**Title**: Wellbeing and Lifestyle in Transplantation (WALT): a qualitative study of health communication and self-care.

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**Abstract**

**Background**: Lifestyle impacts the health of kidney transplant recipients (KTRs) who are at risk of weight gain, post transplantation Diabetes Mellitus and dyslipidaemia.  Self-care is key to adapting lifestyle for health.

**Aims:**To understand how KTRs cope with and adapt their lifestyles post-transplant and exploring self-care support by health care professionals (HCPs) and significant others.

**Methods:**Focus groups and semi-structured interviews with recipients who had been transplanted ≥ 6 months, their significant others and health care professionals, from one UK transplant centre. Purposive sampling ensured both a diversity of KTRs and a range of professionals participating, with data analysed using thematic framework analysis.

**Findings:**Thirty-three participants were involved in one of five focus groups or 15 one-to-one interviews. The themes of effective health communicative interactions and health literacy were found to be integral to developing self-care.

**Conclusion:**Supporting lifestyle post-transplant involves building self-care through effective health communication and health literacy.

**Keywords:** self-care, communication, lifestyle, health literacy, kidney, transplant

**Introduction**

Self-care is high on the NHS care policy agenda as highlighted within the NHS Long Term Plan (NHS, 2019). The WHO’s definition of self-care is “the ability of individuals, families and communities to promote their own health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a health worker (WHO Guidelines Review Committee, Sexual and Reproductive Health and Research, 2021). In renal transplantation, capacity and ability to undertake self-care is critical to wellbeing and lifestyle. Renal transplantation is a sudden life changing event and transplant recipients are at risk of kidney rejection if complex medication regimens are not adhered to. They are also vulnerable to weight gain, Diabetes Mellitus post transplantation and dyslipidaemia, especially if lifestyle is not adapted for life post-transplantation. Self-care to support lifestyle after transplantation, is therefore important to individuals, their significant others and to the health service.

Self-care is a complex concept influenced by intrapersonal, interpersonal, institutional and environmental factors and conceptually it is linked with health literacy. Health literacy ‘entails people’s knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in every- day life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course.’ (Kickbusch et al., 2013). Therefore, encouraging lifestyles that are beneficial for health post-transplant will involve understanding health literacy skills in KTRs and health communication skills of professionals in supporting self-care and health outcomes.

The complexity of understanding self-care, health literacy and health communication makes it challenging to know how best to support these practices in people with long term health conditions such as those with a kidney transplant. Our research adopts a qualitative approach to engaging stakeholder perspectives that gives voice to KTRs, their significant others and practitioners. The aim of this qualitative research is to understand how KTRs cope with and adapt their lifestyles post-transplant and to explore how self-care support is delivered by health care professionals (HCPs) and significant others and the impact of this.

**Methodology**

This qualitative research is based on focus groups and semi-structured interviews involving 33 participants in total. Five focus groups were conducted, four of which were undertaken with KTRs and one with healthcare professionals. Fifteen semi-structured interviews were run with: 5 KTRs, 7 healthcare professionals and 3 significant others. The healthcare professionals who took part were: 4 nephrologists, 3 nurses, 2 allied health professionals and a transplant surgeon. Further details of participants can be found in Table 1.

The study was undertaken between June and December 2021 within a large renal transplant centre in London UK, which performs approximately 210 renal transplants per year (NHS Blood and Transplant, 2022), and provides clinical care to over 2000 KTRs, 50% of whom are from a range of ethnic backgrounds other than White European (UK Renal Registry, 2022).

Participation was either within a focus group or a single one-to-one interview as opted by the participant. During this period, COVID-19 was prevalent which ethically dictated that the interviews were conducted with safety as a primary consideration. Therefore, all focus groups were conducted online through video conferencing whereas one-to-one interviews were conducted through online video conferencing and telephone (as per participant choice).

Purposive sampling ensured a diversity of KTR participants (by age, gender, socio-economic status, ethnic background, education level, duration of transplant, history of previous transplantation, employment status) to capture a range of experiences. The KTR participants were recruited from the renal transplant clinic and had been transplanted for at least 6 months.

Healthcare professionals was also recruited using purposive sampling reflecting a range of professional experience working with KTRs in the transplant centre.

In contrast, recruitment of significant others involved snowball sampling, drawing on referrals from participant KTRs. Due to the small sample size, all participated in one-to-one interviews.

The focus groups and interviews were conducted by three of the authors: AB, SS, LRJ. Prior to the focus groups and interviews, all participants were informed of the research aims and the nature of the project. Participants gave their consent for focus groups and interviews to be audio recorded. The focus group and interview recordings were professionally transcribed and the data were subjected to thematic framework analysis using NVIVO data analysis software programme. The data analysis of all the transcripts involved a close reading and a line-by-line analysis. Keywords, phrases and text were coded and subsequently and iteratively refined and grouped into appropriate themes (Braun & Clarke, 2006). The framework analysis (Spencer et al., 2003) allowed us to reframe the themes to provide additional context relative to the participant’s role in kidney transplantation and self-care .

Table 1: Methods and participant demographics

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Kidney Transplant Recipients** | **Healthcare Professionals** | **Significant others** |
| **n** | 20 | 10 | 3 |
| **Focus groups, n** | 4 | 1 | 0 |
| **One-2-one interviews, n** | 5 | 7 | 3 |
| **Females, %** | 55 | 80 | 100 |
| **Age range, years** | 33-73 | - | - |
| **Non-white ethnic background, %** | 40 | 10 | 0 |

**Findings**

In this section we consider the main topics of health literacy and health communication in developing self-care which corresponds with major themes emerging from our analysis of the data. The emerging themes consider KTRs and healthcare professionals’ perspectives of the barriers and drivers to effective health communication and literacy.

*KTRs perceived barriers to effective health communication and literacy for self-care*

Simple information provision doesn’t always translate into following guidance in KTR’s everyday lives. This was expressed by Joe in speaking to the nature of advice patients receive in post-transplant clinics.

*“It’s all well and good having advice but I don’t think it works. Most people will listen to the advice, they’ll go away and they’ll do nothing, or they’ll feel really inspired for a very short period of time and then they just give it up. And it looks great on paper but it just doesn’t work”* Joe, 51 years old.

Information provision needs to be accompanied by reasonings that make sense to the recipient to lead to effective understanding and an ability to follow the advice as stated by Anjali below.

*“You should be faced with, you know, the problems you have and they should be communicated, and then how you deal with those problems it should be key and then really explained why those things matter. It’s not just about something on a sheet, make sure you don’t do this, don’t do, it should be explained so there’s a real understanding”.*

Anjali, 53 years old

Anjali exemplifies the challenges patients face in accessing lifestyle advice by giving an example of her experience with a health professional during a post-transplant consultation.

*“I did ask Consultant, …when I could start running after the transplant because I thought that’s quite physical and I didn’t want to obviously damage anything and his answer was “just walk”. He didn’t say “don’t run and this is the reason you shouldn’t run”, just said “walk for 45 minutes, that should be enough for you”. So that’s what I did, I didn’t question him further ... And when I got home I said “oh why didn’t he answer my question?” You feel quite rude to be asking, you know, something the doctor’s told you and then you’re going “oh but why can’t you do it?” It’s like you’re questioning their profession basically, you know. So I didn’t ask the question, looked on the internet, got some ideas but wasn’t still sure because everyone was saying a different thing. But I didn’t get any advice other than me asking that question to a consultant, “when can I start running or can I start running now?”*

Anjali, 53 years old.

Anjali illustrates how this patient-professional communication neither attends to patient reasoning nor acknowledges their questions as significant, subsequently excluding her from the interaction, serving to reinforce a lack of understanding. The professional here fails to capitalise on an opportunity to engage and develop Anjali’s health literacy and capacity to self-care.

*Healthcare professional possible drivers to effective health communication and literacy for self-care*

From a healthcare professional perspective, a transplant nurse recognises how information and medical advice are not themselves sufficient for developing health literacy and understanding. The transplant nurse goes onto express how a deeper engagement with the recipient’s own understanding and assumptions are needed to enhance their health literacy. She asserts:

*Okay, so there is this is a word that I use a lot in clinic and it kind of surprises patients, is they feel that the transplant will cure their kidney disease and I tend to tell them this is just a treatment for kidney disease, it’s not a cure and that changes completely the mindset because the expectation was I’m going to be cured, I don’t have to come to hospital anymore, everything will be solved and... Yeah. – Transplant Nurse (emphasis added)*

From a healthcare professional perspective, health communication involves having an awareness and sensitivity to patient’s questions and perceptions, while being responsive to the recipient’s needs and experiences.

*“In terms of lifestyle, again, you know, giving them not only skills, most of them probably will have the skills, but maybe the support, and explain to them, to go through things, give them time to explain why they need to look after their health, why is exercise good, why is diet good, how you can help them with that, you know, by having other healthcare professionals. So, yeah, I mean, I don’t know in terms of skills, I think it all comes down to communication and how you make them try, in the simplest way, and tailor it according to patients, to gain, let them trust in you and be convinced that what we’re advising them is actually the right thing for them in the long-term or in their best interests, I guess.” Nephrologist*

Health communication and clinical advice supporting lifestyle choices and self-care is determined by the quality of the interaction that provides the recipient with the understanding and reasons that justify how the advice is relevant to their day-to-day life. Healthcare professionals in communicating with recipients, sensitive to their individual experiences, can better support recipient health literacy and capacity for self-care.

**Discussion**

The analysis has identified some key themes that contribute to barriers and drivers in effective communication and interaction with kidney transplant recipients and their ability and responsibility for self-care. Clinical advice extends beyond communicating information. It involves a process of communicating with recipients with care and respect, encouraging interactions that aim at developing a relevant and meaningful understanding of clinical advice by relating to KTRs day-to-day experience and lifestyle choices. Health communication not only involves healthcare professionals talking to KTRs but working together with them in partnership, as part of the ongoing health and well-being journey. The literature supports the role of health literacy in self-management in chronic kidney disease, in particular communicative health literacy (Heijmans et al., 2015). A recent longitudinal qualitative study in people struggling to self-manage their type 2 diabetes showed that the level of health literacy for undertaking treatment and monitoring (e.g. taking medications and checking blood glucose levels) was mostly at the functional (basic) health literacy level whereas a more advanced level of health literacy (communicative) was seen for lifestyle related issues such as diet and exercise (Debussche et al., 2022). An enlightening commentary by van der Heide et al discusses how health literacy should be reframed from an individual attribute to one that is dependent on the interactions (e.g. health communication) with healthcare professionals and the healthcare service (van der Heide et al., 2018). Our study illustrates how development of health literacy is dependent on health communication impacting self-care, which is particularly relevant in the context of adapting lifestyle. For example, we showed that when on the receiving end of healthcare communication, a KTR spoke of how they were excluded from a meaningful interaction which would support their ability to change their lifestyle and further develop self-care. On the professional side, however, there is recognition that information and advice alone are insufficient for KTRs to develop self-care.

**Conclusion and research implications**

The analysis has identified some key themes that contribute to barriers and drivers in effective communication and interaction with kidney transplant recipients and their ability and responsibility for self-care. Our aim, given the understanding and appreciation of the complexity of health communication and self-care, is to redress the dearth of qualitative research studies that place emphasis on patient experience and their support networks in building a richer picture of the challenges and possible solutions within healthcare, interactions and resources to improve self-care. The analysis presented here offers merely a snapshot of our findings that illuminates the critical role healthcare communication and health literacy play in developing KTR’s capacities to self-care. A broader analysis has been developed within the project XX which explores and examines these issues in relation to other stakeholders (significant others) and inter-relations between healthcare interactions, lifestyle choices and patient education. These will be reported in forthcoming publications.

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