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"It's very important that you measure throughout that journey…": patient perspectives towards quality-of-life data collection following haematopoietic cell transplant

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Abstract

Background There is increasing interest in using Patient Reported Outcome Measures (PROMs) to provide evidence of how a haematopoietic stem cell transplant (HCT) affects blood cancer patients' long-term quality-of-life (QoL). The purpose of this qualitative study was to explore patients' opinions on what QoL data should be collected post-transplant, when this data should be collected, the use of this data beyond research, and how this data should be captured.

Methods Twenty-one HCT patients with median age of 45 years (range: 26–71 years) took part in a semi-structured interview. Two commonly used PROMs, the Functional Assessment Cancer Therapy – Bone Marrow Transplant (FACT-BMT) and Patient Reported Outcome Measurement Information System (PROMIS-29) were used as discussion prompts. All interviews were audio recorded, transcribed verbatim and analysed in NVivo using thematic analysis. A Patient Advisory Group (PAG) ($n=6$ patients) co-designed the study and were involved in reviewing the coding framework and findings generated.

Results Patients expressed a strong preference for QoL data to be collected which is transplant specific and routinely captured over time. They felt QoL measurement could enable identification of post-transplant concerns, facilitate communication with health professionals, and facilitate access to personalised support. Many patients described being oblivious to the potential long-term implications of HCT and felt it would be reassuring to know the 'typical' trajectory of HCT recovery from patient outcome data collected > 100 days post-transplant. Patients were positive about electronic data capture but did acknowledge that depending on age, digital literacy, and access to electronic devices, a one-size-fits-all approach to QoL data collection would not suit all patients. Additional barriers to QoL measurement included the poor relevance and utility of the individual questionnaire items and concerns about whether PROMs were sensitive enough to capture day to day variation in wellbeing post-transplant.

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Conclusions Findings indicate patients are supportive of QoL data capture specific to transplant and feel such data could be used to support individual self-monitoring and post-transplant recovery. Patients feel that data should be collected routinely on a long-term basis via electronic methods.

Keywords Haematopoietic stem cell transplantation, Patient-reported outcome measures, Patient involvement, Quality of life

Background

Haematopoietic cell transplantation (HCT) is an effective therapy for the management of blood cancers, non-malignant diseases, and bone marrow failure syndromes. Over 4,000 HCTs are performed in the UK each year [1]. There has been a reduction in morbidity and mortality post-transplant because of advancements made in the use of haploidentical donors, conditioning regimens, and effective post-transplant care. The HCT process is intensive, often leading to long-term impairments such as graft-versus-host disease (GvHD), allograft rejection, and infections [2]. In recognition of the burden of treatment on transplant recipients' wellbeing, patient reported outcomes (PROs) are increasingly being used alongside traditional clinical outcome metrics [3–5].

Patient-reported outcome measures (PROMs) are defined as any outcomes related to the patient's health or treatment that is evaluated directly by the patient, without any interpretation by a doctor or anyone else [6], and are used to collect PRO data, including quality-of-life (QoL) data [7]. The use of PROMs allows patient perspectives about the physical and psychosocial impact of disease and treatment to be measured. PROMs are usually developed, standardised, and validated with input from patients and clinicians. Initial questionnaire domains (i.e., general topics or concepts to be measured) are generated through literature reviews and discussion with patients. The draft PROM is then standardised through a series of quantitative studies which aim to psychometrically validate the questionnaire items and scales [8]. These validation studies ensure the final PROM accurately and consistently measures the target construct and captures information that is reflective of patients lived experience [9].

PROMs are defined as either condition specific or generic. Condition specific PROMs gather data which is specific to a particular patient group or condition. An example includes the Functional Assessment Cancer Therapy – Bone Marrow Transplant (FACT-BMT) which assesses the QoL of transplant recipients using the FACT-General (FACT-G) and a BMT-specific subscale [10]. Conversely, generic PROMs assess general health concepts which are relevant to a wide range of population groups. The Patient Reported Outcome Measurement Information System, PROMIS-29 is an example of a generic PROM which assesses QoL across 7 domains including anxiety, depression, fatigue, pain, physical function, sleep disturbance, and social participation [11].

Whilst feasibility of PRO data collection during the HCT pathway has been demonstrated [12], no study to date has investigated HCT patients' views about which measure they think best represents their experience of how and when such data should be collected. As a result, little is known about the patient perspectives towards QoL data collection [13] and there is a lack of consensus about which PROMs are best to use in HCT research and when such data should be collected [14]. The purpose of this qualitative study was to explore patients' opinions towards PROMs and their views on what QoL data should be collected post-transplant, when this data should be collected, the use of this data beyond research, and how this data should be captured.

Methods

Study design

This qualitative study used one-to-one semi-structured interviews to explore and understand patient views towards the collection of QoL data following HCT. The study was sponsored by Anthony Nolan, a UK charity which manages and recruits stem cell donors and provides support to HCT recipients. The study received approval from the Anthony Nolan Research Review Board (RRB) and adhered to the consolidated criteria for reporting qualitative research (COREQ) [15].

Patient involvement and co-design

A Patient Advisory Group (PAG) ($n=6$), made up of individuals who had lived experience of receiving HCT, were involved in the design of the study materials and the interpretation of the results. PAG members attended two online meetings and two in-person workshops. The purpose of the two online meetings was to explore PAG views on key questions to investigate about quality-of-life data collection post-transplant. Following the online meetings, the research team (GP & KD) developed the study materials incorporating the PAG suggestions. Prior to the study, an in-person workshop was held to involve the PAG in co-designing the patient facing materials (patient information sheet, study advert and recruitment process) and test the draft interview guide. Following completion of study recruitment and data collection a second workshop was held and the initial codes and key themes from the study analysis were presented to the PAG to discuss. PAG members were involved in checking the validity, reliability, and relevance of the emergent themes.

Recruitment

Any patient ≥ 18 years of age who had received a HCT regardless of time since transplant was eligible to participate in the study. Participants were recruited via convenience sampling through Anthony Nolan channels. An open invitation to participate was circulated via Anthony Nolan hosted patient and family forums, channels and newsletters through a study advert, containing a link to register interest. Once the participant had completed the expression of interest form a member of the research team shared the participant information sheet, consent form and scheduled an interview time via email.

Semi-structured interview guide and data collection

Interviews for the study followed the semi-structured interview guide (Supplementary File A) and were conducted virtually via Microsoft Teams by a member of the research team (GP, KD or CY). During the interview participants were asked to share their opinion about two validated PROMs commonly used in research involving HCT recipients. The PROMIS-29 and FACT-BMT were chosen to be included within this study based upon existing literature. Participants were sent both PROMs prior to the interview. These were then used as discussion prompts and participants were asked if they felt these measures reflected their experience of QoL post-transplant. During the interviews, participants were able to view copies of the PROMs via MS teams chat and were prompted to reflect on whether specific items within the measures resonated with their experience. Participants were also asked questions around what data they feel should be collected, when and how often, why this data should be collected and by what means. Interviews were continued until reaching data saturation, with no new themes emerging in subsequent interviews [16]. This article presents data on patient preferences on the use of PROMs for QoL data collection. Due to wealth of information collected, data on patient experience of QoL post-transplant is presented in a separate manuscript.

Qualitative analysis

Interviews were audio recorded and transcribed verbatim. Transcripts of the interviews were uploaded to NVivo 14 (QSR International) qualitative software and analysed using Braun & Clarke 6 phase thematic analysis [17]. Initial codes were generated by GP, who also led the analysis of interview material. KD undertook second coding. The research team (GP, KD, and CY) discussed codes and themes that were identified in the data. Once emergent themes were decided, quotations were selected from the transcripts to reflect main themes and sub-themes.

Incentive vouchers

All interview participants were offered a £25 incentive voucher. In line with NIHR funding guidance, the individuals in the PAG received voucher payments (£25p/h) as renumeration for their involvement in the study.

Results

Participant characteristics

Table 1 outlines the demographic and transplant characteristics of study participants. Thirty patients expressed

Table 1 Participant characteristics

Characteristic	**Total *n* = 21**
Median age (range) years	45 (26–71)
Time since transplant, n (%)	
< 1 year	6 (29)
1–5 years	7 (33)
6–10 years	4 (19)
11 + years	4 (19)
Gender, n (%)	
Male	9 (43)
Female	12 (57)
Diagnosis, n (%)	
Acute Lymphoblastic Leukaemia	5 (24)
Acute Myeloid Leukaemia	8 (38)
Myeloma	3 (14)
Myelodysplastic Syndrome	3 (14)
Non-Hodgkins Lymphoma	1 (5)
Multiple Cancers	1 (5)
Transplant, n (%)	
Autologous	2 (10)
Match related	5 (24)
Match unrelated	13 (62)
Mis-match unrelated	1 (5)
Diversity & Inclusion, n (%)	
Live a distance from transplant centre	10 (48)
Receive benefits	5 (24)
Caring responsibilities	6 (29)
Black and ethnic minority	3 (14)
Ethnicity, n (%)	
White British	14 (67)
Asian	2 (10)
Other white	3 (14)
Other ethnicity	2 (10)

an interest in taking part in the study, 2 dropped out due to illness ahead of the scheduled interview, 5 were excluded because they had not received a stem cell transplant in the UK and therefore did not meet the eligibility criteria, and 2 interviews were excluded from analysis due to poor audio quality. The majority of participants were female (57%, $n=12$), White British (67%, $n=14$), and over 45 years of age (71%, $n=15$). The average time since HCT was 6 years (SD: ± 7 years). Almost a quarter (24%, $n=5$) of participants were in receipt of social benefits, 29% ($n=6$) had caring responsibilities and 48% ($n=10$) lived rurally or > 2-h distance from a HCT centre.

Qualitative interviews

All interviews were conducted in September 2023 via MS Teams, each interview averaged 55 min (range 32–82 min).

Emergent themes

Figure 1 outlines emergent themes and sub-themes relating to patients' opinions towards PROMs and their views on what QoL data should be collected post-transplant, when this data should be collected, the use of this data beyond research, and how this data should be captured. Overall, patients preferred transplant specific data to be captured routinely over time and through electronic means. Patients felt PRO data could be used for to support individual self-monitoring and post-transplant recovery.

Further quotations representing themes and sub-themes are presented in Table 2.

What data?

When asked to reflect on the FACT-BMT and PROMIS-29 questionnaires, most participants preferred FACT-BMT as a means of collecting PRO data. Patients felt the items included within the FACT-BMT were more reflective, relatable and in line with their lived experience of receiving a HCT. When reflecting on PROMIS-29, participants described it as '*quite clinical and structured quite clinically or data-ry...*' [P17] (female, 26–39, 17 years post-transplant).

> *"The FACT-BMT is more open, you have more statements there that you can really identify from." [P15] (female, 26–39, 1-year post-transplant).*

Participants were positive overall about the use of FACT-BMT to collect transplant specific data on QoL. However, several patients queried whether PROMs are sensitive enough to capture day-to-day variation and a subtle change over time in relation to patient QoL post-transplant. Patients would often reflect when presented with the FACT-BMT and PROMIS-29 that the binary nature of the response scales don't necessarily reflect

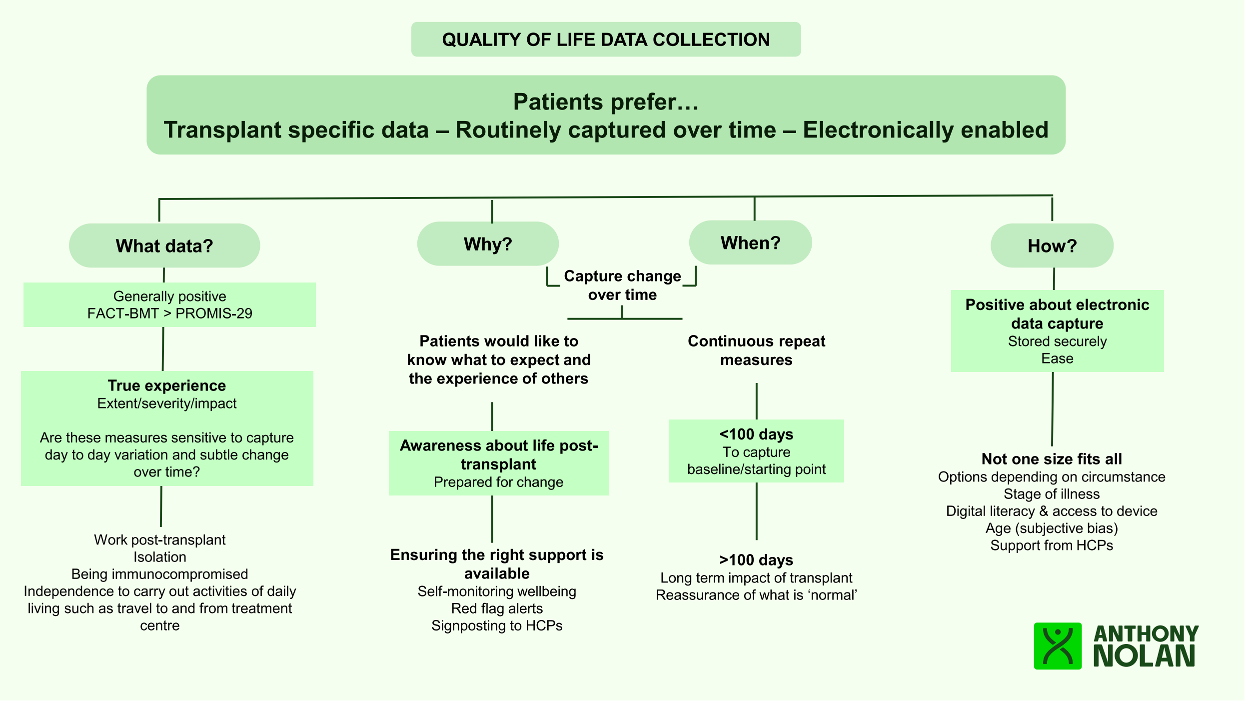

Fig. 1 Diagram of key themes and sub-themes emerging from interview material, discussed, and co-designed with patients (PAG)

Table 2 Representative quotations from emergent themes and sub-themes

Theme	Sub-themes	Quotations
What data?	Transplant specific data preferred FACT-BMT > PROMIS-29 True experience – extent/severity/impact	*"BMT one, because it does have much more specific questions. And it focuses not on the physical activities, necessarily, as part of it, but on the physical wellbeing. Which I think is an important distinction. Just because I can walk 15 min, doesn't mean I don't have fatigue. Just because I can do that, doesn't mean that I don't come home and have a nap straight away, because my body just needs to shut down for an hour. So, I think that more accurately gives patients the ability to answer in a way that isn't just a, "Can you do this, yes or no?"* [P13] (male, 26–39, 3 years post-transplant) *"They cover a lot of ground in terms of the experience of a post-transplant… reading both, my initial observation is that they kind of imply [pause]… what's the word? They kind of a negative tone… if that makes sense"* [P2] (male, 26–39, 1-year post-transplant) *"It didn't seem to take the whole person into account, if that makes sense"* [P17] (female, 26–39, 17 years post-transplant) *"In that one, I don't think I saw it, but a good question would be in terms of pain, they give you these very strong painkillers, to me it was, I don't remember if it was like a sticker that you have on the pack, like morphine, but I don't know. So that one, it did make the pain go away, but it made me feel very sleepy, and I was having hallucinations and dreams, so very weird dreams and stuff like that, so I was feeling like I was not myself. So okay, you can sort out the pain, but not feeling pain, does it trigger something else, so maybe that keep in mind"* [P15] (female, 26–39, 1-year post-transplant) *"I think not asking specifically about that, because that won't be everyone's experience, but asking more specific questions, because we know what common GvHD symptoms are, and the impact that that could have. So, for example people with eye GvHD are going to struggle looking at screens. So, having a question about, "How able are you to work from home on a computer all day?" Well, we know that if the answer to that is, "Unable to do so," it's likely to be linked to eye GvHD. Whereas actually, their questionnaire is more around, "Are you able to work? Include working from home, because you're more likely to be able to do that"* [P13] (male, 26–39, 3 years post-transplant) *"Okay, so, "I feel close to my friends," let's say that first question. I mean, yes. I do. Do I feel as close to my friends as I did three years ago? No. So, am I as happy, or do I think I have as quality relationships now, as I did before? No. But that doesn't mean I'm not close to them. And I think that's an important distinction that the questionnaire misses out"* [P13] (male, 26–39, 3 years post-transplant)
Why?	To capture change over time Knowing what to expect and the experience of others Awareness about life post-transplant Ensuring the right support is available	*"And they're good, because they actually get you to think about how your illness or issue is affecting your life, and it's not until you sit down and you read the different categories about, I don't know, I'll give you an example, I think there was one in there about the type of clothes you wear, or does it interact with you being sociable, or these type of things. Unless you see the question and you think about how your illness is being applied to that area, you don't really break it down and understand where you are in your illness"* [P24] (male, 40–54, 2 years post-transplant) *"So I think these sorts of questionnaires would be… it would be really normalising for people who are going through crazy things with reactions to the drugs and the terrible (unclear 0:44:50) that you have to be on for such a long time after, when you come out of hospital and stuff. It would normalise the reactions they have to those sorts of things and realise that it is a process of getting strong again, slowly but surely"* [P18] (female, 65–71, 5 years post-transplant) *"I would be fine with a call from someone, or more likely an email, with some pre-filled out information about where I can get some support if I choose to. Saying, 'Hey, on this part of the questionnaire, you scored below a certain threshold. We've automatically generated this. And here's some information, and some places you can get support if you wish to'"* [P13] (male, 26–39, 3 years post-transplant) *"They do need to know these extra things, definitely. Because I think it is about the whole package of support, it's not just about the clinical. You do need to know what else there is out there, as well"* [P12] (male, 65–71, 6 years post-transplant) *"Exactly. You are so isolated during treatment and then you are isolated afterwards because of risk of infection,* etc. *And it's really important to find out about other people's experiences"* [P18] (female, 65–71, 5 years post-transplant) *"And there is a level of trust. I know that sounds ridiculous, because of course you trust your clinicians. You have to, in order to embrace all the crap that they are delivering to you on a daily basis. But somehow, they haven't lived it, so they really don't know. They know abstract level, but they don't know in a deep level that you do"* [P22] (female, 40–54, 8 years post-transplant) *"You could use it to really inform patients as to what they are about to embark on… it won't paint a particularly pretty picture, but it will paint a fair one"* [P22] (female, 40–54, 8 years post-transplant) *"I think signposting is good, because I think one of actually the main issues that I've had is that although I do have my check-up once a year, I have questions outside of that time. And I have no idea where to go for a lot of these"* [P23 B2] (female, 26–39, transplant date unknown) *"Yes, I think that would good yes, if someone filled in that they were struggling quite a lot with anxiety or their depression I suppose it'd be good for that to be picked up and then you're pointed in the right direction for groups that you could join or people that you could talk to"* [P3 B2] (female, 40–54, < 1 year post-transplant)

Table 2 (continued)

Theme	Sub-themes	Quotations
When?	Change over time < 100 days > 100 days	*"I think that would be really interesting to see at 1 year post, versus 5 years post, where people suggest their quality-of-life may be impacted. Yeah, really interesting. I do wonder about the 28 days… Day-zero makes sense because it's kind of like a blank canvas, starting from scratch"* [P2] (male, 26–39, 1-year post-transplant) *"I think it's very important that you measure throughout that journey. Because when I reflect back and I think back now, it's very different times, when I felt pain or I felt very low. You know, an example is during stem cell, I lost all my senses. I lost my appetite, and sense of taste. I didn't enjoy eating. I had a mouth full of ulcers. It was just horrendous. So that was a very different experience to the time that I was in hospital with spine pain, with those problems. So, I think it's really important that you measure that and you monitor that difference. And that's, again, I make the point of don't just stop at 100 days, I think it should be something that continues"* [P10] (female, 55–64, < 1 year post-transplant) *"Because sometimes when you are going through it all it doesn't always feel like you are getting anywhere or you really are progressing but when you actually are and sometimes these changes are small and by having that it might actually be another tool for patients to recognise actually I am coming along…"* [P17] (female, 26–39, 17 years post-transplant) *"I think [pause] I could very positively answer most of these now in a way that when I first had my transplant, you wouldn't have got a very positive reflection at all, because I wasn't able to do anything. I regretted actually having the transplant. [laughing] Whereas now, there is absolutely no way I regret it"* [P22] (female, 40–54, 8 years post-transplant) *"So, a snapshot in time is very useful to get your head in the right place to have the conversation I'm just about to have, but actually the more useful part of that tool is trends"* [P24] (male, 40–54, 2 years post-transplant) *"So, yes, because I think the experience changes over time, I think in some ways, it would be good to have it within that first year of transplant, to complete it. But also, then, maybe two years later, or… I think to have that real rounded aspect of information, I think you need to look at it – obviously, it's a long-term treatment, so over a long-term period of time"* [P12] (male, 65–71, 6 years post-transplant) *"Oh, gosh. I think you can't just capsulise a moment. I don't think it's fair, to give a real picture. I think you would have to do it prior to embarking upon it, in the time when you are maybe at home, in those few weeks before you go back in, having had your preconditioning chemo. I think you would definitely have to do it three months post, and six months post, and a year post, to get a true reflection on what is going on. And then maybe even two years"* [P22 B2] (female, 40–54, 8 years post-transplant) *"So, for me it's a really powerful tool that should be used over a period of time. And it builds up a portfolio of your return to a hundred percent quality of life, because you can track it"* [P24] (male, 40–54, 2 years post-transplant) *"As I've said, you're in survival mode, you're not thinking about last week, month, quarter, you're not even thinking about the following week, the next month, you're just thinking about today. And if somebody can take you out of that and show you actually your development, your improvement, it's also emotionally a bit of a pick-up…"* [P24] (male, 40–54, 2 years post-transplant) *"I think you need to go beyond 100 days post-transplant. Because I think that's important. It almost feels like we'll be forgotten afterwards"* [P10] (female, 55–64, < 1-year post-transplant) *"I mean in my eyes the more data that you can get, the better, so if you did, say, every six months until at least five years, I think the more data that we can get about patients post-transplant, the better"* [P17] (female, 26–39, 17 years post-transplant)
How?	Positive about electronic data capture Not one size fits all	*"Oh, yes, that's even easier, and also a bit easier to store the data that you have, because if you do it on paper, then you have to add it to the computer data that you have, so it's easier"* [P15] (female, 26–39, 1-year post-transplant) *"Because I think for a lot of people, older people, they probably don't want to do it online. They'd rather have it in paper form. So, it might be better to have it in both ways, offer both"* [P18] (female, 65–71, 5 years post-transplant) *"So, I think you've got to cater for both and give somebody a choice, so the more digitally literate would go the faster route, and digital and that'd be totally applicable and okay, and I think there's also a subset group where you've just got to go really slow, manual, large font, big bits of paper and an old fashioned pen!"* [P24] (male, 40–54, 2 years post-transplant) *"The patients are sat there for like two hours, in clinic, doing nothing. Typically waiting for a doctor. And they're a captive audience, that are sat there anyway. So, having patient volunteers, as an example, be able to be there, and get them to fill this stuff in, I think it's a huge opportunity that isn't being taken advantage of right now, I would think*" [P13] (male, 26–39, 3 years post-transplant)

their experience. For example, one patient commented about the fatigue response scale:

> *"Just because I can walk 15 min, doesn't mean I don't have fatigue. Just because I can do that, doesn't mean that I don't come home and have a nap straight away, because my body just needs to shut down for an hour" [P13] (male, 26–39, 3 years post-transplant).*

Participants described the lack of detail they could give through PROMs on areas such as their return-to-work post-transplant, social isolation, the impact of being immunocompromised and the loss of independence and ability to carry out tasks as they would have pre-transplant.

> *"And the BMT questionnaire says I am able to work. Well, I am able to work. I'm not able to do my career that I was focused on for ten years before that. But I am able to work. So, my answer to that would be, I'm able to work quite a bit. Because that's a factually correct answer. It doesn't reflect the fact that I've had to give up my career. Because the job, and the career that I had before, I can't do anymore. But I am, by that question, able to work. I could do a normal, nine-to-five job. That's not what I did before, but I'm able to do that" [P13] (male, 26–39, 3 years post-transplant).*

Why?

When asked why they think PROMs data should be captured post-transplant patients often responded that it would be helpful to monitor changes in their health as they recover. Participants described recovery following HCT as a *'rollercoaster'* with some good days and some bad days. Many participants felt PROMs can allow for patients to have a better understanding of their own self-monitoring and wellbeing, as well as reassurance that they are not alone in their transplant journey.

> *"Well, in general, I think after transplant is an up and down thing, it's a rollercoaster. Sometimes you're doing good, sometimes you're not doing good, and being able to measure in which parts you really need the help, in which parts you have it sorted, is very helpful, because you can focus on what you need to do, or where do you need to ask for help..." [P15] (female, 26–39, 1 year post-transplant).*

Most participants said retrospectively that they felt unprepared for what to expect during HCT recovery. Participants felt PROMs should be collected and used to raise awareness about life post-transplant, allowing new patients to feel more prepared for the intensity of recovery and potential HCT side-effects. For example, several participants noted that knowing there are others who have experienced similar symptoms post-transplant would have helped them feel less anxious and isolated:

> *"I didn't have any awareness of what it could be like after treatment. Where if you could fill them in and somebody looks at them and then they say to you 'oh well, that's normal. You're going to feel like that" [P4] (female, 55–64, 3 years post-transplant).*

> *"You could use it to really inform patients as to what they are about to embark on... it won't paint a particularly pretty picture, but it will paint a fair one" [P22] (female, 40–54, 8 years post-transplant).*

Participants felt that collecting QoL data through PROMs could help ensure the right support is available following HCT. By completing transplant-specific PROMs, healthcare professionals (HCPs) could be made aware of patient symptoms and can use the data collected to guide what information and support they offer.

> *"Even shaping those conversations you have at follow-ups and bits like that as well or even then giving patients ideal awareness and signposting them to services by saying, 'Oh we often find that patients experience this around this time. Don't be alarmed about this, this is how we can help you'" [P17] (female, 26–39, 17 years post-transplant).*

> *"They do need to know these extra things, definitely. Because I think it is about the whole package of support, it's not just about the clinical. You do need to know what else there is out there, as well" [P12] (male, 65–71, 6 years post-transplant).*

When?

Participants felt QoL data should be captured routinely, over a long period of time, not just until 100 days post-HCT (100 days is considered the timepoint when the greatest risk for critical side effects is past and when stem cells have engrafted). When asked to think about when QoL data should be collected many participants highlighted that data collected during initial post-transplant recovery (< 100 days) would be helpful to use as a baseline starting point for reflection.

> *"Day-zero makes sense because it's kind of like a blank canvas, starting from scratch" [P2] (male, 26–39, 1 year post-transplant).*

> *"Yes, I think that'd be really good, yes, because I think that when you go in for your transplant your quality of life is what you're used to, and then I think*

> *straight after your transplant is when you're still feeling quite ill and you've probably got the worst side effects, then 100 days you can look back and think 'yes'. I think they're quite good time scales, it gives you enough time to recover and to be able to look back and think 'yeah, I have improved, yeah'" [P3 B2] (female, 40–54, < year post-transplant).*

However, participants felt QoL data collected > 100 days post-transplant would be also useful as they felt this was often an overlooked part of their experience. They felt that long-term, continuous measures would help reflect various timepoints and capture change over time.

> *"I think it would be a good idea, because obviously I've filled it in a couple of months after my transplant, so I'm feeling a lot better now than I was before, so I think it would be a really good idea to fill it in just before you go in for your transplant, and then quite soon after coming out of hospital, and then now, and even going forward perhaps in another six months' time, and then you see how your answers have changed... because I think sometimes when just day to day you think 'oh things aren't getting better', but I think if you had a look back at the questionnaire a month ago I'd think 'well actually yeah, I'm feeling a lot better in this area'... so I think it would be quite a good thing to be reflective" [P3] (female, 40–54, < year post-transplant).*

How?

Overall, participants felt positive about electronic data capture and were positive towards the idea of receiving questionnaires on a tablet device or their phone during clinic visits, or at home.

> *"All for it. Yes, definitely. Anything that can prevent printing and paper waste. And I think nearly everyone now... I guess, 98% of your potential recipients would be able to complete it online" [P2] (male, 26–39, 1-year post-transplant).*

Participants acknowledged that electronic data capture would be more convenient and would allow more certainty about the secure storage of the data. Some participants expressed concerns about their ability to complete ePROMs, with older participants claiming they felt more comfortable with a traditional pen and paper approach. Others shared thoughts on how this issue may be overcome if ePROMs were more prominent in clinic visits, where they would have access to support and guidance from health care professionals when completing the surveys.

> *"So, I think that old fashioned give it to me on a piece of paper and then I'll go home and look through all the bits of paper, but that might just be my age, young people would probably prefer the digital version because they're much better at tracking what they've responded to and what they haven't" [P1] (female, 40–54, 4 years post-transplant).*

> *"I think particularly when we're looking at multiple myeloma, generally, the age is older, so therefore perhaps not as digitally savvy, ...perhaps need some help completing surveys. And again, perhaps that's where some of the support that I mentioned when you were in hospital with the nurses or from a team could assist people when they were in hospital to help complete those surveys" [P10] (female, 55–64, < 1-year post-transplant).*

Participants also highlighted that transplant related side-effects may hinder their ability to complete PROMs electronically. For example, one participant noted the impact of GvHD on their eyesight and how this would have affected his ability to complete electronic PROMs.

> *"I think anybody above that is probably bordering towards more paper, from a vision perspective, if I think back to sometimes, I just couldn't see things online, I didn't use a computer for a long period of time because my vision was too bad with GvHD, I had whacking headaches, I couldn't even open my eyes" [P24] (male, 40–54, 2 years post-transplant).*

Discussion

This study demonstrates that patients are generally positive about the collection of QoL data through transplant-specific PROMs. However, participants questioned whether existing PROMs are sensitive to capture day-to-day variation and subtle change over time in QoL post-transplant. Perspectives on why and when this QoL data should be collected were driven by a desire to know what to expect during transplant recovery, to learn from the experience of others, and to measure the long-term impact of transplant beyond 100 days. By capturing data > 100 days post-transplant, both patients and HCPs could observe symptom change over time, allowing for reflection and awareness of what support may be needed. Participants were positive about electronic data capture however variations in age, digital literacy and stage of illness may have a significant impact on preferences. Options should be given to patients on how to complete PROs to ensure effective data collection.

Previous qualitative work on PROMs has highlighted that often, when completing questionnaires following blood cancer, patients wonder if certain questions are relevant to them and their illness, and some struggle to identify with questions that do not relate to their situation [18, 19]. This study, whilst focused on patient experience post-transplant, shows similar findings when participants were presented with the PROMIS-29 and FACT-BMT. This study revealed that, despite FACT-BMT being the preferred option, patients still felt individual survey items may not fully capture the true patient experience of receiving a transplant. Several participants queried whether PROMs are sensitive enough to capture day-to-day variation and subtle changes over time. One of the benefits of PROs is that they give patients a voice, however these findings suggest that existing PROMs do not reflect patient experience of transplant to the extent that patients would like.

Participants felt QoL data should be collected to highlight patient experience. There has been a growing importance of the need to explore patient experience and the supportive care interventions needed to improve QoL post-transplant [20, 21]. Knowing what to expect post-transplant is essential in the decision-making process for patients when faced with a cancer diagnosis and the possibility of transplant [22]. In this study, participants expressed a desire to learn from others to gain more awareness about life post-transplant to be prepared for the changes to their QoL.

There is evidence to support the idea that routinely collected PROs with timely feedback enhances patient experience and satisfaction with care and enables HCPs to better understand and act on patient needs [23, 24]. Participants reflected on the benefit of capturing change over time. With the use of long-term, routine data capture, patients can reflect on how they felt < 100 days post-transplant to capture starting points and compare that to how they feel > 100 days post-transplant. This can act as a means of reassurance and motivation, as patients can visualise how far they have come in their recovery, as well as gaining awareness of what symptoms are normal, allowing them to raise any concerns with their HCPs.

Participants were unanimous that a 'one size fits all' approach to data capture is not appropriate and that multiple methods of data collection should be available to suit individual preferences. The idea of multi-modal methods of PRO data capture has been suggested in previous studies [25]. Participants shared concerns over the impact of age, digital literacy, and stage of illness in completing ePROMs. These are potential barriers to the use of ePROMs alongside large initial financial investment of purchasing a device to complete ePROMs [26, 27]. In this study participants highlighted concerns about the potential impact of GvHD on a patient's eyesight, affecting their ability to complete PROs digitally. Whilst electronic data capture may be convenient for some patients and HCPs, other considerations should be made of individual circumstances [28]. Thought towards patient preference for PRO data collection should improve patient engagement with individual measures being used.

Strengths and limitations

Our study presents novel data on patients' opinions towards PROMs and their views on what QoL data should be collected post-transplant, when this data should be collected, the use of this data beyond research. This study was developed with patient input through design and patients were involved in data triangulation. A convenience sample was recruited through Anthony Nolan patients and families' channels: meaning a number of participants who live a distance from their transplant centre, receive benefits, and have caring responsibilities were able to take part.

Limitations of this study include potential subjective bias of patient experience and varying levels of health literacy which can lead to different interpretations and responses to specific questions. The use of convenience sampling may restrict full representation of patient population as some participants may have had a connection with Anthony Nolan.

Conclusion

This study has contributed to a significant gap in current literature by exploring patient preferences towards the collection of QoL data following HCT. Results of this study indicate that QoL data should be collected routinely, post-100 days to capture the long-term impact of HCT. Future research should pilot the prospective collection of electronic PRO data and should explore the feasibility of sharing data in real time with patients and health professionals to inform service delivery.

Supplementary Information

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Supplementary Material 1.

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Authors' contributions

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by G.P., C.Y. and K.D. The first draft of the manuscript was written by L.Y. and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data availability
Restrictions apply to the availability of the data within this study, however all data and materials are available upon reasonable request made to the corresponding author and with permission from Anthony Nolan.

Declarations

Ethics approval and consent to participate
This study was performed in line with the principles of the Declaration of Helsinki.
The study underwent a proportionate review and received ethical approval from the Anthony Nolan Research Office.
Informed consent was obtained from all individual participants included in the study. Participants consented to interviews being audio-recorded and transcribed and to publication of the findings.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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References
1. British society of blood and marrow transplantation and cellular therapy. https://bsbmtct.org/activity/2021/2022. 2021 UK & ROI Transplant Activity Table by Disease.
2. Inamoto Y, Lee SJ. Late effects of blood and marrow transplantation. Haematologica. Ferrata Storti Foundation. 2017;102(4):614–25.
3. Cusatis R, Flynn KE, Vasu S, Pidala J, Muffly L, Uberti J, et al. Adding centralized electronic patient-reported outcome data collection to an established international clinical outcomes registry. Transplant Cell Ther. 2022;28(2):112.e1–112.e9.
4. Efficace F, Collins GS, Cottone F, Giesinger JM, Sommer K, Anota A, et al. Patient-reported outcomes as independent prognostic factors for survival in oncology: systematic review and meta-analysis. Value in Health. 2021;24(2):250–67.
5. Patel SS, Lapin B, Majhail NS, Hamilton BK. Patient-reported outcomes in acute graft-versus-host disease: optimizing patient care and clinical trial endpoints. Bone Marrow Transplant. Springer Nature. 2020;55(8):1533–9.
6. Kluzek S, Dean B, Wartolowska KA. Patient-reported outcome measures (PROMs) as proof of treatment efficacy. BMJ Evid-Based Med. BMJ Publishing Group. 2022;27(3):153–5.
7. Bottomley A, Reijneveld JC, Koller M, Flechtner H, Tomaszewski KA, Greimel E, et al. Current state of quality of life and patient-reported outcomes research. Eur J Cancer. 2019;1(121):55–63.
8. Rothrock NE, Kaiser KA, Cella D. Developing a valid patient-reported outcome measure. Clin Pharmacol Ther. 2011;90(5):737–42.
9. Fda. Guidance for Industry Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims. 2009.
10. McQuellon R, Russell G, Cella D, Craven B, Brady M, Bonomi A, et al. Quality of life measurement in bone marrow transplantation: development of the Functional Assessment of Cancer Therapy-Bone Marrow Transplant (FACT-BMT) scale. Bone Marrow Transplant. 1997;19(4):357–68.
11. Hays RD, Spritzer KL, Schalet BD, Cella D. PROMIS®-29 v2.0 profile physical and mental health summary scores. Qual Life Res. 2018;27(7):1885–91.
12. Cusatis R, Flynn KE, Vasu S, Pidala J, Muffly L, Uberti J, et al. Adding centralized electronic patient-reported outcome data collection to an established international clinical outcomes registry. Transplant Cell Ther. 2022;28(2):112.e1–112.e9.
13. Mejdahl CT, Schougaard LMV, Hjollund NH, Riiskjær E, Thorne S, Lomborg K. PRO-based follow-up as a means of self-management support – An interpretive description of the patient perspective. J Patient Rep Outcomes. 2018;2:38.
14. Shaw BE, Lee SJ, Horowitz MM, Wood WA, Rizzo JD, Flynn KE. Can we agree on patient-reported outcome measures for assessing hematopoietic cell transplantation patients? A study from the CIBMTR and BMT CTN. Bone Marrow Transplant. 2016;51(9):1173–9.
15. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57. https://doi.org/10.1093/intqhc/mzm042. Epub 2007 Sep 14. PMID: 17872937.
16. Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. Qual Res Sport, Exer Health. Routledge. 2021;13(2):201–16.
17. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101. Available from: https://www.tandfonline.com/action/journalInformation?journalCode=uqrp20. Cited 2024 Jan 26.
18. Thestrup Hansen S, Kjerholt M, Friis Christensen S, Brodersen J, Hølge-Hazelton B. I am sure that they use my PROM data for something important. A qualitative study about patients' experiences from a hematologic outpatient clinic. Cancer Nurs. 2020;43(5):E273–82.
19. Buckley SA, Jimenez-Sahagun D, Othus M, Walter RB, Lee SJ. Quality of life from the perspective of the patient with acute myeloid leukemia. Cancer. 2018;124(1):145–52.
20. Pidala J, Anasetti C, Jim H. Health-related quality of life following haematopoietic cell transplantation: patient education, evaluation and intervention. Br J Haematol. 2010;148:373–85.
21. Burns LJ, Abbetti B, Arnold SD, Bender J, Doughtie S, El-Jawahiri A, et al. Engaging patients in setting a patient-centered outcomes research agenda in hematopoietic cell transplantation. Biol Blood Marrow Transplant. 2018;24(6):1111–8.
22. Jim HSL, Quinn GP, Gwede CK, Cases MG, Barata A, Cessna J, et al. Patient education in allogeneic hematopoietic cell transplant: what patients wish they had known about quality of life. Bone Marrow Transplant. 2014;49(2):299–303.
23. Chen J, Ou L, Hollis SJ. A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. BMC Health Serv Res. 2013;13:211.
24. Nguyen H, Butow P, Dhillon H, Sundaresan P. A review of the barriers to using Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs) in routine cancer care. J Med Radiat Sci. John Wiley and Sons Ltd. 2021;68(2):186–95.
25. Greenhalgh J, Dalkin S, Gooding K, Gibbons E, Wright J, Meads D, et al. Functionality and feedback: a realist synthesis of the collation, interpretation and utilisation of patient-reported outcome measures data to improve patient care. Health Serv Deliv Res. 2017;5(2):1–280.
26. Glenwright BG, Simmich J, Cottrell M, O'Leary SP, Sullivan C, Pole JD, et al. Facilitators and barriers to implementing electronic patient-reported outcome and experience measures in a health care setting: a systematic review. J Patient-Rep Outcomes. Springer Science and Business Media Deutschland GmbH. 2023;7(1):13.
27. Meirte J, Hellemans N, Anthonissen M, Denteneer L, Maertens K, Moortgat P, et al. Benefits and disadvantages of electronic patient-reported outcome measures: systematic review. JMIR Perioper Med. 2020;3(1):e15588.
28. Kiderlen TR, Schnack A, de Wit M. Essential barriers and considerations for the implementation of electronic patient-reported outcome (ePRO) measures in oncological practice: contextualizing the results of a feasibility study with existing literature. J Public Health (Germany). 2023;31(12):2071–88.

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