Self-management challenges and support needs among kidney transplant recipients: A qualitative study

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ABSTRACT

Aims

This study investigated self-management challenges and support needs experienced by kidney transplant recipients.

Background

After kidney transplantation, recipients are expected to take an active role in self-management. However, evidence suggests that nurses experience difficulties operationalizing self-management support. Greater insight into the recipients' perspective could help to improve the adequacy and efficacy of nurse-led self-management support.

Design

A cross-sectional qualitative study

Methods

Focus groups and individual interviews were carried out with kidney transplant recipients treated in a Dutch university hospital. Directed content analysis (DCA) was used.

Results

Forty-one kidney transplant recipients participated. Challenges after transplantation included becoming an expert patient, adjusting daily life activities, dealing with medical regimen, forming relationships with nurses, dealing with social consequences, dealing with emotions related to transplantation and the donor, and improving self-image. In order to be able to deal with these challenges, participants wished to receive disease specific knowledge and instruction, share personal experiences with fellow patients, share and discuss not only medical but also emotional and social issues with nurses, and wanted to be encouraged through positive feedback. 'One-size fits all' education was seen as insufficient in meeting their needs.

Conclusions

After kidney transplantation, recipients experienced various challenges in dealing with the medical, emotional and social tasks. Current support from nurses overlooked recipients' emotional and social support needs. Nurses need adequate tools and training to be able to meet recipients' self-management support needs.

Why is this research needed?

- After kidney transplantation, recipients needs to learn how to integrate medication and lifestyle advice into daily life routines, adapt changes in social roles and cope with the emotional impact.
- Evidence suggests that nurses experience difficulties operationalizing self-management support.
- Greater insight into recipient's perspective could help to improve the adequacy of nurses' self-management support.

What are the key findings?

- Current self-management support was mostly focused on the medical challenges and overlooked recipients' needs for support in dealing with the emotional and social challenges after kidney transplantation.
- Potential targets for self-management support interventions include a holistic approach, tailoring to individual needs, promoting intrinsic motivation and confidence, and building a relationship of trust.
- Cultural sensitivity is required when assessing needs and tailoring of support offered.

How should the findings be used to influence policy/ practice/ research/ education?

- Tools and training are needed to help nurses to meet the emotional and social support needs of recipients.

INTRODUCTION

Kidney transplantation has become the preferred treatment for patients with end stage renal failure because of better quality of life (Wyld, Morton, Hayen, Howard, & Webster, 2012) and survival (Wolfe et al., 1999) compared to dialysis. After transplantation, recipients need to learn how to integrate medication and lifestyle advice into their daily routines, adapt changes in social roles and cope with the emotional impact (Gordon, Prohaska, Gallant, & Siminoff, 2009). Recipients are expected to take an active role in their post-transplant care in the form of self-management (Anderson & Funnell, 2005; Wagner et al., 2001), which indirectly improves their quality of life (Weng, Dai, Huang, & Chiang, 2010). However, they cannot be expected to self-manage the consequences on their own (Lorig & Holman, 2003). At outpatient clinics in European countries, self-management support is often provided by nurses (Elissen et al., 2013).

In clinical practice, evidence suggests that nurses experience difficulties operationalizing self-management support (Elissen et al., 2013). Distinct perceptions exist about the definition and operationalization of self-management support (Been-Dahmen, Dwarswaard, Hazes, van Staa, & Ista, 2015; Jones, MacGillivray, Kroll, Zohoor, & Connaghan, 2011; Udlis, 2011; van Hooft, Dwarswaard, Jedeloo, Bal, & van Staa, 2015). Self-management support can be defined as the provision of interventions to increase patients' skills and confidence in managing their chronic condition (Institute of Medicine Committee on Identifying Priority Areas for Quality, 2003). Due to the clinical importance of a strict regimen of immunosuppressive medication for maintaining graft functioning and the difficulties experienced with adherence (De Geest et al., 2014; Dew et al., 2007), self-management support in the post-transplant period has tended to focus on promoting medication adherence and self-monitoring (De Bleser, Matteson, Dobbels, Russell, & De Geest, 2009; De Geest et al., 2014; van Lint et al., 2017). However, chronically ill patients indicate that they also struggle with the psychological and social demands of living with their condition (Wagner et al., 2001).

Greater insight into the recipients' perspective could help to improve the adequacy of nurses' support (Fowler, 2017; Schipper & Abma, 2011; Trappenburg et al., 2013). A review of the qualitative literature (Jamieson et al., 2016) highlighted five main themes of motivations, challenges and attitudes to self-management after kidney transplantation: empowerment through autonomy, prevailing fear of consequences, burdensome treatment and responsibilities, medicalizing life, and social accountability and motivation. Self-efficacy and having sense of accountability were conditional for recipients' self-management. Support should consist of multicomponent interventions that included personalised care planning, education, psychosocial support, decision aids, and other self-monitoring tools (Jamieson et al., 2016). Little is known about kidney transplants' needs and preferences for self-management support to help them deal with these self-management challenges.

Background

Self-management is defined as managing one or more chronic conditions (e.g. symptoms, treatment, physical and psychosocial consequences, and lifestyle changes) and integrating them into daily life with the aim of achieving optimal quality of life (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Self-management challenges are often experienced in one or more of these domains: 1) Medical management: managing symptoms, managing treatment; 2) Role management: forming relationships with health-care providers, relating to family members and friends; 3) Emotion management: preparing for an uncertain future, managing emotions, and managing a positive self-image (Lorig & Holman, 2003; Moos & Holahan, 2007). Self-management support can improve patients' lifestyle or adherence; increase quality of life, or empower them (Kendall, Ehrlich, Sunderland, Muenchberger, & Rushton, 2011; Wilkinson & Whitehead, 2009). In addition to support for self-management from professionals, they may also receive support from relatives and fellow-patients (Dwarswaard, Bakker, van Staa, & Boeije, 2016). In a model developed by Dwarswaard and colleagues, generic types of self-management support for chronically ill patients were categorised into relational, instrumental and psychosocial (Dwarswaard et al., 2016). Relational support refers to support that helps patients to interact with others, including: forming partnership and getting sympathy. Instrumental support refers to medical management and involves three themes: knowledge/information and instruction, internalizing knowledge, and adjusting daily life to the chronic condition. Lastly, psychosocial support refers to the resources needed to manage the emotional and psychological aspects of living with a chronic condition. Psychosocial support includes recognition of the emotional burden of the chronic condition, and building self-confidence and empowerment (Dwarswaard et al., 2016). Besides generic challenges, chronically ill patients also experience disease specific self-management challenges and support needs (van Houtum, Rijken, Heijmans, & Groenewegen, 2015). To date, little is known about disease specific self-management support needs after kidney transplantation.

THE STUDY

Aims

In this study, as part of a needs assessment in the development of a nurse-led intervention we aimed to gain insight into (a) recipients' perspectives on self-management challenges after kidney transplantation and (b) what kind of support is needed.

Design

We conducted a cross-sectional qualitative study using focus groups and individual interviews.

Sample and participants

This study was held at the outpatient post-transplantation clinic of the Department of Internal Medicine of the Erasmus Medical Center in Rotterdam (the Netherlands). Recipients are discharged from the hospital 2-3 weeks post-transplant, they receive explanation about self-management from a nurse practitioner prior to discharge and visit the out-patient clinic weekly in the first few weeks thereafter. The frequency is gradually decreased once the patient and their medication stabilise. All recipients (N=195) who visited the outpatient post-transplantation clinic between December 18, 2013 and January 15, 2014, were invited to participate. The nephrologist determined who could be invited, those with acute issues such as rejection or infection requiring re-hospitalization were not approached. No limitations were set as to the number of transplants, the type of donor, time since transplantation, or previous renal replacement therapy. Recipients with difficulties attending the focus groups, were invited for an individual interview. Additionally, recipients with insufficient proficiency of the Dutch language were purposefully selected and invited to participate in an individual interview with an official interpreter.

Data collection

Focus groups (FG) and individual interviews (II) were conducted between January 2014 and March 2015. Each FG lasted a maximum of two hours and was led by a psychologist (JWG), and a trained nursing researcher (JB) who took field notes, recorded participant characteristics, and who acted as a seconder. The FGs were held in the private room in the hospital. The intensive interaction in FGs enabled a broad exploration of experiences and attitudes (J. Kitzinger, 1994; J. Kitzinger, 1995; Polit & Beck, 2008; Wibeck, Dahlgren, & Öberg, 2007). The individual interviews allowed us to include recipients who otherwise have been excluded. Two researchers (JWG and JD) conducted the interviews; these lasted about one hour and were conducted at in a private space in the hospital or at participant's home. Sometimes a partner was present during the interview. To gain insight into the recipients' demographic characteristics, a questionnaire was completed by participants before the start of the individual interviews or focus groups. All interviews were audio recorded and transcribed verbatim. Both focus groups and individual interviews focused on post-transplant life, received self-management support, and preferred support. Table 1 provides an overview of the main questions addressed during the focus group and individual interviews. An item pool was developed and discussed within the research team and patient panel to come to a final set of questions. Participants were encouraged to give examples, details and circumstances.

Table 1. Interview questions about recipients' self-management challenges and support needs

- Could you please tell me about the challenges you face in dealing with the consequences of your kidney transplantation?
- What kind of support do you receive in dealing with the consequences of your kidney transplantation? And how do you experience this support?
- What kind of support do you need and/or prefer in dealing with the consequences of your kidney transplantation?
- Do you have suggestions for nurses with regard to providing self-management support?

Ethical considerations

All invited recipients received written information via post or during their outpatient clinic visit from their nephrologist or nurse practitioner. Those who returned the signed informed consent form were invited for the focus groups and individual interviews. Participants received financial compensation for travel costs and a gift voucher (€10). All participants were assured of confidentiality, the anonymous processing of the data, and that medical staff did not have access to the data. The researchers (JB, JWG, EI, AvS, EM) had no access to patient records, while LM and WW – who were involved in the medical care – were neither involved in data collection nor had access to non-anonymous data. The study protocol was approved by the Institutional Review Board of the University Medical Center Rotterdam (MEC-2013-350).

Data-analysis

A directed content analysis (DCA) approach was used to analyze the focus groups and individual interviews. This form of content analysis uses a more structured analytic strategy than the conventional open approach. Using this analytic method helps to focus the analysis and is appropriate when there is prior research or an existing theoretical framework about a phenomenon (Hsieh & Shannon, 2005). First, JB and JWG read the interview transcripts to gain an overall impression of the content. Subsequently, these researchers independently assigned data-driven codes to the text. The results were compared and discussed to reach agreement. Thereafter, all codes were sorted into predetermined categories based on existing theoretical models described in the introduction. To analyze data about recipients' perspectives on self-management challenges we used the models of Lorig and Holman (2003) and Moos and Holahan (2007). To analyze the data about support needs we used the model reported by Dwarswaard et al. (2016). Table 2 provides overview of how these three models were integrated. The qualitative analysis package Atlas.ti 6.2 was used for analysis. Data saturation was achieved when the data became repetitive after analyzing four focus groups and nine individual interviews (Polit & Beck, 2008).

Table 2. Integration of the models of Lorig and Holman(Lorig & Holman, 2003), Moos & Holahan(Moos & Holahan, 2007), and Dwarswaard et al (Dwarswaard et al., 2016) about self-management tasks and support needs of chronically ill patients

	RESEARCH QUESTION 1	RESEARCH QUESTION 2
Three domains of self-management tasks (Lorig & Holman, 2003)	*Adaptive tasks of living with a chronic condition (Moos & Holahan, 2007)*	*Self-management support needs of chronically ill patients (Dwarswaard* et al.*, 2016)*
Medical management	- Managing symptoms - Managing treatment	Instrumental support: - Knowledge: information and instruction - Internalizing knowledge - Adjusting daily life to the chronic condition
Role management	- Forming relationships with health-Care Providers - Relating to family members and friends	Relational support: - Partnership - Sympathy
Emotion management	- Preparing for an uncertain future - Managing emotions - Managing a positive self-image	Psychosocial support: - Recognition of emotional aspects of the chronic condition - Building self-confidence and empowerment

Study rigour

Both researcher and method triangulation (Lincoln & Guba, 1985; Polit & Beck, 2008) were used to enhance the validity of the data. All data was collected and analyzed in a team-based fashion. Agreement in coding was reached by consensus between the two researchers. To increase the dependability of the research, the design, methods, (preliminary and final) analyses and results were all discussed within the research team. Details of the participants and settings are described below, allowing readers to conclude on the degree of transferability. The description of the methods also contributes to the conformability of this study. The COREQ guidelines were followed in reporting the methods.

FINDINGS

One hundred and ninety-five recipients were handed out the information packet, of which 53 agreed to participation in a focus group. Due to logistical difficulties with planning and acute illness, 32 recipients eventually participated in one of 4 FG (7-9 participants per FG). Six non-Dutch and three Dutch-speaking recipients participated in an individual interview. Sample characteristics are shown in Table 3. One non-Dutch speaking participant did not fill out the sample characteristics form.

Table 3. Patients' characteristics

Characteristics	Participants focus groups (n=32)	Participants individual interviews (n=9[a])
Age: in years (mean; SD)	56 (8.7) Median = 56.5; Range = 31-69	56 (11.3) Median 52; Range = 42-71
Gender: Male (n; %)	20 (62.5)	3[a] (37.5)
Marital status:		
Married/living together (n; %)	26 (81.3)	6[b] (75)
In paid employment (n; %)	8 (25)	0[a] (0)
Highest educational attainment (n; %)		
None		3[a] (37.5)
Primary school	3 (9.4)	2 (25)
Secondary school	15 (46.9)	2 (25)
Further education	14 (43.7)	1 (12.5)
Nationality		
Dutch	26 (81.3)	2[a] (25)
Indonesian	1 (3.1)	-
German	1 (3.1)	-
English-Ghanaian	1 (3.1)	-
Iraqi	1 (3.1)	-
Dutch-Surinamese	1 (3.1)	-
Dutch-Antillean	1 (3.1)	-
Filipino	-	1 (33)
Turkish	-	3 (37.5)
Moroccan	-	2 (25)
Number of transplants (mean; SD)	1.3 (0.5); Median = 1; Range = 1-3	1.38 (0.7); Median = 1; Range = 1-3
Comorbidity[c]: yes (n; %)	14 (43.8)	6 (75)

[a] one respondent did not fill out the sample characteristics form

[b] two missing values

[c] The most commonly reported comorbidity were cardiovascular problems (n=7) and diabetes (n=6). Others included cancer, rheumatoid arthritis, and amputations.

Self-management challenges after kidney transplantation

Participants described a variety of challenges they experienced after their kidney transplantation, varying from medical to psychological and social challenges (Table 4). Depending on participants' unique personal situation, these challenges posed specific problems. For example, difficulties dealing with medical regimens in daily life: some

Table 4. Recipients' self-management challenges after kidney transplantation

Self-management domain (Lorig & Holman, 2003)	Adaptive task (Moos & Holahan, 2007)	Self-management challenges	Related quotes
MEDICAL MANAGEMENT			
	Managing symptoms	*Becoming an expert patient in transplantation* - Understand all aspects of the condition, lifestyle and medication regimen - Receive accurate and correct information about the condition - Understand the information and instructions provided by professionals correctly - Develop self-awareness to recognize bodily signals and understand when there is a real problem - Struggling to find solutions for experienced medical problems - Dealing with relatives who have an insufficient level of knowledge	- *"You almost become a doctor." (FG1-R5)* - *"You've got to be careful of course. There are always stories, I mean, I'm not the kind of person who goes looking for information on the Internet…What happens if… you read the most horrendous stories." (FG1-R6)* - *"At a certain point you get the hang of it [self-management]." (FG3-R4)* - *"One of my cousins used sea salt in the cooking because she thought it wasn't real salt. So I have to explain again and again that no, I can't have any sodium. Not even sea-salt." (FG2-R5)*
		Adjusting daily life activities - Adapt their daily life program to their current physical condition - Manage the impact of medical problems and side-effects of medication in daily activities - Find a balance between activity and rest - Find a new and meaningful daily routine	- *"I realized I have a rickety car and I should drive not too fast in it. Now I drive according to the recommended speed limit. I know it and I need to deal with it. I'd be crazy if I didn't." (FG1-R6)* - *I pretend nothing is wrong. Then you make it difficult for yourself. I make it "difficult for myself I know. I don't let on to my husband and kids, who don't live at home anymore, that there's anything wrong. So I make it difficult for myself. I am aware of that." (FG4-R3)* - *"I've been unemployed since last year. So yeah, I don't do anything anymore, just sit behind the computer." (FG2-R3)*

Table 4. Recipients' self-management challenges after kidney transplantation (*continued*)

Self-management domain (Lorig & Holman, 2003)	Adaptive task (Moos & Holahan, 2007)	Self-management challenges	Related quotes
	Managing treatment	*Dealing with medical regimen in daily life* - Adhere to the prescribed lifestyle rules and the medication regimen - Internalize and find work routines for dealing with the various regimens in daily life - Find balance in adhering to the regimen	- *"You can't even tell a healthy person not to eat at a café occasionally, I get that. That's why I understand that it's difficult to get people [patients] to stick to a healthy eating programme. I think that will always be hard."(FG3-R1)* - *"I had to get used to it [taking medication]. We weren't used to it in the beginning. I was thinking 'did or didn't I use my medication'. Now it is a habit." (II-R2)* - *"I actually don't have my meds with me now, I forgot them. Normally, I take them at eleven…So I need to be at home at eleven o' clock at the latest. So I'm sat here thinking what if my car breaks down? Than they [family] will have to come and bring my medication, so I can take them at eleven. It's never happened, this is the first time." (FG2-R4)*
ROLE MANAGEMENT			
	Forming relationships with health-care providers	*Forming a relationship with nurses* - Work on a relationship of trust - Deal with staff changes - Deal with nurses and health care professionals who do not have any attention for personal issues - Deal with non-empathic professionals - Learn to defend own interests - In case of a language barrier, communication with nurses and other health care professionals is more difficult	- *"Now if I don't like the ways things are going I will tell them [professionals]. I wouldn't have done that twenty years ago, because I was very shy. I did not tell [the nurse and doctor] when I was in pain. I was scared he [doctor] was thinking: "What an old nag". Then a lady doctor told me: "How can I know if you're in pain if you don't tell me? I can't see from the outside if you're in pain or not". Since then, I sometimes say something."(II-R2)* - *"I try to create some kind of relationship. Something more personal. I don't want to get too personal, but to show some personality. It's also important for him to know about not only the medical side but also the emotional one, you have to take that into consideration." (II-R9)* - *"I missing some personal attention [from my doctor]. Someone who looks further than just at my blood and urine levels." (FG1-R3)* - *"We have been to a couple of [patient education] sessions. But we don't speak the language, that's our own fault. I wanted to understand. I would like to have an interpreter so I could have understood it. It was a waste of time each time." (II-R3)*
	Relating to family members and friends	*Dealing with social consequences* - Indicate limits to others - Deal with evolving relationships	- *"[After transplantation] I was so selfish that I ruined my marriage." (FG3-R1)*

Table 4. Recipients' self-management challenges after kidney transplantation (*continued*)

Self-management domain (Lorig & Holman, 2003)	Adaptive task (Moos & Holahan, 2007)	Self-management challenges	Related quotes
EMOTION MANAGEMENT			
	Preparing for an uncertain future	*Dealing with emotions related to kidney transplantation* - Deal with the emotional and serious impact of transplantation - Deal with positive emotions: e.g. thankfulness and happiness - Deal with negative emotions: e.g. impatience, disappointment, anger, sadness, worry, and stress - Accept being chronically ill - Accept to receive this kidney as a gift from their God - Reconsider life goals	- *"Here I am, very happy [with the received kidney]. [Because of the transplantation] Because I'm a grandfather now. And those are the things I get to experience." (FG3-R1)* - *"I'm always scared when I'm shopping. With kids. They're of course always running around and what if the shopping trolley hits my side. I always try to be aware of that. … You've got to be careful with physical contact." (FG2-R1)* - *"It is always on your mind. It starts with taking all that medication of course. You're confronted with it three or four times a day. If I want to go on holiday, I've got to get a letter about which medication I take, permission to go, take it with you blablabla." (II-R2)* - *"After my first transplantation, I really panicked when I didn't pee enough. Looking back I think nobody pee's the same amount every day. But you first need to experience it before you know what to look for." (II-R2)* - *"You can do loads of really fun things. Just a month after transplantation I was already going to the gym. But you know, you just divide you energy better over the day. You're more conscious of it. You think about it first. And I didn't do that before. I used to think I'll see how it goes, just do it and enjoy." (FG3-R4)*
	Managing emotions	*Emotions related to the donor (relative)* - Deal with high expectations of expressing (a lot of) gratitude for receiving a kidney - Feel pressure to live healthy, feel well, and be adherent - Feel responsible for the health of their donor	- *"I don't dare to say anything to my sister if it's not going so well. Once I did say something but go told off by my mother for saying something, she said I shouldn't burden my sister with it and just be happy I got her kidney. Then I think, do I have to be grateful all my life?" (FG1-R3)* - *"[After donation] my brother developed diabetes. I find that hard. When I think about it. Cos yeah, his life is, he often has to go to the hospital, that kind of thing, you have to call and ask how it's going you know." (FG2-R7) "Do you feel guilty?" (FG3-R4). "Yes, of course I do." (FG3-R7)*
	Managing a positive self-image	*Improving self-image* - Building up (new) confidence in own body and capability to self-manage	- *"You need to learn to deal with it [having a chronic disorder] and need to learn to listen to your body. Then it's do-able" (FG4-R1)*

participants experienced difficulties with medication regimen during irregular working hours; others struggled to find ways to exercise when they have a busy family life. The extent to which participants experienced challenges after their kidney transplantation varied. The disease-specific self-management challenges experienced by kidney transplant recipients fit into the generic domains and adaptive tasks of chronic illness self-management (Lorig & Holman, 2003; Moos & Holahan, 2007). Several self-management challenges were identified: becoming an expert patient in transplantation, dealing with medical regimen in daily life, dealing with emotions related to kidney transplantation, dealing with emotions related to the donor (relative), daily life activities (leisure and work), and social consequences.

Support needs

Participants' needs for receiving support seemed to vary according to the number of transplantations, duration of illness, time since transplantation, presence or absence of a social network, dialysis prior to transplantation, and their current medical condition. For example, patients had a greater need for support when they experienced a lot of challenges and less need for support the longer ago they received the transplant. We found some differences between Dutch-speaking and non-Dutch speaking participants. In contrast to Dutch-speaking participants who would have liked more emotional support, Non-Dutch speaking participants stressed that they did not wish to share their emotions with others.

Participants support needs are described below according to the 'self-management support needs' model (Dwarswaard et al., 2016). Support could be provided by nurses (or other health care professionals), relatives and fellow patients. Table 5 provides an overview of the reported support needs linked to the three self-management domains.

Instrumental support

Providing knowledge and instruction

Becoming an expert patient in transplantation was mentioned as one of the biggest challenges after kidney transplantation. In order to reach this goal, participants wished to receive adequate information and instruction from nurses. 'One-size fits all' education was seen as insufficient in meeting their needs. More tailored education was desirable because personal circumstances, disease history and current medical situation of participants vary greatly. Participants wished to be involved in deciding what kind of information and instruction was needed for their specific situation. In the period directly after transplantation, a lot of participants struggled to find solutions for medical issues. Then participants expressed a greater need for tailored information about their specific medical situation.

Table 5. Preferences for self-management support after kidney transplantation

Self-management Task (Lorig & Holman, 2003)	Self-management challenges	Types of support needs (Dwarswaard et al., 2016)	Indicated self-management support needs by recipients in this study		
			Nurses	*Relatives*	*Fellow patients*
MEDICAL MANAGEMENT	*Becoming an expert patient*	Instrumental support	*Providing knowledge and instruction* - Providing tailored information and instruction (very important for non-Dutch speaking recipients) - Arranging an interpreter during consultation if knowledge and instruction will be provided to non-Dutch speaking recipients	*Providing knowledge and instruction* - Reading disease specific information - Listening to nurses' education and instructions about kidney transplantation - Trying to understand the medical consequences where recipients are dealing with. - Fulfilling the role of interpreter (in case of non-Dutch speaking recipients)	*Providing knowledge and instruction* NOT MENTIONED
	Adjusting daily life activities		*Internalizing knowledge* - Giving space to ask questions - Discuss personal circumstances	*Internalizing knowledge* NOT MENTIONED	*Internalizing knowledge* - Sharing their experiences of a kidney transplantation
	Dealing with medical regimen in daily life		*Adjusting to daily life* - Paying attention to recipients' daily life changes - Discussing how to reorganize daily life structures and find new routines	*Adjusting to daily life* - Stimulating recipients to modify their lifestyle or be adherence - Offering practical support in daily life	*Adjusting to daily life* - Discussing experiences with kidney transplantation
ROLE MANAGEMENT	*Forming a relationship with nurses* *Dealing with social consequences*	Relational Support	- Investing in a relationship of trust with recipients - Supporting shared decision making (less important for non-Dutch speaking recipients) - Paying attention to recipients social changes in daily life	NOT MENTIONED	NOT MENTIONED

Table 5. Preferences for self-management support after kidney transplantation (*continued*)

Self-management Task (Lorig & Holman, 2003)	Self-management challenges	Types of support needs (Dwarswaard et al., 2016)	Indicated self-management support needs by recipients in this study		
EMOTION MANAGEMENT	*Dealing with emotions related to kidney transplantation* *Emotions related to the donor (relative)*	Psychosocial support	*Recognition of emotional aspects after kidney transplantation* - Recognizing the emotional impact of kidney transplantation - Providing opportunities to discuss emotional issues - Proactively asking about recipients' emotions - Listening to recipients' personal stories - Providing education about emotions that frequently occurs - Paying attention to potentially emotionally taxing relationship with the living donor	*Recognition of emotional aspects after kidney transplantation* - Listening to recipient's stories - Providing the opportunity for recipients to talk about their emotions and feelings	*Recognition of emotional aspects after kidney transplantation* - Share and discuss experienced emotions with other recipients
	Improving self-image		*Building self-confidence and empowerment* - Providing feedback and encouragement about how recipients fulfilling of their role as expert patient	*Building self-confidence and empowerment* - Providing feedback and encouragement about how recipients fulfilling of their role as expert patient	*Building self-confidence and empowerment* - Providing feedback and encouragement about how recipients fulfilling of their role as expert patient

"[Then] I wanted to get information because it [the side-effects and complications] makes me restless." (FG2-R1)

The complex medical aspects of kidney transplantation can be difficult for participants to understand and they complained about 'conflicting and vague advice'. This confused them. Some participants felt that they had to translate general information provided by nurses to their own situation, indicating that education was not always tailored to participants' specific situation. Participants described that it would help them if nurses explore gaps in knowledge and provide information accordingly. In contrast, the majority of non-Dutch speaking participants did not wish to receive information about their chronic disorder from nurses. They did not search for information in Dutch or in their native language even though they often had difficulties understanding their disease.

"For me it is not important to know [what kind of medication] I use (…). The doctor prescribed them, so it'll be good for something. And they seem to work." (II-R5)

Next to education, participants wanted to be trained in developing self-awareness to recognise bodily signals and understand when there is a real problem. Receiving instruction by nurses about recognising these issues was seen as an important prerequisite for effective self-management. It helps participants to build confidence in their capability to self-manage.

Many participants indicated an insufficient level of knowledge among their relatives. As a result, relatives did not always recognise or acknowledge the challenges participants were dealing with in daily life. Relatives could support participants by reading information about participant's chronic disorder and listen to nurses' instructions. Trying to understand their situation was also considered helpful.

Participation of family members during outpatient consultations was important for non-Dutch speaking participants. They often fulfilled the role of interpreter. However, most of the non-Dutch speaking participants preferred a professional interpreter given that family members are not always able to explain medical content sufficiently.

Internalizing knowledge

To be able to integrate knowledge and instruction provided, participants need the opportunity to ask questions and discuss personal circumstances with nurses during outpatient consultations. It is important for nurses to create an environment where this is enabled:

"Sometimes you plan to ask some questions beforehand. But, during the appointment he [doctor] is so preoccupied that it's over before you realise [it]." (FG1-R3)

When nurses did discuss participant's personal issues and questions, this appeared to their understanding of how to self-manage in daily life. Fellow patients could support them by sharing their experiences, thus helping them to understand their own situation:

> *"It is helpful to hear from fellow patients that it's normal to be tired."* (FG2-R4)

However, sometimes fellow patients' experiences added confusion for example when it contradicts nurses' advice.

Adjusting daily life

After kidney transplantation, participants needed to adapt daily life to their current medical situation. Given that the new regimen can be stressful, discussing changes participants are dealing with was seen to be important. Nurses could help to find new routines to bring structure to daily life, which assists in adhering to lifestyle and medication regimens. Tailoring was a requirement, because life circumstances were unique. For example:

> *"[seeking for a] routine. In the beginning it was very difficult. Now I have found one."* (II-R3)

Positive stimulation by relatives could also help participants to modify their lifestyle or be adherent: Practical support from relatives, for example with housekeeping or buying groceries was also very much appreciated. Particularly, non-Dutch speaking participants seemed to receive a lot of practical support from relatives, mentioned to be customary within their own culture.

Several participants wished for contact with fellow patients for the purpose of sharing and discussing experiences about coping with the regimen and consequences of kidney transplantation. Participants also wanted to support others by sharing their experiences on how they dealt with medical problems, the lifestyle regimen and therapy adherence. But there was variation in the extent to which participants appreciated support from peers.

Relational support

One condition for receiving self-management support from anyone was a relationship of trust. When there is no relationship of trust, participants did not want interference. Being empathetic, reliable and a good listener were mentioned as important competences for nurses when building a relationship of trust with participants. It was also appreciated when nurses proactively asked about medical and personal issues.

Continuity of care was also important for building up this relationship. Given that participants often seek a balance between quality of life and limitations, nurses are expected to create an environment in which adjustments can be discussed and tried out.

> *"You [the recipient] search for a balance between quality of life and the limitations… They [nurses] should give you tools [for making choices], which is missing now."* (FG1-R7)

Also, shared decision-making is favored: participants wanted to work together with nurses on the basis of collaborative partnership. This was less important for non-Dutch speaking participants who tended to rely on nurses' expertise.

"I told them several times to do what is right. I am not a professional. They should decide what is good for me. I hope it makes me better." (II-R12)

Psychosocial support

Recognition of emotional aspects after kidney transplantation

Kidney transplantation was reported to be an emotional and serious life-event. Apart from medical support that was given high priority by all, most Dutch-speaking participants wanted support fitting their emotional needs. Participants needed to deal with various emotions, such as thankfulness, happiness, regret and fear. Given the fact that most participants were very emotional, it was appreciated when nurses were empathetic and recognised the psychological impact. Instead, according to participants, nurses mostly overlooked the social and emotional challenges they faced:

"The technical support is good...But, the human support [for emotional issues] is lacking. I expected to receive this kind of support." (FG1-R6)

Participants appreciated the opportunity during consultations to share and discuss emotional issues. It was helpful when nurses proactively asked about their emotions and just listening to their personal story was already sufficient in most cases. Participants would appreciate receiving information about frequently occurring emotions after kidney transplantations. The fact that they are not alone in these emotions would reassure them. Nurses were considered the most appropriate persons to provide this kind of support, because doctors were reported to have 'a business-like attitude'.

Nurses should also pay attention to potentially emotionally taxing relationships with the living donor:

"The second time, I received a kidney from my sister. Although I am very happy with it, it also feels somewhat like a burden…Just a conversation about this would have helped me." (FG3-R9)

One participants needed more intense professional support, because of psychological problems. In these situations, a referral to mental health services was appreciated.

Relatives can offer emotional support by listening to participants' stories. They should provide participants the opportunity to talk about their emotions and try to understand them. Discussing these emotions with fellow patients would also be helpful. In contrast, non-Dutch speaking recipients did not wish to discuss emotions.

Building self-confidence and empowerment

Participants indicated the need for feedback from nurses, relatives and fellow patients on how they are fulfilling their role as expert patient:

> *"You can motivate each other [fellow patients]." (II-R9)*

Moreover, encouragement from positive feedback about how others performed the different adaptive tasks would help to build self-confidence and regain confidence in one's own body.

DISCUSSION

This qualitative study aimed to gain insight into recipients' perspectives on self-management challenges after kidney transplantation and what kind of support they need for optimal self-management. Self-management challenges after transplantation have been investigated before (Jamieson et al., 2016), however the exploration of the fit between patients' needs and support offered is particularly unique to this study.

To become an expert patient in transplantation, participants felt the necessity to understand all relevant aspects of their condition, lifestyle and medication regimen. They wished to develop self-awareness to recognise bodily signals and understand when there is a real problem. They indicated a need to receive tailored, disease-specific information from nurses. Supporting recipients in increasing their disease-specific knowledge could have medical and psychological benefits (Coster & Norman, 2009). Tailored education has been shown to lead to larger effects than standardised patient education (Hawkins, Kreuter, Resnicow, Fishbein, & Dijkstra, 2008). Instead, nurses tended to provide standardized patient education rather than tailoring, as has previously been reported (Been-Dahmen et al., 2015). Given that participants vary in their attitude, needs and preferences toward self-management support, personalised support after kidney transplantation is necessary (Grijpma et al., 2016). To enable nurses to respond to recipient's unique educational needs, they must assess recipient's knowledge, information needs and desired methods of education (Bos-Touwen et al., 2015). Providing standard education alone will not lead to behavioral change and is not sufficient for improving recipients' self-management skills (Barlow, Cooke, Mulligan, Beck, & Newman, 2010; Coster & Norman, 2009). Also nurses should consider involving relatives in this personalised educational strategy to ensure sufficient knowledge among the recipients' social network.

Having a relationship of trust was reported as conditional to receiving any kind of support. This is in line with previous studies, which have found that partnership between nurses and recipients is an important prerequisite to successful self-management support (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Lorig & Holman, 2003). However, realizing collaborative partnership is often difficult for nurses (Ter Maten-Speksnijder, Grypdonck, Pool, Meurs, & Van Staa, 2015; Thorne, Ternulf Nyhlin, & Paterson, 2000; Wilson, Kendall, & Brooks, 2006). Traditionally in healthcare, professionals were the authority on medical issues and patients to passively followed their instructions. This has changed over the past decades into a more collaborative, less hierarchical model. Chronically ill patients have greater access to medical information, play a more active role in decision-making and expect partnership with professionals (Alt & Schatell, 2008; Holman & Lorig, 2000; World Health Organization, 2002). Participants in this study reported that being empathetic, reliable and a good listener were important competencies for nurses to build a trustful relationship. It was also appreciated when they proactively ask about medical and personal issues. This corresponds with literature, which describes communication as the cornerstone of a good patient-professional relationship that determines the quality of patient-centered care. Underlying principles of a therapeutic relationship are respect, genuineness, empathy, and active listening (Kennedy Sheldon & Foust, 2013).

In this study, kidney transplantation was reported to be a major life-event with emotional impact. Participants had to deal with several positive and negative emotions such as thankfulness, fear and sadness. Emotions can affect patients' self-efficacy to cope well with challenging situations (Bandura, 2004). For example, depressive symptoms can affect patients' therapy adherence after kidney transplantation (Cukor, Rosenthal, Jindal, Brown, & Kimmel, 2009). Self-efficacy is a predictor of patients' successfulness in managing a chronic disorder (Bandura, 1977, 2004). The core element of nurses' self-management support should therefore be coaching recipients to develop problem-solving skills and increase their self-efficacy. Support focusing on internal processes and perceived locus of control is effective for the persistence and performance of new behavior (van Hooft, Been-Dahmen, Ista, van Staa, & Boeije, 2016) and generalization of acquired skills to new challenges in the future. Nurses mostly overlook these emotional challenges and importance of promoting these skills (Been-Dahmen et al., 2015; Ter Maten-Speksnijder, Dwarswaard, Meurs, & van Staa, 2016). We note that not all participants wished to discuss emotional challenges, in particular the non-Dutch speaking participants (Mesquita & Frijda, 1992). This again highlights the importance of the assessment phase, adequate tailoring and cultural sensitivity.

Limitations

For qualitative research a large sample is not necessary, but it is important to have varied respondents that represent differing views on the topic. Therefore, an important strength of this study was the sample variation with regard to sociodemographic and medical characteristics. In contrast to other studies that often exclude potential participants who do not speak the dominant language, we involved them in individual interviews. Moreover, in the Dutch-speaking group various nationalities were also represented. Including a broad sample and using both group and individual interviews helped to develop a more comprehensive understanding of recipients' needs and to validate conclusions (Polit & Beck, 2008). Despite our efforts to create a representative sample, half of those approached did not participate, often due to illness. There may be specific self-management support needs among those who did not participate that we did not capture here. Furthermore, the study was conducted in a single-centre in the Netherlands. Therefore, results may be not generalizable to all kidney transplant recipients in other settings. Finally, although using pre-existing theoretical frameworks to guide the categorization of data could be seen as restrictive, we highlight that we were alert for new themes that fell outside these models in order to capture novel information that could inform the development of such models. This study goes beyond a description of challenges through giving recipients a voice to improve support.

Practice Implications

Findings should inform the development of self-management interventions, education and training, particularly of nurses who are often the first port of call for self-management support. Tools and training are needed to help nurses and other health care professionals to meet the emotional and social support needs. For example, self-management support skills should be a core competency in nursing training. To connect to recipients' individual daily life challenges, we encourage nurses to assess post-transplant self-management needs and tailor education and support accordingly. For example, for some patients using trained fellow patients could be a welcome addition. Cultural sensitivity is also required, for example, following the patient in which topics they wish to focus on according to their cultural values and norms.

CONCLUSION

Participants in this study expressed various challenges in dealing with the medical, emotional and social tasks after kidney transplantation: becoming an expert patient in transplantation, managing treatment, forming relationship with professionals, adjusting daily life activities, dealing with social consequences, improving self-image, and dealing with emotions related to transplantation and the donor. Current support from nurses was mostly focused on the medical challenges and overlooked recipients' needs for support in dealing with the emotional and social challenges after kidney transplantation. There was a need for more holistic support. Recipients agreed that nurses, relatives, or fellow patients can only provide self-management support effectively when there is a relationship of trust. In this study, some differences were found between Dutch and non-Dutch speaking participants therefore cultural sensitivity is required when assessing needs and tailoring of support offered.

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