EXPLORING THE IMPACT OF HAEMATOPOIETIC CELL TRANSPLANTATION ON BLOOD CANCER PATIENTS'

SOCIOECONOMIC WELLBEING: A QUALITATIVE STUDY Lauren Young¹, Christina Yiallouridou¹, Karen Dean¹, Dawn Hart¹, Robert Danby^{1,2}, Gemma Pugh¹

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Introduction

It is well documented that haematopoietic cell transplant patients experience financial toxicity during treatment. However, the impact of socioeconomic status on long-term health and wellbeing is unknown.

Aims

To explore i) the extent of financial burden post-transplant, ii) how this affects **transplant recipients' wellbeing**, and iii) what **support and resources** are needed to support socioeconomic wellbeing post-transplant.

Methods

This was a qualitative study, using one-to-one semistructured interviews. Participants were recruited through Anthony Nolan hosted patient forums, groups and community channels. Interviews were conducted via videocall or phone call and followed the same semi-structured interview guide. Interviews were recorded and transcribed verbatim. Analysis was performed using NVivo 14 qualitative analysis software and applied the Braun and Clarke six-phase approach to thematic analysis.

Results

Participants likened transplant recovery to a game of snakes and ladders, with too many snakes and not enough ladders. Snakes represent challenges such as loss of income, inability to return to work, out of pocket costs and barriers to accessing welfare advice and support. Ladders represent the support systems patients rely on to overcome these challenges. However, support services are often difficult to find, navigate and access.

Conclusion & next steps

Social determinants of health and individuals' living circumstances determine the level of financial toxicity experienced and in turn, influences patients' quality-of-life post-transplant. Addressing and reducing socioeconomic hardship could improve patient outcomes, particularly in relation to their social and occupational wellbeing.

'Nobody understands what you have been through unless you have been through it' (female, 65-72, 11 years post-transplant).

'I was struggling through six or seven weeks and financially that's a lot of cold and flu tablets and cough sweets and paracetamol and hot water bottles and what-have-you' (female, 40-54, 5 years post-transplant).

'The added costs of me actually being in hospital were quite great... You've got all the congestion charging and the diesel and everything. The parking was astronomical for my husband to park at [transplant centre]. But I desperately needed to see him' (female, 55-64, 14 years post-transplant).

- Need for support across all aspects of recovery
- Patients want to know they are not alone

Need for a crutch

The Financial Battle

"It's like a game of 'snakes and ladders' with too many snakes and not enough ladders."

Uncertainty and frustration

- Long distances to TC
- Private treatment and cost of medications
- Financial burden and impact on social life

• Loss of income

- Barriers to accessing benefits
- Access to pensions
- Reliance on savings

The loss / rediscovering of identity and purpose

- Part-time return to work, drop in salary & change in responsibilities
- Change in career prospects and goals
- Reasonable adjustments not made

'As I say, I did have quite considerable savings as well... I was thinking about this the other day, and I think I probably used about £50,000 of savings in that time to keep everything going, between the time when my salary went down and when my pension kicked in. I suppose also since then we have relied on savings a bit to top things up because obviously, my pension isn't as much as my salary was' (male, 65-72, 5 years posttransplant).

'Not being able to work and not being able to predict how long I'd be able to work for and in what context I would be able to work... that then impacts finances and that obviously had a knock-on effect of still needing to pay the rent and the mobile phone bill and all the other bills... trying to budget for those sorts of things was quite difficult" (female, 40-54, 5 years post-transplant).

'I definitely feel having, being off that time and only being able to go back on a part-time basis has definitely hindered that for me. I don't think that I get the same opportunities as other people because of my ability to do things.' (female, 29-39, 8 years posttransplant).

Patient Involvement

A Patient Advisory Group (PAG) of individuals (n=6) with lived experience of receiving a stem cell transplant were involved in the development of the study design and materials. PAG members gave feedback on the study materials, as well as study aims and objectives, to ensure the study was designed to reflect the full patient experience of the impact of transplant on social and financial wellbeing. Following completion of interviews, the initial emergent themes were presented to the PAG. Data triangulation occurred with the PAG, who were involved in checking the validity and reliability of the emergent themes and agreeing the final thematic definitions.



