SSM - Qualitative Research in Health 2 (2022) 100187

Contents lists available at ScienceDirect

SSM - Qualitative Research in Health

journal homepage: www.journals.elsevier.com/ssm-qualitative-research-in-health

‘It's about what I'm able to do’: Using the capabilities approach to understand the relationship between quality of life and vascular access in patients with end-stage kidney failure

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ARTICLE INFO

Keywords:
Capabilities approach
Chronic illness
Dialysis
Quality of life
Vascular access

ABSTRACT

Prevalence rates of End-Stage Kidney Failure (ESKF) have risen in across the world in recent years, making it one of the most common chronic illnesses. The main treatment for ESKF is haemodialysis, where one is ‘connected’ to a dialysis machine to clean and filter the blood via a surgically-created portal, also known as ‘vascular access’. Without functioning vascular access, dialysis is impossible. People with ESKF have different experiences with their access modalities, but universally describe their access point as a ‘lifeline’. Previous research has emphasised the impact it can have on wellbeing (Kalloo et al., 2016; Casey et al., 2014; Quinn et al., 2008), and specifically on short- and long-term outcomes.

Capturing Quality of Life (QoL) within ESKF populations has traditionally focused upon assessing wellbeing from an objective, normative, top-down stance, rather than appreciating the nuanced effect vascular access can have as experienced by those living with kidney failure. In this article, we argue current QoL measures used with ESKF groups are insufficient at capturing the impact of vascular access on wellbeing. Using the accounts of twenty-four haemodialysis patients, we share insights into the direct and indirect influences vascular access has upon QoL, using Nussbaum's Capabilities Approach as an analytical lens. By prioritising and privileging the voices of those directly affected, the Vascular Access Specific Quality of Life (VA Specific-QOL) model provides a starting point for a more representative way to assess wellbeing in this group.

1. Introduction

End-Stage Kidney Failure (ESKF) occurs when kidney function can no longer sustain everyday life. ESKF is a rapidly increasing global health problem which carries significant healthcare burden and is associated with increasing age. An estimated 2.6 million people received Kidney Replacement Therapy (KRT) in 2010; however, 2–3 times that number were estimated to need KRT, and died because of lack of access. This is also reflected in morbidity rates, with an estimated worldwide prevalence rate of 9.1% and loss of 35.8 million Disability-Adjusted Life-Years (GBD CKD Collaboration, 2020).

KRT comprises three main modalities – kidney transplantation, haemodialysis (HD; home or in-centre), or peritoneal dialysis (PD). Globally, access to KRT is influenced by prevailing healthcare infrastructure and funding (Thurlow et al., 2021), and access to treatment varies; the proportion of people with ESKF not receiving KRT is significantly higher in low (96%), and lower-middle (90%) income countries compared to upper-middle (70%) and high-income countries (40%). An estimated 80% of those receiving KRT will undergo HD in-centre, with regional variation observed in New Zealand, where home-based HD is more prevalent (17%), while PD was commonly used in Hong Kong, Mexico, and Guatemala.

In the UK, 68,111 adults and 832 children received KRT in 2019 (UK Renal Registry, 2021); over half received a transplant (56.8%), while

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Abbreviations: ESKF, End-stage kidney failure; KRT, Kidney replacement therapy; QoL, Quality of life; VA, Vascular access.

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https://doi.org/10.1016/j.ssmqr.2022.100187
Received 13 July 2021; Received in revised form 22 August 2022; Accepted 15 October 2022

over one-third (35.8%) had HD in-centre, 2% had home HD, and 5.4% received PD. Approximately 61% of this population are male, while in terms of ethnicity, three-quarters identify as White, 14.5% Asian, and 8.9% Black. The reasons for ESKF are diverse, with diabetes (19.5%) and glomerulonephritis (18.3%) being the most common. While access is theoretically universal in the UK via the National Health Service, variation is observed and stratified by race, socioeconomic status, and underlying comorbidity (Pruthi et al., 2020).

While awaiting transplantation, most people opt for haemodialysis, where blood is removed and passed through a dialysis machine to remove waste, electrolytes, and excess fluid before being returned to the body. Patients typically dialyse in a dialysis unit for 4 hours, three times a week. To enable haemodialysis, patients must have a form of ‘vascular access’ (VA) with three options regularly used in the UK:

i. **Arteriovenous fistula (AVF/fistula):** surgically created by joining a vein to an artery in the arm that enlarges over time. While offering the longest lasting and lowest infection risk for dialysis, fistula operations have a success rate of only 50%, and often need several interventions (Stoumpos et al., 2019).
ii. **Arteriovenous graft (AVG/graft):** synthetic tube surgically inserted in arm or leg, joining an artery and vein, where needles can be inserted (cannulated) for dialysis. While nearly always successful, grafts require more intervention to maintain function, and have a more limited durability.
iii. **Central Venous Catheter (CVC/line):** plastic tubes inserted through the skin surface, tunnelled under the skin, and then passing into a large vein in the neck. Although lines do not require needling to allow dialysis, 20–50% require replacement within the first six months, have the highest rate of serious infection, and can lead to long-term scarring of the central draining veins which is difficult to treat.

Whilst it is well recognised that significant underlying disease and the state of kidney failure can affect wellbeing, it is less understood how the widely varying modality of vascular access *specifically* impacts on wellbeing. For most requiring KRT, treatment is supportive rather than curative, thus making the impact on quality of life an essential determinant in selecting vascular access modality.

This research sought to explore the relationship between vascular access and Quality of Life of patients with ESKF in the UK. In this paper, we make the case for *why* current QoL measures are insufficient, and do not fully encapsulate the experience of living with ESKF. We use evidence gathered through interviews to demonstrate the value of adopting Nussbaum's *Capabilities Approach* in formulating a better understanding of quality of life for those with ESKF.

1.1. Defining quality of life

Quality of Life (QoL) refers to “individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL Group, 1998, p. 551). *Health-Related* Quality of Life (HR-QoL) focuses specifically on the role health has upon determining QoL (Carr et al., 2001). There is a complex inter-relationship between objective and subjective indicators used to derive QoL/HR-QoL – including social, environmental, psychological, and physical factors, integral to a person's interpretation of their wellbeing (Ferriss, 2004).

Objective indicators represent ‘normative functionings’ – actions most able-bodied people can perform, such as walking, dressing, and bathing. Conversely, subjective indicators focus on elements pertinent to enjoyment and satisfaction. Both indicators are typically framed within normative understandings of what constitutes a ‘good’ life, which Muschenga (1997: 21) argues “are relevant for medical decision making”. Despite this, objective measures are utilised more frequently in assessing and quantifying the effects of treatment on QoL, consequently privileging normative functioning over subjectively interpreted understandings of wellbeing and happiness. As Taylor and Mykitiuk (2011) explained, ‘normalcy’ is presented as an objective way to understand human beings, “a means to represent or quantify ‘what is’ on the basis of statistical averages”. They problematise this:

> “… the “normal” also contains often opaque and unquestioned value judgments, and is used to represent what is right, and desirable. Often, when normalcy is invoked, there is a blurring of the distinction between fact and value, confusing what is, with what should be.” (Taylor & Mykitiuk, 2011)

Consequently, the voices of ‘non-normative’ bodies – those falling outwith the expected, healthy, functionable ‘norm’ – are silenced and ignored.

This study focuses on ‘non-normative’ bodies with ESKF, changed through the presence of a chronic, life-limiting illness. Non-normative bodies typically have their ability to attain abstract, culturally-defined norms required for the fulfillment of subjective markers integral to a ‘good’ QoL – e.g., having children or a ‘professional’ career – restricted by both bodily, corporeal limits *and* societal and structural barriers impeding their ability (see Oliver, 1990). We argue the incorporation of such normative markers within QoL measures further compounds the able-bodied/disabled dichotomy – in many cases, presenting an unattainable ‘ideal’ by which non-normative bodies are measured against, compounding the wider impact of ableism from something seemingly innocuous. Taylor and Mykitiuk (2011), emphasised the wider socio-economic and political impact:

> “Within a democratic notion of citizenship, each individual is assumed to possess the characteristics of self-reliance, efficiency and competitiveness. As a result, an idealized version of the “average person” has come to exist, while those who do not possess these privileged characteristics are considered abnormal—often because of the perception that they are not healthy. [… Disabled people] are seen as both political and medical challenges, and problems.”

Thus, reframing the ‘ESKF body’ within an impairment-inclusive QoL model was a central aim of this project.

1.2. Measuring quality of life & End-Stage Kidney Failure

Several HR-QoL instruments have been used to evaluate QoL with ESKF patients. Generalised measures capturing one's overall assumption of their health dominate the ESKF field, with EuroQol Five-Dimension (EQ-5D), WHOQOL-BREF, and Short Form-36 (SF-36) being the most frequently used (see Table 1).

Generalised measures help gauge QoL *beyond* one's illness, providing a means to loosely compare both between *and* beyond parameters derived by health conditions. However, such generalisability means subtle ways specific conditions may influence QoL are lost. Of relevance here is Kalloo and colleagues' (2016: 152) work which drew attention to the effect vascular access can have upon one's QoL, particularly through access-specific issues such as “frequent cannulations, long periods of immobility during haemodialysis, post-dialysis fatigue, and possibly frequent interventions to mature and maintain their vascular access”. We argue a model that does not account for this complexity is not fully capturing QoL, instead focusing on normative conceptions of what *quality of life* means and privileging objective over subjective factors.

This concern has been noted by others, and *kidney-specific* HR-QoL have been devised. Based on SF-36, the ***Kidney Disease Quality of Life (KDQOL)*** and the short form version sought to provide a means to assess the impact of kidney disease on “functioning and well-being in physical, mental and social dimensions of life” (Hays et al., 1994, p. 329). It is typically used in a clinical setting to provide a base evaluation within four months of beginning dialysis, and repeated annually (Cohen et al., 2019). Using KDQOL-SF, Lopes et al. (2007) found respondents dialysing

Table 1
Summary of generalised and QoL measures.

Measurement Tool	Ranking System	Domain	No. of Questions	Vascular Access Items
Generalised Measures				
EQ-5D (e.g. Cleemput et al., 2004; Jardine et al., 2017)	**EQ-5D-3L:** 1 to 3 (none, some, severe problems)	Mobility	1	N/A
	EQ-5D-5L: 1 to 5 (none, slight, moderate, severe, extreme problems)	Self-Care	1	
		Usual Activities	1	
		Pain or Discomfort	1	
		Anxiety or Depression	1	
WHOQOL-BREF (e.g., Sathvik et al., 2008; Theofilou, 2011)	1 to 5 (Likert scale)	Physical Health	7	N/A
		Psychological Health	6	
		Social Relationships	3	
		Environment	8	
SF-36 (e.g., Maglakelidze et al., 2011)	Variety of scales used:	Physical Health (includes physical functioning; physical role; bodily pain; general health)	21	N/A
	1 to 3 (10 questions)	Mental Health (includes vitality; social functioning; emotional role; mental health	14	
	1 to 5 (9 questions)	Health Change	1	
	1 to 6 (10 questions)			
	Yes or No (7 questions)			
Generalised Measures				
KDQOL-36 (e.g., Cohen et al., 2019; Hays et al., 1994)	Variety of scales used:	General Health	12	1
	1 to 3 (2 questions)	Kidney Disease	16	
	1 to 5 (27 questions)	Effects of Kidney Disease on Life	8	
	1 to 6 (3 questions)			
	Yes or No (4 questions)			
Vascular Access Specific Measures				
SF-VAQ (e.g., Quinn)	1 to 7 (Likert scale)	Satisfaction with Access	1	13
		Physical Symptoms	4	
		Social Functioning	4	
		Dialysis Complications	4	
HARQ (e.g., Nordyke et al., 2020)	No scale reported	Symptoms Physical function, Emotional impacts, Social and role functioning Sleep Care-related burdens	47	Draft items not reported

via line reported lower levels of life satisfaction compared to other access modalities. This link between access modality and wellbeing emerged incidentally, providing support for further exploration within a diagnosis category and able to extrapolate differences based on type of vascular access used.

The ***Vascular Access Questionnaire (VAQ)*** (Quinn et al., 2008) sought to elicit reports of access-related problems among ESKF patients. Shortened to ease the time-burden on respondents, ***Short Form–Vascular Access Questionnaire (SF-VAQ)*** (Kosa et al., 2015) focuses on: patient satisfaction with vascular access, experience of physical symptoms (including pain or bleeding), vascular access and social functioning, and experience of dialysis complications. SF-VAQ has been used in cross-sectional, cohort studies in the UK to assess patient satisfaction across different vascular access modalities and dialysis units with the aim of identifying areas for quality improvement (Kosa et al., 2015; Field et al., 2019). More recently, Nordyke et al. (2020) devised the ***Haemodialysis Access-Related Quality of Life (HARQ)***. HARQ originated from a 'conceptual framework' derived from expert practitioners and areas of concerns identified within literature to produce the final instrument.

Through the development of KDQOL, VAQ, and HARQ, attention has been drawn to the link between vascular access and QoL. A systematic review of existing qualitative evidence supported the need for a more nuanced exploration of these issues (Casey et al., 2014; also, Woo et al., 2021) as overarching themes pertained to vulnerability, disfigurement, and bodily integrity demonstrate the important role vascular access takes in determining one's QoL. Similarly, both patients and clinicians highly rated the importance of vascular access functioning in wellbeing, alongside other associated problems such as pain, hospitalisations (Viecelli et al., 2020). Despite this clear importance to patients, their views are poorly captured in clinical trials; Viecelli et al. (2018) reported only 3% of haemodialysis trials presented patient reported data on QoL outcomes. Research utilising VAQ/SF-VAQ and HARQ has been limited thus far, but initial work has produced illuminating insights. Comparing access types, Kosa et al. (2015), Lee (2017) and Sridharan et al. (2018) found respondents were most satisfied with fistula access. Nordyke et al. (2020) found patients were twice more likely to mention 'worry' or 'anxiety' in relation to their vascular access compared to other factors explored. Similarly, needle cannulation of fistula and grafts were considered as a 'major source of dissatisfaction,' leading Kosa et al. (2015) to argue for the development of strategies to mitigate patient's fear and pain linked to cannulation.

1.3. *Advancing the discussion*

The review of haemodialysis-specific QoL measures presents a clear and compelling justification for the development of a HR-QoL measure focusing specifically on the impact of the *vascular access* – whether line, graft, or fistula. However, following a critical engagement with model derivation, we propose the exploration of two approaches to further advance developments in this area: (i) expanding the theoretical grounding, and (ii) focusing on a 'bottom-up', patient-centred approach to determining *'what matters'*.

1.3.1. *Theoretical grounding: Capabilities Approach*

Models discussed thus far typically focused on overall health, or symptoms related to a condition, and do not fully capture one's ability to 'function' within the realms of normative societal expectations. However, the inherent challenge comes with attempting to synthesise the abstract notion of 'functionality,' with the visceral, lived experience of living with a chronic illness. We propose utilising the Capabilities Approach as a theoretical lens.

Emerging in the 1980s, the Capabilities Approach (CA) was developed by Sen and Nussbaum as a culturally sensitive, 'normative' philosophy of what constitutes a 'good' life. It provides an alternative means of understanding wellbeing, where emphasis is placed on one's "freedom to lead the kind of lives they value – and have reason to value" (Sen, 1999, p. 18). Nussbaum (2011) identified ten, core capabilities all democratic societies should support: life; bodily health; bodily integrity; senses, imagination, and thought; emotions; practical reason; affiliation; other species; play; control over one's environment. Nussbaum's interpretation of CA focuses on the intersection between 'capabilities' and 'functionings', where one's *capability* to do, to be, or to have something, is realised through the act of doing, being, or *functioning*. For example, one may hold the ‘capability’ to be educated or be nourished but is through engaging in ‘doings’ – such as going to school or eating a varied diet – this is achieved. It provides us with a relational understanding of how QoL intersects with health and wellbeing and encompasses the role personal agency plays within bounded social structures. It allows us to think beyond physiological measures to consider how people “possess capabilities to ‘be’ and ‘more than just be’ rather than focusing on indicators of health status” (Grewal et al., 2006, p. 1898).

CA has been utilised in several QoL measures (Lorgelly et al., 2015; Simon et al., 2013), including the ***Investigating Choice Experiments for the Preferences of Older People (ICEPOP)*** project, which led to the creation of ICECAP-O – a CA approach to measuring QoL with older people. The model used mixed methods research to establish five key domains: a*ttachment, social roles, enjoyment, security, and control* (Grewal et al., 2006). ICECAP has been revised for working-age adults (Al-Janabi et al., 2012), encompassing alternative domains to represent the needs of this group: *stability, attachment, achievement, autonomy, and enjoyment*. ICECAP has been validated and used in health economic evaluations (Proud et al., 2019).

ICECAP's success in providing a meaningful measure of QoL is of relevance to ESKF patients with vascular access. Physiological results provide insight to physical functionality of the body; however, they do not capture the personal, subjective interpretation of life in a body with kidney failure. Many of the models outlined in this article provide a glimpse into this, but do not fully consider the person *beyond* the condition. Rather than a ‘top down’ professional opinion about specific symptoms, using the Capabilities Approach as a theoretical grounding provides a means to develop a relational understanding, valuing what is important to people, to meaningfully compare across the affected population, and look beyond the corporeal bounds of pain and disease.

1.3.2. Patient inclusivity: ‘bottom up’ models

Including patients in the creation of QoL instruments should be essential to development. Condition-specific measures, such as KDQOL, VAQ, and HARQ, involved accounts of patient's experience, however the extent to which qualitative accounts informed the creation of these models varied. KDQOL utilised widely varying heterogenous types of data: a systematic review, statistical information obtained from administering the SF-36, and qualitative data from focus groups with patients and healthcare providers (Hays et al., 1994). Similarly, VAQ was derived through semi-structured interviews with twelve haemodialysis patients about “advantages and disadvantages of their current vascular access” (Quinn et al., 2008, p. 123), supplemented by four interviews with practitioners. Beyond gender, and experience of peritoneal dialysis and/or haemodialysis, limited demographic information is shared about who took part in this research. By contrast, HARQ involved more patients throughout the development process (Nordyke et al., 2020); however, the conceptual framework and initial item pool – determined by practitioners – informed the structure of data collection, and thus predetermined most interaction with participants. Abma et al. (2009) argue patients should be integral to the research process; the limited numbers of participants engaging in qualitative components underpinning the development of QoL models mean this involvement is minimal, and often restricted to a ‘top-down’, professional framing of the issue.

2. Methods

Given the underlying onto-epistemological priorities of amplifying patient experience (Hayes et al., 2012), it was essential to the research team that participant voices were embedded throughout this project. To maximise this, three phases of data collection were designed. Phase 1 involved scoping interviews (n = 6), to explore the biographical narratives of their ‘illness journey’ (Bell, 2000). Phase 2 involved semi-structured interviews (n = 18) and explored vascular access using the Capabilities Approach. Phase 3 involved two focus groups to sense-check the data gathered previously and verify the items for the proposed QoL measure. Table 2 provides a summary of data collection, recruitment, and analysis. This paper focuses on data gathered in Phase 2; information about Phases 1 and 3 is provided to contextualise the overarching study design.

Data were collected between January and August 2018 in hospitals and dialysis units within NHS Greater Glasgow and Clyde; preceding this, ethical approval was sought from NHS Newcastle Research Ethics Committee. All data collection took place within clinical settings and ranged from one to 4 h in length. All participants were identified by gatekeepers within clinical settings and approached by a member of the research team. Informed consent was obtained before, and reviewed after, each research encounter to provide an opportunity for withdrawal (Nusbaum et al., 2017). Audio files were transcribed by administrative staff in NHS Greater Glasgow and Clyde, and each transcript was verified, cleaned, and anonymised by SG.

Six participants took part in Phase 1; an exploratory stage of the research process, allowing the researcher to immerse themselves in the patient's perspective of living with vascular access. Table 2 provides an overview of data collection; the analysed data fed directly into the construction of the semi-structured interview guide for Phase 2. Eighteen participants were recruited to take part in this phase. Interviews[1] involved a focused discussion of vascular access and haemodialysis within their ‘illness journey’; narratives were typically framed biographically, emphasising the cumulative impact of living with a life-limiting, chronic illness (Bury, 1982).

Phase 2 utilised a quota sampling framework (Robinson, 2014) to ensure a range of experiences were captured; this allowed us to explore the heterogeneity of the vascular access patient population. Quota sampling categories (Table 2) were identified by the clinical team based on known factors that affect creation and maintenance of vascular access. This approach ensured patients undergoing haemodialysis were not constructed homogenously, absent of varied intersectional identities. Instead, participants were considered as a heterogenous group, with specific areas of commonality.

Data from Phase 2 were thematically analysed (Braun & Clarke, 2006) in NVivo12 using inductive and deductive coding (Saldaña, 2016) – the latter informed by broad concepts linked to the *Capabilities Approach.* Themes reflected the intertwined nature of vascular access and haemodialysis. These were discussed with the wider research team, where a process of refinement led to a disentanglement of vascular access issues from primarily haemodialysis or KRT issues. These themes were further scrutinised during Phase 3, where two focus groups were carried out (one with patients, another with practitioners). The focus group involved Nominal Group Technique (Harvey & Holmes, 2012), allowing discussion to centre on ranking themes by importance. This deviates from other VA-specific QoL measures, as practitioner perspectives typically dominate the construction of the final measure.

Participant demographics

Over half (54%) Phase 1 and 2 participants (n = 24) identified as female. Ages ranged from 23 to 77, with the average being 57 years (SD = 13.2). Three participants (13%) identified as being of colour. One third (n = 8) of the group had a diabetes diagnosis, and under half had experience of receiving a kidney transplant (n = 10, 42%). In terms of access modality almost all (92%) had experience of fistulas, three-quarters (75%) had experience of lines, and half of participants had experience of grafts. Current vascular access use was evenly distributed with 33% (n = 8) using a fistula, 33% using a graft, 21% (n = 5) using a line. Three participants were not using their access at the time of interview (two recent and one failing transplant). Detailed demographics and vascular access history of participants is summarised in Appendix A - Supplementary data.

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[1] Topic guide available in Appendix A - Supplementary data.

Table 2
Overview of research design.

Phase	Data Collection	Recruitment	Analysis
1. Scoping Interviews (n=6)	Scoping interviews were open-ended and focused on eliciting biographical narratives of 'illness journeys' (Bell, 2000).	Gatekeepers identified participants with a diverse range of experiences with ESKF, HD, and VA. Participants approached and recruited by SG.	SG thematically analysed biographical narratives, using Nussbaum's capabilities approach as a theoretical lens. Common experiences between all participants were easily identified – this informed the creation of a semi-structured interview guide (see Appendix A - Supplementary Data).
2. Semi-structured interviews (n=18)	Semi-structured interview guide informed by Phase 1 analysis. Aim was to explore the capabilities approach in relation to VA experience. Topics included: • Experience of VA, ESKF, and perceived impact on QoL • Capability domains, and relevance to lived experience.	Quota sampling used (Robinson, 2014); essential criteria defined based on clinical expertise in the research team to maximise diversity in responses: • age • gender • ethnicity • diabetes diagnosis • experience of type(s) of VA • length of time on HD Gatekeepers helped identify suitable candidates.	Thematically analysed using NVivo12 by SG. Analysis sense checked with broader research team.
3. Focus groups x 2	Nominal Group Technique (Harvey & Holmes, 2012) used to verify and sense-check the findings of Phase 2 – particularly the use of Capabilities Approach.	Practitioners emailed by KS asking for expressions of interest. A range of healthcare professionals were approached (e.g., VA nurses, nephrologists, radiologists, surgeons, psychologists).	Transcripts of focus groups were thematically analysed using NVivo12.
• Practitioner (n = 7)	Guidance provided in Appendix A - Supplementary Data.	Patient participants were required to have substantial experience of VA and KRT (over 1 year). All approached by local gatekeepers.	Ranking exercise slips used in discussion were gathered and used to inform research term discussion. Fig. 1 presents a comparison of patient and practitioner views.
• Patient (n = 4)		Informed consent obtained from participants at start of focus group.	

3. Results

This research sought to explore the relationship between vascular access and quality of life (QoL). Analysis of interview data[2] highlighted direct and indirect themes that vascular access affected QoL as analysed through the lens of the Capability approach. Additional illustrative quotes are provided in Appendix A - Supplementary data.

3.1. Direct influences

The most prominent influence reported by participants was the physical function of their vascular access; all spoke about working access that enabled dialysis, with the majority considering it an essential factor in determining QoL. Participants had a wide range of experience with vascular access, with the majority (20 out of 24) having experienced more than one fistula, graft, or line to varying levels of success, thus experiencing loss of working access.

Functionality transcends the entire lifecycle of vascular access: from the point of creation, to use for dialysis, maintenance, and for some, failure, and medical intervention. Participants frequently spoke about their access in physical terms, describing pain, swelling, and bruising (Casey et al., 2014; Nordyke et al., 2020), and it was common to describe the impact on autonomic, everyday actions. Maryam (60, fistula) would often be kept awake by the noise and sensation of her fistula 'buzzing'; something she found *'annoying'*, yet *'reassuring'* of functioning. The visual appearance of vascular access made many participants feel self-conscious, describing their fistulas, grafts, and lines as *'ugly'*, *'bulbous'*, and *'deformed'*. This concern impinged on their ability to feel comfortable with others, with many discussing the ways they used clothing, such as long sleeves and trousers to conceal forms of access and 'pass for normal' (Scott, 2015).

The primacy of vascular access function was apparent in many accounts, superseding other factors like appearance. Sarah (36, graft), who described her graft as her *'lifeline'*, had various experiences of losing function. Her frustration was apparent: *"I wanted an access that would work. I'd passed all the vanity bits"*. Unfortunately, losing working access was a frequent experience for participants, with many experiencing vascular access blockage or failure, leaving them *'disappointed,' 'deflated,'* and *'anxious'* at the prospect of further hospitalisations and medical intervention(s). These encounters were frequently cited as negatively impacting everyday activities and impinged on respondent's QoL. Alexander (66, newly transplanted), spoke of the cumulative burden of lengthy hospital stays to rectify vascular access issues:

> "… They never were able to tell me why I was clotting so badly. […] If I had been one of the successful ones in terms of it not clotting, that would have been a good form of access. I don't know what the statistics are, I don't know if I was one of the worst examples of what happens … but I would need to be convinced if I was going on something like that again."

Alexander's account mirrors the wider apprehension, frustration, and anxiety felt by those who had experienced hospitalisations due to access problems like clotting or infections. These encounters of physical dysfunctionality led participants to view their access as an integral factor in their QoL. Participants also described variation in the sensations and impact of their access when it was being used for haemodialysis either at cannulation or during a HD session and described differences outwith haemodialysis sessions.

3.2. Indirect influences

Participants saw beyond the physical nature of their lines, grafts, and

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[2] Data presented foregrounds the voices of participants; where appropriate, direct quotations are used, supported with the participant's age and mode of vascular access at time of interview.

fistulae, and recognised vascular access was part of their long-term, chronic illness. They frequently drew connections to the ways vascular access indirectly affected their general enjoyment of health, relationships, autonomy and control, and everyday tasks – consequently influencing how they felt about their QoL.

All participants stressed the importance of 'good' physical health in determining a 'good' QoL. Carole (62, fistula) emphasised the importance of being *"healthy and free from pain"*, stating *"you could live a long life, and your life could be miserable"*. Most interpreted their present QoL in 'before and after' terms, emphasising the notable impact of being diagnosed with ESKF, and adapting to life with vascular access and KRT. Rosie explained life 'now' was marked by not *"being what you were like before"*, while Donald (67, graft) described his QoL as *"dropping dramatically … because I couldn't do what I wanted to do"*.

Most saw QoL as holistic, comprised of physical and psychological wellness. Problems encountered with vascular access were typically generalised and interpreted within the wider context of living with a life-limiting, chronic health condition *and* associated comorbidities (e.g., hypertension, diabetes). Melissa (35, graft) felt overwhelmed with the cumulative impact of living with ESKF and diabetes:

> "I found the diabetes really hard to deal with on its own … then I've got [ESKF]. It's hard mentally on me."

Frequently mentioned in connection with QoL and wellbeing, participants valued the ability to maintain positive relationships. All cited positive familial relationships as integral to a 'good' QoL, and a means to preserve 'normality' and 'stability'. Kathy (56, line) spoke fondly of her children and grandchildren, emphasising the importance role relationships take in maintaining a sense of normality:

> "… we bake, we sew, we knit, y'know? We spend loads of time together […] that's my life. If it wasn't for them, I wouldn't have a life."

Kathy's vascular access mediated the physical connection she was able to have with her grandchildren; her fistula meant being unable to hold new-born grandchildren, while her line – named *'nannie's pipes'* by her grandkids – made it difficult to embrace them. Others were affected more broadly; Maryam (60, fistula) spoke about her reliance on dialysis being a barrier to visiting family over 4000 miles away, and her sadness at potentially never seeing them again.

Spousal relationships were frequently cited as integral to maintaining a good QoL and coping with the difficulties posed by vascular access. Both Lynne (52, graft) and Rosie (61, line) mentioned how they *'couldn't function'* without daily support from their husbands. This need was heightened for those dialysing at home – Brian, Scott, Carole, and Phil all lived with a supportive partner, who was able to support them in dialysing at home. Each couple had an intricate breakdown of the tasks that each half would perform to ensure that dialysis went as smoothly as possible; for example, Brian (67, fistula) would place the needles in his arm, while his wife would ensure he was connected to the dialysis machine. Carole's (62, fistula) husband was *"very conscious of keeping the fistula safe"* given the imperative role of *working* access in maintaining a good QoL. Given his role in her treatment, this placed her husband in a position of responsibility for Carole's wellbeing, and her QoL – echoing findings from previous studies (Giles, 2004; Tong et al., 2013).

Most participants spoke of shifts (resulting from ESKF) affecting their ability to 'do' friendship (Pahl & Spencer, 2010) as negatively affecting their QoL (see Charmaz, 1993). Fiona (49, graft) lost friends when her health forced her to withdraw from work, while both Frank (77, graft) and Scott (46, fistula) felt their friends *'dissipated'* as their health deteriorated, and they became unable to socialise. Friendship was highly valued by participants, but the pressure to be 'present' affected many participants QoL; Lynne (52, graft) and Kathy (56, line) reflected on being 'absent' in friendship circles due to the fluctuating nature of their condition, and indeed, their vascular access – mentioning *direct* impacts, such as vascular access functioning and appearance influencing their friendships. Sarah (36, graft) has lived with ESKF since birth, with a short respite in her twenties following a successful transplant. Referring to haemodialysis and issues with vascular access, she spoke about not wanting to let her friends *"see this part of my life"*:

> "[Friends] don't want to know. It's just the kind of thing you do when you meet somebody isn't it. 'Hi, how are you?' – You don't want them then to stand there and tell you 'well, my [graft] clotted … '"

Participants took solace in connecting and building relationships with other ESKF patients. Situational friendships with other patients often arose from dialysing at the same place and time, being hospitalised together on the same ward, or travelling together with patient transport. This understanding and companionship continued, even when one party received a transplant; Alice (61, graft) spoke fondly about her friendship with a woman she started dialysis with who had received a successful transplant, explaining *'she still understands'*. However, this support is two-fold, with the importance of being able *to* support as well as *being* supported frequently emphasised; Jack (70, line) detailed how he had supported someone in a similar situation, and how grateful their family members were:

> "His wee wife and daughter came over: 'We cannot thank you enough' – they saw a big change in him. I said 'Och, that's what I'm here for'."

Being able to provide support – as well as *being* supported – was frequently mentioned as positively influencing QoL. Shared experience and peer support are argued to *"inspire confidence and ignite action"* (Greenhaugh, 2009). Finding spaces to enhance one's capability to do this was reported by many to have a positive impact on wellbeing. In sum, participants felt relationships were a significant component of a 'good' QoL, thus a reduced capacity to 'do' friendship negatively affected their wellbeing (Vassilev et al., 2011), affecting their sense of autonomy.

The ability to be autonomous and independent was considered by participants to be integral to a 'good' QoL. Most participants framed their 'illness journey' (Bell, 2000) with ESKF as an identity shift from being 'abled' to disabled (Bury, 1982; Charmaz, 1993). Self-worth was typically derived from possessing the capability to *do* everyday tasks on their own without having to rely upon others for assistance, as Alice (61, graft) explained:

> "It's very frustrating. When you've been so used to being totally independent and leading a busy life, to suddenly be hit with this weariness […] sometimes you just can't be bothered lifting your hands. And that's it."

Frustration was commonly felt among participants, with all mentioning feeling *'trapped'* or *'restricted'* by haemodialysis, and the visible presence of vascular access on their body. This feeling heightened when connected to the dialysis machine, differing according to the means of being tethered to the machine; those with lines could move more freely, while those with fistulas – predominantly arm – reported feeling more restricted than others. Moving in certain ways caused the machine to make loud, jarring noises alerting patients and staff to potential restrictions, blockages, or problems with blood flow. Changing position sometimes helped, but often the issue had to be rectified by a care provider to ensure their access was not damaged. Carole (62, fistula), who dialyses at home, detailed the intricate balancing act of reading a magazine, while Kathy (56, line) spoke about being unable to eat a snack without help:

> "… you're trying to hold the paper down, and you're trying to flick pages, and [it] drops … you can't get down to get it, because the machine won't let you stretch that far […] if you try and lift your arm up or down, the machine alarms and then my husband's got to come out and fix it." (Carole)

> "I've got to rely on the lassies [nurses] to absolutely everything […] it's very, very restricting, you know what I mean? The machine just goes bonkers." (Kathy)

Rosie rather aptly summarised these points saying: "*You've got to rely on other people to do this [live with ESKF], that's what I hate the most*". Vascular access was continual reminder of restricted independence (Williams & Wood, 1988) in relation to everyday tasks had a negative impact feeling 'normal' and maintaining a good QoL.

Participants found interactions with healthcare providers often impinged upon their ability to feel 'in control', in turn affecting perceived QoL. Both Mateusz (66, fistula) and Zoya (53, fistula) had negative encounters with care providers; they described feeling ignored and feeling despondent about the control they had over their vascular access, and ESKF. Zoya spoke about feeling 'pigeonholed' into a one-size-fits-all system, when, she felt *"patients should be at the centre of care"*, particularly in relation to access creation. Other participants experienced staff who lacked knowledge in the proper care of vascular access; Lynne (52, graft) recalled being incorrectly dialysed for three weeks, while Sarah's (36) graft was damaged during dialysis by a nurse. Fortunately, examples like this were in the minority, and most emphasised the positive role healthcare providers – particularly those creating vascular access, and those involved in day-to-day dialysis – took in supporting decision-making and feelings of control.

The impact of vascular access affected doing 'everyday' things, like essential tasks (e.g., household chores, paid work, and study) and hobbies, consequently impeding feelings of autonomy. Kathy (56, line), like many others, spoke about the impact of vascular access on hobbies; swimming was frequently mentioned, as specific types of access cannot be submerged in water. Others had to give up hobbies they enjoyed because of the potential risk of damaging their access, including fishing or inability to walk dogs using a fistula arm. Everyday 'chores' were difficult, with many participants (particularly those who had arm grafts or fistulas) requiring assistance with carrying groceries, and household tasks like vacuuming. In addition, most participants saw their condition – and associated access – as a barrier to maintaining employment and/or study; only three participants fell into this category (one freelancer, one volunteer, one student), and four had given up paid work within the previous six months. Participants spoke about the treatment time-burden and requirement for flexible employment affecting their ability to engage with paid labour. While those with an ESKF diagnosis in the UK legally qualify as 'disabled' and protected by associated legislation, reasonable adjustments were not routinely offered. Alice (61, graft) can do freelance work that allows her the flexibility to fit work around the unpredictable nature of her condition: *"I wouldn't be able to do that if I had a full-time job"*. Having a graft meant she frequently required sudden surgical intervention, making it difficult to meet the typical requirements from paid employment. By comparison, educational institutions provided more flexibility. Priya (23, fistula) was able to continue studying for her undergraduate qualification even when she began dialysis and found her university to be very accommodating and supportive.

3.3. Verifying analysis and deriving the VA-specific QoL model

Earlier we identified the need for a HR-QoL measure specifically tailored to the nuances of living with vascular access as part of ESKF. We argued this needed to be theoretically grounded and patient-centred in development. Interview data analysed with reference to the *Capabilities Approach* (Nussbaum, 2011) and presented here, identifies direct and indirect ways participants felt vascular access affected their QoL. Direct influences centred upon physical functionality of a line, graft, or fistula: appearance, feeling, and anxiety of failure. Indirect influences on QoL fell into various categories – general enjoyment of health, relationships, autonomy and control, and everyday tasks. These typically stem from direct issues with functionality, providing additional nuance to how we understand QoL as mediated by the existence of vascular access.

Table 3 provides an overview of the evolution from Nussbaum's theory, how domains were introduced to participants in Phase 2, and related themes appearing in analysis. Phase 3 involved 'sense-checking' these themes through focus groups carried out with patients and practitioners. Using Nominal Group Technique, focus group participants were asked to rank statements. Mirroring interview data, both the patient and professional groups ranked direct influences as the most important aspect. However, this diverged, with patients focusing on the influence vascular access had on their everyday life and their ability to exercise autonomy and perform everyday tasks, while practitioners felt the ability to engage with work and study was most important (Fig. 1). Agreement on the item set was achieved after two rounds of discussion.

Following Phase 3, the experienced interdisciplinary research team (including surgeons, nephrologists, specialist nurses, social scientists, and data scientists) reviewed and ratified the item set for readability and redundancy, ensuring patient-led language was embedded throughout. Items related to capability themes were worded using phraseology to assess interference as to why a 'functioning' could not be achieved rather than to describe a specific action itself. It was decided statements would be based on the patient's experience with their vascular access during the last week, based on the frequency of vascular access use, and interaction with haemodialysis, ensuring the time frame was manageable for recall, while also capturing the day-to-day impact of vascular access on everyday life. The Vascular Access Specific Quality of Life (VA-Specific QOL) (Table 4) has been developed to be theoretically informed, evidence-based, with patient opinions are the heart of development. It is relevant to all forms of vascular access (fistula/line/graft), and not burdensome to complete.

4. Discussion

The VA-Specific Quality of Life measure aims to assess the impact on QoL across Nussbaum's capability domains, making it useful in routine clinical interactions between patient and healthcare providers. Haemodialysis patients interact with multiple professionals from dialysis nurses, nephrologists, interventional radiologists to surgical specialities. Decisions about vascular access are nuanced and often skewed towards what professionals view as the 'best access,' or wider, national policy decisions to minimise complications related to vascular access. The need for shared decision making in vascular access has been highlighted as a priority (Murea et al., 2021); however, it is crucial for professionals to understand the wider impact of vascular access on quality of life for ESKF patients to improve and facilitate shared decision making. Measures derived from patient voices, rather than imposed from professional viewpoints are important in implementing PROMs (Patient Reported Outcome Measures) in clinical practice, and in future vascular access trials.

Two reflections can be shared about patient and professional viewpoints: first, patients and professionals both saw the impact of direct and indirect influences of vascular access on maintaining a 'good' quality of life. Second, the divergence between patient and practitioner responses may reflect normative presumptions embedded in our relative construction of what a 'good' quality of life entails, demonstrating the value in considering the influence vascular access has beyond its physical manifestation.

The VA-Specific QoL measure outlined here advances wider understandings of vascular access. Both direct and indirect factors identified mirror results from other qualitative studies (Kalloo et al., 2016; Casey et al., 2014; Quinn et al., 2008). In turn, this emphasises the generalisability and transferability of the results to countries with a similar cultural context, and supports our call for a QoL measure, sensitised to the importance of vascular access. However, the impact on 'non-haemodialysis days' was not identified by prior models focused on vascular access. This holds implications for those who have had a form of pre-emptive vascular access created but are not yet using it for haemodialysis - and specifically draws attention to an absent group within

Table 3
Mapping of Nussbaum's domains with VA-Specific QoL study.

Capability Domain and Descriptor (Nussbaum, 2011)	Phase 2: Discussion Prompts	Phase 2: Thematic Analysis Categories	Phase 3: Ranking Statements	VA-Specific Item
1. **Life:** "Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living."	• To live a long life.	• Life expectancy • Vascular access as a 'Lifeline' • Vascular access function	"My access keeps me alive"	• Worry that my line/fistula or graft may stop working. • General life satisfaction.
2. **Bodily Health:** "Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter."	• To be healthy, and free from pain. • To have a comfortable standard of living - i.e., enough food, good housing	• Freedom from pain and physical disease • Ability to engage in daily activities/tasks	"My access makes me feel good about my health"	• Worry that my access has a problem or infection • How my access feels day to day • How my access feels during dialysis
3. **Bodily Integrity:** "Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction."	• To be able to move locations. • To be free from violence. • To have the opportunity for sexual satisfaction. • To have choice in terms of reproduction.	• Physical independence • Relationships	"My access does not affect my relationships with partners, family or friends"	• Worry my access has got in the way of good relationships
4. **Senses, imagination and Thought:** "Being able to use the senses, to imagine, think, and reason—and to do these things in a "truly human" way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing works and events of one's own choice, religious, literary, musical, and so forth. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid non-beneficial pain."	• To have access to education. • To be happy.	• Education, training, work • Freedom from pain	"My access allows me to go to school, college, or university and or have a paid job" "My access means I can do everyday things"	• How my access feels day to day • Worry my access interferes with tasks I have to do, work, or study
5. **Emotions**: "Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)"	• To have positive relationships with those who love and care for us. • To be compassionate towards others.	• Intimate/Family Relationships • Social relationships • Freedom from anxiety/worry	I am happy with how my access looks My access functions well	• My access has got in the way of good relationships • How my access looks • Worry about function/infection/problem
6. **Practical Reason:** "Being able to form a conception of the good and to engage in critical reflection about the planning of one's life.	• To be able to establish our own morals. • To be safe, and not live in fear	• Absence of disruptive events	"I feel in control of my access"	• Involved in decision about the care of my access • Interfere with work/social activities
7. **Affiliation:** "(i) Being able to live with and toward others, to recognize and show concern for other humans, to engage in various forms of social interaction; to be able to imagine the situation of another. (ii) Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin and species."	• To have compassion for others, and to be respected.	• Respect • Independence • Lack of discrimination	"Those caring for my access treat me with dignity and respect"	• How my access looks • Involved in decision about the care of my access
8. **Species:** "Being able to live with concern for and in relation to animals, plants, and the world of nature."	• To be able to enjoy nature.	• Appreciate nature/pets/gardening/fishing	"My access means I can do the things I enjoy"	• Interference with hobbies or other social activities
9. **Play:** Being able to laugh, to play, to enjoy recreational activities."	• To be able to laugh, to play, to enjoy recreational activities.	• Enjoy recreation	"I am happy with my access"	• Interference with things I enjoy
10. **Control over environment:** "(i) Political. Being able to participate effectively in political choices that govern one's life; having the right of political participation, protections of free speech and association. (ii) Material. Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek	• To be able to engage in paid work. • To have possessions – i.e., house, car, money.	• Employment. • Tasks (home/work) • Need to be able to do	"My access allows me to engage in paid work/study"	• Interference with tasks I need to do

(*continued on next page*)

Table 3 (*continued*)

Capability Domain and Descriptor (Nussbaum, 2011)	Phase 2: Discussion Prompts	Phase 2: Thematic Analysis Categories	Phase 3: Ranking Statements	VA-Specific Item
employment on an equal basis with others; having the freedom from unwarranted search and seizure. In work, being able to work as a human, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers."				

Fig. 1. Radar Plot of Ranking Exercise of Ranking Statements in Phase 3. (Scale: 1 = most important, 10 = least important).

Table 4
Vascular access specific quality of life (VA-Specific QOL) items.

In the last week:

1. I am satisfied with how my line/fistula/graft **looks.**
2. I am satisfied with how my line/fistula/graft **feels during dialysis.**
3. I am satisfied with how my line/fistula/graft **feels day-to-day.**
4. I have been concerned that my line/fistula/graft **may stop working.**
5. I have been concerned that my line/fistula/graft may have a **problem or infection.**
6. My line/fistula/graft has limited me in **doing things I enjoy.**
7. Ignoring the time spent on haemodialysis, my line/fistula/graft has **got in the way of having good relationships.**
8. I have been **satisfied with life** in general.
9. I feel I have been **included in decisions** about the care of my line/fistula/graft
10. My line/fistula/graft has **interfered with my hobbies**, social activities, or other things I enjoy.
11. My line/fistula/graft has **interfered with everyday tasks** I have to do, work or study.

research in this area. Furthermore, the emphasis patients place on relationships and the importance of patient involvement in decision making about their care for ensuring autonomy have been excluded from previously published models.

There are two main limitations associated with this study. This research was conducted in the UK – a country with a universal healthcare system, where simple access to KRT is not a key concern. While results were consistent with qualitative studies conducted in other high-income countries (i.e., Canada, Ireland, Singapore, Sweden, Taiwan, USA), this may not reflect experiences of patients in low- or middle-income countries, where access to KRT is harder. This research was completed prior to the COVID-19 pandemic, which had a vast impact on all areas of life – including work, social activities, and the wider context of healthcare. While haemodialysis and vascular access were maintained as an essential healthcare service during this period due to the life-maintaining nature of treatment, patients and professionals were not immune from the impact on service provision (e.g., Jimenez et al., 2022). This consequently further entrenches inequalities – and the impact on LMIC.

In terms of diverse representation, quota sampling was utilised to recruit participants from varied ethnic backgrounds, but participants predominantly identified as White, and all participants spoke English – although not necessarily as their first language. While interviews were conducted by SG (a non-clinical sociologist), they were conducted in clinical settings which may have affected how comfortable participants felt disclosing their experiences.

5. Conclusion

Throughout this paper we argued for the creation of a Quality of Life measure that more aptly represents the experiences of living with the "unpredictability of vascular access" (Polkinghorne & Lok, 2016). Through critically and systematically exploring patients' vascular access journeys, we have demonstrated the importance of having a model that is informed by both theory and patient experience – specifically using Nussbaum's *Capabilities Approach* to unpack the narrative accounts of twenty-four people with extensive experience of haemodialysis and vascular access. This work provides a response to a recent call (Woo et al., 2021) for the development of vascular access specific patient reported outcomes which encompass issues surrounding anxiety, physical symptoms, access functionality, appearance and visual reminders of disease and emphasised the importance of engaging patients in every step. The VA-Specific QOL measure, derived from this qualitative work, is undergoing cognitive and psychometric validation to assess its reliability, validity, and responsiveness in working. This work has placed the most important stakeholder – the patient – at the centre of its development and has the potential to contribute to a more holistic and innovative approach in future vascular access care.

Data availability statement

Data unavailable due to privacy/ethical restrictions.

Funding statement

This work was supported by an investigator-led small research grant from W.L. Gore.

Conflict of interest disclosure

No COI to declare with regards to this work. Other Disclosures: DK, KS, and PT have received honoraria for speaking from W.L. Gore & Associates. DK. and PT have received an investigator research grant from Proteon Therapeutics. DK has received an investigator-led small research grant from W.L. Gore & Associates.

Ethics approval statement

Ethical approval for this study was granted by NHS Newcastle Research Ethics Committee (REC 17/NE/0320), NHS Greater Glasgow and Clyde board (GN17RE548), and the University of Glasgow's College of Social Science Ethics Committee (Ref: 400170007).

Patient consent statement

Clinical data not used. Written and audio (for those with accessibility requirements) consent obtained by SG and retained in line with NHS Data Management Practices by KS and DK.

Permission to Reproduce Material from Other Sources.

N/A.

Contribution statement (CRediT)

SG led on data curation, data gathering, methodological design, and writing the original draft, supported by KS and DK. KS and DK supervised the project and acquired funding. KS led on obtaining ethical approval supported by SG, PT, and DK. All authors were involved in the conceptualisation, administration, data analysis, validation, and reviewing/editing the final paper.

Acknowledgements

We thank all the participants who took part in all steps of this research – particularly the patients, who gave the lead author a deeply honest insight into their experiences, and the staff, who work tirelessly to improve quality of life for their patients. Ethical approval for this study was obtained from NHS Newcastle, NHS Greater Glasgow and Clyde, and the University of Glasgow. Funding for SG to conduct qualitative data collection was through an Investigator-led small research grant from W.L. Gore.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ssmqr.2022.100187.

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