

Implementing a tailored education program: renal transplant recipients' experiences

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Tailored education for renal transplant recipients

ABSTRACT

Aim: Patient-centred education is a key element in the care of patients going through kidney transplantation. The aim of the study was to explore renal transplant recipients' experiences after implementing a new tailored education program provided for the post-transplant phase.

Methods: A total of 12 renal recipients participated in semi-structured interviews. The interviews were audiotaped and analyzed by thematic data analysis inspired by Kvale and Brinkmann's method for meaning condensation.

Results: Two main themes were generated: 'Situating tailoring to the persons' everyday life knowledge', and 'Tailoring as a standard procedure regardless of the person'.

Conclusion: Viewing knowledge as continuously changing from controlled study contexts into clinical settings we here demonstrate the need of evaluating new knowledge also after becoming implemented. Divergent considerations may be taken by the health personal considering the new practice and this may impact directly on the care provided, so also within the context of educating renal transplant recipients.

Key words: implementation, patient experiences, qualitative research, renal transplantation, tailored education program.

Introduction

Transplantation is the treatment of choice for end-stage renal disease; it increases survival and quality of life, while being more cost-effective compared to dialysis (1-4). However, transplantation brings new challenges in patients' life in terms of life-long medication, care of the graft and various restrictions in everyday life (5-9). In order to reduce rejection episodes, graft loss, and negative consequences of immunosuppressive medication renal transplant recipients need to acquire knowledge in relation to medication regime, graft surveillance, and the benefit of specific lifestyle behavior (10-14).

In a randomized trial performed at a Norwegian hospital in 2012 the effect of a tailored education program for renal transplant recipients was tested (15), based on tailoring the education to individual needs, active patient participation and timing of the education sessions. Results showed that the program significantly increased the patients' knowledge and compliance. As a consequence the education program was implemented at the hospital in 2014 (16). There are several challenges when implementing results from controlled studies into clinical settings, such as lack of connection between the producers and users of research, and knowledge being a package transferred to clinicians (17). Viewing knowledge as continuously changing and social constructed, it is important to study the results also after being implemented into every day practice (18, 19). Hence, we performed a broad research project containing several substudies that included different aspects of implementing results from a clinical trial within the context of renal transplantation. An overview of the project is recently reported (20). An important perspective in this project is patient's own experiences of the new education program. Hence, the research question of the actual sub study was: How do renal transplant recipients experience this evidence based tailored patient education program?

Methods

Design

A qualitative content analysis design was chosen to generate descriptions of the patients' experiences.

Context

The present hospital is the only transplant centre for patients going through renal transplantation in Norway. The centre employs about 100 nurses, comprising a surgical and medical ward, and an outpatient department. Renal transplant patients' education was previously provided during their stay at the surgical and medical ward. Before implementing the new education program all nurses at the centre providing education for this patient group underwent training sessions to get a common understanding of tailoring education for renal transplant recipients. The new program consisted of three main knowledge areas: medication, rejection, and lifestyle. The content was contextualized to each patient's unique needs: before starting the sessions the nurses asked screening questions to patients to tailor the education to personal needs, life style and home context.

Participants

Twelve renal transplant recipients were purposeful recruited during their stay at the hospital post transplantation. The following inclusion criteria were used: being 18 years or older, having undergone the new tailored education program, speaking and understanding Norwegian. No patients rejected to participate. The interviews were performed 8 weeks post transplantation, usually the week the recipients departed from hospital, and lasted between 40-60 minutes.

Interviews

Two trained researchers, also being clinical experts within renal transplantation (MHA, KHU), performed the semi-structured interviews. The interviews took place in a suitable room with a relaxed atmosphere. The participants were introduced by a short briefing about the purpose of the study and then asked to describe their experience of going through the education program. A semi-structured interview guide was used during the conversation to ensure relevant topics to be discussed (Table 1). The interviews were rounded off by a debriefing by asking if the participant had anything to add, and inviting the participant to share experiences of the interview situation. Each interview was recorded and then transcribed verbatim by one of the authors of this paper (MHA).

Table 1 about here.

Data analysis:

Data were analyzed inspired by Kvale and Brinkmann's method of meaning condensation (21). First, the whole interview was read through independently by two of the researchers (MHA, KHU) to get a sense of the wholeness. In step two the text was divided into units of meaning, in order to grasp the most probable interpretation of the informants' statements. Third, the theme dominating a natural unit of meaning was stated as simply as possible. At this stage it was important to read the participant's answer with an open attitude and to attend critically to our own prejudices and pre-understanding. The fourth step consisted of interrogating the meaning units in terms of the specific purpose of the study: to give answer to how renal recipients experience to go through a tailored education program post transplantation. The themes of the meanings units were addressed with respect to, "What does this statement tell me about participants' experiences?" In the fifth step, the essential themes of the entire interview were tied together. The method thus involves a condensation of the

expressed meanings into more and more comprehensive refinements of subcategories and themes. Example from the data analysis process is shown in Table 2.

Table 2 about here.

Trustworthiness

Different strategies were used to enhance rigor throughout the study. The research question and the interview guide were based on literature reviews and the researchers' experiences in the field. In the first phase of the data analysis two members of the research group (MHA, KHU) met regularly to discuss subcategories and propose preliminary themes. This implied switching back and forth between the transcripts and themes to assure an accurate reflection of the interview data. Then two senior researchers not affiliated to the clinic (AKW, EE) joined the group and questioned the preliminary analysis. All researchers then discussed carefully alternative ways of interpreting, categorizing and organizing the data until consensus was reached.

Ethical considerations

The study was in compliance with the guidelines of the Helsinki convention throughout the entire research process (World Medical Association, 1983). All participants were informed about the study both orally and in writing. Approval was obtained from The Institutional Review Board at Oslo University Hospital, number #2014/5573.

Results

Twelve adults participated in the study. The sample captured a broad variation in background characteristics (Table 3):

Table 3 about here.

Two themes derived from the interviews: Education tailored to the persons' everyday life knowledge vs Education as a standard procedure regardless of the person.

Education tailored to the persons' everyday life knowledge

The patients expressed that the education content was closely linked to their personal needs, life style and home context. Their statements demonstrated how the learning material was adjusted and differently highlighted to match individual life situations. For instance about risk of infection, being an essential topic of learning for renal transplant recipients, the patients` described how the nurses chose different strategies when tailoring the education to the patients' everyday life. One of the patients described how the focus on infection risk was closely related to her lifestyle. She was a farmer and in close contact with animals every day:

“Well, I'm a farmer and I am in more risk of such things (infections) so this issue was highlighted for me... I have to be a bit more aware of this since I am occupied with horses. I clean the horse stable and I have a low immune system, you know, so I must be extra careful. So all these aspects were taken good care of for me... being an individual person» (1)

For patients having children the nurses situated the education to the patients' life situation and circumstances. The nurses then chose a different strategy when addressing aspects of risk of infection. Because the patient had a small child at home the nurse stressed issues related to childhood diseases, such as varicella:

«I have a child attending kindergarten. So the nurse asked me: Has your son had varicella? I answered no. Then she told me that I had to be careful in case my son is infected. If it happens, I should see my doctor immediately and get medication (vaccine). Perhaps, I then need to move out of the house for a period to avoid close contact - because my immune system is low. I didn't know this» (6)

The patients highly appreciated the nurses' attempt to get to know each patient thoroughly before start of education. Mapping of unique life situations and everyday life were considered important and valued steps as seen from the patients' perspective. Areas for mapping usually were related to life situation, family, network, work, and interests:

“The nurses were really good at asking us what we are occupied with, about our life situations. Each of the nurses started the education session with asking how I was and so on. I felt that each and one of them talked to me as the person I am, being focused on where I am” (1).

On the basis of an individual approach, the nurse and patient discussed possible challenges and solutions related to immunosuppressive medication regimes, living as a renal transplant and the various restrictions of everyday life. One example could be within the area of physical exercise and healthy dietary. A patient told that since he was not used to cooking, extra attention was paid to dietary issues. His wife was invited to attend the education sessions to provide extra support.

The value of being looked upon as a whole person seems to be a clear pattern in the patients' experience of the nurses tailoring processes. The patients' experiences of not being just a "case" were reflected in many descriptions. Clearly, the tailoring process provided the patients with more than relevant educational content; it also provided feelings of being a unique individual. When being placed in a patient role within a hospital system, separated from familiar social roles, such experiences seems to be highly appreciated:

"They recognised me so I did not feel just like an identity number. That feels good!" (5). "In a way... the nurses were so human. They were not like robots, rather informal, relaxed, humoristic, and being very compassionate. They are not just doing routine work, they see you as a person also, and that's important" (8).

The patients expressed tailoring of education not solely being limited to the content; tailoring seemed to be extended to also include educational program structure and communicative approaches. Patients described how nurses captured their mood and used strategies such as humour or spending time on listening to their worries at the start of the education sessions in order to make them more relaxed and prepared for education. Although the structure of the program was pre-determined to consist of three individual sessions within a certain time limit, patients expressed that the structure was modified and was flexible in special situations:

«It was not that way.....that we ended the session when the session was scheduled to finish. No, not until all my questions were answered» (6)

One patient, transplanted for the first time some years ago, compared the new education program to the old one and expressed a positive change *“I experience the education this time to be very different from last time I went through renal transplantation. Then I did not receive specific information. Now I get confirmed concerning own knowledge and by that avoid to made mistakes”* (2)

Education as a standard procedure regardless of the person.

Although experiencing the education tailored to personal needs several patients simultaneously perceived the education to be based on the nurses` desire to “keep their hands clean”. The patients experienced that some topics were taught regardless of their existing knowledge. They felt that sometimes the nurses` focus seemed to be more on their loyalty towards the hospital system aiming at preventing graft rejections:

« For me, it seemed that the nurses` focus was most on assurance. It was more like that. (..) But I clearly understand why. The operation is expensive. They really want this to work. I do, too. So I understand why» (3).

The feeling of assurance also occurred during the knowledge screening meant for revealing unique patient needs. Some patients experienced it more like an interview or a test:

«I guess I was interviewed so they were sure that I had the knowledge needed. (..). They tried to assure themselves that I knew what I should know. It was pretty much the focus. (..) I was asked a bit about why I took the medication, so they could be assured that I knew the things I needed to (4).

One patient, being transplanted twice, had to reason actively to convince the nurses that he had sufficient knowledge within some areas: *“We went through a couple of themes of the information material, and I said that I have been living with this for 10 years so we don’t need to spend any more time on this, because I know this stuff»* (9).

Also, patients experienced that the education consisted of many repetitions. Sometimes they felt that the reason for all the repetitions was the nurses’ need of affirmation of patients’ knowledge level, rather than the need of the patients: *«It is a bit doubled up – a little bit on top of each other, I think. Actually, the same things occurred repeatedly and to me it seemed like the nurses wanted assurance»* (3). For some patients repetitions also seemed to be alright: *«It was pretty much the same things over and over again, it was repetitions, but it was OK to get repetitions* (10).

As a part of the education program, the patients practiced on administrating of medications by putting their daily pill doses in a medication dispenser. This seemed to be a particularly area for reception. The patients, although expressed being grateful for being taken so good care of, indicated that it sometimes felt too much. The following statements illustrate this:

“Yes, they were watching me while I was preparing my medication - I put my pills into the dispenser and they controlled it. You can be sure that nothing was left to chance, no! This was done a lot of times, I don’t remember how many, but it was a lot of times” (4)

Discussion

Discussion

The findings of this study were two-folded: simultaneously to acting patient-centered the nurses demonstrated loyalty towards the hospital system probably aiming to prevent rejections of the graft. The most typical example was when nurses were teaching the patients how to put their daily pill doses into medication dispensers regardless of patients' existing knowledge.

We think this finding reflect a well-known dilemma within the care of renal recipients: on the one side considering renal recipients as autonomous human beings tailoring the education to personal needs, on the other side taking a paternalistic perspective reflecting the goals of the organization to assure quality (22). Our study demonstrates that care of patients in hospitals takes place in a complex environment. Incorporation of patient values and shared decision making in general have increased the last decades. At the same time loyalty to the institution and evidence-based practice are in play, the latter having become a gold standard within modern health care. Divergent considerations and values may challenge the health personal own values and also place stress on them. Sometimes health personal may assume that they share common goals and values with patients (23). However, cultural norms may differ between patients and professionals, as demonstrated in our data. To open consciously on this topic it is essential to address it to both leaderships and their employees (24). Hospital managers need to understand which factors that motivate and engage care providers, as well as balance values of the organization to personal and professional values of employees, and in special when new practices are implemented.

We found that the participants had an overall positive attitude towards the new tailored education program, expressing satisfaction by attending a program adjusted to match personal needs, life style and home context. They also felt they were seen as whole persons. Several factors may explain the findings. Starting the implementation process implied educating

transplant nurses about the importance of tailoring patient education to individual needs to achieve behavior changes and improve transplantation outcomes (16, 20). Our findings are supported by previous research within patient education stressing the importance of tailoring individual patient needs, both in the context of renal transplantation and patient education in general (25, 26). In a study of patients' and health professionals' views on the management of diabetes type 2 it was found that when more time was allowed during the education sessions patients felt care was more personal (27). Further, according to Tong et al, recent years the focus on patient participation in general has been strengthened within medical treatment and care. There has been a paradigm shift in health care policies and research toward greater patient centeredness. A core tenet of patient-centered care is that patients' needs, values, and preferences are respected in clinical decision making, so also within the area of renal care. Health professionals are now in general more aware of shared decisions making supporting the active role of the patients (28).

Our findings may also be explained by recent years' focus on patient participation in general, being strengthened within medical treatment and care. According to Tong et al. there has been a paradigm shift in health care policies and research toward greater patient centeredness. A core tenet of patient-centered care is that patients' needs, values, and preferences are respected in clinical decision making, so also within the area of renal care. Health professionals are now in general more aware of shared decisions making supporting the active role of the patients (28).

Finally, our findings may be seen in the perspective of organizational changes. Changes as result of an implementation process should not be underestimated when evaluating outcomes. During the implementation process all nurses were trained to cooperate between units and to

focus on continued care when the renal recipients were transferred between units. Changes towards a more seamless care pathway may have led to a more systematic approach to patient education. In our first report of the nurses' attitudes towards the new education program we found that the nurses viewed the program as a positive change towards a more united and patient centered patient education. In a report from UK (29) about organizational changes within healthcare it is stressed that communication and common goals throughout the patient pathways is necessary to obtain high delivery of care.

Methodological considerations

The findings from the study should be interpreted in context with its methodological strengths and limitations. The study, focusing on the patient perspective, is part of a broad, innovative research project investigating different aspects of implementing a new education program for renal recipients. The findings of the actual study indicating a successful implementation are supported by other sub studies from the project (20). Another strength concerns informant recruitment. As there is only one transplant center in Norway the participants represented different part of the country, including rural and urban districts.

A limitation is the time when the interviews were performed. We interviewed the patients when they were still in hospital. It is possible that interviewing the patients at a later stage post-transplant would provide multiple nuances and variations to the findings.

Also there may be biases towards positive results due to gratefulness of a successful transplantation and being interviewed by transplant professionals. We tried to minimize this bias by thorough information to the patients before interview start, and by 2 researchers conducting the interviews.

Conclusion

Viewing knowledge as continuously changing from controlled study contexts into clinical settings we here demonstrate the need of evaluating new practice also after being implemented. Divergent considerations may be taken by the health personal considering the new practice and this may impact directly on the care provided, so also within the context of educating renal transplant recipients.

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Authors' contribution

MHA, AKW, EE and KHU planned and designed the study. MHA and KHU collected the data. MHA, KHU performed the first phases of the analysis process, AKW and EE contributed to the final phases of the analysis process. MHA, AKW, EE and KHU contributed to writing and revising of the report.

Conflicting interests

The authors declared no conflicts of interests with respect to research, authorship, and/or publication of this article.

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