Intervening on health literacy by knowledge translation processes in kidney transplantation: A feasibility study

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Abstract

Background: Patients awaiting kidney transplantation need to be prepared ahead of the upcoming transplantation by developing targeted pre- and post-transplant knowledge. On this background, we designed a new health literacy intervention, including a film and a counselling session, based on motivational interviewing for dialysis patients provided by dialysis nurses.

Aim: To explore patients' and nurses' experiences of the feasibility and acceptability of the intervention, focusing on the patient as a prepared knowledge actor.

Design: An explorative qualitative study.

Participants and Methods: Data included in-depth interviews with nine patients and three nurses who participated in the intervention. The interviews were audiotaped and analysed following Kvale and Brinkmann’s method for thematic data analysis.

Findings: Three main themes were identified: a different kind of health intervention stimulating new insight; a challenging kind of health conversation and changed relationships and increased security.
INTRODUCTION

Significant improvements have been made within kidney transplantation regarding surgical techniques and the handling of adverse events. However, shorter stays in the hospital and shorter follow-ups may have hampered patients’ ability to acquire necessary post-transplant knowledge. Although patients’ strict compliance with their immunosuppressive drug therapy is crucial for keeping the kidney, this does not always occur (Rebafka, 2016). Non-adherence is associated with an increase in late acute rejections and late kidney graft failure (Dörje et al., 2013).

Health literacy (HL) has been defined by the World Health Organization (WHO) as ‘cognitive and social skills which determine the motivation and ability of an individual to access, understand and use information in ways which promote and maintain good health’ (WHO, 1998). As the kidney transplant process is complex, it can be difficult to navigate and most likely requires an adequate amount of HL (Kazley et al., 2015).

Literature review

Innovative educational interventions to improve self-management in patients suffering from chronic diseases have been highlighted in recent years (NHS England, 2019). This also applies to patients suffering from chronic kidney disease, and several studies have concluded the importance to support the patients to effectively manage their health challenges (Lopez-Vargas et al., 2016; Rainey et al., 2020).

In a Norwegian randomised controlled trial, the effect of a tailored patient education programme for renal transplant recipients was tested (Urstad et al., 2012). As the programme seemed to increase patients’ knowledge and compliance, it was systematically implemented at the hospital, and a broader study of the implementation process was conducted (Engebretsen et al., 2014). Findings from this and other studies demonstrated that patients need to be more thoroughly prepared as knowledge actors ahead of transplantation, to access, understand and use the information provided during and after the education programme (Andersen et al., 2019; Lillehagen et al., 2018; Urstad et al., 2018). In other words, patients must be supported in developing their HL skills (Dahl et al., 2019).

Knowledge translation (KT) is defined as a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge (Straus et al., 2013). KT is increasingly used in medicine to represent a process of moving what may promote learned through research to the actual applications of such knowledge in a variety of practice settings and circumstances (Greenhalgh & Wieringa, 2011). In this sense, HL represents the final step in the translational chain. To intervene in knowledge management, KT processes are of great importance. One approach to knowledge is the notion of thinking as a craft or a practice. Knowledge is knowing; it is something that you do (Burke, 2015). Hence, looking at knowledge management and HL from a ‘knowing’ perspective gives the possibility to rethink traditional knowledge transfer. Understanding processes of ‘knowing’ within the context of the translation of patient education, puts the spotlight on healthcare professionals skills and attitudes regarding how a person creates the meaning of his own situation and not only if he has ‘received information’. Furthermore, to practice patient education as interacting KT processes, the practice needs to comprise not only more than actual ‘medical knowledge’ but also a philosophy of interpersonal relationships (Engebretsen et al., 2015; Hoving et al., 2010). Here, the patients’ degree of self-understanding is perhaps the most important predictor of their behaviour.

On this background, we planned and designed a novel HL intervention for patients awaiting kidney transplantation. The aim of the study was to explore patients’ and nurses’ experiences of the feasibility and acceptability of the intervention, focusing on the patient as a prepared knowledge actor. We expected the intervention to strengthen the patients’ ability to acquire targeted knowledge about going through kidney transplantation.

MATERIALS AND METHODS

Design

An explorative qualitative design inspired by Kvale and Brinkmann’s (2009) was employed to gain insight into how the intervention was operationalized when it was translated into clinical practice, and how it was experienced by the patients awaiting kidney transplantation and by the dialysis nurses. Data included in-depth interviews with
nine patients and three nurses who had participated in the intervention.

The study was conducted in a nephrology department at a university hospital in Norway. The department employs approximately 30 nurses and provides haemodialysis treatment and care to a dialysis population of about 100 patients. By the end of 2019, 364 patients in Norway were on the active waiting list for a deceased donation renal graft. The recipients who were transplanted had a median waiting time of 13 months for the first transplant and 17 months for a retransplant and a maximum of 51 months for grafting (Annual Report The Norwegian Renal Registry, 2019). Respectively, the waiting time for living donor kidney transplantation were 6–8 weeks.

The intervention

The intervention was two-folded and included a short information film about the upcoming transplantation and an individual counselling session. In the latter, the nurses had roles as facilitators involving the patient in decision-making about own health rather than acting as medical experts; core communication methods, such as open-ended questions, reflective listening, affirmations and summarising and eliciting change talk were employed in the sessions.

The aim of the intervention was to strengthen the patients’ role and capacity as active knowledge actor by combining the theory of KT from the humanities (Engebretsen et al., 2015) and motivational interviewing (MI) technique (Miller & Rollnick, 2013). Rather than focusing on the specific health information content, the intervention, in particular, targeted KT processes between the healthcare personnel and the patients. According to the Canadian philosopher Lonergan, active transfer of knowledge involves critical awareness about four different processes: (1) Data gathering: What kind of information do I need?; (2) Understanding: How do I understand the information given to me?; (3) Judgement: How do I judge the value of this information—useful or not useful, accurate or not accurate? and (4) Deliberation: How should I act upon this knowledge? What kind of behavioural change does it imply? (Engebretsen et al., 2015).

The film

When included, the patients got access to the information film. The film, which the patients watched before the counselling session, could be accessed through patients’ own digital device or through devices at the hospital.

The role of the 5-min informational film was visualising and concretising the transplantation phases in the hospital. The aim was to provide succinct information that could serve as a base for active reflections and encouraging the patients to ask questions during the transplant pathway. The script was developed through discussions between clinicians and researchers in the transplant department. The film presented different healthcare personnel, provided a ‘glimpse’ into the different rooms at the transplant centre and described the patient education space (see Figure 1).

The counselling session

The counselling session was held at the dialysis unit at the nephrology department and lasted between 20 and 60 min. An experienced, trained dialysis nurse took on the role of facilitator in the session, following a conversation guide developed with clinicians and researchers in the field of transplantation. The guide aimed to facilitate reflections around how to approach important health information, make contextual meaning of health information and act upon the knowledge in different real-world situations. Questions included:

- What is important for you to know in relation to waiting for kidney transplantation? How do you feel about going through transplantation with the knowledge that you now possess?
- How do you picture yourself finding answers to your questions?
- How do you consider your role in finding answers to your questions?
- Could you tell me how you experience and understand the information that you have received from health personal in relation to going through transplantation?
- How do you consider this information to be useful for your everyday life? Do you think it has been adapted to your needs?
- What has the information meant to you and how has this affected your everyday life and how you feel?

Principles from MI were used as a communication tool in the sessions (Miller & Rollnick, 2013). MI employs tailored dialogue to encourage patients to take an active role in their therapy using core communication methods, such as open-ended questions, reflective listening, affirmations and summarising and eliciting change talk (Miller & Rollnick, 2013). The MI approach employs a style of collaborative dialogue in which the counsellor rarely offers arguments or explicit information or advice to the patient (Schulman et al., 2011). Instead, the counsellor expresses empathy for the challenges the patients face and acknowledges that both parties share dual expertise (Lal & Korner-Bitensky, 2013; Mallisham & Sherrod, 2017; Miller & Rollnick, 2013). An essential MI principle is that the uptake of knowledge is not exclusively dependent on its dissemination, but rather on the enhancement of stakeholders’ reasons, needs, capabilities and commitments, which may vary across individuals (Greenhalgh & Wieringa, 2011; Mallisham & Sherrod, 2017). Hence, the MI techniques were considered to be an appropriate dialogue tool in accordance with the intervention’s objectives. Nurses participating in the study and performing the counselling sessions participated in a two-and-a-half-day workshop that included MI theory and simulation training for utilising MI techniques.

Participants

To be included in the study, patients had to be on the waiting list for a kidney transplant; above 18 years of age; able to read and speak Norwegian and have access to internet resources. The patients were recruited by ward nurses. As cognitive impairment is common in patients undertaking dialysis (Lambert et al., 2017), the nurses considered potential informants’ level of cognitive impairment when recruiting informants. Due to few patients being on the waiting list during the inclusion period, the nurses consecutively asked all patients who are available to participate.

Inclusion criteria for nurses were more than 2 years nursing experience in the dialysis department within patient education for patients awaiting kidney transplantation. Two head nurses at the department recruited nurses fulfilling these criteria and recruited them consecutively.

A total of nine male patients awaiting a kidney transplant were included in the study, six of whom were on limited care-dialysis (performing the dialysis with less assistance from staff) while three received traditional haemodialysis treatment. They ranged in age from 35 to 71, and three had previously undergone kidney transplantation. Four nurses were included in the study, all of them involved in the daily care of the patients participating in the study. However, only three of them performed the intervention because of a busy period at the dialysis unit when the counselling sessions were held. Background characteristics of all study participants are presented in Table 1.

### TABLE 1 Background characteristics of the informants

<table>
<thead>
<tr>
<th>Patients, all males</th>
<th>N = 9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>30–49</td>
<td>2</td>
</tr>
<tr>
<td>50–69</td>
<td>4</td>
</tr>
<tr>
<td>70–89</td>
<td>3</td>
</tr>
<tr>
<td>Previous kidney transplant</td>
<td>3</td>
</tr>
<tr>
<td>Receiving self-dialysis</td>
<td>6</td>
</tr>
<tr>
<td>Receiving traditional haemodialysis</td>
<td>6</td>
</tr>
<tr>
<td>Nurses</td>
<td></td>
</tr>
<tr>
<td>N = 4</td>
<td></td>
</tr>
<tr>
<td>Caring for dialysis patients &gt;5 years</td>
<td>4</td>
</tr>
<tr>
<td>Employed at self-dialysis unit</td>
<td>1</td>
</tr>
<tr>
<td>Employed at the traditional haemodialysis unit</td>
<td>3</td>
</tr>
</tbody>
</table>

Data collection

An external researcher trained within qualitative research methodology conducted in-depth interviews with patients and nurses 1–3 weeks after the intervention from December 2018 to March 2019. The patient interviews lasted between 19 and 60 min, and the nurse interviews between 22 and 53 min. All interviews were performed at the nephrology department. Each interview was recorded and then transcribed verbatim by an external person trained within verbatim transcription.

The guide for the patient interviews focused on the perceived value of the intervention, the health information seeker’s role and their relation to the health personnel. The guide for the nurse interviews focused on aspects related to their own competence in performing the intervention, perceptions of the intervention’s value and perceptions of the patients’ experiences of the intervention. The questions of the interview guides were thoroughly collaborated on, debated and revised accordingly in the interdisciplinary research group until consensus was reached. All interviews were audiotaped and transcribed verbatim.

Analysis

The data analysis was inspired by Kvale and Brinkmann’s (2009) method of meaning condensation. We performed an inductive analysis process to generate meanings from the raw data to identify patterns and relationships. First, all data were read through independently by three of the researchers (M. H. A., A. K. W. and K. H. U.) to obtain an
during fall 2018. Meetings for informational purposes and for discussing the project staff affiliated at the actual nephrology department participated in planning and publishing the work. Also, nurse leaders and nursing user representative (A. N.) was part of the research team when Norwegian Ethics Committee for Health Research (#2017/2224). A study both orally and in writing. Approval was obtained from the nurses to be something different from ordinary pre-counselling session was also considered by both patients and talking directly to the patients awaiting transplantation. The concrete scenes from the transplant centre, including the staff associated this part of the intervention. The film represented some-...thing different and was considered useful in that it demonstrated...
The nurses also confirmed the patients’ experience of the intervention as encouraging reflection and validating their own knowledge processes of knowing.

I think it was informative, that film. And then there is this with self-reflection. I got the impression that they reflected in a slightly different way. I think it’s easier to invite them to have this kind of conversation now, after having this learning session and facilitating these conversations. That it is a very exciting way to talk with patients because everyone has thoughts about it. And to explore what these thoughts are... I really think it’s simply a better way to inform patients. And make them aware (...) I really like the method.

They need it [the conversation], so absolutely. Yes, yes.

You get to know what the patient is focusing on. What is important for the patient. It gets more personal. Usually we provide more standard information.

**A challenging kind of health conversation**

The nurses experienced the counselling sessions as challenging. They referred to the MI method as complicated and in particular their efforts to elicit change talk from the patients. They found performing the MI technique effectively to be demanding, especially with regard to preparing them to be active knowledge actors while awaiting kidney transplantation. The nurses depicted a tension between a need to focus and be highly conscious throughout the conversations and a feeling of uncertainty due to a perceived lack of competence. Although the MI training was experienced as good and thorough, the nurses at the same time experienced the different techniques as difficult to learn.

It is quite comprehensive if you are going to use the whole method. I was a little happy that I did not have to get into the motivational part, really. I didn’t feel like I was mastering that part at all (...) I did not feel I had enough expertise.

The nurses also felt that the conversation guide was problematic to use, as the questions proved too abstract, indirect and overlapping. Consequently, they often deviated from the guide during the sessions.

Basically, I really think it’s a good idea, to have your own conversations with [the patients], to prepare them a bit and find out what they actually know. And what they would like to know more about. But right in this situation here, with those kinds of questions, and the way they were organized, I don’t think it worked at all. All the questions really blended together. And in a way, there was never anything new in what they were asked about. And I saw that the patients became confused.

My opinion is that the questions overlapped a little bit. And that the patients were a little confused—they thought they did not answer the questions correctly. They were confused by being asking almost the same question again. The questions could have been more precise.

The nurses were mostly satisfied with the training they received ahead of the implementation of the intervention but were unprepared for how complicated the intervention would actually be. Thus, while they wanted the training to be simplified (i.e., to not include all the steps in the MI technique), they also wanted further training.

I like to know a little bit about everything. But since we had three training sessions (...) it can be a bit much. But I concentrated only on that part, in terms of teaching me to shut up, and asking the patient open questions. So I just concentrate on what I can. About what I feel I can. The other parts we will take later.

The patients experienced the intervention as mostly straightforward. However, some also felt that the conversation guide was problematic, as they, too, felt the questions to be somewhat overlapping and abstract.

**Changed relationships and increased security**

Both patients and nurses described experiences that appeared related to reversed roles and changed relationships. For instance, patients mentioned that both the film and the counselling conversation allowed for a more equal and active relationship between both parties. The patients experienced this as beneficial and felt comfortable with this new way of relating to health professionals.

It becomes a more equal relationship, really. Now I am actively working and helping with the connection [to the dialysis machine].

What was different was that she [the nurse] pushed the conversation forward and was much more active. That I experienced as very positive. So if you manage to transfer this to more than this project and that conversation, then I think you’ve done something really good! And if you were to relate this to my
The nurses, for their part, pointed to a changing dynamic between themselves and the patients, experiencing an improved patient–nurse relationship due to the opportunity to practise actual listening, be present and focus on the patients’ story. As a result, they got to know the patients better. However, some nurses wondered if the patients expected more direct health information pertaining to the kidney transplantation process.

Yes, a better relationship, in fact, unfortunately to put it that way... You show a lot of care and presence in everyday practice, but through this [intervention], that you are a little more genuinely concerned about that patient in another way.

I really think [the patients] thought it was okay. At least with the film. But then I think they (...)—even if they never said it, I think they expected more information. That we should sit there and tell them things they didn’t know. Although we said in advance that we were meant to only find out what they know.

The patients and the nurses also experienced the intervention as providing a sense of security. For the patients, it appeared to strengthen their trust in the healthcare system, giving them a source of comfort and calm important for managing the pre-transplant situation.

You feel safer! I go around with more lowered shoulders because we had a good conversation. That’s probably what has changed most.

Indeed, the informants considered the counselling session vital for the patients’ preparedness and security in a pre-transplant context. Moreover, having a scheduled conversation whose explicit purpose is for patients to ask questions, be listened to, and reflect in-depth on relevant topics satisfied both the patients and the nurses. This context enabled the building of mutual trust.

To arrange a conversation appointment with the patient means a lot both to me and the patient.

The film, too, appeared to provide the patients with an increased feeling of security. They described the film as representing a visual approach helpful for preparing them for their upcoming transplantation. In particular, they found it useful to see the actual transplant professionals, the transplant centre and the clinical units. They appreciated hearing the transplant nurse, transplant surgeon, nephrologist and physiotherapist talking about the transplant pathway in a concrete manner.

The nurses, too, found the film to be informative for the patients, and that demonstrating the transplantation pathway in a realistic way provided the patients with confidence and made them feel more secure. They also felt that getting a visual impression of the transplant centre, ward and staff was important for the patients awaiting transplantation. Moreover, one of the nurses added that she found the film helpful, as it provided her with additional knowledge about kidney transplantation. Like the patients, however, the nurses wanted the film to be a little more informative.

They know where to go (because of the film), they see the people who work there, and the department, so it was helpful. I also think it was good to see it myself as it provided me with some answers (about kidney transplantation).

Well, [the patients] said they thought it was nice to see [the film]. But some of them were already familiar with the transplant centre. So it was nothing new to them. But it was good to see the place itself and see some of the staff.

Concerning the patient–nurse conversation, all informants considered this part vital for preparedness and security in a pre-transplant context. To explicitly have a planned conversation meeting, to ask questions and be listened to, and to have in-depth reflections on relevant topic that satisfied both the patients and the nurses. Such a context opened up for building mutual trust.

DISCUSSION

In this study, we have explored the feasibility and acceptability of a new HL intervention for patients awaiting kidney transplantation. Our research provides vital knowledge on the adoption of a new communication approach between dialysis nurses and patients in a clinical setting. The main finding was that both the patients and the nurses had an overall positive attitude towards the new intervention, providing a new kind of dialogue to prepare dialysis patients for going through kidney transplantation. This finding demonstrates the significance of the intervention. The result is understandable in that the intervention satisfied the basic needs of patients awaiting kidney transplantation. The film was based on a realistic and visual insight into a standard kidney transplant pathway to provide a sense of meaning concretely relevant to the pre-transplant situation. Furthermore, it encouraged the patients to be active knowledge actors, for example, by posing questions to the healthcare personnel. The counselling sessions represented an invitation by health professionals to reflect on the pre-transplant situation and to receive targeted information relevant to the patients’ upcoming kidney transplantation. The value of being seen and treated as an individual has also been reported in several studies of patients undergoing transplantation (Andersen et al., 2019; Chisholm-Burns et al., 2018; Demian et al., 2016).
(2019) concluded that listening to patients and encouraging self-reflection had a beneficial impact on the patient-provider relationship.

An important finding from this feasibility study was that the nurses found the MI methodology to be quite challenging. Although they experienced the intervention to be useful for patients, the nurses' feelings about the counselling session, in particular, were more mixed. One reason for this could lie in the complexity of the MI techniques used in the conversations. Too few training sessions beforehand may explain the nurses' ambivalence, as well as the fact that they had only conducted a few counselling sessions at the time of the interview—and thus had not yet gained confidence in their MI skills. Indeed, the MI technique is known to be somewhat time-consuming to learn, and mastering it requires thorough experience and training (Miller & Rollnick, 2013).

The conversation guide developed for the intervention may also have been insufficient or unclear, contributing to the nurses' ambivalence. They described the questions in the guide as overlapping and felt that some of the questions complicated the conversations and created uncertainty in both parties. Finally, while the patients appreciated the intervention because it allowed the shared translation of knowledge between the nurse and the patient, the nurses expressed ambivalence about having such an in-depth conversation with their patients.

The nurses proposed that the counselling session should be adjusted by excluding the most challenging steps of the MI technique (such as eliciting change talk and summarising) to make it more feasible. This brings us to our second question: How can the intervention be better tailored for everyday practice? Both patients and nurses noted a need for more concrete information about the transplant pathway during the conversation session. A pre- and post-transplant strategy might provide such information, as the focus would be both on preparing for transplantation, and on how to be a knowledge-reflective transplanted patient. Moreover, the patients in our study demonstrated a clear need for patient-nurse reflections on relevant topics to develop their HL skills. As positive change behaviour takes time (Miller & Rollnick, 2013), an extended intervention for transplant patients may strengthen adherence to a healthy, post-transplant regime. We, therefore, recommend that the intervention be extended to three or four counselling sessions, and include the postoperative phase.

Findings also raise questions regarding how new communication approaches should be taught to nurses. When introducing a comprehensive communication method like MI, potential training and supervision needs for the nurses must be addressed.

Conclusions about kidney transplantation, tailored HL interventions should also be included to encourage patients to take an active role and develop their HL skills in the context of kidney transplantation. Transplant professionals must provide information and conversations in a way that enables patients to successfully navigate the healthcare system.

CONCLUSION

Both the patients and the nurses had an overall positive attitude toward the intervention, providing a kind of dialogue to prepare dialysis patients for going through kidney transplantation. The nurses found the MI methodology to be challenging. When introducing a comprehensive communication method like MI, potential training and supervision needs for the nurses must be addressed.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

Marit H. Andersen, Astrid K. Wahl, Kristin H. Urstad and Eivind Engebretsen planned and designed the study. Marie H. Larsen trained the dialysis nurses using MI techniques. Gina F. Henriksen collected the data. Marit H. Andersen, Astrid K. Wahl and Kristin H. Urstad performed the first phases of the analysis. Eivind Engebretsen, John Ødemark contributed to the final phases of the analysis. Marit H. Andersen, Astrid K. Wahl, Kristin H. Urstad, Marie H. Larsen, Eivind Engebretsen, Gina F. Henriksen, John Ødemark, Aud-Eldrid Stenehjem, Anna V. Reisæter and Arve Nordlie contributed to the writing and revising of the manuscript.
HEALTH LITERACY IN KIDNEY TRANSPLANTATION

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Declarion of Helsinki, amended by the 64th WMA General Assembly, Fortaleza, Brazil, October 2013.

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