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Attitudes towards medication non-adherence in elderly kidney transplant patients: a Q methodology study

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Abstract

Background. Non-adherence to the post-transplant regime is a common problem in kidney transplant patients and may lead to rejection or even graft failure. This study investigated attitudes towards the post-transplant regime of immunosuppressive medication among the ever growing population of elderly kidney recipients.

Methods. Q methodology was used to explore attitude profiles. Participants (>65 years) were asked to rank-order opinion statements on issues associated with (non-)adherence. The rankings were subject to by-person factor analysis, and the resulting factors were interpreted and described as attitudes.

Results. Twenty-six elderly renal transplant recipients participated in the study. All passed the Mini-Mental State

Examination. Two attitude profiles were found: (i) satisfied and easy-going (attitude A), and (ii) reserved and concerned (attitude B). Elderly patients with attitude A want to enjoy the new life following their kidney transplant, are not very concerned about having to recommence dialysis, now and then even forget their regime, and do not really worry about it. Elderly patients with attitude B feel more insecure about their kidney transplant, are fairly concerned over issues like rejection or going back on dialysis, and try to adapt their way of life to the regime. One-third of these elderly patients forget their medication at least once a month, but there was no difference between attitude groups.

Conclusions. Attitudes about the post-transplant regime differ among elderly patients, implying different needs

for assistance, monitoring and risk of non-adherence to the regime. The proportion of elderly patients who forget their medication is considerable, but may be much higher among those with mild and severe cognitive limitations.

Keywords: adherence; elderly; kidney transplantation; Q methodology

Introduction

Kidney transplantation is the optimal treatment for end-stage renal disease. Life expectation is significantly improved among transplant patients compared with that of the age-matched wait-listed patients on dialysis [1–5]. Also, elderly patients may benefit as they experience a better quality of life after transplantation compared with dialysis treatment [6]. Therefore, the number of transplanted elderly patients is increasing. At the same time, we are not informed how elderly patients view their post-transplant lifestyle. Moreover, still little is known about their adherence to the medication regime. Non-adherence has been shown to be related to rejection and even graft failure [7–10]. Non-adherence to medication is a common problem in young kidney transplant patients, but this issue has yet to be studied in elderly transplant recipients. Risk factors of non-adherence are depression, less structure in daily life and social isolation [11]. We hypothesized that these risk factors are likely to play an important role in adherence among the elderly population. Also, other problems specific to the elderly may also interfere with medication adherence, e.g. label reading and interpretation, child-resistant containers, and short-term memory [12]. Non-adherence to immunosuppressive medication may add to older age-related risk factors such as cardiovascular complications and psychogeriatric morbidity. The way in which patients think about their medication and lifestyle is suggested to be linked to their behaviour. It is supposed that attitudes are concealed and not directly observable in themselves, but they cause actions and behaviours that are observable, i.e. health-related behaviours [13]. The present study investigated elderly kidney transplant recipients' attitudes towards their post-transplant immunosuppressive medication regime. This study is comparable with a similar study conducted among young renal transplant recipients [10]. We expected to discover a limited number of attitude profiles specific for elderly transplant patients that would be related to medication-taking behaviour and ultimately to adherence. Understanding patients' perspectives might help predict health behaviours and implement more effective interventions.

Materials and methods

Q methodology was used to investigate attitudes towards post-transplant health lifestyle. Participants are presented with a sample of opinion statements and are asked to rank-order these statements according to the extent to which they agree with the statement. The individual rankings of statements are subject to by-person factor analysis so as to reveal corresponding patterns in the way the statements were ranked by respondents. The results of a Q methodological study can thus be used to describe a population of viewpoints, not a population of people [14]. Q methodology emphasizes the qualitative 'how' and 'why' people think the way they do, but

does not count 'how many' people think a certain way. For this purpose, Q methodology does not need large numbers of subjects [15,16].

The current study consisted of four phases. First, self-referent statements that elderly patients can make about post-transplant health lifestyle were collected through interviews with elderly transplant patients, observations in the clinic and studying the literature [10]. The WHO defined different dimensions of non-adherence [17]: socioeconomic-related factors, healthcare team- or health system-related factors, condition-related factors, treatment-related factors, and patient-related factors. The second step was therefore to categorize the collected statements according to these dimensions by experts and condense them to a manageable set for the population under study. Statements were chosen that represented the pertinent issues within each dimension. The final set consisted of 35 statements (Table 1) that were randomly numbered and printed on cards. Many studies have indicated that depression is a risk factor for non-adherence [7,11,18,19]. Therefore, we included statements 1, 2 and 5 that we used as indicators of depressive symptoms in the Q set (Table 1).

Third, all patients who had been transplanted at the Department of Internal Medicine, Erasmus MC, had received their transplant after their 65th birthday and, with a follow-up of at least 1 year, were selected to participate in this study ($n = 72$). We included only these patients because they experienced this major life event at an older age. Of these, 46 patients had an outpatient clinic appointment during the period of inclusion and were therefore invited to participate. The other 26 patients were not invited because they had no appointment during the study period or some ($n = 5$) were lost to follow-up. In total, 26 elderly patients of the 46 who were invited to participate responded (response rate of 56.5%). The main reasons for non-participation were limitations in vision or hearing impeding participation in the study, and refusal by children of the elderly declining participation of their parent because of admission to a nursing home or cognitive limitations. The characteristics of participants are shown in Table 2. There were no statistically significant differences between respondents and non-respondents in age, gender or ethnicity. All interviews were conducted in a private room in the outpatient clinic. During the interview, participants were asked to rank-order the 35 cards containing the opinion statements, using a score sheet (Figure 1). Furthermore, as a way of checking for completeness of the statement set, respondents received two additional blank cards on which they could indicate an aspect they missed in the set; these cards could be ranked at the bottom of any of the columns of the score sheet. In post-sort interviews, participants were asked to explain the reasoning behind their choices, in particular the cards positioned on the extreme ends of the score sheet.

Finally, in phase four, the data were analysed and interpreted. The individual rankings of statements were analysed using common by-person factor analysis (extraction method: centroid; rotation method: varimax). The data were analysed using PQMethod 2.11 (dedicated software and manual are available via <http://www.rz.unibw-muenchen.de/p41bsmk/qmethod>). The resulting factors represented clusters of elderly transplant patients whose attitudes about their post-transplant health lifestyle were similar.

Q methodology is an established method that can be used to study subjectivity in a systematic way, such as peoples' viewpoints, beliefs and attitudes [20,21]. It combines the strengths of qualitative and quantitative research, and is regarded as a more robust technique than alternative methods for the measurement of attitudes and subjective opinion [13,22].

Mini-Mental State Examination

All 26 patients were asked to complete a standardized Mini-Mental State Examination (MMSE) [23]. Patients scoring <25 points (of the maximum attainable 30 points) were considered cognitively unable to participate in the study.

Self-reported non-adherence

All respondents answered four questions of the Siegal scale [24], in order to assess adherence to immunosuppressive drugs during the last month and the reason why they were non-adherent [25]. In a non-accusatory, information-seeking way, participants were asked how often they (i) had not taken their immunosuppressive drugs (IS), (ii) had forgotten to take their IS, (iii) had not taken their IS because they believed that they did not need them and (iv) had reduced the prescribed amount of IS. The frequency of these factors was measured using a seven-point scale ranging from 0 (never) to 6 (daily). Patients answering 'never' were considered to be adherent. All other scores (i.e. once a month, twice a month, three

Table 1. Statements and factor array

Statements	Post-transplant lifestyles	
	Satisfied and easy-going	Reserved and concerned
1. I feel lonely	-2**	-1
2. I think a lot about death	0*	-1
3. I am happy with my new kidney	+3	+3
4. I am worried that my kidney will be rejected	-1**	+3
5. I often feel gloomy and depressed	-3**	-1
6. I'm scared I will have to go back on dialysis again	-2**	+2
7. I feel guilty if I do something that is not so healthy	0	0
8. I should never have had this kidney transplant	-3	-3
9. I am sometimes forgetful	+1*	0
10. Other people sometimes think that I'm forgetful	0*	0
11. I am able to prepare and take my medication myself	+1	+1
12. I know what I have to take these medications for	+1	+1
13. I would appreciate more information about my transplantation	0	0
14. If you forget your medication once in a while, nothing really bad will happen	0**	-3
15. I don't want my life to evolve around my disease	+2**	+1
16. When I stay in bed late, I just take my medication later	+1**	0
17. After the transplantation I can do everything normally again	+2**	0
18. I would rather not tell others that I have been transplanted	0	0
19. Other people sometimes think that I complain about how I am doing	-1*	-1
20. I receive enough support from friends and/or family	+1	+1
21. I feel more tired than my peers	0	+1
22. I would appreciate meeting with other elderly kidney transplant patients	0*	-1
23. I do what the doctors tell me, they know what is best for me	+2	+2
24. I miss the companionship of the dialysis ward	-1*	-2
25. I have a lot of confidence in my doctor	+2	+2
26. In the clinic they treat me like an infant	-2	-2
27. I don't understand what the doctor says because he uses difficult words	-2	-2
28. I am not changing my health lifestyle because a doctor wants me to	0**	-1
29. I find it reassuring that they check my kidney function regularly at the outpatient clinic	+3	+2
30. Travelling to the hospital costs me a lot of energy	-1*	0
31. I sometimes forget my medication	+1**	-1
32. I have problems swallowing larger pills	-1	0
33. I have side effects from my medication	-1**	+1
34. A pillbox is a handy aid	+1	+1
35. If I'm not sure whether I have taken my pills already, I just take it again	-1	-2

A '-3' score indicates that a typical elderly with that health lifestyle attitude would disagree most with that statement, and a '+3' score indicates that (s) he would agree most. * $P < 0.05$. ** $P < 0.01$.

times or more) indicated non-adherence with medication taking. To test convergent validity, Pearson's correlation was conducted between the Siegal scale and the following statements: 'I sometimes forget my medication', 'When I stay in bed late, I just take my medication later', and 'If I'm not sure whether I have taken my pills already, I just take them again' (statements 16, 31 and 35 in Table 1).

Results

Twenty-six elderly kidney transplant recipients (67–82 years) participated in this study. All participants were included because they had an MMSE score of ≥ 25 ; median score was 29. Analysis of their Q sorts resulted in a two-factor solution (eigenvalue > 1), indicating there were two distinct post-transplant health lifestyle attitudes (Table 2). Twelve elderly patients defined factor 1, and 14 elderly patients defined factor 2.

The elderly patients who defined the first factor were not worried that their kidney will be rejected (statement 4; see Table 2) but nonetheless thought that it is important that their kidney function be monitored regularly (statement 29). If dialysis is necessary, they were not afraid of

it (statement 6). They were sometimes forgetful (statement 9), but were not concerned about the consequences of forgetting their medication once in a while (statement 14) and taking their medication later if they sleep late (statement 16). They did not evidence signs of depression (statements 1 and 5), did not want life to revolve around their disease (statement 15) and were of the opinion that after transplantation, they can lead a normal life (statement 17). They experienced few side effects of their medication (statement 33). This factor was labelled 'Satisfied & Easy-going'. The post-sort interviews indicated that these elderly patients were satisfied with the new life that was made possible thanks to their kidney transplant. They found it important to have their kidney function checked regularly, to confirm that they are doing well. They tended to forget their medication now and then, but did not make a big deal out of it or feel guilty about it. The following quotes illustrate this attitude profile: 'I sometimes think I don't need my medication and I would like to try not taking them' and 'I don't mind forgetting my medication, I would like to have less medication anyway'. Another respondent said: 'Sometimes I take my medication later, the nurses did not give me a hard time when I forgot, so why should I mind'.

Table 2. Patient characteristics

Patient characteristics	Respondents (n = 26)	Non-respondents (n = 20)
Age (years)	67–82 (median 73)	67–84 (median 72.5)
Time after transplantation (years)	1–10 (median 5)	1–16 (median 4.5)
Gender	5F/21M	7F/13M
Education level	1 university, 5 high, 2 middle, 18 low	Unknown
MMSE score	25–30 (median 29)	Unknown
Ethnicity	Caucasian	16 Caucasian, 3 Asian, 1 African
Kidney transplant	14 living/12 post-mortal	11 living/9 post-mortal
Living status	All living independently	Unknown
Civil status	21 married/2 single/3 widowed	Unknown

The elderly patients who defined the second factor were worried that their kidney could be rejected (statement 4) and were afraid of going back to dialysis (statements 6 and 24). They were of the opinion that forgetting medication will have harmful consequences for them (statement 14), but also indicated that they experienced some negative side effects from their medication (statement 33). These elderly patients appeared less happy and comfortable with their post-transplant life than the elderly in the other factor (statements 1, 5 and 17), and generally felt more tired than their peers (statement 21). They were more sensitive to their doctor’s opinion about their health lifestyle (statement

28). This factor was therefore labelled ‘Reserved & Concerned’. The post-sort interviews confirmed these findings. These elderly patients did not want to go back on dialysis: ‘It was horrible to lay there for four hours’. Some of these elderly said that they would rather die than go back on dialysis but at the same time contemplated that they might change their opinion if this happened, depending on their partner still being alive. Because they worried about the consequences of forgetting their medication, they tried to be accurate (‘I had a clock for my medication, when it was broken it was really hard for me’) and compliant to their doctor’s advice (‘My doctor is my teacher, so

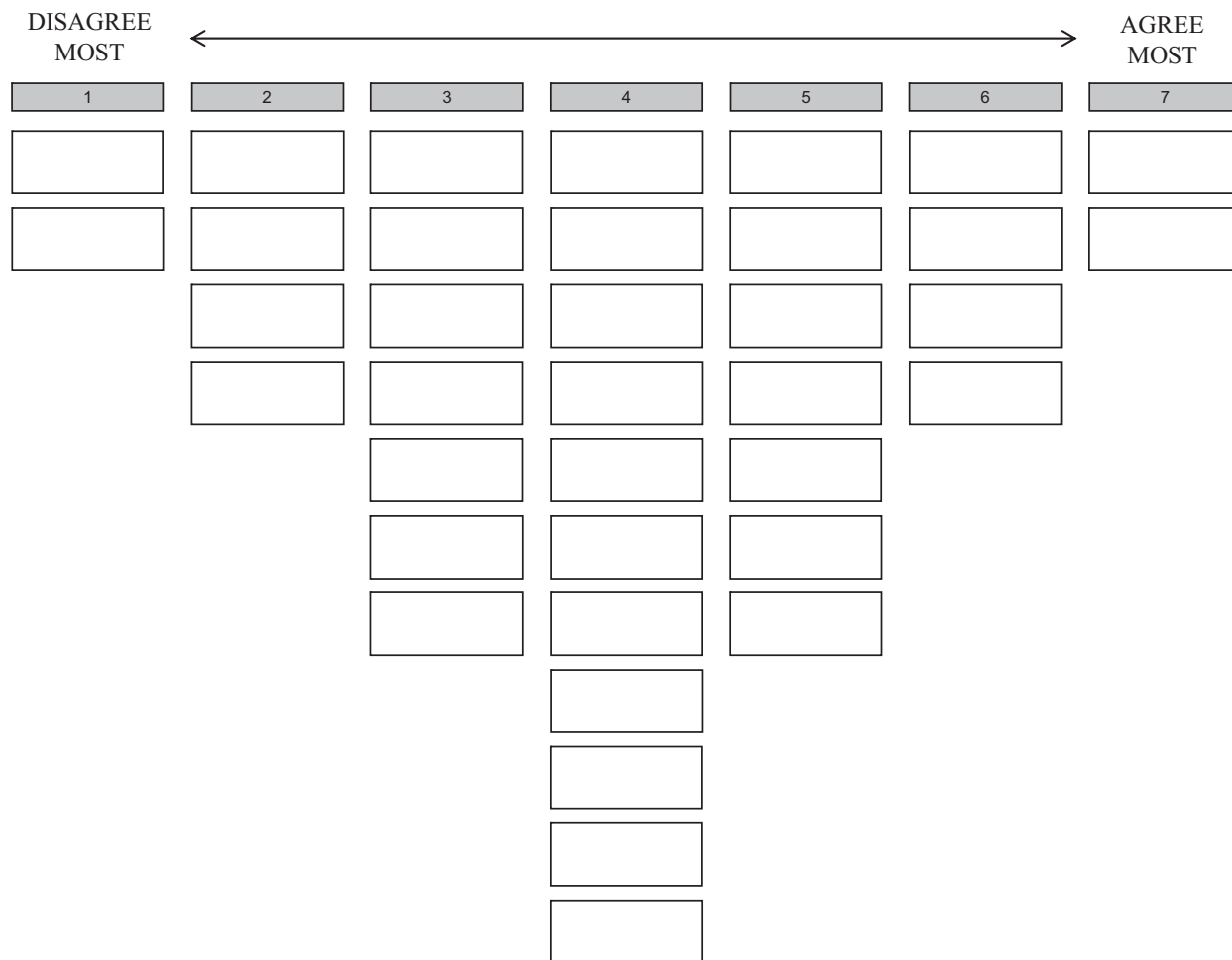


Fig. 1. Score sheet.

I change something if he thinks that is necessary'). Based on this combination of attitudes, we would expect adherence to be high among these patients.

We observed consensus about several issues between elderly patients with the two different attitudes. Firstly, elderly patients trusted and had a lot of faith in their doctor, and were satisfied with the way they are treated by hospital staff (statements 23, 25, 26 and 27). In addition, despite the some worries, all the elderly seemed happy with their kidney transplant (statements 3 and 8). One respondent for instance said: 'If I would need another kidney transplantation tomorrow, I would not hesitate'. Finally, social isolation was not a serious issue in these elderly patients, and they appreciated the support they got from friends and family (statement 20). Almost all patients ($n = 21$) were married, and indicated that their partner supported and sometimes even managed their medication regime.

The Siegal scale revealed that 8 of the 26 (30.8%) respondents had not taken their medication, once or more, over the last month; the main reason for not taking medication was forgetfulness ($r = 1.000$, $P < 0.000$). Although the number of respondents is small, there was no significant difference ($r = 0.162$, $P < 0.43$) in adherence to the medication regime between the two attitude profiles, 3 of the 12 elderly with the 'Satisfied & Easy-going' attitude, and 5 of the 14 with the 'Reserved & Concerned' attitude. Elderly patients with both attitudes tended to forget their medication now and then, but unintentionally. We observed convergent validity between the statement 'I sometimes forget my medication' (statement 31) and the Siegal scale with a significant correlation ($r = 0.416$, $P < 0.034$). There was no significant difference on sociodemographic factors like age or time since transplantation.

Our elderly participants showed little signs of depression because statements 1, 2 and 5 were generally placed negatively (i.e. they disagreed with these statements). Only 3 of 26 patients agreed with the statement 'I think about the death a lot' (statement 2).

Discussion

Prior to this study, little was known about how elderly experienced problems with adherence to the post-transplant medication regime. This study revealed two distinct attitudes among elderly transplant recipients: 'Satisfied & Easy-going' and 'Reserved & Concerned'. Satisfied and easy-going patients focus on leading a normal and enjoyable life and are not fearful or worried about the consequences of not taking their medication correctly. Reserved and concerned elderly patients experience more physical and psychological complaints, and are more fearful of the consequences of not taking their medication correctly. Elderly patients with both attitudes tend to forget their medication now and then, but unintentionally—as found among young transplant recipients [10].

We observed a substantial level of non-adherence (30%) in our study population. This is comparable with the findings from a systematic review of the literature that 28% of the adult renal population is non-adherent

[7]. Non-adherence is associated with poor clinical outcomes; however, death with a functioning graft is still the most common cause of death in the elderly renal transplant population. The two most common causes of death in the elderly are cardiovascular diseases and infection-related mortality after transplantation [4,6]. Although the attitudes towards the post-transplant regime in our study population of elderly patients differed within the sample, a comparable non-adherence score was found for the two groups with distinct attitudes. These results are remarkable because our study population was cognitively well functioning, as they were screened for this in the MMSE test. One consistent determinant of non-adherence is social isolation [7]. The patients in our study were all living independently and were active in their social network. The risk of non-adherence could be far higher among elderly transplant recipients not enrolled in the present study and those with visual or auditory impairment or moderate to severe cognitive limitations. This indicates that the non-adherence observed here, although considerable, could very well be just the 'tip of the iceberg'.

The sorting of the cards was feasible for these elderly transplant patients, and the post-sort interviews indicated that they comprehended the task and the contents. Because the elderly patients had a tendency to be very accurate, the sorting of the cards took a lot of time. In that sense, the post-sort interview also served as a validity check because any incongruence between the sorting of the cards and explanations of the sort could be remedied. But this was rarely necessary, which is an indication of the validity of the results. The statements and placing them on a score sheet stimulated open communication about the topic. The respondents talked freely and easily about sensitive issues (i.e. death, loneliness), when confronted with these statements. This indicates that the process of sorting a set of opinion statements may also be a helpful instrument in clinical practice to commence and deepen discussions with patients. In doing so, they may be able to learn more about how elderly kidney transplant patients experience and deal with their disease, their treatment and their prospects after treatment, and what constitutes these attitudes.

Limitations of the study

Although this sample was sufficient to be able to discover attitude profiles, further research with a larger non-selected sample is needed to explore and confirm the relationship with adherence. In particular, investigating the attitude profiles and adherence patterns of hard-to-reach elderly patients who are less independent or have greater comorbidity would be interesting. However, this is another argument that the real non-adherence in elderly patients is probably higher than the 30% we observed. In addition, if we want to conduct further studies in this patient population, we should develop methodologies that facilitate participation of vision- or hearing-impaired patients so we can study the elderly in a broader sense. In this study, the Siegal scale was used, which has been criticized for its lack of sensitivity, as self-reporting scales have the tendency to underestimate adherence. Future studies should follow

current recommendations in the literature to use multiple measures of adherence [26].

Notwithstanding these limitations, this study offers a unique insight into the attitudes of elderly transplant patients and how these may relate to medication adherence.

Conflict of interest statement. None declared.

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