

Immunosuppressive Drugs and Young Adults: A Difficult Combination

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Background: In our center we encounter serious problems with a number young adult (18-25yrs) renal transplant recipients that are non-compliant to the medication regime. This could well be one of the reasons for the significantly worse unadjusted 10 years kidney graft survival in this patient group compared to that in recipients > 25 years: 47.2% versus 64.0%. This paper focuses on the attitudes and behavior of young adults towards compliance with the immunosuppressive drugs.

Method: We used Q-methodology to identify attitude profiles associated with noncompliant behavior. Adolescent renal transplant recipients (n=25) sorted a set of 37 statements (Q-set) along a continuum of preferences to reveal categories of individuals who shared common viewpoints. The same Q-set was also used as a topic list for an in-depth interview. In this paper, we focus on the interview results of four statements, related to compliance with immunosuppressive drugs. Each interview was fully written down, using the software program Atlas.Ti® for coding and labeling.

Results: Almost half of respondents (40%) think that forgetting medication will not lead to serious consequences. They feel they took so much medication over the years that they had developed a certain reserve immunity against rejection. Others state that they had become indifferent after experiencing that 'nothing happened' after forgetting their medication. Most adolescents declare having no problems taking their medication when going out with friends. They do not feel ashamed, but some lose track of time and simply forget taking medication when they are out with friends. Remarkably, 18 of the 25 young adults (72%) admit to not always taking their medication on time. When they sleep late, only 7 of them set the alarm clock in order to take their medication as prescribed.

Conclusion: Using the Q-set statements as interview topics triggered young adults to ventilate their opinion and reveal their medication practice. Confronting statements on cards appeared to be very useful in communicating with adolescents about difficult subjects such as non-compliance. This helps caretakers in the outpatient clinic to explore and discuss reasons for non-adherence to immunosuppressive drugs. Many young adults are not very accurate in taking medication on time, and 40% even think nothing bad will happen when they forget their immunosuppressive drugs. Healthcare professionals should be aware of this grossly underestimated problem.

Introduction

Young adults try to establish their identity and autonomy and want to be independent while at the same time they are dependent on the help from adults and healthcare professionals when they are chronically ill [1]. This struggle for independency in a situation of dependency often leads to non-compliance which may result in graft rejection. In our experience, non-compliance is a major problem in young adult patients. In our outpatient clinic we often see young male adults who appear indifferent and careless, whom we sometimes call ‘the baseball caps’.

The impact of non-compliance is more obvious in adolescent transplant recipients than in the older transplant population. We analyzed renal graft survival of all our kidney transplant patients between 1971-2005. We stratified them according to age: older and younger than 25 (Fig.1). We found, as has also been suggested in literature, a significant worse graft survival for young adults compared with older adults [2,3,4]. While young adults may have a more vigorous immune system resulting in more rejection [5], this is probably not the only explanation. Non-adherence can also be a cause of late graft loss [1,6,7]. In a previous study we used Q-methodology to identify 4 behavior patterns in young adults [8]. These four profiles are A; Concerned & Controlled, profile B; Appearance orientated & Uncommunicative, profile C; Opinioned & Independent and profile D; Easy going & Pliable. The young adults in profile A have the lowest risk of noncompliance and the young adults in profile D have the highest risk. One of the key issues in non-compliance concerns proper taking of immunosuppressive drugs as prescribed. Therefore, in this paper we focus on the ideas of young adults regarding this sensitive topic.

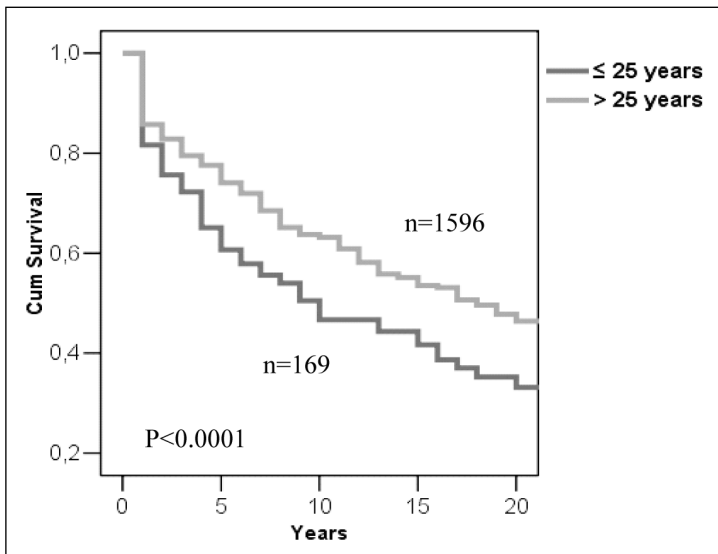


Fig. 1: Graft survival censored for death of all kidney transplants performed in Rotterdam from 1971-2005

Methodology

The goal of Q-methodology is, first and foremost, to uncover different patterns of thought (not their numerical distribution among the larger population) [9,10]. Q-methodology exists of three stages: first, to develop a set of statements to be sorted (called a Q-sample), second, to require participants to sort the statements along a continuum of preference, and last, to analyze and to interpret the data [11,12]. We made a list of 37 statements (Q-set). The statements are matters of opinion only, not facts. All statements are related to issues related to non-compliance. We followed the different dimensions of non-adherence described by WHO [13]. Adolescent renal transplant recipients (n=25) sorted the Q-sets along a continuum of preferences ('disagree most' to 'agree most') to reveal categories of individuals who shared common viewpoints (Fig. 2). Afterwards, we performed an in-depth interview about all the statements, using the statements as a topic list. We asked the respondent to comment on each statement. The interviews were recorded and later transcribed *ad verbatim*. For qualitative analysis, consisting of coding and labeling followed by thematic analysis using constant comparison, we used the computerprogramme Atlas.Ti®.

This paper focuses on the responses to four statements concerning compliance to immunosuppressive drugs:

1. "If you forget your medication, nothing really bad will happen"
2. "I never forget my medication"
3. "When I stay in bed late, I just take my medication later"
4. "When I am out with friends, I am not very punctual with medication"

The figure shows a Q-sorting answer sheet. At the top, there is a horizontal continuum with a double-headed arrow. On the left end, it is labeled 'DISAGREE MOST' and '1'. On the right end, it is labeled 'AGREE MOST' and '7'. Below this continuum are seven vertical columns, numbered 1 through 7 from left to right. Each column contains a series of empty rectangular boxes for sorting statements. The number of boxes in each column is as follows: Column 1: 2 boxes; Column 2: 4 boxes; Column 3: 5 boxes; Column 4: 6 boxes; Column 5: 5 boxes; Column 6: 4 boxes; Column 7: 2 boxes. This arrangement of boxes forms a symmetrical, inverted bell-shaped curve centered on column 4.

Fig. 2: Answer sheet

Results

Patients characteristics of the 25 participants are shown in table 1. Ten recipients felt that forgetting medication would not lead to serious consequences (Table 2). One girl said: *“I did it a few times (forgetting medication) and nothing happened. I take my pills on Tuesday, Wednesday, Thursday and Friday, on Saturday I do not. And then I take them again”*. When asked if she wasn’t scared her kidney would reject, she said: *“Sometimes I am scared because I think if I lose this kidney, I will regret that I did not take my medication”*.

Some recipients thought that after taking so much medication over the past years, a certain reserve immunity against rejection had been developed. Others stated they had become indifferent after experiencing that *‘nothing happened’* after forgetting their medication. One young man thought that, because he was prescribed a low dose of immunosuppressive drugs, he could more easily forget his medication than someone who needed a higher dose of immunosuppressants. Two of the eight young men who all disagreed with the statement *“when you forget your medication nothing bad will really happen”* had learned this the hard way; one went through an acute rejection from which he fully recovered and the other had experienced graft loss due to non-compliance. From the ten recipients who admitted to non-compliance, five had received a deceased donor- and five a living donor kidney.

In contrast, the responses to the statement *“I never forget my medication”*, were quite different. Half of the respondents (48%) stated that they never forget their medication. They are so used to take medication, a girl said: *“I can’t imagine how people can live without any med-*

Tab. 1: Patient characteristics (n=25)

Patient characteristics	Respondents
Age	18-25yrs
Sex	10 (40%) female/ 15 (60%) male
Graft	21 (84%) functioning graft/ 4 (16%) failures
Education level	8 (32%) high/ 8 (32%) middle/ 9 (36%) low
Ethnicity	18 (72%) Caucasian/ 7 (28%) others
Type of transplant	18 (72%) living donor kidney/ 7 (28%) deceased donor kidney
Living environment	9 (36%) independent/ 16 (64%) with parents

Tab. 2: Agree and disagree of the 4 statements

Statement	Agree	Disagree
"When you forget your medication nothing bad will really happen"	40% (n=10)	60 % (n=15)
"I never forget my medication"	48% (n=12)	52% (n=13)
"When I am out with friends, I am not very punctual with medication"	20% (n=5)	80% (n=20)
"When I stay in bed late, I just take my medication later"	72% (n=18)	28% (n=7)

ication, I have medication everywhere, in the car, with friends, if I forget, then I have them everywhere". But half of the interviewed forget their medication sometimes, however not intentionally: they are too occupied or in a hurry. One young man who sometimes forgets his medication, says he does not feel like taking medication at that time and then simply forgets. Another one states: "When I forget my medication, I am really angry [with myself], when it happens twice a week I think it goes really bad and I have to focus more". One respondent thinks it is important to take his medication since he received a transplant kidney. When he was still on dialysis he intentionally forgot his medication, because he did not feel like it and did not see the point of taking medication all the time.

Most adolescents say they have no problem taking medication when going out with friends (80%). They claim not to feel ashamed, but some lose track of time and simply forget taking medication when they are out with friends. A young man explained it was hard to remember his medication when he was on holiday with friends, because there was 'no structure'. But a young woman said: "You do crazy things when you are on holiday, but I always take care of my kidney, even when I drink a lot of alcohol, I think about my kidney, you never forget your kidney".

Remarkably, 18 of the 25 young adults (72%) admit to not always taking their medication on time (Table 2). Especially after going out with friends the day before, they forget to take their medication on the prescribed time. Only seven respondents claim to set the alarm clock when they are sleeping late, in order to take their medication as prescribed. After taking the pills, they go back to sleep. One girl said she took her medication regularly when admitted to hospital, but when at home, she preferred to look at a television program and postponed her medication with one or two hours. Especially during the weekend young adults experience problems with the regular intake of immunosuppressive drugs. A girl said: "In the past, my parents used to wake me up. I was always mad because of that, nowadays I do it myself, but I don't care to take the medication later".

Discussion

To better detect and understand non-compliance, Q-methodology was used to gather information about various issues regarding non-compliance. After the sorting of the cards with statements (Q-set), young adults were asked to give their opinion about each statement. Statements in the middle had a 'neutral' meaning for them (issues not so important to young adults as compared to the other issues on the cards put at the extremes). Remarkably, these neutral statements turn out to be of special interest to healthcare professionals. Rianthavorn and Attenger described a group of *invulnerable* non-compliers, i.e. recipients who don't think that missing medication can hurt them [1]. They feel invulnerable to the effects of discontinuing of immunosuppressive drugs. In our study, we found a similar group of *invulnerable* non-compliers. The statement: "Forgetting medication will not lead to serious consequences" turned out to be a distinguishing and characteristic statement in Q-profile D, the most non-compliant group [8]. In contrast, almost every young adult put the card with the statement: "When I sleep till late, I just take my medication later" in the middle, neutral zone. The interview afterwards revealed that young adults think it is normal to take medication much later when they sleep late. Russel et al. also discovered patterns in patients who take medication later or missed a dose [14]. Apparently, young adults are not too accurate with

the medication, especially when it does not fit in with their life style and with important social activities such as going out with friends.

Adolescents are more vulnerable and less approachable for various psychological reasons [15]. Strikingly, young adults were willing to talk easily about sensitive issues when confronted with statements on a card. The interviewer in this study (M.T.) is a nurse practitioner familiar with and also slightly older than the respondents. This could, on theoretical grounds, be a disadvantage because of a possible infringement on their privacy. However, we feel it turned out to be an advantage as the respondents felt comfortable with her, which resulted in frank answers.

Conclusion

Q-methodology was used to create attitude profiles among young adults. In this study, we discovered that using these statements as interview topics proved to be of great help in communication with adolescents. The cards triggered them to ventilate their opinion and reveal their ideas and their medication practices. This is extremely relevant for healthcare professionals in their attempt to understand the motivation of young adults. Discussing these sensitive issues may very well help young adults to better comply with their strict medication regime. Many young adults are not very accurate with taking medication on time, and a lot of them think nothing bad will happen if they forget their immunosuppressive drugs. Healthcare professionals should be aware of this grossly underestimated problem.

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