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Kidney transplant patients' attitudes towards self-management support: A Q-methodological study



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ABSTRACT

Objective: Kidney transplant recipients face many self-management challenges. We aimed to identify profiles of attitudes towards self-management support (SMS) shortly after kidney transplantation. *Methods:* Profiles were generated using Q-methodology: In face-to-face interviews participants rank-ordered opinion statements on aspects of SMS according to agreement. Socio-demographic and medical characteristics were assessed using a questionnaire. By-person factor analysis was used to analyze the rankings and qualitative data was used to support choice of profiles. The resulting factors represent clusters of patients with similar attitudes towards SMS.

Results: Forty-three patients (mean age = 56; 77% male) participated. Four profiles were identified: (A) transplant-focused and obedient; (B) holistic and collaborative; (C) life-focused and self-determined; and (D) was bipolar. The positive pole (D+) minimalizing and disengaged and the negative pole (D-) coping-focused and needy represent opposing viewpoints within the same profile. Socio-demographic and medical characteristics were not related to profile membership.

Discussion: Each profile represents a specific attitude on post-transplant life, responsibility for health and decision-making, SMS needs, and preferences for SMS.

Practical implications: Patients vary in their attitude, needs and preferences for SMS indicating the necessity of providing personalized support after kidney transplantation. Health professionals should explore patients' SMS needs and adapt support accordingly.

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1. Introduction

Following kidney transplantation, patients start a lifelong undertaking of managing the consequences of the transplantation and integrating those consequences into their lives. The ability to manage the consequences of a (chronic) condition is called self-management [1–3]. Self-management can be categorized into three broad categories: focusing on illness needs, activating resources and living with a chronic illness [4] or alternatively

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http://dx.doi.org/10.1016/j.pec.2015.11.018 0738-3991/© 2015 Elsevier Ireland Ltd. All rights reserved. medical, role and emotion management [3]. For kidney transplant patients, this entails for example adhering to a complex medication regime, managing bodily symptoms, changing lifestyle, regular appointments with health professionals, adapting to changes in social roles and relationships, managing emotions and developing new perspectives on life [5–8]. In order to perform these self-management tasks, patients require knowledge, skills, beliefs, and a supportive social network (including health professionals) [9].

Difficulties with self-management tasks after kidney transplantation are common [10]. Moreover, self-management issues negatively affect graft and patient survival, quality of life and result in increased healthcare costs [11–15]. Therefore, interventions are needed to promote self-management after transplantation. Two systematic reviews have investigated which self-management support (SMS) strategies have been employed to address SMS among transplant recipients [16,17]. They show that of the 24 interventions, most are focused on cognitive strategies

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(information giving), behavioral strategies (increased monitoring and feedback) or a combination of these. Less than half of studies also incorporated an emotional component (increasing selfefficacy and social support). Given the clinical importance of medication, interventions tend to focus solely on medication adherence as outcome, with little attention to outcomes related to other illness needs of patients, their resources or adjusting to a life with a chronic illness [16]. Despite differences in design and content, these SMS interventions have shown limited effectiveness. De Bleser et al. [17] and Low et al. [16] offer suggestions in order to improve effectiveness. First, interventions should be based on evidence-based behavior-change theories, be multidimensional (cognitive, emotional and behavioral) and address multiple ecological levels (patient, health professional, healthcare setting, and/or healthcare system). Second, an adequate dosage, duration and uptake of the intervention is required. Third, interventions should be tailored to patients' goals, needs and situation, rather than one-size fits all.

The call for tailored interventions was repeated by Trappenburg et al. [18]. In a critical reflection on the current evidence, these authors identified tailoring as a method to improve effectiveness of SMS interventions. They suggest that variances in effectiveness of SMS interventions are related to the 'fit' between the individual patient and the design of the intervention. SMS interventions may include components, act on ecological levels, and/or aim for outcomes, which may not resonate with a patient. Furthermore, this is complicated by the fact that patients' SMS needs change over time and are influenced by individual characteristics [19]. Sarkar et al. [20] also showed that patients have divergent preferences for the channels used for SMS (e.g. telephone or internet).

Little is known about the specific attitudes and preferences of kidney transplant patients with regard to SMS. The objective of this study was therefore to identify profiles of patients relating to preferences and needs for SMS shortly after kidney transplantation.

2. Methods

2.1. Q-methodology

To elicit the views of kidney transplant patients, Q-methodology was used. "Q-methodology is a research technique, and associated set of theoretical and methodological concepts, originated and developed by William Stephenson, which focuses on the subjective or first-person viewpoints of its participants" [21]. This mixed-methods design has previously been used successfully among kidney transplant patients to identify attitudes towards medication adherence [22,23] and among chronically ill patients and professionals to identify attitudes towards selfmanagement [24–26]. A Q-methodological study starts with the development of a set of statements on a topic (the Q-set) which is then sorted in order of agreement per participant (the Q-sort). Qsorts are then compared to identify groups of individuals who have similar attitudes on the subject of interest [21].

We conducted the following five Q-methodology steps: Q-set development, participant selection, data collection (conducting

Table 1

Q-set statements and factor arrays.

Number	Statement		Factor arrays			
			В	С	D	
1.	The more care I receive, the better	-1	-1	-1	-2	
2.	Care should cost me as little time and effort as possible	-2	-1	-1	1	
3.	I want health professionals to take a broader interest in me than only my medical details	-1	0	1	0	
4.	I think that care should be adapted to me and my situation	0	1	0	2	
5.	I would like contact with other kidney transplant patients	-1	-2	$^{-1}$	-3	
6.	I want one of my loved-ones to be involved in my care	0	2	0	-1	
7.	Only I am responsible for my health	1	-2	3	2	
8.	I want to discover myself how I want to live my life after kidney transplantation	-2	0	0	2	
9.	I want health professionals to guide me in getting on with my life	-2	$^{-1}$	$^{-1}$	-3	
10.	I want to receive care from the same health professional every time	0	3	-2	0	
11.	I want to receive immediate assistance when I feel that it is needed	0	1	2	-1	
12.	I only need to receive care from a nephrologist	-1	-2	$^{-1}$	3	
13.	I want to have a good relationship with my health professionals	1	1	2	1	
14.	Part of the care I receive could be provided via internet	-3	-1	0	$^{-1}$	
15.	It is important for me to see health professionals in person	2	1	0	1	
16.	It is okay for me if my life revolves around keeping the kidney graft	3	$^{-1}$	3	1	
17.	I want to have access to my medical records any time I want	0	0	2	-2	
18.	I prefer to think as little as possible about the transplant and its consequences	-3	-2	0	0	
19.	If I need care I will let it be known	0	0	2	0	
20.	I want health professionals to be committed to my well-being	0	1	1	0	
21.	I do what health professionals say is good for me	1	0	0	0	
22.	My health professionals and I should make treatment choices together	2	3	1	2	
23.	Health professionals should ask regularly whether I am following their recommendations for medication and lifestyle	1	$^{-1}$	-2	-1	
24.	It's important to me that health professionals try to motivate me to live healthily	1	0	-2	1	
25.	I want health professionals to think beyond just my current health status	0	2	1	0	
26.	Health professionals should be my main source of information	0	0	0	1	
27.	If I am living unhealthily, my health professional can confront me about it	2	0	0	0	
28.	Guidance on life after transplantation should start before transplantation	0	2	0	-1	
29.	I want to receive as much information as possible about my kidneys and my treatment	1	2	1	0	
30.	I want health professionals to understand if I decide to deviate from their advice	-1	1	-2	1	
31.	I appreciate it if my loved-ones remind me about my medication and healthy lifestyle	0	$^{-1}$	0	-2	
32.	It's important to me to know exactly how well the kidney is functioning	3	1	1	-2	
33.	Only taking the medication is sufficient for my recovery	-2	-3	-3	-1	
34.	I only want to receive care from health professionals who are experts in kidneys	1	0	-1	3	
35.	My religious beliefs influence my preferences for care after transplantation	-1	-3	-3	0	
36.	It is easy for me to follow the advice and recommendations that the health professional has prescribed for me	2	0	1	0	
37.	I would like help learning to cope with situations that I find difficult	-1	0	$^{-1}$	-1	

the Q-sort), data analysis, and factor interpretation. Extensive descriptions of Q-methodology can be found elsewhere [21,27,28].

2.1.1. Step 1: Q-set development

For the development of the Q-set statements, we used selfmanagement literature and focus groups with patients. From these sources, we collected 328 statements representing attitudes on SMS (not facts). Subsequently, we combined statements with the same meaning and deleted those that were not directly related to the objective of our study. Seventy-six statements remained. We sought advice on further reduction from experts in Q-methodology, self-management, and transplantation. Thirty-seven statements remained. These were pilot tested among an advice committee, consisting of kidney transplant recipients, and further refined the phrasing (Table 1). The word 'care' as used in the statements was defined as post-transplant care received and associated self-management tasks.

2.1.2. Step 2: participant selection

We invited all recently (<6 months) transplanted patients in our center to participate between August and December 2014. By employing this method of consecutive sampling, we aimed to minimize selection bias and to ensure inviting patients with a heterogeneous medical history and socio-demographic characteristics. Inclusion criteria included age >18 years, sufficient command of the Dutch language, and a functioning graft (absence of dialysis treatment). Exclusion criteria included visual, auditory and cognitive impairments that would hamper collection of reliable data (as assessed by the treating physician).

In Q-methodological studies, large samples are not required when applying a sound sampling procedure. As a rule of thumb, approximately the same number of participants is needed as the number of statements in the Q-set [21]. Therefore, our target was 37 participants.

2.1.3. Step 3: data collection

Nephrologists provided potential participants with a patient information form, informed consent form and return envelope during regular clinic consultations. Those who returned the signed consent form were contacted to make an appointment for a faceto-face interview in the outpatient clinic. The interview was divided into three sections: completing questionnaires, the Osorting, and the post-sorting inquiry. The questionnaires measured socio-demographic (age, marital status, employment, education, ethnicity) and medical characteristics (amount of transplants received, types of donors, time since transplantations, type and duration of dialysis, comorbid disorders), and self-management (knowledge, skills, confidence, preferences, needs). To measure self-management, the PAM-13 NL [29] was used. The PAM (Patient Activation Measure) [30] consists of thirteen items on knowledge, skills and confidence in managing one's health and care. Patients answered each item on a 4-point Likert scale, ranging from totally disagree to totally agree (or not applicable). The total score results in categorization into one of four progressively higher selfmanagement levels: (1) disengaged and overwhelmed; (2) becoming aware, but still struggling; (3) taking action; (4) maintaining behaviors and pushing further.

The Q-set was printed on individual, numbered cards. Participants were asked to read the statements and to sort them in three piles: agree, neutral, or disagree. Then they further sorted the statements in each pile on the forced-choice, quasi normal grid (Fig. 1) which ranged from -3 'disagree most' to 3+ 'agree most'.

The post-sorting inquiry started when participants were satisfied with their final Q-sort. The interviewer (JWG/EM) explored the reasoning behind the choices of the statements most agreed/disagreed with, conflicting patterns within the Q-sort, and other noteworthy information about the Q-sorting. This qualitative data was written down by the researcher for later use in the analysis.

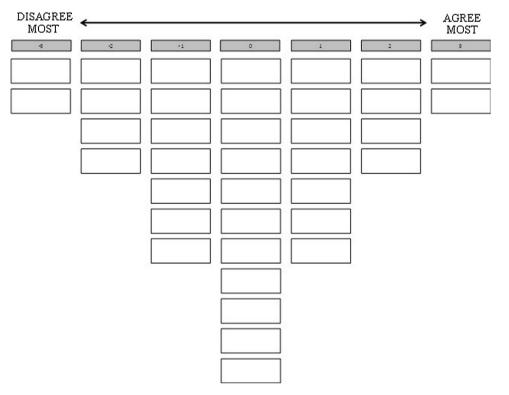


Fig. 1. Q-sort scoring sheet (reprinted with permission from Tielen et al. [14]).

2.1.4. Step 4: data analysis

The Q-sorts were analyzed using factor analysis in POMethod 2.35 developed by Schmolck and Atkinson in 2002 (see http:// schmolck.userweb.mwn.de/qmethod/#PQMethod). Each statement was entered per person as ranked from -3 to +3. Intercorrelations were calculated and a by-person factor analysis (centroid factor analysis with varimax rotation) was conducted. Various solutions (number of factors) are possible. In this study we assessed the fit of solutions ranging from 2 to 7 factors. Selection of the most appropriate factor solution was done by calculating factor loadings to determine which Q-sorts load onto each factor and investigating the qualitative data to assess support for the factor structure. Factors should be coherent, differentiated and clinically relevant. For a Q-sort to load significantly on a factor, it had to correlate >r = .45 with one factor and <r = .45 with the other factors. Q-sorts loading significantly on the same factor are sorted in a similar fashion. This implies that they share similar views on the topic under study [32].

To analyze the correlations between socio-demographic variables, medical variables, PAM scores and factors, we used one-way ANOVAs and Fisher's exact tests.

2.1.5. Step 5: factor interpretation

The overall aim of factor interpretation is "... to uncover, understand and fully explain the viewpoint captured by the factor and shared by the significantly loading participants" [21]. We used the systematic method for factor interpretation provided by Watts and Stenner [21]. They use factor arrays as the basis for factor interpretations, as they facilitate comparisons between factors. Factor arrays are the merged Q-sorts of all participants in a factor into a single prototypical Q-sort. Factor arrays were calculated by the weighted averaging of the Q-sorts in that factor. To facilitate the process of comparing factors, factor arrays were transformed back to the whole numbers as used in the Q-sorting (from -3 to +3) (Table 1). Only looking at factor.

Therefore, the next stage of factor interpretation was identifying, per factor (profile), the highest ranking statements, the lowest ranking statements, statements that were ranked higher in a factor than in any of the other factors, and statements that were ranked lower in a factor than in any of the other factors. We combined the quantitative with the qualitative data to better understand the reasons behind the rankings. This stage allowed us to identify issues pertinent to each individual factor, and to compare those to the other factors. Next, we evaluated the statements in the middle of the distribution and investigated if this position in the factor indicate neutrality or if their position influenced the meaning of the extremes (for example add a certain nuance or exception). Then we started developing a textual description of the factors focusing on the distinguishing features/statements. Lastly, we tried to explain any intra-factor discrepancies, and to make sure the factor interpretation included a large proportion of the statements.

2.2. Ethical approval

The study was evaluated and approved by the Medical Review Ethics Committee of the Erasmus University Medical Center (MEC-2014-270).

3. Results

3.1. Patient characteristics

Forty-three patients participated out of 59 invited (73%). Common reasons for declining to participate were already having participated in other studies, and (acute) medical problems.

Table 2

Participant socio-demographic and medical characteristics.

Variable	
Mean age (years)	56 (21–79)
Gender (male)	77%
Marital status (married or living together)	70%
Employment status	
Unemployed	65%
Paid work	28%
Volunteer work	7%
Education level	
Elementary school	9%
High school	51%
Further education	40%
Ethnicity (Dutch)	93%
Number of kidney transplantations	
1	84%
2	9%
3 or more	7%
Mean time since last kidney transplantation (weeks)	20 (6-38)
Type of kidney donor (living)	72%
Pre-emptive kidney transplantation	42%
Time on dialysis (range)	1 month-10 years
Comorbidity (1 or more)	58%
PAM Levels (1 = lowest, 4 = highest)	(1) 9%
	(2) 16%
	(3) 51%
	(4) 23%

Table 2 shows the patient characteristics. Some patients were interviewed later than six months since their last transplantation, due to the time between the invitation and the interview.

3.2. SMS profiles

A four factor solution was found to best fit the data. Each factor represents a patient profile of shared views on SMS. The four factors explain 45% of the variance. Thirty-two of the 43 Q-sorts loaded significantly on one of the factors, three Q-sorts loaded on more than one factor (i.e. confounded), and eight Q-sorts did not load on any factor (Table 3). The four profiles are summarized in Table 4.

There was no significant relationship between the factors and medical or socio-demographic characteristics. Nor was there a significant relationship between the factors and PAM levels.

3.2.1. Profile A: transplant-focused and obedient

Thirteen patients loaded onto this factor. For patients in this profile, life revolves around preserving the donor kidney (16:+3). They indicate that without the transplantation, they would not survive. Therefore, it is their obligation to do whatever it takes to prevent rejection of the kidney. Self-management support should focus on medical management as opposed to a broader focus on reestablishing life goals (3:-1, 9:-2). They spend a lot of time and energy thinking about and doing what is needed (18:-3) and adherence comes easily to them (36:+2).

Even though patients feel they have some responsibility in preserving the donor kidney, they feel that health professionals are mainly responsible (7:+1). Health professionals have the knowledge and experience to keep the kidney functioning. So it is important to see health professionals in person (15:+2). This means that the health professional should have an extensive role in self-management support. They should tell patients how to live their life after transplantation (8:-2). Furthermore, part of this role of the professional is to check if patients are following their recommendations (23:+1), confront them if they are not living

Table 3 O-sorts defining the four factors.

Factor	Q-sorts loading on the factor	Total number of Q-sorts loading per $factor^b$	Cumulative total	Eigen values	% explained variance
А	3, 6, 8, 14, 22, 25, 27, 28, 32, 33, 35, 36, 40	13	13	11.04	15
В	1, 2, 4, 5, 18, 21, 30, 31, 41	9	22	3.66	14
С	9, 10, 11, 19, 23, 24, 43	7	29	2.66	9
D	7, 16, 39 ^a	3	32	2.01	7
Confounded	12, 20, 34	3	35		
Non-significant	13, 15, 17, 26, 29, 37, 38, 42	8	43		

^a significant negative factor loading.

^b the total number of Q-sorts loading on each factor is equivalent to the number of participants represented by the factor.

Tabl	e 4	4
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Key components of the four profiles.

	Profile A transplant-focused and obedient	Profile B holistic and collaborative	Profile C life-focused and self- determined	Profile D+ minimalizing and disengaged	Profile D– coping-focused and needy
Attitude towards life	Preserving kidney	Re-establishing quality of life	Integrating life and treatment goals	Minimizing impact of transplantation	Coping with demands and consequences
Responsibility for health and decision-making	Health professionals	Shared responsibility	Patient	Patient	Health professionals
Self-management Support: content	Medical	Holistic	As indicated by patient	Medical	Holistic
Self-management Support: amount	Extensive	As indicated by patient	As indicated by patient	Minimal	Extensive
Attitude towards health professionals	Tractable	Cooperative	Assertive	Resistant	Tractable

healthily (27:+2), and motivate them to do so (24:+1). Patients in this profile are careful to follow professionals instructions (21:+1). Since contact with health professionals is so important, they are not interested in online support (14:-3) or ways to reduce their time and energy investment in support (2:-2).

3.2.2. Profile B: holistic and collaborative

Nine patients loaded onto this factor. For patients in this profile, life is about (recovering) quality of life. The transplantation was a means to this end. They hope that their transplantation enables them to (re) start desired activities, to feel well, and to achieve personal goals. Therefore, they are reluctant to let the transplantation and its consequences be the main priority in their life (16:-1). Self-management support should be holistic in nature and provided by a multidisciplinary team (12:-2).

Patients are not solely responsible for their health (7:-2), but it is rather a shared responsibility between themselves, their lovedones (6:+2) and health professionals. They see themselves as part of a team. Their own role is to learn as much as possible about their condition and treatment (29:+2). Their loved-ones should take an interest in their condition and support patients. Health professionals should discuss treatment choices with patients (22:+3), show interest in how their patients are doing (20:+1), and develop a good relationship with their patients (13:+1). In order to develop this relationship, there should be consistency in health care providers (10:+3). Self-management support should start before the transplantation (28:+2) and focus on more than the patients' current health status (25:+2). Support should also take into consideration the balance between treatment and life goals, because these can come into conflict with each other and in this case patients may wish to deviate from treatment goals (30:+1). Finding this balance also means that adhering to treatment guidelines does not come easy to patients (36:0).

3.2.3. Profile C: life-focused and self-determined

3.2.3.1. Seven patients loaded onto this factor. Patients in this profile are focused on integrating the consequences of the transplantation into their lives. For them it is important to preserve the kidney (16:+3) and to discuss the impact of the transplantation on the rest of their lives with their health professionals (3:+1, 25:+1). Self-management support should be adapted to the needs of patients, and be provided by a specialist who is best suited to deal with a particular self-management issue (34:-1). Self-management support should therefore have a broader approach (not only medical) (33:-3, 3:1). This profile finds it moderately easy to follow self-management recommendations (36:+1).

Patients in this profile feel solely responsible for their health (7: +3). Therefore, they want to receive immediate assistance when they feel it is needed (11:+2) and to be involved in their treatment: learning about their condition and treatment (29:+1), and have access to their medical records (17:+2). Health professionals have a supporting and advising role. It is not necessary that the transplant team understands their decision to deviate from recommendations (30:-2) and these patients indicate their support needs if and when necessary (19:+2). Professionals do not need to check (23:-2) nor motivate these patients (24:-2). Loved-ones do not appear to have an important role in self-management support (6:0, 31:0).

3.2.4. Profile D

Three patients loaded onto this factor. Profile D is a bipolar profile whereby participants that load either positively or negatively are represented. This means that this profile is made up of diametrically opposing viewpoints (e.g. a positive loading participant would place a statement on +2, a negative loading participant would place this statement on -2). Subsequently, this profile should be split up in two narrative accounts [21,33]. During

profile interpretation this profile was analyzed twice, once with the two positive loading participants and once with the negative loading participant. It was not possible to split this bipolar factor into 2 separate factors as a minimum of 2 Q-sorts must load onto each factor [21].

3.2.5. Profile D+: minimalizing and disengaged

Patients in the positive pole of profile D try to minimize the impact of the transplantation on their life. They do not see themselves as patients, and do not want others to see them as such. These patients want to receive only the most necessary care, and they decide themselves what they will and will not do for their treatment. Self-management support should be as minimal as possible (1:-2) and cost minimal time and effort (2:1).

Patients in this profile feel that their health is their sole responsibility (7:+2), they want to figure out their post-transplantation life on their own (8:+2). They do not want the involvement of loved-ones (31:-2, 6:-1), fellow patients (5:-3), nor health professionals (9:-3). Health professionals should focus on the medical health of the patient (26:+1, 3:0).

3.2.6. Profile D-: coping-focused and needy

For patients in the negative pole of profile D, life revolves around coping with the demands and consequences of the transplantation. These patients feel insecure and worried, experience a variety of (unexpected) consequences and want to learn how to get on with their lives (9:+3). They do not think that adhering to treatment guidelines is easy (36:0), indicate they want to learn to cope with difficult situations (37:+1) and guidance in learning to live their life (8:-2).

Patients have difficulty with the responsibility for their health (7:-2). They have low confidence in their own judgments about their health. They rely on the expertise of health professionals for choices in their treatment (22:-2), the support of loved-ones (6:+1, 31:+2) and are open to the assistance of multiple health professionals (34:-3). Patients in this profile are open to and feel they need extensive self-management support. They think that more care is better (1:+2), and that spending time and effort into care is worth it (2:-1). They see the benefits of coming into contact with fellow patients (5:+3). Online support would be a good idea (14:+1), so they can always see their current kidney function (32:+2). Care before transplantation should prepare for life after transplantation (28:+1).

4. Discussion and conclusion

4.1. Discussion

In this study we aimed to identify differentiated profiles on patient preferences and needs for self-management support (SMS) shortly after kidney transplantation. We found four distinct profiles. The participants in these profiles have different attitudes towards life after transplantation, responsibility for health and decision-making, and the manner in which SMS is offered and received. Patients with the same profile have similar views on these issues.

In general, each profile appears to represent different life priorities or focus. Profile A focuses on preserving the kidney, profile B on re-establishing quality of life (perhaps even at the cost of adhering to treatment goals), profile C on integrating life and treatment goals and finding balance between these two, profile D+ focuses on reducing impact of kidney transplantation as much as possible, and profile D– is trying to cope with the demands and consequences of the transplantation. Second, the profiles appear to represent different attitudes on the responsibility for their health and treatment-related decisions. Profile A places health

professionals in charge, profiles B and D- want shared responsibility, and profiles C and D+ feel that they are solely responsible. Profile C does, however, appreciate the support and advice given by health professionals, and will adhere to recommendations. Profile D+ will adhere only if the recommendations match their perspective. Third, the specific needs for SMS vary across the profiles. Profiles A and D- need extensive support, as they are concerned about their kidney. Their attitude towards SMS is one of obedience. Profile B needs a holistic approach, as the transplantation affects their overall quality of life. Their attitude towards SMS is tractable as long as the care for their kidney does not dominate their life. Profile C only needs support for the issues they indicate as pertinent. Profile D+ needs as little support as possible as they want to spend as little time and effort on the (consequences of the) transplantation. The attitude of profile C towards SMS is therefore one of assertiveness, while profile D+ shows resistance. These findings have similarities with attitude profiles found among adolescents with chronic conditions, specifically the level of desired involvement in treatment and views on the role of the professional [24].

Of the four profiles, profile D was statistically speaking the weakest (three significantly loading Q-sorts, bipolar, 7% explained variance). However, we decided to keep this profile after discussing it with various health professionals. Health professionals recognize in D+ the patients who appear to position themselves outside the patient-professional relationship. These patients are thus difficult to reach and to influence when necessary. While we did not measure adherence, we speculate that they may be at risk for nonadherence and/or early drop out from post-transplantation care. We also believe that this type of patient might be underrepresented in this study, as they might be less likely to participate in studies which also contributed to our decision to maintain and present the profile. Therefore, the two patients in Profile D+ might be the tip of the iceberg. D- seems to combine certain aspects from Profile A (wish for extensive support and an obedient attitude) and Profile B (shared responsibility for health and the wish for holistic support).

This study showed that socio-demographic and medical characteristics were not related to profile membership as in a previous Q-methodological study [24]. Therefore, a priori prediction of SMS needs and preferences remains difficult based on such characteristics. We conclude that health professionals should explore patients' SMS needs and preferences during consultations. Tools to explore patients' preferences, attitudes and needs would help support this evaluation process. Asking patients which of the four profile descriptions they most identify themselves with may facilitate exploring these differing attitudes. Alternatively, the distinctive themes of roles and responsibility, post-transplant focus, and SMS needs and preferences can be discussed or rated. In addition, we did not find a relationship between the attitude profiles and the measure of self-management knowledge, skills and confidence. This could be due to the small sample size and requires further investigation. Health care professionals should also be aware that they too have specific attitudes and preferences regarding self-management support [26,34]. Part of the challenge is therefore to be flexible in their approach towards patients with differing self-management support needs. For example, a more directive, medical focused support style, typified by the 'Clinician' perspective described by van Hooft et al. [26], may be more appropriate to use with patients in profile A. Similarly, a 'Coaching', holistic approach may be more appropriate with patients in profile B. Telemedicine [35] and home-testing of blood pressure and creatinine [36] may be most appreciated by patients in profile D+. We note however that, despite advances in eHealth to support selfmanagement, this patient population unanimously appreciated personal contact with professionals.

This study has a number of strengths and limitations. The mixed-methods approach facilitates uncovering authentic viewpoints of the study participants with a relatively small sample size [37]. As a small sample size can be seen as a problem for the quantitative analyses, this study included more participants than the generally agreed upon rule of thumb of an equal number of participants as statements [21], and even more participants would likely not alter the findings of the O-sort analysis [28]. However, a larger sample would increase power to find associations between socio-demographic or medical characteristics and the profiles. Also, generalizing our results to the entire kidney transplant population might be problematic, because of the specific inclusion and exclusion criteria. We focused here on the recently transplanted, Dutch speaking patients with a functioning graft. The extent to which ethnic minority patients or those with a failed graft are represented in the profiles is uncertain. The subjective nature of data analysis and factor interpretation is a potential source for researcher bias. We took several steps to combat this: we used standardized methods from Watts and Stenner [21], we consulted with Q-methodological experts throughout the analysis and verified findings with health professionals to assess clinical relevance, and a patient advice committee to assess identification and the wording of profiles.

4.2. Conclusion

Based on the differences in attitudes towards SMS, we conclude that SMS should be a personalized practice. This conclusion coincides with previous recommendations that, in chronic care, patients and health professionals should discuss processes and outcomes of care [38,39] and that interventions aimed at improving patient self-management should be tailored to improve effectiveness [16–18]. Interventions aimed at promoting selfmanagement among kidney transplant recipients should commence with an open exploration of attitudes towards support in order to aid tailoring.

4.3. Practice implications

Each profile has unique needs and preferences for SMS. Health professionals should be aware of these differing needs and adapt support in the post-transplant period accordingly (personalized support). Since profiles were not related to socio-demographic or medical characteristics of the patients, we advise health professionals to explore each patient's SMS needs and preferences regularly in the appointments post-transplantation as previous research highlighted change over time. This aligns with the recommendations of the 5A model of self-management support: Assessment [40]. This way, a good fit between supply and demand can be established and patients receive optimal care.

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