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What they want: Inclusion of Blood and Marrow Transplant Survivor Preference in the Development of Models of Care for Long-Term Health in Sydney, Australia

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Abstract

Four hundred and forty-one adult allogenic Blood and Marrow Transplant (BMT) survivors participated in a cross-sectional survey to assess Long Term Follow Up (LTFU) model of care (MOC) preference. Survey instruments included the Sydney Post Blood and Marrow Transplant (BMT) Survey, FACT-BMT, DASS 21, The Chronic GVHD Activity Assessment- Patient Self Report (Form B), the Lee Chronic GVHD Symptom Scale and The Post Traumatic Growth Inventory. We found most BMT survivors (74%) would prefer LTFU with their transplant physicians alone or in combination with transplant-centre linked services (satellite clinics or telemedicine) Over a quarter indicated a preference for receiving comprehensive post-transplantation care in a 'satellite' clinic staffed by their BMT team situated closer to their place of residence, with higher income, higher educational level and sexual morbidity being significant social factors influencing this preference. Regular exercise was reported less often in those who preferred telemedicine which may reflect reduced mobility. The factor most strongly associated with a preference for transplant centre follow-up was

the severity of chronic graft-versus-host-disease (cGVHD). Full and part time work was negatively associated with transplant centre follow-up, possibly implying decreased dependency on the centre and some return to normalcy. This study is the first to explore the preferences of BMT survivors for long-term post-transplant care. This data provides the basis for LTFU model of care (MOC) development and health service reform consistent with the preferences of BMT survivors.

Introduction

Advances in transplantation technologies, better patient and donor selection and improved supportive care over the past two decades have significantly improved outcomes of Blood and Marrow Transplantation (BMT) such that 70-80% of those who are alive at 2 years can expect to live long term[1,2]. Unfortunately many of these survivors experience significant late morbidity and mortality. A collective effect of underlying disease and co-morbidities, prior treatment, the toxicity of conditioning therapies and immunosuppression, and the effects of Graft Versus Host Disease (GvHD)[3-5] results in a 59% cumulative incidence of developing a chronic health condition by 10 years post-transplant[6], a 3.5 fold increased risk of developing a severe or life-threatening condition compared to siblings[7] and a 30% lower life expectancy in adult BMT survivors [8]. Each of these long term and late effects are even more profound in adult survivors of childhood BMT[9-11]. Life-long follow up is therefore essential to optimise the benefit and minimise the prevalence and impact of the adverse late effects of BMT[12].

Consensus guidelines for screening and preventative practices for long-term survivors of BMT have been available for almost a decade[13,14]. These guidelines, agreed by seven international BMT organisations, outline the surveillance tests, clinical assessments and preventative care that BMT survivors require at regular intervals, for life, to monitor for recurrent and secondary malignancies, chronic GvHD, infections, respiratory, cardiovascular, renal, musculoskeletal, ocular, oral, gastrointestinal, dermatological and endocrine dysfunction, and psychosocial issues, among others. Given the range of morbidities experienced by BMT survivors it is unsurprising that a BMT survivor receiving follow up care according to these guidelines would require up to 34 assessments annually including health history, clinical examinations, laboratory analysis, diagnostic imaging, psychosocial assessments, health counselling and education, and involve at least 6 clinical specialties[14]. This demand is likely to increase in coming years as the indications for BMT expand, more recipients of BMT survive[15], knowledge of late effects increases and the BMT physician workforce plateaus'[16,17]. While there is broad agreement about the necessity for comprehensive follow up of BMT survivors, the demand for long term follow up (LTFU) is placing overwhelming demand on the capacity of transplantation centres (TC) that have historically been responsible for such care. Given the diverse needs of transplant survivors and the variable capacity of TC to provide LTFU[18], different models for delivery of long-term health care for BMT survivors have been developed. Drawing on experience in both cancer survivorship and chronic care, these models of care include variations of specialised LTFU clinics at BMT centres, referral back to local haematologists and/or primary care providers, shared care models, telemedicine and videoconferencing [12,19-25].

Patterns of BMT activity, BMT survival and issues with BMT LTFU in Australia mimic international trends[26]. BMTs are only performed in selected major urban tertiary centres who have the necessary expertise, training, resources and accreditation. BMT recipients who live in rural and regional areas must relocate to metropolitan areas for the pre, peri and acute post-transplant period. Returning to their homes, many BMT survivors experience difficulties with access to and cost of specialist services, fragmentation of care and poor communication in a complex health care system, which includes public and private services, and are easily lost to follow up, particularly as time from transplant increases. This has meant large variations in care and long term outcomes particularly for BMT units that perform less than 50 allogeneic transplants per year. Establishing an effective model

of long term care is essential in order to reduce late effects and prevent premature mortality[12]. We report the results of a cross-sectional study of long-term survivors of BMT in NSW, Australia to identify their preferences for long-term care; to examine the demographic, socioeconomic and transplant factors and sequelae associated with different preferences for follow up; to identify gaps in service provision provided to this vulnerable and high-risk patient group; and to support clinical and health policy decision-making around long-term care.

METHODS

Background to NSW BMT Service

New South Wales (NSW) is Australia's most populous state with a population of ~ 7.5 million and covers an area of 800,628km^2. Over a third of residents live outside the greater Sydney area[27]. At the time of study commencement there were four adult allogeneic centres in NSW, all based in Sydney and collectively performing approximately 175 BMTs annually[26]. A survey of BMT survivors was undertaken to explore survivors' health status, demographics, service utilisation and follow-up preferences.

Patients and procedures

Potential participants were identified from allogeneic transplant databases from all adult allogeneic TC in NSW. Participants were eligible if they were $\geq$18 years of age (at the time of survey) and had undergone an allogeneic BMT at an adult BMT centre between 1st January 2000 and 31st December 2012, were $\geq$17 years at the time of transplant, could read and write English and could provide consent. Names and phone numbers were provided to the research team. Consenting participants were given the option to self-complete the questionnaire or complete it via a phone interview with one of the researchers. A second round of telephone calls was made to 178 participants who had not returned the survey within a month. All authors had access to primary clinical trial data. The study protocol was approved by the Northern Sydney Local Health District Human Research Ethics Committee (NSLHD Reference: 1207-217M).

Instruments

The Sydney Post BMT Study Survey (SPBS) was developed by the research team from a review of the literature and discussion with patients attending BMT long-term follow-up (LTFU) clinics. The survey comprised 402 questions grouped into 20 domains and included questions relating to specialist referrals and LTFU preferences with respect to location and provider. Other relevant domains included demographics, medical complications, tests and assessments, medications and therapies, infections, vaccinations, complementary therapy use, cancer screening, relationship status income (Australian Dollars (AUD)) and lifestyle factors, following allogeneic BMT. The questionnaire used tick box responses, short answer questions and 5-step Likert scales measuring attitudes and other factors and took approximately 1 hour to complete. The questionnaire was piloted with six BMT survivors in clinic and phone interviews to assess face and content validity and to check for comprehension. For each consenting participant data was collected on dates of diagnosis and transplant, stage/remission status at transplant, transplant conditioning, GvHD prophylaxis, stem cell source and donor type.

Preference for LTFU for specialist care, and health service utilisation were analysed according to a range of demographic, transplant, psychosocial and lifestyle variables assessed using the *Functional Assessment of Cancer Therapy – Bone Marrow Transplant (FACT-BMT Version 4)* [28,29], anxiety stress and depression (*The DASS 21)*[30-32], chronic GVHD (*The Chronic GVHD Activity Assessment – Patient Self Report (Form B)*[33] *and The Lee Chronic GVHD Symptom Scale)*[34] and *The Post Traumatic Growth Inventory score*[35,36]. For ease of completion all instruments were combined into one booklet.

Statistical analysis

Categorical responses were summarised using frequencies and percentages. Parametric continuous variables were summarised using means and standard deviations, and non-parametric variables using medians, interquartile ranges (IQR) or ranges. Odds ratios and 95% confidence limits, Pearson chi $\chi 2$ test or Fishers Exact tests were used for comparative analysis of dichotomous categorical variables. Adjusted odds ratios (AOR) to account for potential confounding effects were determined using multivariable logistic regression analysis. Two sample comparisons of parametric and nonparametric data were determined using the independent t test, and Wilcoxon Rank Sum tests respectively; greater than two sample comparisons were determined using one way Analysis of Variance (ANOVA) and Kruskal Wallis tests, respectively. A two-tailed p value <0.05 was used as the level of statistical significance.

Statistical analysis was performed using STATA version 12.1 statistical package (StataCorp, College Station, TX, USA).

Results

A total of 1,475 Allogeneic BMT were performed in the study period. Of the 667 recipients known to be alive at study sampling, 581 (87%) were contactable and were sent study packs. Four hundred and forty one (66% of total eligible, 76% of those contacted) returned the completed survey. Three percent declined participation.

Of those completing the survey, 250 (57%) were male and 191 (43%) female. The median age of survey respondents was 54 years (Range: 19-79). The median age at time of transplant procedure was 49 years (Range: 17-71). (Table 1)

Table 1. Demographic, social and clinical characteristics of post-transplant survivors responding to survey (n=441)	
Characteristic	**Distribution**
Socio-Demographic	
Gender (Male) n/total (%)	250/441 (57%)
Median Age in years (range)	54 (19-79)
Postcode Location	
City/inner regional n/total (%)	396/431 (92%)
Income status (AUD) n/total responses (%)	
Low income $20,000-$39,999	155/423 (37%)
Middle income $40,000-$79,999	123/423 (29%)
High income >=$80,000	145/423 (34%)
Educational status n/total responses (%)	
Some high-school	53/333 (16%)
Completed High school	79/333 (24%)
Trade qualifications/diploma	47/333 (14%)
Some university	24/333 (7%)
Completed university	130/333 (39%)
Transplant factors	
Years since transplant- Median (Range)	5 (1-14)
Underlying diagnosis n/total responses (%)	

Acute Leukaemia	226/423 (53%)
Other **	197/423(47%)
Donor type n/total responses (%)	
Sibling related	250/439 (57%)
Matched Unrelated	158/439 (36%)
Haploidentical/Mismatched	31/439 (7%)
Conditioning n/total responses (%)	
Myeloablative	214/439 (49%)
Reduced Intensity	225/439 (51%)
Post transplant Morbidity and Quality of life	
cGVHD	
Total reported cGVHD since transplant n/total responses (%)	301/434(69%)
Total LEE GVHD score-Median (range)	19 (0-77)
Chronic Diseases/ Psychological morbidity n/total responses (%)	
Bone Disease (osteopaenia, spinal fractures or avascular necrosis)	126/400(32%)
Cardiovascular risk factors (Diabetes, Hypertension or elevated cholesterol)	180/414 (43%)
Cancer (mouth, skin, or other)	108/389 (28%)
Anxiety	83/403 (21%)
Depression	95/407(23%)
Depression, Anxiety, Stress (DASS21) Median score (range)	20 (0-118)
Lifestyle n/total responses (%)	
Smoke	33/438(7%)
Drink alcohol	282/441(64%)
Exercise/play sport	300/436(69%)
Always Use sun-protection(sunscreen, hat, clothing sunglasses	333/431(77%)
Median BMI (range) for males	25(17-63)
Median BMI (range) for females	24(16-53)
Total FACT BMT –Median (Range)	110(32-144)
* CML, CLL, SAA, NHL, HL MM, MDS/Myeloproliferative disease, other(unspecified)	

LTFU Provider preferences

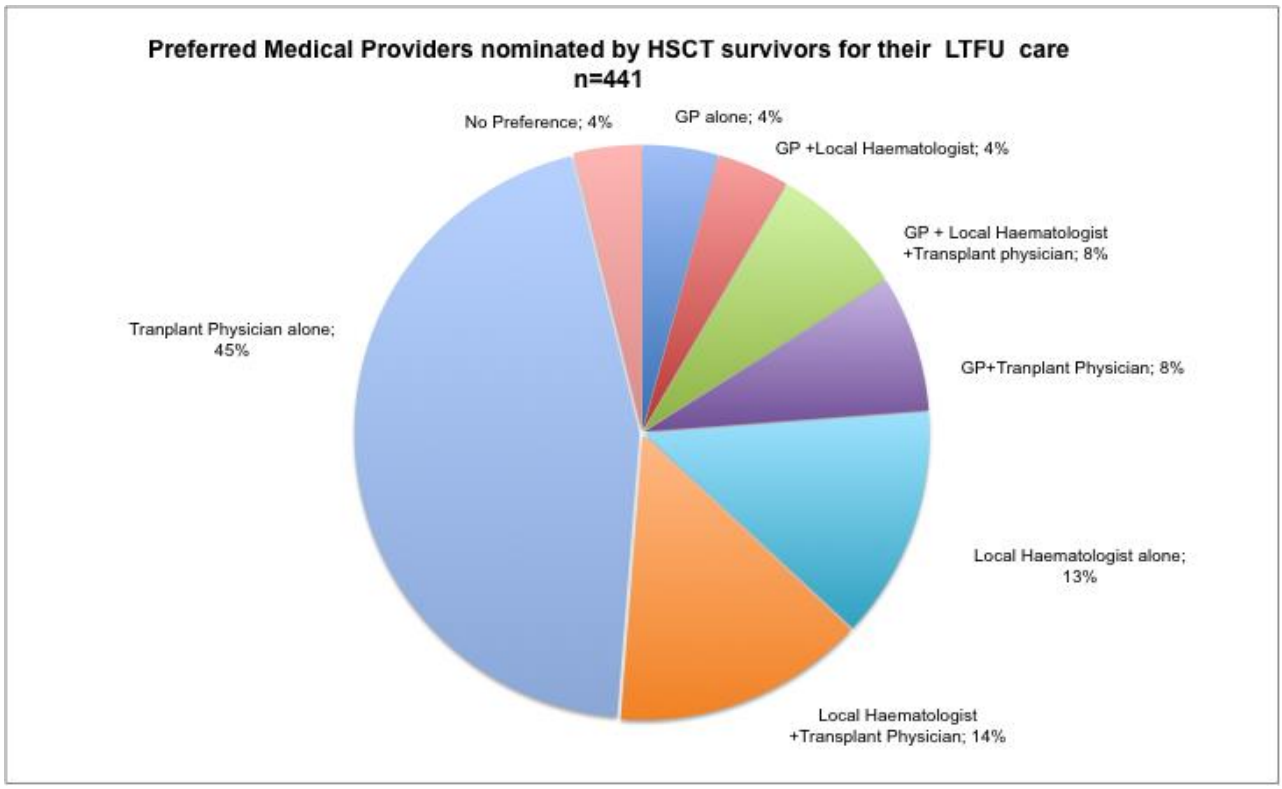
One or more preferences for medical follow-up were indicated by those surveyed (Figure 1). Overall 275 (62.3%) preferred a single provider for their primary transplant follow-up (ie General Practitioner (GP) alone, Local Haematologist (LH) alone or Transplant Physician (TP) alone. An additional 149 (33.8%) preferred a combination of providers, and 17 (3.8%) indicated no preference**.**

The majority (44.9%) of those surveyed indicated a preference for their Transplant Physician (TP) (alone) to be primarily responsible for their long-term follow-up care. The second preferred option included a combination of TP and LH (14.2%), followed by LH alone (13.1%), GP+LH+TP (7.7%) GP+TP (7.7%), GP alone (4.3%) or GP and LH (4.1%) (Figure 1).

Of the 441 patients surveyed, 329 (74.6%) indicated a follow-up preference that included a TP, 173

(39.2%) a LH, and 105 (23.8%) a GP.

Figure 1: Distribution of Preferred Medical Providers nominated by HCST survivors for their LTFU care

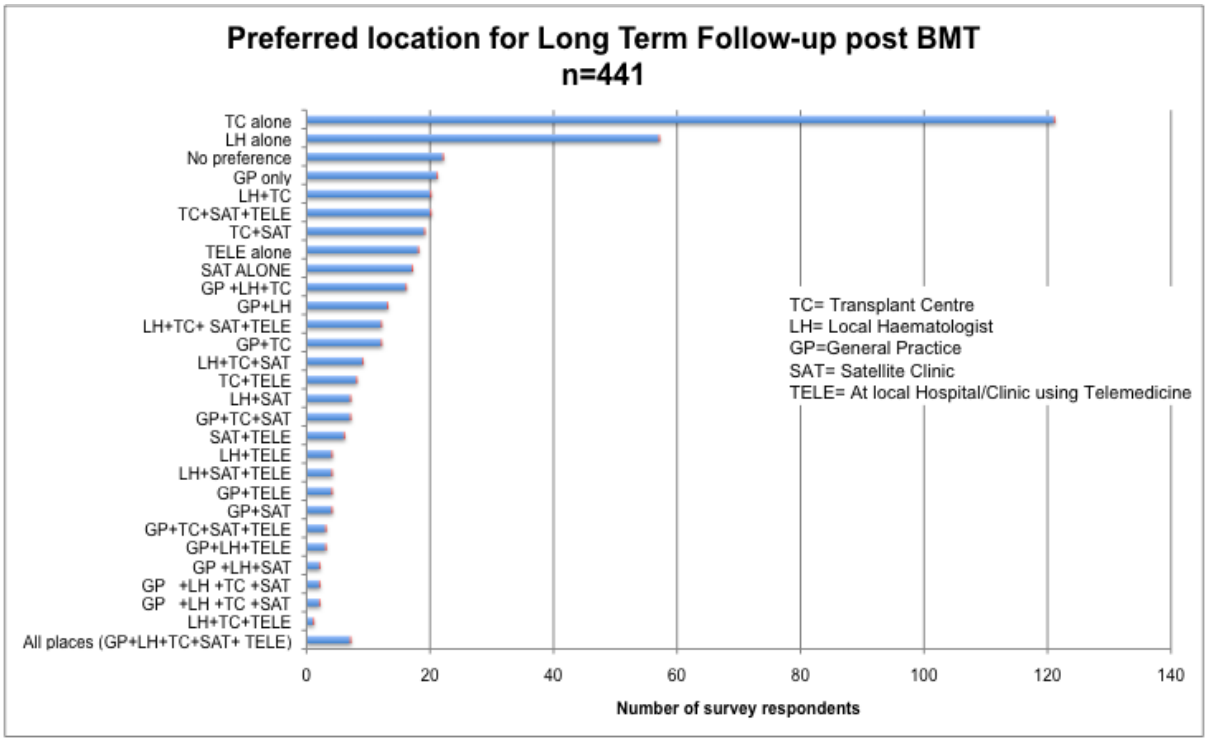


GP= General Practitioner; LH= Local haematologist; TP= Transplant Physician

Setting or location for LTFU care (Figure 2)

Of the locations for delivery of LTFU care, 234 (53%) survey respondents indicated a single site as their preferred option, and 185 (42%) a combination of locations. Overall 22 (5%) indicated no preference for LTFU location.

Figure 2: Location preference for LTFU



Transplant centre (Appendix 1)

Overall 328 of 441 (74%) BMT survivors reported a preference for follow-up at TC alone or in combination with other provider locations - such as satellite clinics linked with a transplant centre (TC) or telemedicine services administered by the primary TC. Of the entire cohort TC alone were the preferred option in 121(27.4%), local haematology practice (LHP) alone was preferred by 57 (12.9%). Twenty-one (5%) indicated a preference for follow-up with GP practice (GPP) alone, 18(4.1%) for telemedicine (TELE) alone and 17 (3.8%) for satellite clinic alone (Figure 2). Four of seven patients with post transplantation haematological malignancies (2 relapse, 5 unspecified), nominated a LTFU preference with local haematologist alone.

On univariate analysis variables associated with an increased preference for TC or TC-linked follow-up included being in a married/defacto relationship (OR=1.67; p=0.04) and sexual dysfunction (OR 2.15; p=0.006). Those in full-time or part time employment indicated a decreased, though non-significant preference for follow-up with TC or TC linked services (OR 0.67; p=0.08). On multivariable analysis, no variables showed a significant association with a preference for TC or TC-linked follow-up. Those reporting increased severity of GVHD symptoms showed a trend towards increased preference for TC or TC linked follow-up (adjusted OR 1.16; 95% CI 0.99, 1.36; p=0.06) and those in full or part-time employment showed a trend towards decreased preference for TC or TC linked follow-up (Adjusted OR 0.44; 95% CI 0.19, 1.03; p=0.06).

No significant differences in non-transplant related chronic disease, cancer or psychological morbidity was observed in those who preferred LTFU in a transplant or transplant-linked service.

No significant difference in cancer screening was observed between survivors preferring LTFU with TC or TC-linked service, with the exception of Pap smear uptake in females. Females preferring follow-up through TC or TC-linked services were less likely to report having had a post-transplantation Pap smear (OR 0.50; 95% CI 0.22, 1.06: p=0.05) After adjusting for potential confounders including age, educational status, residential location, marital status GVHD severity and

sexual dysfunction, no significant difference was observed (Adjusted OR 0.19; 95% CI 0.03, 1.25; p=0.08) .

Satellite Clinic (Appendix 2)

Overall 119 of 441 (27.0%) BMT survivors indicated a preference for LTFU that included a 'satellite clinic', attended by a transplant physician from the centre where they had received their allograft. Of these 17 (14.3%) indicated a preference for satellite clinic follow-up alone, with the remainder indicating a preference for satellite clinic in combination with other LTFU options.

Those preferring LTFU in satellite clinic settings were more likely to be from a middle/high income group (OR 1.98 95% CI 1.20, 3.33; p=0.005) and to have a higher educational status (OR 2.07 95% CI 1.23, 3.49; p=0.003) - defined as partial or complete attainment of a university qualification.

The rates of cGVHD did not differ significantly between groups expressing a positive or negative preference for satellite clinic follow-up. However the self-reported cGVHD symptoms described as moderate/severe was significantly lower in those preferring follow-up in a satellite clinic setting (OR 0.55; 95% CI 0.29, 1.0; p=0.04) and median self-reported current GVHD severity scores were significantly lower (p=0.05).

Sexual dysfunction was significantly higher in those expressing a preference for satellite clinic follow-up (OR 2.61; 95% CI 1.46, 4.74: p<0.001))

After adjusting for potential confounders, those factors that retained a significant association with a preference for satellite clinic care included higher income status (Adjusted OR 4.67; 95% CI 1.22, 17.8: p=0.02), educational status (Adjusted OR 3.26; 95% CI 1.28, 8.30: p=0.01) and sexual dysfunction (AOR 3.27; 95% CI 1.21, 8.78; p=0.02)

Telemedicine location for LTFU (Appendix 3)

Overall 92 of 441 (20.9%) BMT survivors reported a preference for follow-up that included a telehealth facility. Of these, few (18; 19.6%) indicated a preference for LTFU using telehealth alone, with the majority indicating a preference for telehealth in combination with LHP, TC, satellite clinic or GPP.

Patients preferring the use of telehealth in LTFU compared to those who did not tended to be younger (median 52 compared to 55 years; p=0.07), to have significantly higher educational status (p=0.004) and to have been conditioned using a myeloablative regimen (p=0.06).

Higher psychological morbidity in those preferring telemedicine was reflected in higher median DASS21 scores (22 compared to 18; p=0.03), and a trend towards higher self-reported anxiety and/depression (p=0.06). Sexual dysfunction was more commonly reported in those expressing a preference for telemedicine (OR 3.96 95% CI 1.20, 16.8; p=0.06). Following adjustment for potential confounders using multivariable logistic regression, those factors that retained significance included educational status (AOR 5.10; 95% CI 1.72, 15.1; p=0.003) and sexual dysfunction (AOR 3.25; 95% CI 1.02, 10.3; p=0.05).

A reduced odds of regular exercise (OR 0.6; 95% CI 0.4, 1.0; p=0.04) was reported in those patients reporting a preference for telemedicine. After adjusting for age, gender, chronic diseases and GVHD severity, exercise remained an independent and significant association with reduced telemedicine preference (AOR 0.46; 95% CI 0.24, 0.87; p=0.02)

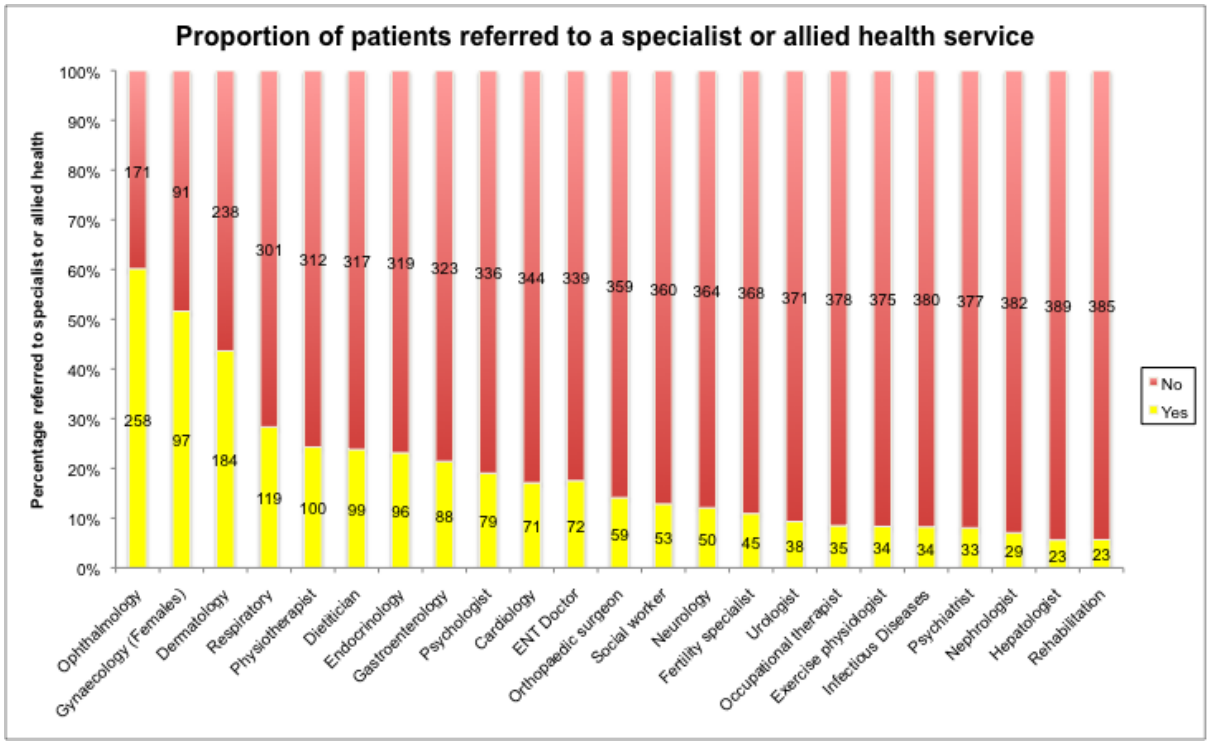
No significant differences were reported for cGVHD, self-reported severity of GVHD symptoms and Lee GVHD scores in those preferring telehealth compared to non-telehealth based locations for LTFU.

Specialist and allied health referrals

The median number of specialist medical referrals was 3 (IQR 1, 4; range: 0-11) with the most common referral being to ophthalmologists (60.1%), dermatologists (43.7%), and, in women, gynaecologists (51.6%). Forty-eight percent had been referred to 1 or more allied health professionals (Range 0 -6) including physiotherapists (24.3%), dietitians (23.8%) and psychologists (19.0%) (Figure 3).

One third (19/57, 33.3%) of those who were within two years of transplantation were attending a hospital or medical /practice facility at least once per month, and of these, 9/19 (47%) were being seen at least weekly. Of those who were two or more years post-transplant, medical practice or hospital attendances were reported at least monthly in 98/376 (26%), and of these 76/98 (77%) were attending a medical facility at least weekly. A requirement to stay overnight, close to the hospital/medical facility was reported by 52/439 (11.8%) of survey respondents. The variety of accommodation arrangements for those who are required to stay overnight included hospital accommodation (16/52, 30.8%) other subsidised accommodation (from charitable organisations/foundations (10/52, 19.2%), lodging with friends or family (23/52, 44.2%) and paid accommodation (20/52, 38.5%).

Figure 3: Referral patterns**



**** Additional referrals: Oncologist-Breast cancer(1) Cataract surgeon(1) Chiropractor(3) Counsellor(2) Dentist(6) Diabetes Educator(1) Dietitian(1) Drug Trial(1) Endocrine clinic(1) Gastroscopy(1) Haematology(2) Head/Neck surgeon(1) Lung Transplant Team(1) Multiple(1) Maxillofacial surgeon(1) Oral clinic(1)Osteopath(1) Palliative medicine(1)Pelvic Physiotherapy(1) Podiatrist(2) Rheumatologist(7) skin cancer specialist(1) Upper GI surgeon(1) Hormone replacement review (Testosterone) (1) Tricologist(1) Urogynaecologist (1) Vascular Surgeon(1) Unspecified(1)**

Discussion

There is now broad agreement that LTFU is necessary to reduce the mortality and morbidity associated with BMT12,14 How this care should be delivered, however, remains uncertain and contested 20 21. This study is the first to explore the preference of BMT survivors for long-term post-transplant care.

The results of this study confirm what is known about post-BMT survival that health care utilisation by long term BMT survivors is high 37, that chronic GVHD is a major determinant of quality of life 38 and that medical issues, fatigue, depression and emotional distress are high compared to other cancer survivor populations 3,4,39-41. A model of care for LTFU must therefore address the increased health care needs of this population in ways that are sustainable, cost-effective and consistent with the preferences of BMT survivors.

This study demonstrated that the majority of BMT survivors would prefer LTFU with their transplant physicians and that 74% preferred follow-up at a transplant centre or through a satellite clinic or telemedicine service linked with or administered by that transplant centre. One quarter indicated a preference for receiving comprehensive post-transplant care in a 'satellite' clinic staffed by their BMT team situated closer to their place of residence. A number of social factors, including higher income, educational status and sexual morbidity were significantly associated with a preference for satellite care. Fewer patients expressed interest in telemedicine/web-based care, with those interested in these options having higher educational status and sexual morbidity. The observation that exercise was reported less often in those who preferred telemedicine may reflect reduced mobility. The factor that showed the greatest trend towards preference for transplant centre follow-up was the severity of cGVHD symptoms. In contrast, those in full time or part-time work showed a trend towards decreased preference for TC or TC-linked follow-up, which may reflect a declining dependency on transplant centre-based care as patients' lives return to normal.

These are important findings, particularly for countries like Australia where transplant centres are concentrated in major urban centres, as they provide support for the development of models of care that are responsive to different medical and socio-demographic needs of BMT survivors. But 'devolved' models of post-transplant care that integrate facilities, specialties and models of care beyond the transplant centre are only likely to work where they are sufficiently organised and resourced[42]. In this regard it is noteworthy that recent studies suggest that the survival of BMT patients from rural/regional areas is not inferior if LTFU is carefully and rigorously structured and if there is good communication between referring specialists and GPs[43-45]. Likewise, it is reassuring that recent data in a range of patient populations, including solid organ transplant recipients and patients with cancer, suggests that satellite clinics staffed by personnel from tertiary hospitals have shown similar patient outcomes, subjective health status and clinical efficiency when compared to tertiary clinics[46-48] and that telemedicine can be successfully used to deliver preventive health care, including for sexual and relationship counselling, weight management, advice regarding nutrition and exercise and mental health care[49-53].

Although the sample size and high response rate (76%) make it likely that these results represent an accurate account of BMT survivor's preferences for long-term care, there are a number of limitations to our study that may limit the generalizability of these results to BMT survivors in other countries and other settings. These limitations are principally a function of our study population and include Australia's geographical size, predominantly urban population, concentration, climate and health system (which includes both universal publicly funded and private health care). Additionally, we did not specifically ask participants if they had private health insurance or relied upon public health care (in large measure as these are not generally regarded as influencing the standard post-BMT care in Australia) and so are not sure of the impact this has on preferences for follow-up. Also, we did not ask about preferences for nurse-led services, which are commonly used in international BMT centres

and cancer care but less a feature of BMT care in Australia[54,55]. It is also possible that the account of patient preferences for post BMT care is compromised by the use of quantitative instruments incorporate dichotomous variables, however each of the instruments used in the study have been validated in the target population and so provide the basis for further qualitative study.

This study has provided important insights into BMT survivor preferences for long-term care in an Australian cohort. Given the number of survivors who opted to prefer LTFU at and/or coordinated by their transplant centre, it is clear that transplant centres need to standardise their follow-up, clearly define referral pathways for ancillary and specialist medical services, ensure LTFU guidelines are disseminated to all relevant health providers and communicated effectively with the range of primary and tertiary care providers involved in post-BMT care[56]. Should other models of care be integrated into the long-term care of BMT survivors, including satellite clinics and telehealth, attention should be paid to the likely adopters of these services and their needs – particularly if these modes of care are chosen for delivery of psychosexual health care and health education. As the success of any model of care is likely to reflect the specific context of its application, further work will be required to establish if this care does indeed decrease morbidity and mortality of long-term BMT survivors.

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Authorship Contributions

GD, NG, LB and IK designed the study. All authors contributed to study recruitment, data analysis and to drafting of the publication.

Disclosure of Conflicts of Interest

Conflicts of interest: none.

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The authors have no financial conflict of interest to disclose in relation to the study.

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Appendices

Appendix 1: Socio-demographic, transplant factors and post transplant complications associated with a preference for long term follow-up where there is transplant centre involvement (transplant centre, satellite clinic or telemedicine)					
	LTFU with Transplant Centre, satellite clinic , or telemedicine **N=328**	**LTFU that excludes TC or TC-linked care (local haematologist , GP or no follow-up preference)** **N=113**	**Odds ratio** **(95% CI)**	**P value**	**Adjusted *** **Odds ratio (95% CI)** **P value**
Gender					
Male	188 (57.3%)	62 (54.9%)	1.1 (0.70, 1.74)	0.65	1.36(0.60, 3.05)
Female	140 (42.7%)	51 (45.1%)			p=0.46
Age (years)					
(median, IQR; range)	54(45, 62; 19-79)	53(43, 62; 21-74)	1.00(0.99, 1.02)	0.52	1.00(0.97, 1.03)
					p=0.92
Postcode					
RA1/2 (Major city/ inner regional)	298 (93.1%)	98 (88.3%)	1.79 (0.80,3.89)	0.12	1.62(0.51, 7.22)
RA3/4 (Outer regional/remote)	22 (6.9%)	13 (11.7%)			p=0.41
Relationship status					
Married /Defacto	265 (81.5%)	79 (72.5%)	1.67 (0.97, 2.85)	0.04	1.15(0.39, 3.39)
Single, divorced, separated	60 (18.5%)	30 (27.5%)			P=0.78
Income Status (AUD)					
Middle/High income (>$40,000)	205 (64.9%)	63 (58.9%)	1.29 (0.80, 2.07)	0.27	
Low income ($20,000-$39,999)	111 (35.1%)	44 (41.1%)			
Education status					
Some/completed University	117 (48.0%)	37 (41.6%)	1.29 (0.77, 2.18)	0.30	
Other (diploma, trade, secondary)	127 (52.0%)	52 (58.4%)			
Occupational status					

Full-time/Part Time Other (home duties, casual, retired Unable to work, retired)	149 (48.2%) 160 (51.8%)	60 (58.2%) 43 (41.8%)	0.67 (0.41, 1.07)	0.08	0.44(0.19, 1.03) p=0.06
Age (years) at transplantation Median (IQR; rang**e)**	**49** (39, 57; 17-71)	**46** (36, 55; 17-70)		0.35	
Time (years) since transplantation Median (IQR; range)	**5** (3, 8; 1-14)	**5** (3, 9 ; 1-14)		0.44	
Underlying disease Acute Leukaemia Other‡	172 (54.3%) 145 (45.7%)	54 (50.9%) 52 (49.1%)	1.14 (0.72, 1.82)	0.55	
Stage of disease at transplant 1st or 2nd Remission (CR1/2) Other‡‡	200 (61.0%) 128 (39.0%)	71 (62.8%) 42 (37.2%)	0.92 (0.58, 1.47)	0.73	
Conditioning Myeloablative RIC	158 (48.5%) 168 (51.5%)	56 (49.6%) 57 (50.4%)	0.96 (0.61, 1.50)	0.84	
Donor Type Matched (sibling, unrelated) Haploidentical/Mismatched	304 (93.2%) 22 (6.8%)	104 (92.0%) 9 (8.0%)	1.19 (0.47, 2.81)	0.67	
cGVHD Yes No	227 (70.7%) 94 (29.3%)	74 (65.5%) 39 (34.5%)	1.27 (0.78, 2.05)	0.30	
Patient Global ratings GVHD **1** Mod/Severe None/mild	74 (37.2%) 125 (62.8%)	22 (32.3%) 46 (67.7%)	1.24 (0.67, 2.34)	0.47	
2 Severity score (0-10) Median (IQR)	3 (1,6)	3 (1,5)	1.06(0.96, 1.17)	0.24	1.16(0.99, 1.36) p=0.06

3 Reporting GVH worse cf 1 month ago	17 (8.5%)	2 (3.2%)	2.83 (0.64, 25.9)	0.26	
	183 (91.5%)	61 (96.8%)			
LEE cGVHD symptom score					
Median (IQR)					
Skin	10 (0, 25)	7 (0, 25)		0.14	
Eye	33 (8, 75)	25 (0, 67)		0.12	
Mouth	0 (0, 25)	0 (0, 38)		0.12	
Lung	5 (0, 19)	3 (0, 15)		0.39	
Nutrition	0 (0, 5)	0 (0, 5)		0.46	
Muscle/joint	2 (0,6)	2 (0, 6)		0.41	
Energy	32 (17, 50)	32 (18, 46)		0.70	
Mental emotional	17 (0, 42)	8 (0, 25)		0.01	
Total	20 (9, 31)	17 (10, 26)		0.40	
Chronic Diseases					
Any chronic disease^	231/317 (72.9.5%)	76/105 (72.4%)		0.92	
Any cancer^^	80/287(27.9%)	27/101 (26.7%)		0.82	
Psychological & sexual morbidity					
Anxiety	65/300 (21.7%)	18/103 (17.5%)	1.30 (0.71, 2.48)	0.36	
Depression	72/303 (23.8%)	23/104 (22.1%)	1.10 (0.63, 1.96)	0.73	
Anxiety and/or depression	92/304 (30.3%)	26/105 (24.8%)	1.32 (0.78, 2.28)	0.28	
Total DASS21 score (Median, IQR)	20 (10, 40)	18 (6, 38)		0.27	
Sexual dysfunction	138/222 (62.2%)	29/67(43.3%)		0.006	1.61(0.73, 3.55)
			2.15(1.19, 3.90)		p=0.24
CANCER Screening					
Skin check	172/324 (53.1%)	56/112 (50%)	1.13 (0.72, 1.78)	0.57	
Bowel Check	106/321 (33.0%)	34/111 (30.6%)	1.11 (0.68, 1.84)	0.64	
Pap smear (F)**	80/135 (59.3%)	38/51 (74.5%)	0.50 (0.22, 1.06)	0.05	0.19(0.03, 1.25)

					p=0.08
Mammogram (F)	73/133 (54.9%)	25/51 (49.0%)	1.26 (0.63, 2.54)	0.47	
Prostate (M)	64/184(34.8%)	25/62 (40.3%)	0.79 (0.42, 1.50)	0.43	
LIFESTYLE					
Smoking	21/326 (6.4%)	12/112(10.7%)			
Alcohol	205/328 (62.5%)	77/113 (68.1%)			
Exercise/sport	220/326 (67.5%)	80 /110 (72.7%)			
Sun protection	252/319 (67.3%)	81/112 (72.3%)			
BMI (all)- median, (IQR)	25 (22, 28)	25 (22, 28)		0.79	
Total FACT BMT	110 (94, 121)	109 (92, 127)		0.47	
Post transplant Growth Inventory score	58 (43, 72)	59 (33, 68)		0.20	

‡ CML, CLL, SAA, NHL, HL MM, MDS/Myeloproliferative disease, other(unspecified)

‡‡ > 2 complete remissions , Refractory, Chronic phase,Accelerated phase, Blast crisis, Partial remission, Other(unspecified)

^ Any chronic disease includes hypetension, hypercholesterolaemia, diabetes, bone disease (osteoporosis, osteopaenia, spinal/hip fractures or avascular necrosis), iron overload, thyroid disease

^^ Any cancer includes skin, mouth or other specified

*Adjusted odds derived from multivariable logistic regression fitting the following potential confounders : age, gender, occupational status, marital status, residential location (metro/inner regional), GVHD severity, sexual dysfunction

** Adjusted odds derived from multivariable logistic regression fitting the following potential confounders: age, educational status, marital status, residential location, sexual dysfunction, GVH severity

Appendix 2: Socio-demographic, transplant factors and post transplant complications associated with a preference for long term follow-up that includes a satellite clinic

	LTFU with satellite clinic + /-other option **N=119**	**Options that exclude satellite clinic** **N=322**	**Odds ratio** **(95% CI)**	**P value**	**Adjusted #** **Odds ratio (95% CI)** **P value**
Gender					
Male	70 (58.8%)	180(55.9%)	1.13(0.72,1.77)	0.58	1.20(0.49, 3.00)
Female	49 (41.2%)	142 (44.1%)			p=0.68
Age (years)					1.03(0.99, 1.08)
(median, IQR; range)	54(45,61; 22-75)	54(44,62;19-79)	1.0(0.98, 1.02)	0.77	p=0.09
Postcode					
RA1/2 (Major city/ inner regional)	106(91.3%)	290 (92.0%)	0.91(0.41, 2.21)	0.82	0.70 (0.12, 4.08)
RA3/4 (Outer regional/remote)	10 (8.7%)	25(7.8%)			p=0.70
Relationship status					
Married /Defacto	96(81.4%)	248 (78.5%)	1.20(0.68, 2.15)	0.51	
Single, divorced, separated	22(18.6%)	68(21.5%)			
Income Status (AUD)					
Middle/High income (>$40,000)	84(74.3%)	184(59.3%)	1.98(1.20,3.33)	0.004	4.67(1.22, 17.8)
Low income ($20,000-$39,999)	29 (25.7%)	126 (40.7%)			p=0.02
Education status					
Some/completed University	54 (59.3%)	100 (41.3%)	2.07 (1.23, 3.49)	0.003	3.26(1.28, 8.30)
Other (diploma, trade, secondary)	37 (40.7%)	142 (58.7%)			p=0.01
Occupational status					
Full-time/Part Time	55(49.5%)	154 (51.2%)	0.94(0.59, 1.48)	0.77	0.71(0.25, 2.03)
Other (home duties, casual, retired Unable to work)	56(50.4%)	147(48.8%)			p=0.53
Age (years) at transplantation	49(39, 55)	49(37, 56)			

				0.95	
Median (IQR; rang**e)**					
Time (years) since transplantation					
Median (IQR; range)	5(3,8)	5(3, 8)		0.49	
Underlying disease					
Acute Leukaemia	60 (53.6%)	166 (53.4%)	1.01(0.64, 1.59)	0.97	
Other*	52 (46.4%)	145(46.6%)			
Stage of disease at transplant					
1st or 2nd Remission (CR1/2)	73 (61.3%)	198 (61.5%)	1.00(0.64, 1.59)	0.98	
Other*	46(38.7%)	124 (38.5%)			
Conditioning					
Myeloablative	59 (49.6%)	155(48.4%)	1.05(0.67, 1.63)	0.83	
RIC	60(50.4%)	165(51.6%)			
Donor Type					
Matched (sibling, unrelated)	113 (95.8%)	295(91.9%)	1.99(0.73, 6.80)	0.21	
Haploidentical/Mismatched	5 (4.2%)	26 (8.1%)			
cGVHD					
Yes	86(74.1%)	215 (67.6%)	1.37(0.83, 2.30)	0.19	
No	30 (25.9%)	103 (32.4%)			
Patient Global ratings GVHD					
1					
Mod/Severe	21(26.6%)	75(39.9%)	0.55 (0.29, 1.00)	0.04	
None/mild	58 (73.4%)	113(60.1%)			
2 Severity score (0-10)					
Median (IQR)	2 (1,4)	3(1,6)		0.05	0.99(0.83, 1.18) p=0.94
3 Reporting GVH worse cf 1 month ago	2(2.6%)	17(9.1%)			
	75(97.4%)	169(90.9%)	0.26(0.03, 1.17)	0.07	
LEE cGVHD symptom score					

Median (IQR)					
Skin	15(5,30)	10(0,25)		0.03	
Eye	25(17,67)	33(8,75)		0.94	
Mouth	0(0,12)	0(0,37)		0.006	
Lung	5(0,10)	5(0,20)		0.16	
Nutrition	0(0,5)	0(0,5)		0.17	
Muscle/joint	2(0,5)	2(0,6)		0.56	
Energy	29(17, 43)	32(17,50)		0.42	
Mental emotional	17(0,33)	17(0,33)		0.90	
Total	17(8,28)	20(10, 32)		0.23	
Chronic Diseases					
Any chronic disease^	84/114(73.7%)	223/308(72.4%)	1.07(0.64,1.80)	0.79	
Any cancer^^	30/109(27.5%)	77/279(27.6%)	0.99(0.58, 1.67)	0.99	
Psychological & sexual morbidity					
Anxiety	20/114(17.5%)	63/289(21.8%)	0.76(0.41, 1.36)	0.34	
Depression	26/116(22.4%)	69/291(23.7%)	0.93(0.53, 1.59)	0.78	
Anxiety and/or depression	33/116(28.4%)	85/293(29.0%)	0.97(0.58, 1.60)	0.91	
Total DASS21 score (Median, IQR)	18(10,34)	20(8,40)		0.65	
Sexual dysfunction	63/86(73.3%)	104/203(51.2%)	2.61(1.46, 4.74)	<0.001	3.27(1.21, 8.78) p=0.02
CANCER Screening					
Skin check	68/118(57.6%)	160/318(50.3%)		0.17	
Bowel Check	38/116(32.3%)	102/316(32.3%)		0.92	
Pap smear (F)**	27/46(58.7%)	91/140(65%)		0.44	
Mammogram (F)	30/46(65.2%)	68/138(49.3%)		0.06	
Prostate (M)	26/69(37.7%)	63/177(35.6%)		0.76	
LIFESTYLE					

Smoking	8/118(6.8%)	25/320(7.8%)		0.72	
Alcohol	83/119(69.7%)	199/322(61.8%)		0.12	
Exercise/sport	76/118(64.4%)	224/318(70.4%)		0.22	
Sun protection	92/118(78.0%)	241/313(77.0%)		0.83	
BMI (all)- median, (IQR)	25 (22, 28)	25 (22, 28)		0.50	
Total FACT BMT	110(94, 120)	109(93, 125)		0.70	
Post transplant Growth Inventory score	57(44, 71)	59(38, 70)		0.77	

#Adjusted odds derived from multivariable logistic regression fitting the following potential confounders : age, gender, occupational status, income , educational status, residential location (metro/inner regional compared to outer regional/remote), GVHD severity, sexual dysfunction

Appendix 3: Socio-demographic, transplant factors and post transplant complications associated with a preference for long term follow-up that includes telemedicine

	LTFU with telemedicine+ /- other option N=92	LTFU Options that exclude telemedicine N=349	Odds ratio (95% CI)	 P value	Adjusted [##] Odds ratio (95% CI) P value
Gender					
Male	55(59.8%)	195(55.9%)	1.17(0.72,1.93)	0.51	1.02(0.38,2.74)
Female	37(40.2%)	154(44.1%)			p=0.97
Age (years) **(median, IQR; range)**	52(43,58; 24-70)	55(44,63;19-79)	0.99 (0.97, 1.01)	0.07	1.02(0.98, 1.07) p=0.33
Postcode					
RA1/2 (Major city/ inner regional)	81 (91%)	315 (92%)	0.87(0.36, 2.29)	0.74	0.46(0.08, 2.60)
RA3/4 (Outer regional/remote)	8(9%)	27(8%)			p=0.38
Relationship status					
Married /Defacto	74(82.2%)	270(78.5%)	1.26(0.68, 2.47)	0.43	
Single, divorced, separated	16(17.8%)	74(21.5%)			
Income Status (AUD)					
Middle/High income (>$40,000)	56(62.9%)	212(63.5%)	1.02 (0.61, 1.70)	0.92	
Low income ($20,000-$39,999)	33(37.1%)	122(36.5%)			
Education status					
Some/completed University	42 (61.8%)	112(42.3%)	2.20(1.23, 3.98)	0.004	5.10(1.72, 15.1)
Other (diploma, trade, secondary)	26(38.2%)	153 (57.7%)			P=0.003
Occupational status					
Full-time/Part Time	35(42.2%)	174(52.9%)	0.65(0.39, 1.08)	0.08	0.77(0.26, 2.28)
Other (home duties, casual, retired Unable to work)	48(57.8%)	155(47.1%)			p=0.64
Age (years) at transplantation	47(37, 52)	50(38, 57)		0.06	

Median (IQR; rang**e)**					
Time (years) since transplantation Median (IQR; range)	5(3,8)	5(3,8)		0.56	
Underlying disease Acute Leukaemia Other*	48(53.3%) 42(46.7%)	178(53.4%) 155(46.5%)	1.00(0.61, 1.63)	0.98	
Stage of disease at transplant 1st or 2nd Remission (CR1/2) Other*	58(63.0%) 34(37.0%)	213(61.0%) 136(39.0%)	1.09 (0.66, 1.81)	0.72	
Conditioning Myeloablative RIC	53(57.6%) 39(42.4%)	161(46.4%) 186(53.3%)	1.57(0.96, 2.57)	0.06	1.80(0.62, 5.22) P=0.28
Donor Type Matched (sibling, unrelated) Haploidentical/Mismatched	88 (96.7%) 3(3.3%)	320 (91.9%) 28 (8.1%)	2.57(0.76, 13.47)	0.16	
cGVHD Yes No	64(70.3%) 27(29.8%)	237(69.1%) 106(30.9%)	1.06(0.62, 1.83)	0.82	
Patient Global ratings GVHD **1** Mod/Severe None/mild	21(37.5%) 35 (62.5%)	136 (64.4%) 75 (35.6%)	1.08(0.56, 2.08)	0.79	
2 Severity score (0-10) Median (IQR)	3(1, 5)	3(1,6)		0.79	0.95(0.79, 1.16) p=0.63
3 Reporting GVH worse cf 1 month ago	6(10.9%) 49(89.1%)	13(6.3%) 195(93.7%)	1.84(0.54, 5.49)	0.24	
LEE cGVHD symptom score					

Median (IQR)					
Skin	10(0,31)	10(0,25)		0.38	
Eye	33(17, 75)	33(8,75)		0.52	
Mouth	0(0,25)	0(0,25)		0.49	
Lung	5(0,20)	5(0,15)		0.69	
Nutrition	0(0,5)	0(0,5)		0.78	
Muscle/joint	3(0,7)	2(0,6)		0.20	
Energy	36(21,54)	32(14, 50)		0.10	
Mental emotional	21(8, 42)	17(0,33)		0.18	
Total	19(9, 36)	18(9,29)		0.44	
Chronic Diseases					
Any chronic disease^	66/89(74.2%)	239/331(72.2%)	1.10(0.63, 1.97)	0.71	
Any cancer^^	19/94(22.6%)	87/303(28.7%)			
Psychological & sexual morbidity					
Anxiety	21/84(25.0%)	62/319(19.4%)	1.38(0.74, 2.50)	0.26	
Depression	27/87(31.0%)	68/320(21.2%)	1.67(0.94, 2.90)	0.06	
Anxiety and/or depression	32/87(36.8%)	86/322(26.7%)	1.60(0.93, 2.70)	0.06	1.34(0.44, 4.02) p=0.60
Total DASS21 score (Median, IQR)	22(10, 46)	18(8, 38)		0.03	
Sexual dysfunction	48/62 (77.4%)	119/227(52.4%)	3.96(1.20, 16.8)	<0.001	3.25(1.02, 10.35) p=0.05
CANCER Screening					
Skin check	43/91(47.2%)	185/345(53.6%)	0.77(0.47,1.26)	0.28	
Bowel Check	26/91(28.6%)	113/340(33.2%)	0.8(0.46, 1.37)	0.40	
Pap smear (F)	20/35(57.1%)	98/151(64.9%)	0.7(0.3,1.6)	0.39	
Mammogram (F)	23/36(63.9%)	75/148(50.7%)	1.7(0.8, 4.0)	0.15	
Prostate (M)	15/54(27.8%)	74/192(38.5%)	0.61(0.29,1.23)	0.14	
LIFESTYLE					

Smoking	5/92(5.4%)	28/346(8.0%)		0.39	
Alcohol	63/92(68.5%)	219/349(62.7%)		0.30	
Exercise/sportΔ	55/92(59.8%)	245/346(70.8%)		0.04	0.46 (0.24, 0.87) p=0.02
Sun protection	73/91(80.2%)	260/340(76.5%)		0.45	
BMI (all)- median, (IQR)	25(22, 28)	25(22, 28)		0.86	
Total FACT BMT	108(94, 119)	110(93, 125)		0.30	
Post transplant Growth Inventory score	53(41, 71)	59(40, 71)		0.66	

##Adjusted odds derived from multivariable logistic regression fitting the following potential confounders : age, gender, occupational status, educational status, residential location (metro/inner regional compared to outer regional/remote), anxiety/depression, GVHD severity, conditioning at transplant, sexual dysfunction

ΔAdjusted odds for exercise derived from multivariable logistic regression fitting the following potential confounders : age, gender, GVHD severity, any chronic disease