

Who Gets Left Behind?

Employment Inequity and Financial Toxicity After Allogeneic Haematopoietic Stem Cell Transplantation

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Importance of Employment

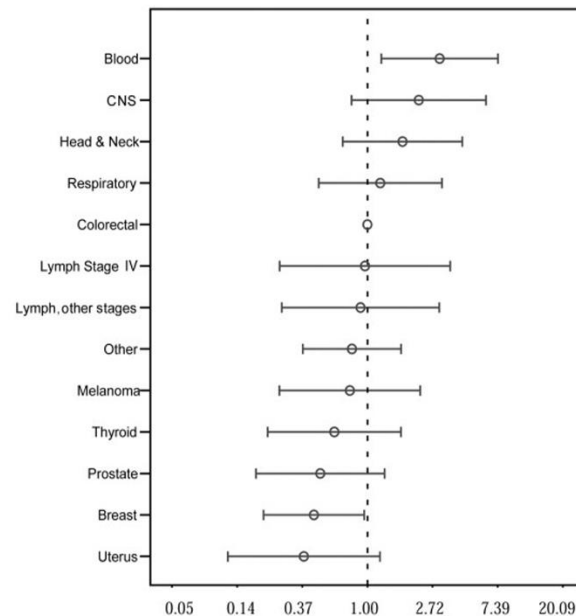
Beyond economic importance, survivors of cancer view **work** as a measure of

- Self-worth
- Competence
- Independence
- Contribution

Those **unable** to return to work (RTW) can lose:

- Identity
- Personal challenge and satisfaction
- Companionship
- Structure of everyday-life

Patients with haematologic malignancies are at greater risk of delayed RTW, unemployment, and reduced work capacity



Quitting Work (Both Genders)

Cancer 2005;103:1292-1301

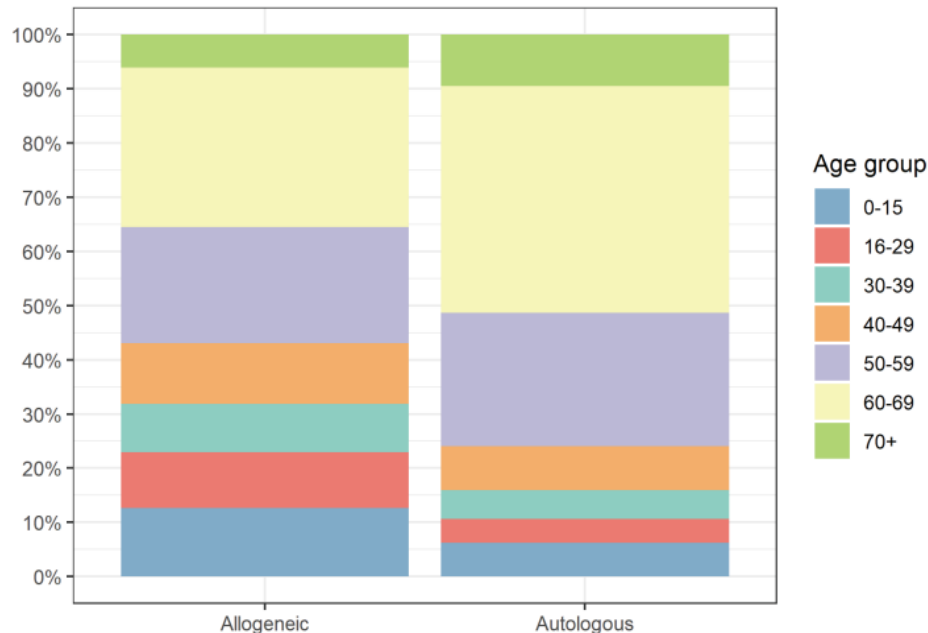
Psycho-oncology 2008;17:1232-1238

Psycho-oncology 2005;14:992-1004

Support Care Cancer 2012;20:1957-1964

Age at alloHSCT

Transplant recipients by age group



In Australia

- Pension age: 67 years
- Minimum access age to superannuation: 60 years
- Unconditional access to superannuation: 65 years

In New Zealand

- Pension age: 65 years (NZ super)

The significant bulk of alloHSCT patients are below retirement age

What do we know about RTW in local alloHSCT recipients?

Sydney survivor study

Cross-sectional survey: adults, median age at survey 54yrs (19-79), at transplant, 49yrs (19-71)

- 87% ≥ 2 years post-transplant at questionnaire completion
- Pre-transplant, 282/441 (64.2%) in full-time employment vs 131/441 (29.7%) post-transplant

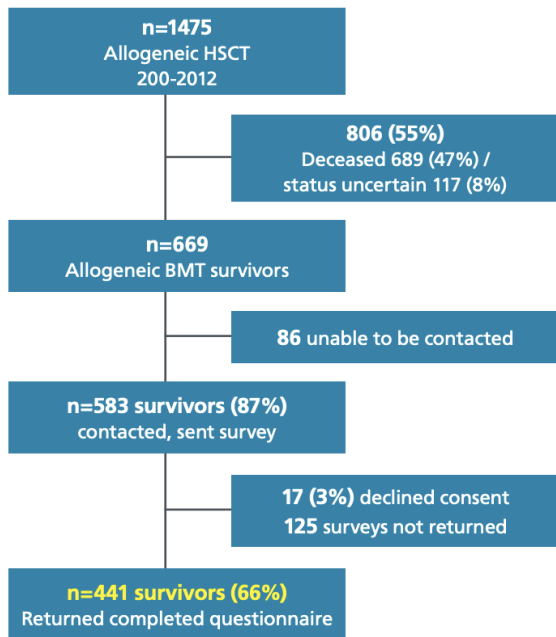


Table 16: Occupational status: pre and post transplant

		POST –TRANSPLANT OCCUPATIONAL STATUS								Pre-transplant totals (%)
		Full-time	Part-time	Homemaker	Casual	Unemployed	Unable to work – ill health	Retired	Missing	
PRE-TRANSPLANT OCCUPATIONAL STATUS	Full-time	115	40	6	13	10	35	42	22	283 (64.2%)
	Part-time	5	32	4	2	2	8	8	0	61 (13.8%)
	Homemaker	1	1	10	0	0	2	0	1	15 (3.4%)
	Casual	3	2	0	10	1	0	2	1	19 (4.3%)
	Unemployed	5	1	0	0	6	1	1	0	14 (3.2%)
	Unable to work – ill health	1	1	0	1	1	9	1	0	15 (3.4%)
	Retired	0	0	0	0	0	0	22	1	22 (5.0%)
	Missing	1	1	1	0	0	1	4	4	12 (2.7%)
	Post-transplant totals (%)	131 (29.7%)	78 (17.7%)	21 (4.8%)	26 (5.9%)	20 (4.5%)	56 (12.7%)	80 (18.1%)	29 (6.6%)	441

Sydney survivor study

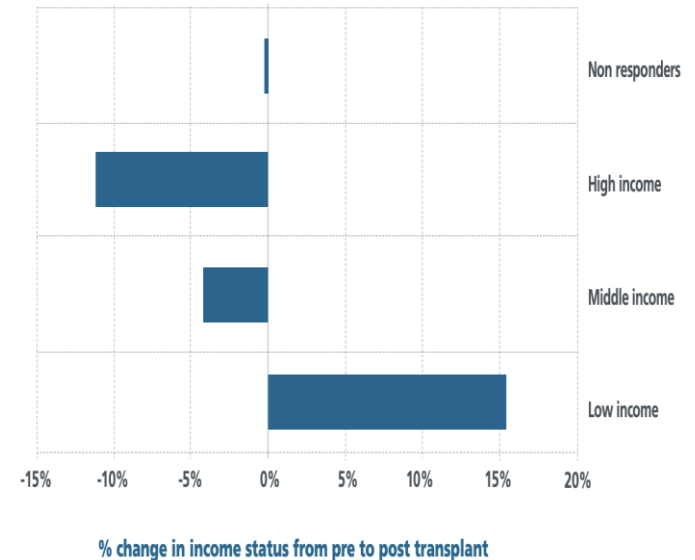
19.7% of low-income status pre transplant -> 35.1% post transplant (+15.4%)

44.0% of high-income status pre transplant -> 32.9% post transplant (-11.1%)

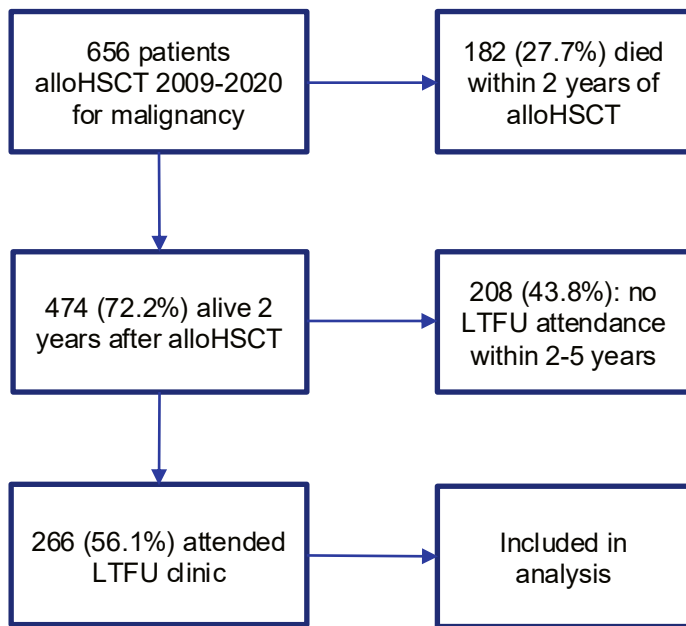
Table 16a: Income status: pre and post transplant

		POST -TRANSPLANT INCOME				Pre-transplant totals (%)
		Low income	Middle income	High income	Missing	
PRE-TRANSPLANT INCOME	Low income	73	9	5	0	87 (19.7%)
	Middle income	53	73	14	1	141 (32.0%)
	High income	27	41	126	0	194 (44.0%)
	Missing	2	0	0	17	19 (4.3%)
	Post-transplant totals (%)	155 (35.1%)	123 (27.9%)	145 (32.9%)	18 (4.1%)	441

Figure 23: Changes in pre- and post-transplant income status



Royal Melbourne Hospital



Participant Demographics

	Median	Range
Age at transplantation (years)	54	18-68
Years post-transplant	3	2-5
	n	%
Male / Female	158 / 108	59.4 / 40.5
Age group (years)		
16-29	38	14.3
30-39	40	15
40-49	62	23.3
50-59	84	31.6
60-69	42	15.8
Years post-transplant		
2	144	54.1
3	64	24.1
4	28	10.5
5	30	1.3

Participant Demographics

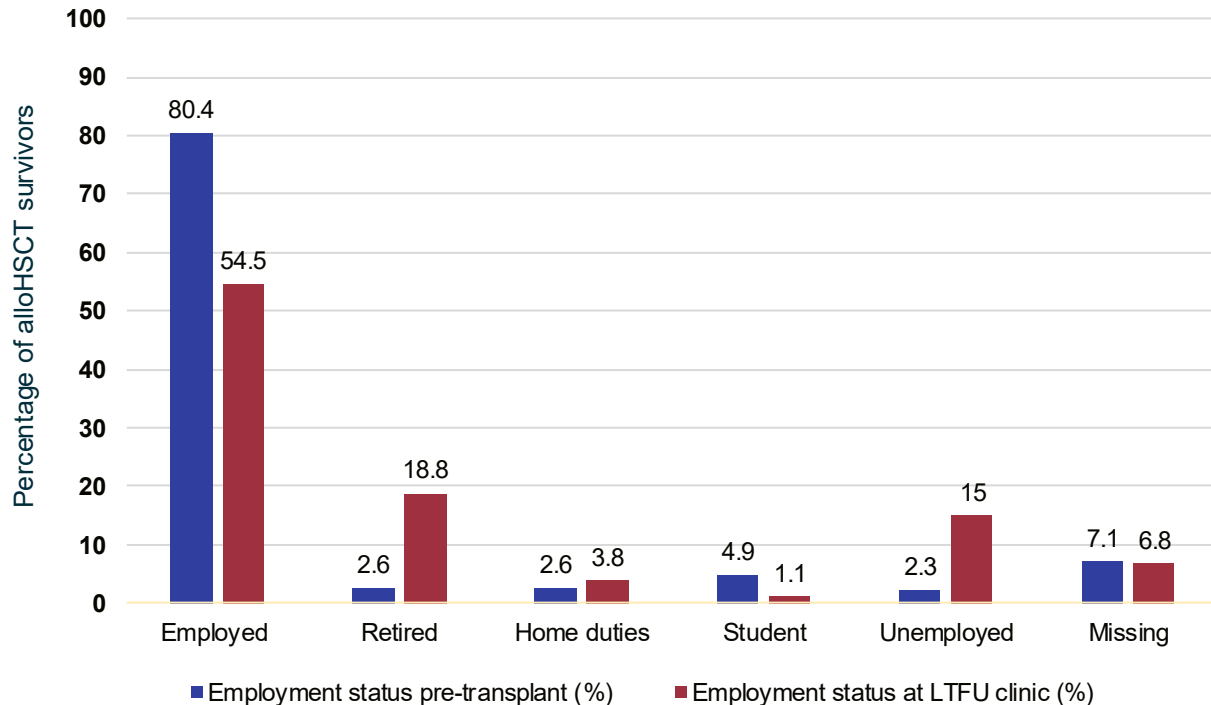
	n	%
Year of transplant		
2009	3	1.1
2010	10	3.8
2011	12	4.5
2012	30	11.3
2013	33	12.4
2014	31	11.7
2015	28	10.5
2016	36	13.5
2017	39	14.7
2018	20	7.5
2019	23	8.6
2020	1	0.4
Underlying disease		
AML	114	42.9
ALL	37	13.9
MDS	20	7.5
MF	11	4.1
Other myeloid disorder	5	1.9
NHL	42	15.8
MM	6	2.3
CLL/SLL	9	3
CML	8	3
HL	9	3.4
Other	5	1.9
Education level pre-transplant		
Non-tertiary	50	18.8
Tertiary	95	35.7
Missing	121	45.5

Participant Demographics

	n	%
Recipient CMV serostatus		
Negative	114	42.9
Positive	144	54.1
Missing	8	3
Graft source		
Peripheral blood	235	88.3
Bone marrow	16	6
Umbilical cord blood	15	5.6
Donor match		
Matched sibling	114	42.9
Matched unrelated	116	43.6
Haploidentical	13	4.9
Mismatched donor (<8/8)	1	0.4
Missing	7	3.6
Conditioning intensity		
Myeloablative	121	45.5
Reduced intensity	116	43.6
Nonmyeloablative	26	9.8
Missing	3	1.1
ATG GVHD prophylaxis		
No ATG	161	60.5
ATG	98	36.8
Missing	7	2.6
aGVHD requiring systemic therapy		
No	250	94
Yes	16	6
cGVHD requiring systemic therapy		
No	110	41.4
Yes	153	57.5
Missing	3	1.1



Occupation pre-transplant vs long-term follow-up (LTFU) review



Patients retired at LTFU review (n=50)

Employment status pre-transplant	n	%
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Employed	42	84
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Retired	7	14
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Home duties	1	2
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Age at transplant

16-29	0	0
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30-39	1	2
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40-49	7	14
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50-59	26	52
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60-69	16	32
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Factors Associated with Employment Status post alloHSCT

Univariable regression

Variable	OR	95% CI	p-value
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Age group

16-29	Ref		
30-39	0.726	0.225-2.342	0.592
40-49	0.282	0.102-0.780	0.015
50-59	0.194	0.072-0.517	0.001
60-69	0.159	0.052-0.491	0.001

Education level

Non-tertiary education Ref

Tertiary education	2.853	1.273-6.395	0.011
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Donor match

Matched sibling Ref

Matched unrelated	1.675	0.956-2.934	0.047
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Cord blood	2.406	0.720-8.044	0.154
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Haploidentical	1.75	0.496-6.169	0.229
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Mismatched donor ($<8/8$)	14135404 87	0	1
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Multivariable regression

Variable	OR	95% CI	p-value
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Age group (years)

16-29	Ref		
30-39	0.718	0.150-3.441	0.679
40-49	0.291	0.077-1.100	0.069
50-59	0.134	0.038-0.475	0.002
60-69	0.123	0.026-0.576	0.008

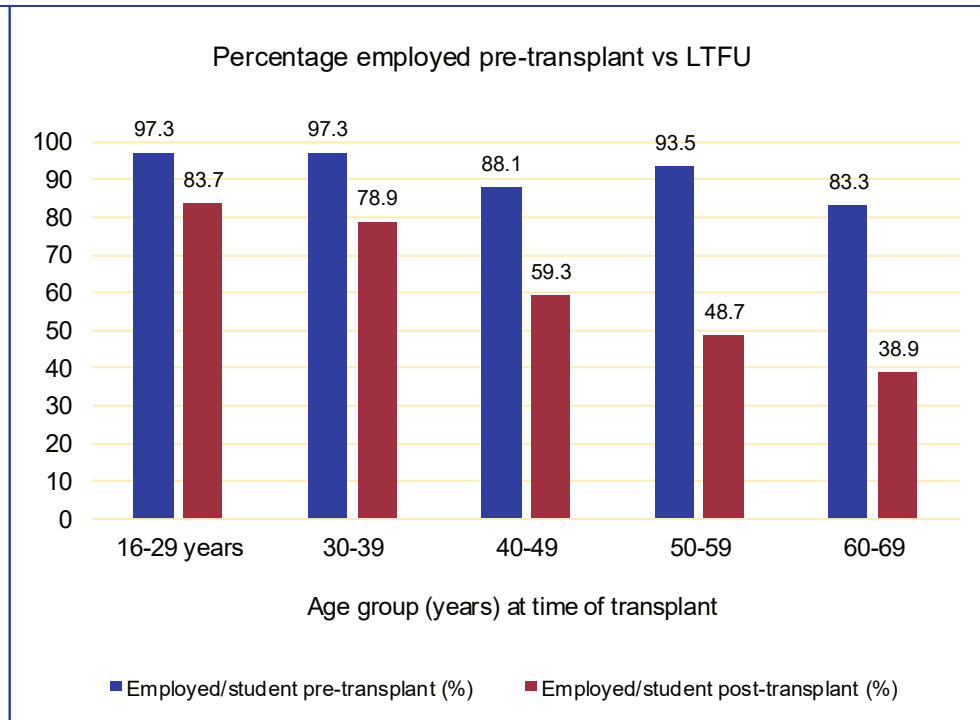
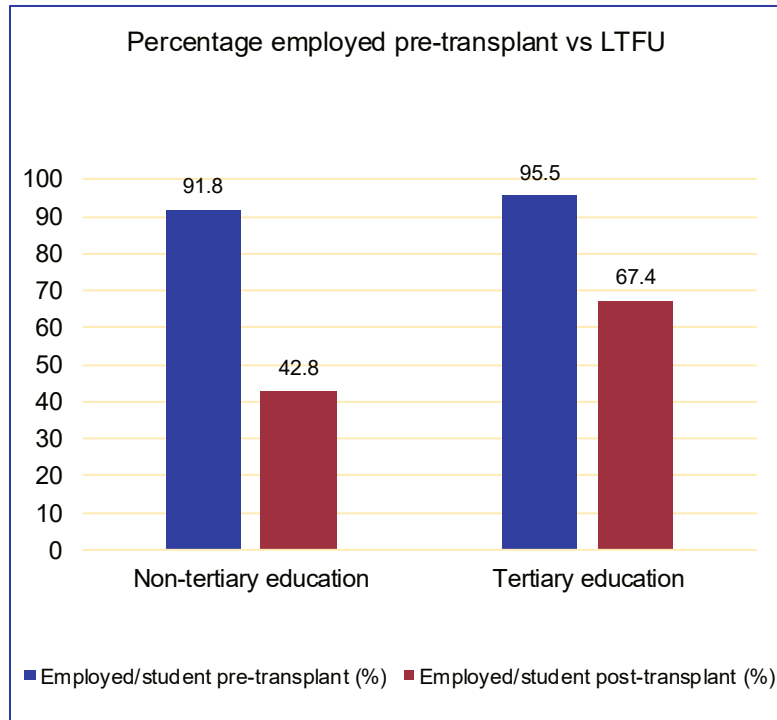
Non-tertiary education Ref

Tertiary education	2.853	1.273-6.395	0.011
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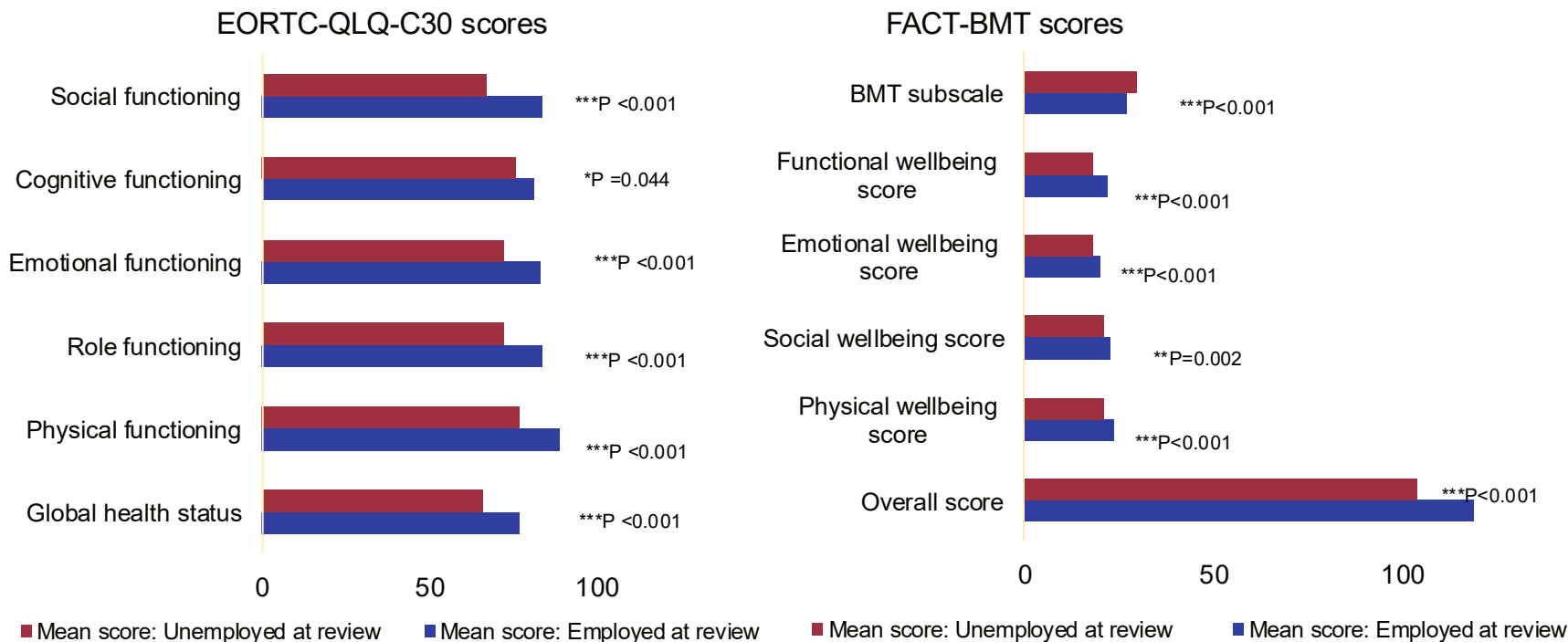
No significant associations with:

Sex, disease subtype, CMV serostatus, graft source, conditioning intensity, ATG use, history of significant aGVHD or cGVHD, relationship status

Factors Associated with Employment Status post alloHSCT

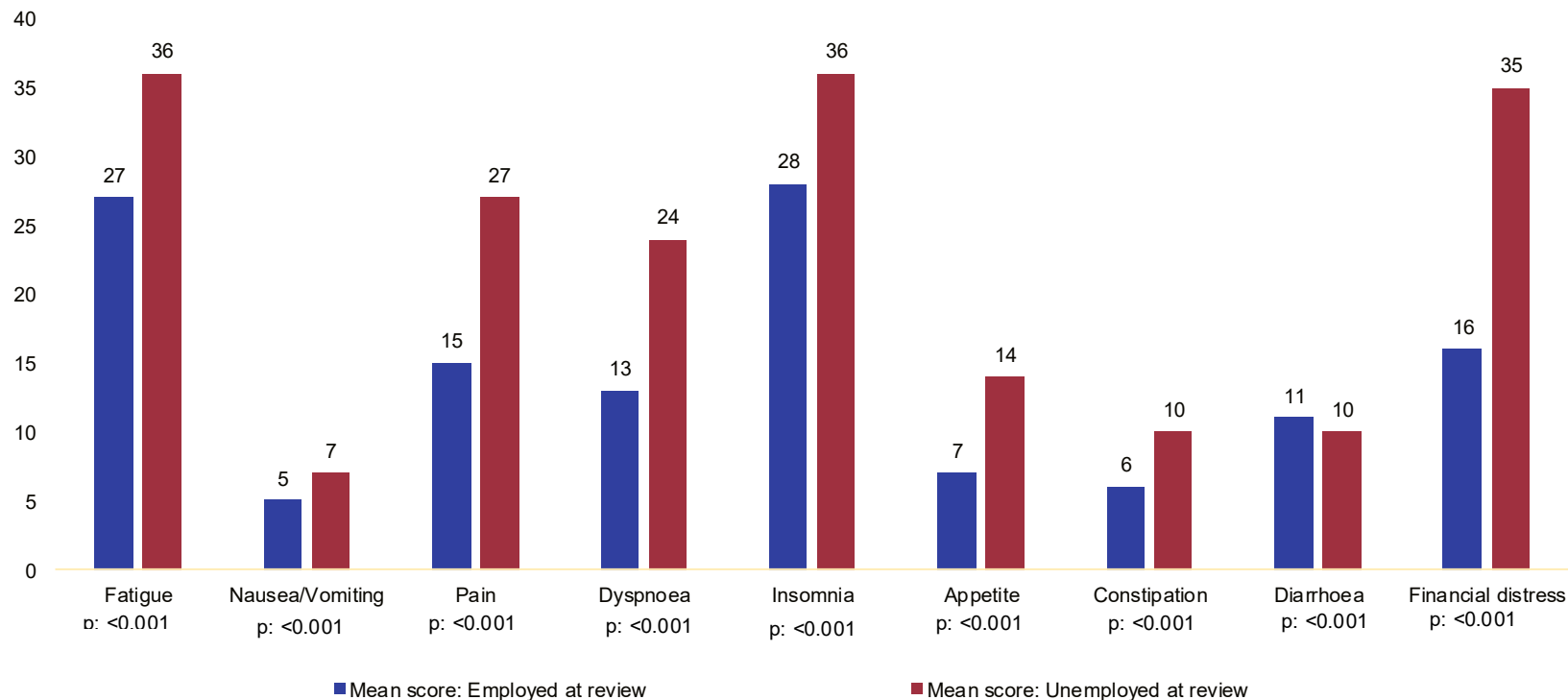


QoL in employed vs unemployed LFTU patients



EORTC-QLQ-C30 Symptom Burden

Employed vs Unemployed Patients



Employment Stressors in Hematopoietic Stem Cell Transplantation (HSCT) Questionnaire

Instructions. Listed below are a number of problems related to your job or study that some people have said are upsetting to them. If you were employed or enrolled in a course of study at ANY time during your diagnosis, treatment, transplant or recovery period, please indicate whether you experienced each event and how upset you were by it.

Were you employed or enrolled in a course of study at ANY time during your diagnosis, treatment, transplant or recovery period?

• ☐ No (stop here and skip remaining questions)							
• ☐ Yes (answer remaining questions)	Please circle all relevant work and/or study descriptions below						
	<table border="1"> <tr> <td>Work</td> <td>Study</td> </tr> <tr> <td>Wage earner or Self employed</td> <td>Primary or secondary or tertiary</td> </tr> <tr> <td>Full Time or Part time</td> <td>Full time or Part time</td> </tr> </table>	Work	Study	Wage earner or Self employed	Primary or secondary or tertiary	Full Time or Part time	Full time or Part time
Work	Study						
Wage earner or Self employed	Primary or secondary or tertiary						
Full Time or Part time	Full time or Part time						

	A. Did this happen to you?		B. If it did happen, how upsetting was it?				
	No	Yes	Not at all upsetting	A little bit upsetting	Moderately upsetting	Very upsetting	Extremely upsetting
1. Resigned from your job or withdrew from study voluntarily	No	Yes	0	1	2	3	4
2. Fired from your job as a result of your illness/transplant	No	Yes	0	1	2	3	4
3. Had to take a paid leave of absence due to your illness/transplant	No	Yes	0	1	2	3	4
4. Had to take an unpaid leave of absence due to your illness/transplant	No	Yes	0	1	2	3	4
5. Had to quit your job or retire as a result of your illness/transplant	No	Yes	0	1	2	3	4
6. Experienced a pay cut or loss of income due to your illness/transplant	No	Yes	0	1	2	3	4
7. You had to go on disability due to your illness/transplant	No	Yes	0	1	2	3	4
8. You were threatened with losing your job due to your illness/transplant	No	Yes	0	1	2	3	4
9. Your partner's work situation was hurt by your illness/transplant	No	Yes	0	1	2	3	4
10. Your employer was unsupportive	No	Yes	0	1	2	3	4
11. Your partner's employer was unsupportive	No	Yes	0	1	2	3	4
12. You had to go back to work too soon after your illness/transplant	No	Yes	0	1	2	3	4
13. You could not go back to work as soon as you wanted after your illness/transplant	No	Yes	0	1	2	3	4

266 attended LTFU clinic

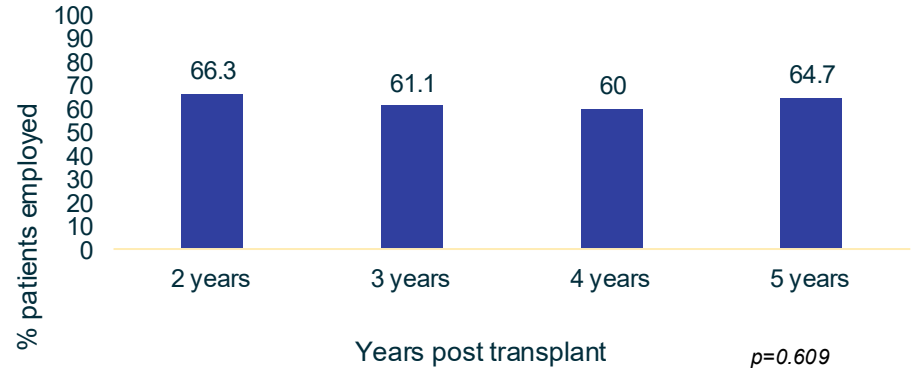
Included in employment analysis

181 (68%) completed Employment Stressors survey

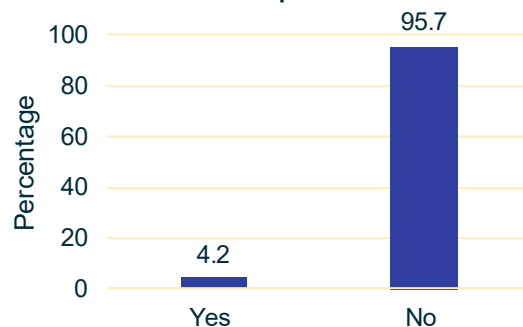
Median time survey was completed post-transplant = 2 years (range 2-5 years)

- ☐ 2 years: n=106 (58.6%)
- ☐ 3 years: n=40 (22.1%)
- ☐ 4 years: n=16 (8.8%)
- ☐ 5 years: n=19 (10.5%)

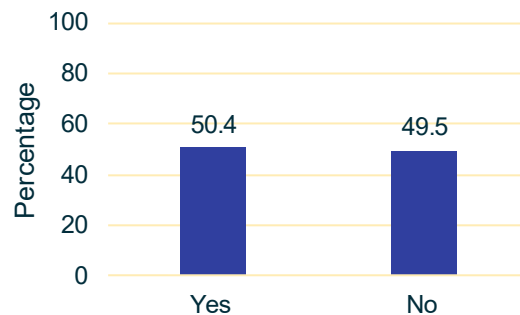
Percentage patients employed



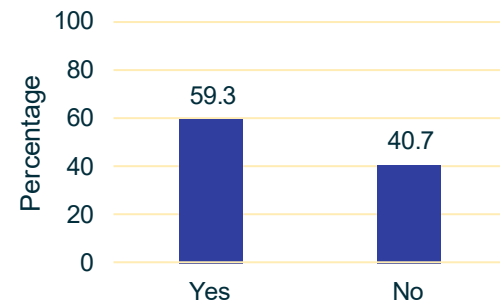
% Fired because of illness
/ transplant



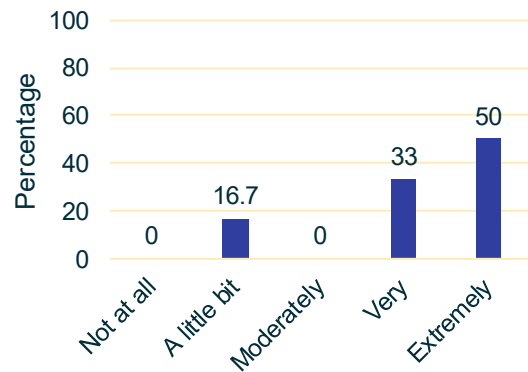
% Took paid leave of
absence



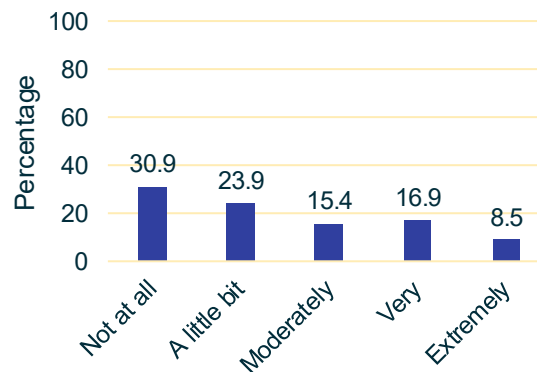
% Took unpaid leave of
absence



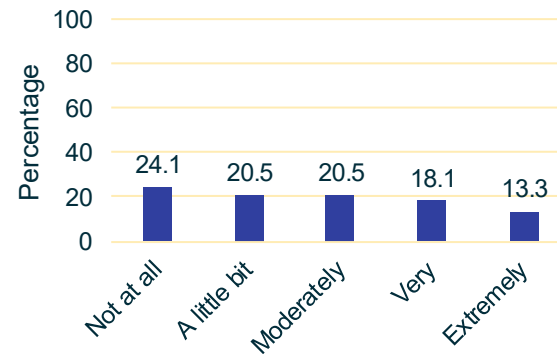
Upset score (if fired)



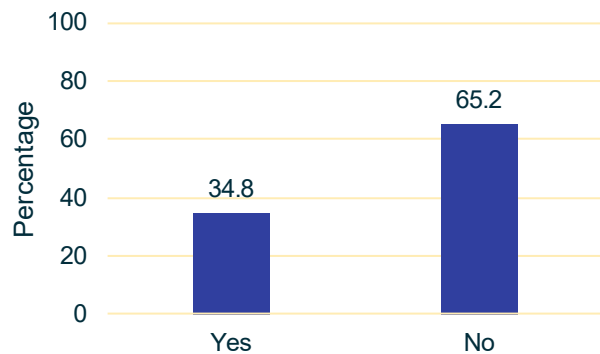
Upset score (if took paid
leave)



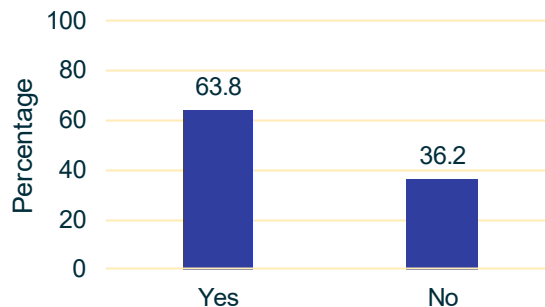
Upset score (if took unpaid
leave)



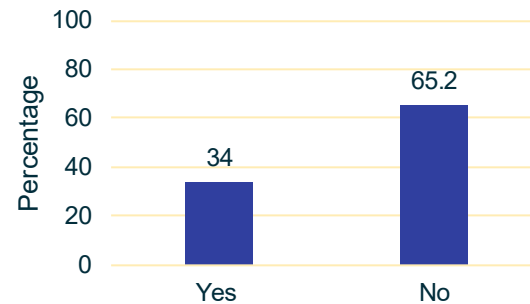
% Had to quit/retire



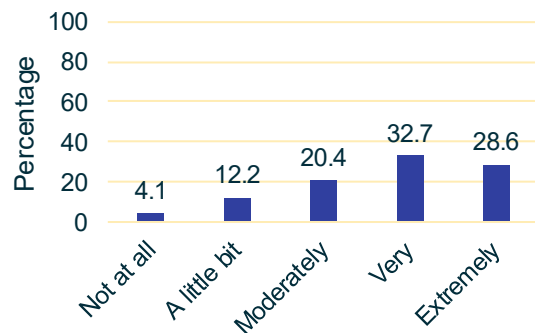
% Experienced pay cut / loss of income



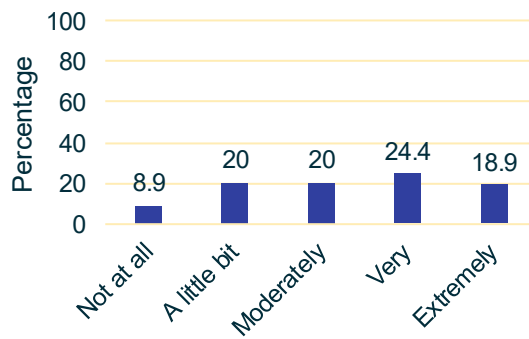
% Had to go on disability support



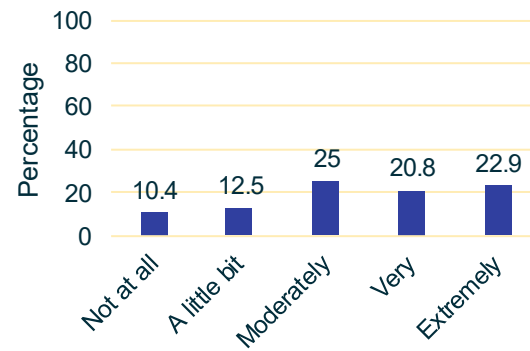
Upset score (if had to quit / retire)



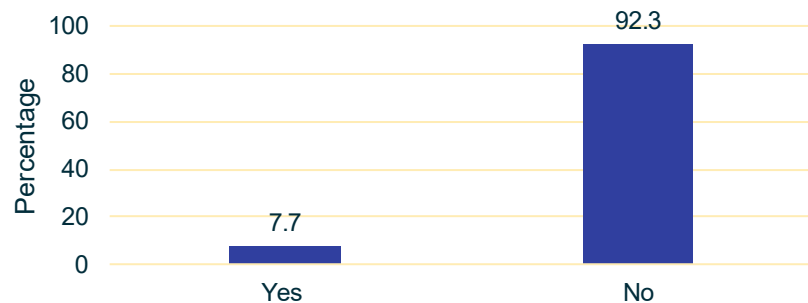
Upset score (if experienced pay cut / loss of income)



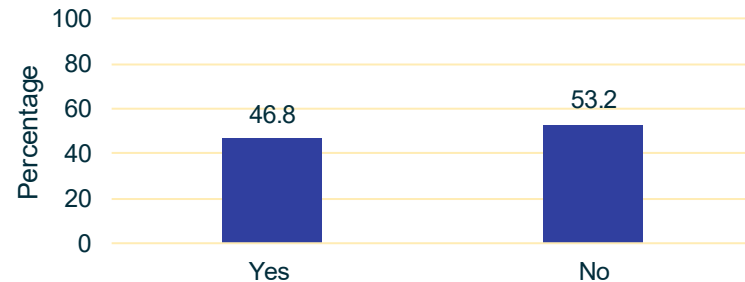
Upset score (if required disability support)



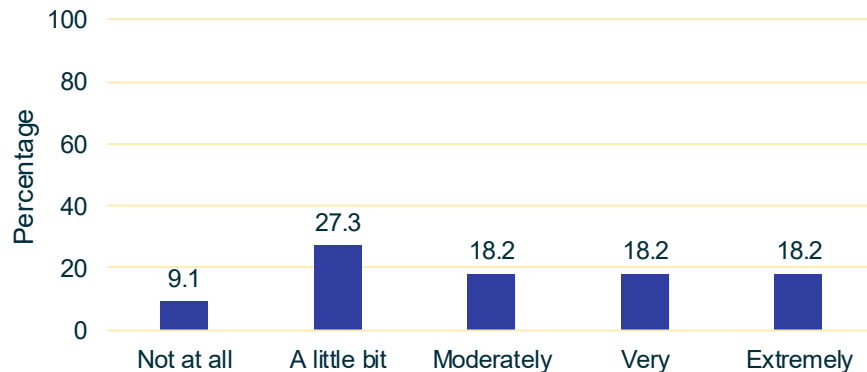
% Had to go back to work too soon



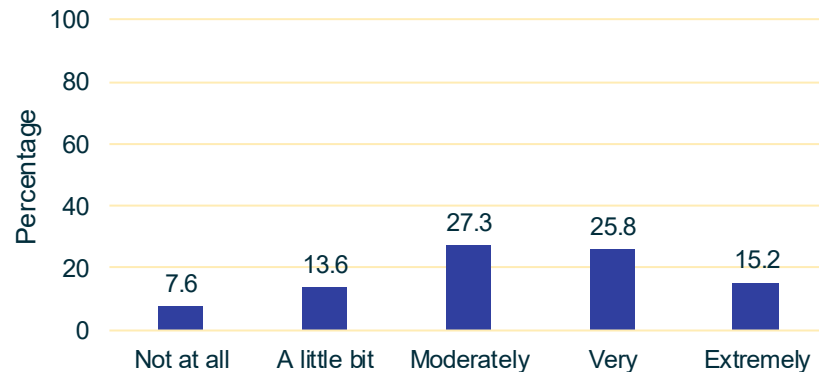
% Could not go back to work as soon as wanted



Upset score (if had to go back to work too soon)



Upset score (if could not go back to work soon enough)



Conclusions

- At a median of 3 years, 54% of patients are employed compared to 80.4 pre-transplant (26% reduction in employment rate)
- Risk factors for unemployment: age ≥ 50 years, lack of tertiary education
- Unemployment associated with reduction in all domains of QoL and worse symptom burden
- Financial distress reported in 35% of those unemployed compared to 16% in those employed – suggests not a “choice”
- Many patients are upset by having to quit/retire/take time off work, and many would like to return sooner than they do

Returning to work after treatment for haematological cancer (Australia)

Qualitative (consumer perspective) study (QLD)

- 50 patients ($n=26$ male; $n=24$ female) >1-year post-treatment for haematological cancer
- Myeloma ($n=15$), Lymphoma ($n=14$), Leukaemia ($n=17$) and Other ($n=4$)
 - 26 participants had alloHSCT
- Identified 3 groups in relation to the experience of returning to work

Group 1

Going back not an issue

Near or past age of retirement

Group 2

Returned to work successfully

Time away from work varied months-years

Employer support noted as important with flexibility for working hours and time management

Overall, individuals pleased to be working

Group 3

Major obstacles to working

Physical symptoms and co-morbidities (e.g. AVN, GVHD, pain, insomnia, fatigue)

Lower sense of confidence and competence

Psychosocial stress caused by inability to RTW

Returning to work after treatment for haematological cancer (Australia)

Consensus from participants

- Specific assistance needed to find appropriate work
 - Accounting for medical and physical limitations
- Did not know which services were available to help
 - Routine services felt not sensitive to specific needs
- Called for a support worker with specific knowledge and expertise in employment within this context
 - Possibly with ability to network and find suitable employment / matching skills

Overall recommendation to implement formal assistance with RTW

RTW after HSCT – US experience

Survey study of auto- and alloHSCT survivors 1-5 years post-transplant (FHCC)

- Of 994 invitees, 345 (35%) responded to survey
 - 158 (58.1% alloHSCT)
- Median follow-up 3 years, mean age 53yrs (range 21-65)
- 79% working prior to diagnosis ->53% working at survey completion
- Factors significantly associated with successful RTW
 - Autologous transplant > allo ($p=0.003$)
 - Communication with employer >1x per month ($p=0.014$)
- Sociodemographic factors (age, sex, ethnicity, education, type of profession) nor clinical variables were not significant factors
 - The large majority were college educated (comparison factor used was no yrs at college: <4 vs ≥ 4)
 - ANZ population likely different

RTW after HSCT – US experience

Timing of RTW post-transplant

- 3-6 months: 54%
- 7-12 months: 18%
- 1-2 years: 22%
- >2 years: 6%

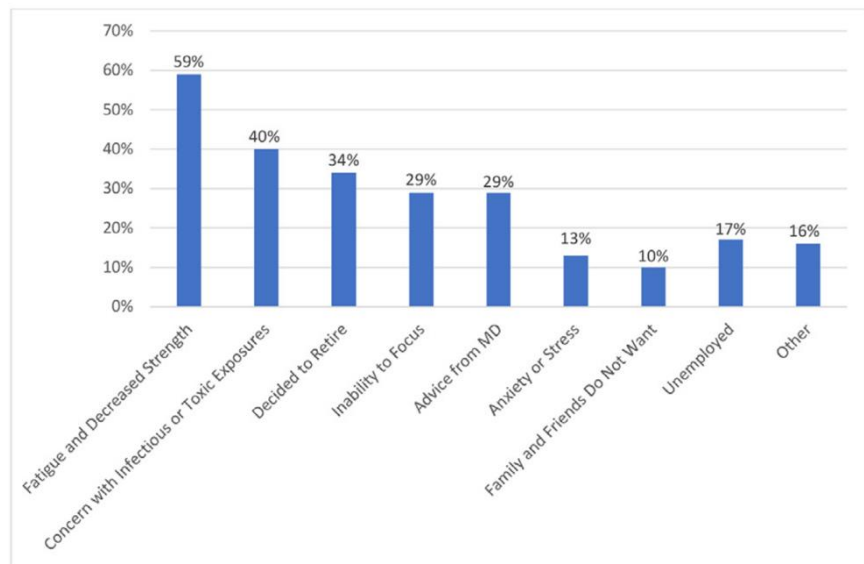
49% of patients who RTW 3-6 months post-transplant were alloHSCT vs 61% auto

Several survivors commented that:

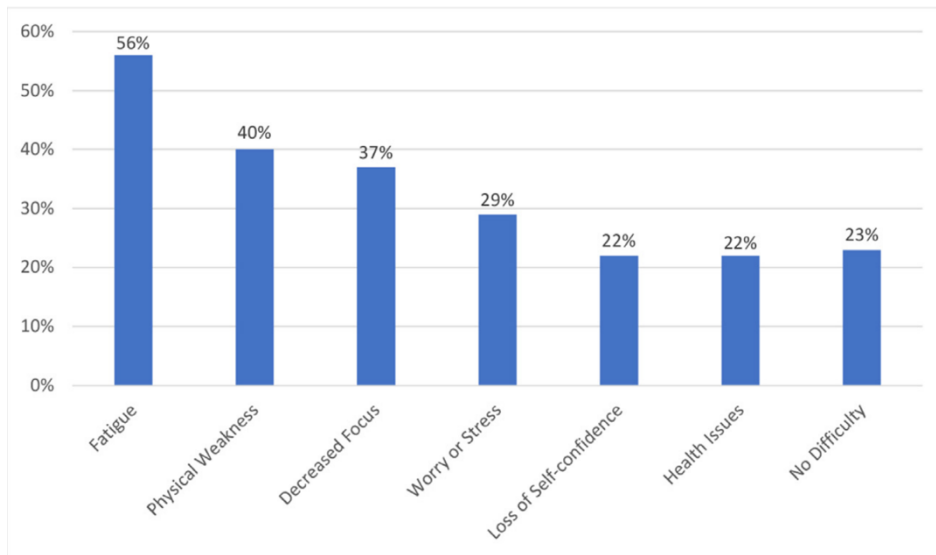
- Ability to **work from home allowed earlier RTW** than if needing to be in an office / group setting
- 54% reported that a transplant physician, nurse or social worker had discussed with them the **timing** of RTW
 - Only 13% received any specific resources or assistance
- 95% of respondents thought RTW issues should be addressed by the transplant team

RTW after HSCT – US experience

Barriers for patients **who did not RTW**



Barriers for those who are **currently working** or ever returned to work



In Conclusion

We know that:

- RTW rates in local survivors of alloHSCT are 30-54% despite many patients
 - Being hopeful of returning
 - Experiencing upset / stress regarding finances and ability to RTW
 - Having significant financial difficulties
- Inability to RTW associated with social factors
 - Lack of tertiary education
 - Age ≥ 50
- QoL and symptom burden worse in those who do not RTW
 - Probable barriers to RTW; equally may be contributed to by not RTW

We need to:

- Know more about the scale and changing nature of the problem since COVID19 (increased WFH / flexibility), PTCy, etc
- Know how best to identify and keep collective track: currently no formal / routine employment surveys designed / validated / utilized
- Design and implement RTW programs in collaboration with consumers

Acknowledgments

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Teresa Garcia: Long-term follow-up clinic,
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Amanda Shapley: Bone Marrow Transplant
Data Manager, Austin Health

Matthew Hillman: Bone Marrow Transplant
Data Manager, Royal Melbourne Hospital

Michael Brown: Rare & Non-Malignant
Haematology Clinical Nurse Consultant,
Royal Melbourne Hospital

Medical and Nursing teams of Haematology
ward 7B, Royal Melbourne Hospital, and
Haematology ward 7S, Austin Hospital

Patients of Haematology wards 7B, Royal
Melbourne Hospital and 7S, Austin Hospital