex, demanding treatment with a high treatment-related mortality and morbidity, requiring a prolonged hospital stay and an extended recovery period (Heinonen et al 2003). Approximately 35-80% of transplant recipients will become long-term survivors who may experience late effects capable of impairing quality of life (QoL) (Pidala et al 2009; Syrjala et al 2004; Socie et al 1999; Curtis et al 1997).

Allogeneic transplant is performed only in major urban tertiary referral centres. BMT may therefore impose additional strains for the 26% of Australians living in rural or regional areas, such as travel, isolation, separation from social support, family upheaval, and financial strain due to distance from the treatment centre (Underhill et al 2006; Burkitt 2003; McGrath et al 1999). These people may also experience difficulties arising from limited access to specialist services and fragmentation of healthcare between regional and metropolitan services (Drury and Inma 2009; Baldwin et al 2008; Hubbard et al 2006; Martin-Macdonald et al 2003; Fitzgerald et al 2001; Davis et al 1998). These challenges may increase psychological and emotional distress following BMT and impair treatment compliance, QoL and even the likelihood of survival (Hubbard et al 2006; Grulke et al 2005; Lock et al 2005).

In recent years, Cancer Care Coordinators have been employed in key regional centres to address the specific needs of cancer patients living in rural and regional areas (Drury and Inma 2009). While there is some literature on the experience of Australian women with chronic illness and cancer living in rural and remote areas, there is no published data on the QoL, experiences and health service utilisation of patients from rural/regional areas of Australia referred for BMT (Drury and Chutarat 2010; Baldwin et al 2008; Clavarino et al 2002; Fitzgerald et al 2001; McGrath et al 1999). This is an important omission as one would anticipate from international literature that patients from rural and regional Australia would have a poorer experience of BMT and consequently have a reduced QoL. This study therefore aimed to evaluate the experiences of and services to patients from regional areas undergoing BMT at a large metropolitan centre in NSW, and to compare the QoL in this sample with similar patients based on previous studies.

## PATIENTS AND METHODS

### Background to the service

Each year, 10-15 patients from the Hunter New England area are referred from the Calvary Mater Hospital, Newcastle (CMN) to Westmead Hospital, Sydney, for allo-HCT. The Hunter New England area is located approx 150km north of Sydney, covers an area of 130,000km<sup>2</sup>, and has a population of 840,000. This represents 12% of the total population of New South Wales, the most populous state in Australia (HNE Health District 2010). Most BMT recipients spend four to six weeks as an inpatient in the transplant ward. Following discharge from hospital, all allo-BMT recipients attend a weekly outpatient clinic at Westmead Hospital for up to three months. To attend, patients from rural and regional areas must initially remain in Sydney. Most stay in local accommodation provided by the Leukaemia Foundation (LF). Later, patients must commute weekly to Sydney from home, which often entails a round trip of 400-500km. Once medically stable, the care of BMT recipients from the Newcastle and Hunter region is transferred to a monthly clinic run by a BMT CNC at the CMN and staffed by BMT physicians from Westmead Hospital.

## Patients

Patients eligible for this study were adult (age > 15 years) survivors of allo-BMT from a regional or rural area referred to Westmead Hospital from the Haematology Department at CMN who underwent transplant at Westmead Hospital between 1999 and 2008, and were at least three months (range 3-96 months, mean 30 months) post-transplant at the time of recruitment. Eligible patients were sent a letter describing the study, copies of the questionnaires and a stamped self-addressed envelope. Follow-up phone calls were made to non-responders after two and four weeks. Participants were asked to complete the Functional Assessment of Cancer Therapy – Bone Marrow Transplant (*FACT-BMT* Version 4) and the *Regional/Rural BMT Needs Assessment Survey*.

## Assessment

The *FACT-BMT* is a validated questionnaire for measuring quality of life in BMT recipients. (McQuellon et al, 1997) It takes 10-20 minutes to complete and combines two instruments, the *FACT-G* and a BMT subscale. The *FACT-G* is a 28-item self-report instrument that measures QoL in cancer patients (Cella et al 1993). It consists of five subscales measuring physical, functional, social and emotional well-being and satisfaction with the doctor/patient relationship. The BMT subscale includes 12 items designed to test QoL in BMT patients. The *FACT-BMT* plus the BMT subscale provides an overall quality of life score. Patients rated themselves over the past seven days using 5-step Likert scales. Responses were used to calculate overall quality of life and subscale wellbeing scores.

The *Regional/Rural BMT Needs Assessment Survey* was developed following a review of relevant literature and discussions with patients attending BMT long-term follow-up clinics. It consists of 64 questions grouped into four sections covering personal and transplant details, medical complications, information and preparation for transplant, support and return to work. The questionnaire uses tick box responses, short answer and Likert scales and takes about 25 minutes to complete. It was piloted in phone interviews with four current patients.

Descriptive statistics were compiled for all items on the *Regional/Rural BMT Needs Assessment Survey* and summary scores were calculated for the *FACT-BMT*. The 'relationship with doctor' sub-score was not used as participants had multiple clinicians involved in their care. QoL scores were extracted from other published reports for comparison. The 'relationship with doctor' score was removed. The study was approved as a quality improvement project by the Hunter New England Research Ethics Unit.

## RESULTS

Completed questionnaires were received from 37 eligible participants (92.5% response rate). The study population was balanced in terms of gender and marital status (table 1). The majority of participants (78%) were

**Table 1: Participant characteristics (N=37)**

<b>Average age (years)</b>	<b>41.8 (range 20-61)</b>
<b>Gender</b>	
Male	21 (57%)
Female	16 (43%)
<b>Family circumstances</b>	
Single	14 (38%)
Married/De facto	23 (62%)
Children	24 (65%)
No children	13 (35%)
<b>Employed pre-BMT</b>	
Yes	29 (78%)
No	8 (22%)
<b>Donor</b>	
Unrelated Cord blood	1 (3%)
Related	23 (62%)
Adult Unrelated	13 (35%)
<b>Conditioning</b>	
Myeloablative	34 (92%)
Reduced intensity	2 (5%)
Not known	1 (3%)
<b>Time since transplant</b>	
<1 yr	6 (16%)
1-5 yr	24 (65%)
>5 yr	5 (14%)
Not known	2 (5%)

employed prior to transplant and were surveyed between one and five years post transplant. Of those transplant survivors who returned surveys, 30 (82%) had undergone transplant as treatment for acute leukaemia, while the remainder had been transplanted for other conditions including aplastic anaemia, lymphoma and chronic leukaemia. The distribution of donor and transplant type were typical for this patient population. Participants reported receiving information about BMT mainly from clinicians and from resources and events designed specifically for them (table 2). Most (78%) reported feeling prepared for the transplant by the information received beforehand, and most also reported feeling physically (78%) and emotionally prepared (62%) for transplant at the time of admission with very few reporting not feeling either physically (8%) or emotionally (3%) well-prepared for transplant. This finding was supported by concordance between expectations of the BMT experience and reports of what it was actually like (table 3).

Most participants (89%) experienced significant adverse effects of allo-HSCT with 27% requiring readmission to hospital and 15% admission to Intensive Care. The most frequently reported acute complications of transplant were acute graft-versus-host disease (GVHD), nausea, vomiting, diarrhoea, mucositis, bacterial infection (central venous line infection and pneumonia) and cytomegalovirus (CMV) reactivation. Many (39%) also reported chronic GVHD.

**Table 2: Sources of information about BMT**

<b>Main information sources before admission</b>	
BMT coordinator (CMN)	30 (81%)
Transplant physician (Westmead)	24 (65%)
BMT coordinator (Westmead)	22 (59%)
Haematologist (CMN)	22 (59%)
BMT patient education day (Westmead)	19 (51%)
Haematology nurses (CMN)	19 (51%)
Leukaemia Foundation	13 (35%)
Internet	9 (24%)
Other transplant recipients	8 (22%)
NSW BMT Network	3 (8%)
Other sources	1 (3%)
<b>Received BMT Network Booklet</b>	
Yes	29 (78%)
No	8 (22%)
<b>Read some or all of booklet (n= 29)</b>	
Yes	26 (90%)
No	3 (8%)
<b>Understood most or all of what they read (n=26)</b>	
Yes	24 (92%)
No	2 (8%)
<b>Satisfaction with BMT patient education day (n=19)</b>	
A little or somewhat satisfied	4 (21%)
Quite or very satisfied	14 (74%)
<b>Felt prepared for transplant with the information</b>	
A little or somewhat	7 (19%)
Quite or very	29 (78%)

**Table 3: Expectations and experience of BMT**

	<b>A terrible ordeal</b>	<b>Very difficult</b>	<b>Somewhat difficult</b>	<b>Not very difficult</b>
Expectations of BMT	5 (14%)	13 (35%)	15 (41%)	3 (8%)
Assessment of actual experience	3 (8%)	10 (27%)	18 (49%)	5 (14%)

Spouses (22; 59%) and parents (12; 32%) were the main sources of support during BMT. Extended family (26; 70%), friends (27; 73%) and work colleagues (11; 30%) also provided support in Newcastle during the transplant period. Overall, reported perceptions of support suggest that – despite a degree of loneliness – the participants' needs were met most of the time, and that effective support was provided during and after BMT by both lay and professional carers (table 4).

**Table 4: Perceptions of support**

	Not at all	Some of the time	About half of the time	Most of the time	All of the time
Felt that needs were met	0 (0%)	0 (0%)	2 (5%)	11 (30%)	24 (65%)
Felt alone	12 (32%)	17 (46%)	5 (14%)	1 (3%)	2 (5%)
Felt supported by staff	0 (0%)	3 (8%)	2 (5%)	8 (22%)	24 (65%)
Felt supported by carer	1 (3%)	1 (3%)	0 (0%)	4 (11%)	29 (78%)
Felt supported post-BMT by Westmead staff	0 (0%)	3 (8%)	0 (0%)	16 (43%)	17 (46%)
Felt supported post BMT by CMN staff	1 (3%)	2 (5%)	1 (3%)	7 (19%)	24 (65%)

Of the 29 respondents who were employed before transplant (table 5), 11 (38%) reported feeling some pressure to return to work while preparing for and recovering from the transplant. At the time of the survey, two thirds (19/29, 66%) had returned to work after a median lapse of seven months (range 1 to 18 months). One third (10/29, 34%) had not yet returned to work, and all but one planned to do so. Of the 19 who had returned to work, most (13, 68%) reported some degree of difficulty and eight changed the nature of the work by reducing work hours or by shifting to casual or seasonal employment.

Patients main source of income were welfare payments (49%), spouse's income (41%), personal savings (24%), insurance (14%) and superannuation (14%). Disturbingly, a third of respondents (13; 35%) reported having insufficient finances during the transplant. The majority of respondents relied primarily on private transport whilst undergoing BMT (29; 78%), and afterwards while travelling between Newcastle and Sydney (27; 73%), although a significant number used transport provided by the LF (13; 35%). More than three quarters of respondents (77%) relied on accommodation provided by the LF, and were overwhelmingly satisfied with the accommodation in Sydney. A significant proportion of respondents used other services provided by the Foundation, including educational resources (32%) and seminars (19%). The majority (62%) made use of the services of the BMT co-ordinator in Newcastle before transplant, as well as other medical and allied health services, including social workers (30%), clinical psychologists (27%), dieticians (27%) and psychiatrists (14%). There was little evidence of unmet needs for medical, nursing, allied health, pastoral care or support services in Newcastle pre-BMT.

Most patients reported an acceptable quality of life with the *FACT-BMT* scores in the study population being comparable to those from similar studies done internationally (table 6).

**Table 5: Employment**

Employment pre-transplant (n=29)		
Full time	17 (59%)	
Part time	7 (24%)	
Casual	3 (10%)	
Unknown	2 (7%)	
	Yes	No
Returned to work post-transplant	19 (66%)	10 (34%)
Felt pressure to return to work	11 (38%)	18 (62%)
Difficulty returning to work	13 (68%)	6 (32%)
Reduced or changed employment	8 (42%)	11 (58%)

**Table 6: Quality of Life scores compared with other studies of BMT patients**

Study	Participants	Location	Physical wellbeing	Social wellbeing	Emotional wellbeing	Functional wellbeing	FACT-G	BMT subscale*	FACT-BMT
McQuellon et al (1998)	45 patients 12 months post-BMT	Salem NC, USA	22.6	23.2	16.8	19.5	82.1	33.6	115.7
Kopp et al (1998)	41 patients 12 months post-BMT	Austria	23.37	20.63	19.63	21.29	82.22	36.61	118.83
Heinonen et al (2001)	91 patients > 12 months post BMT	Finland	23.97	21.6	16.5	19.63	81.7	37.37	119.07
This study (2008)	41 patients, most >12 months post-BMT	Newcastle, Australia	22.29	22.60	16.25	20.55	81.69	35.58	117.27

\*12 Items (McQuellon 1997)

## DISCUSSION

Cancer patients need long-term follow-up to ascertain their long-term prognosis and ongoing needs, and to assess the adequacy of existing services and interventions. To date, there has been no data on long-term follow up for patients from rural and regional areas of Australia referred for BMT. The instrument developed and tested in this study – the *Regional/Rural BMT Needs Assessment Survey* – can be used in combination with validated QoL instruments for this purpose.

While this study makes a significant contribution to the literature on patient experiences of transplantation, care must be taken in generalising the results to other populations given the small sample size, the variable length of survival post-transplant and the recruitment of participants from a single geographical region and haematology/transplant service.

This study demonstrates that the majority of transplant recipients experience significant short-term effects of BMT, but most go on to report an acceptable level of functional and social well-being. This is consistent with longitudinal studies of QoL following BMT, which demonstrate early moderate reductions in QoL that largely return to pre-transplant levels within three to 12 months of transplant, with the majority (>60%) of patients who survive more than a year reporting good to excellent QoL (Pidala et al 2009; McQuellon et al 1998; Kopp et al 1998). It is also consistent with both longitudinal studies of BMT survivors and cross-sectional studies which suggest only modest reductions in the QoL of BMT recipients compared to healthy controls or population normative data. (Pidala et al 2009; McQuellon et al 1998; Sutherland et al 1997) Sutherland et al, found that allogeneic BMT recipients were indistinguishable from the ‘normal’ population in terms of physical functioning, emotional role functioning, bodily pain and general health three years after BMT. Other studies have found long-term allo-BMT survivors generally report good functional wellbeing relative to population norms while continuing to be troubled by fatigue, insomnia, lethargy and sexual dysfunction (Andrykowski et al 1997; Sutherland et al 1997; Zittoun et al 1997; Bush et al 1995; Schmidt et al 1993).

Given that other studies have reported reduced QoL in patients with cancer living in rural/regional areas, the fact that participants in this study reported reasonable QoL suggests the support provided to patients in this sample compensated for any disadvantage resulting from living a long distance from the transplant centre.



Due to the small sample size it was not possible to test whether transplant-related complications were associated with a lower QoL. Notably, however, despite the fact many respondents experienced some degree of acute (79%) and chronic (39%) GvHD, the majority still reported an acceptable QoL.

Most participants felt sufficiently informed about the potential complications of allo-HSCT, although imperfect levels of physical (78%) and emotional (63%) preparedness is a reminder that no amount of information can fully prepare patients for the full impact of BMT. The results also suggest that, notwithstanding the increasing popularity of the internet, events and resources tailored for this patient population, particularly, discussion with health professionals responsible for the care of patients referred for transplant, provide the most important and effective means of communicating information about BMT. This is consistent with other evidence that involvement of cancer nurse coordinators may improve the experience of illness and health care delivery of cancer patients in rural/remote settings (Drury and Inma 2010).

About a third of the participants in this study experienced financial pressures associated with transplantation and reported feeling pressure to return to work. This is consistent with other evidence that, while many BMT recipients are able to return to work post-transplant, many have difficulty doing so and may benefit from some form of occupational/vocational rehabilitation (Friedrichs et al 2010; Heinonen et al 2001). Since rural/regional patients are likely to be disadvantaged when it comes to accessing such services, it is reasonable to infer that many may be returning to work prior to full recovery due to financial pressures.

While this study provides some insights into the significance of occupational pressures for survivors of BMT, further research is needed to establish the degree to which such concerns are shared by other populations and to establish whether pre and post-transplant interventions, including education, counselling and support services may assist patients return to work and help them cope with the financial and social impacts of transplantation. Likewise, while this study suggests that the involvement of a clinical nurse coordinator may assist BMT recipients cope with the broad impacts of transplant, further research involving different regions and health services should be conducted to establish whether nurse coordinators may have a more extensive role to play in the management of BMT recipients and to ascertain the optimal model of nursing and medical care for BMT patients referred from different rural and regional areas.

## CONCLUSIONS

Patients should be advised that BMT is an arduous treatment associated with serious risks and complications and that most BMT recipients will experience short and long-term consequences of transplant that may compromise QoL and conflict with expectations of recovery. While advice to potential BMT recipients should be tailored to specific circumstances, patients can be advised that approximately 25% of BMT recipients will have ongoing medical complications. These complications may impair QoL and life-satisfaction and most survivors will experience some symptoms, such as fatigue (Jacobs et al 2007; Lee et al 2001; McQuellon et al 1998). They can also be reassured, most BMT recipients (>60-70%) return to acceptable levels of functioning within one to two years of transplant and experience a good QoL.

Whilst BMT recipients receive a lot of information about BMT from many different sources, patients may benefit from additional psychosocial and emotional support prior to transplant and from practical assistance with, for example, the financial costs associated with transplant, and vocational rehabilitation, to assist patients in returning to work when ready.

The experience of patients from rural/regional areas appears no worse than that reported in similar populations. This suggests that any adverse impact of distance on rural/regional patient's experience of BMT may be ameliorated by the supportive care provided before and after transplant by a clinical nurse coordinator, combined with support from the LF and social networks.

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