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When referring to the publication, use the full reference:

Andersen, M. H., Urstad, K. H., Larsen, M. H., Engebretsen, E., Ødemark, J., Eriksen, A. & Wahl, A. K. (2021). Processes of knowing in the translation of a health communication intervention for dialysis patients awaiting kidney transplantation. *Patient Education and Counseling*, 104(3), 517-523.
<https://doi.org/https://doi.org/10.1016/j.pec.2020.09.009>

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Publisher's version: DOI: <https://doi.org/https://doi.org/10.1016/j.pec.2020.09.009>

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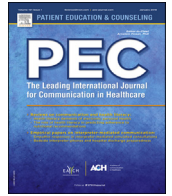




Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou



Processes of knowing in the translation of a health communication intervention for dialysis patients awaiting kidney transplantation

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ARTICLE INFO

Article history:

Received 2 June 2020

Received in revised form 2 September 2020

Accepted 8 September 2020

Keywords:

Health communication intervention

Knowledge translation

Health literacy

Dialysis patients

Kidney transplantation

ABSTRACT

Objective: To strengthen patients' health literacy and their role as active knowledge actors, we developed a health communication intervention including a film-viewing and counselling session for patients awaiting kidney transplantation. We aimed to explore processes of knowing in the translation of the intervention.

Methods: We applied an ethnographic research approach, observing nine intervention sessions with patients and dialysis nurses. Afterwards, the patients and the nurses were interviewed in-depth. Data were analysed using Engebretsen's modified version of Lonergan's four-step model of knowing.

Results: The following knowing processes were identified: i) Knowing as meaning-making; ii) Knowing as acquiring confidence; and iii) Accessing professionals' and peer experts' knowledge. Divergent considerations were taken by the different knowledge actors, which had a direct influence on the knowing processes and knowledge translation.

Conclusions: The findings support active interactions between patients and healthcare providers in processes of knowing. These include self-conscious approaches and critical questioning in both parties.

Practice implications: For transplant professionals, this study demonstrates knowing processes in a real-life context. It also spotlights professional skills and attitudes regarding the importance of self-conscious questioning and a critical interrogating position (for both patients and providers).

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1. Introduction

Health communication is the practice of communicating health information to influence personal health choices by improving health literacy, understood as the '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'. Thus, health literacy focuses on that which people need in order to make effective decisions about health for themselves, their families and their communities [1,2].

For patients with end-stage renal disease, kidney transplantation is considered to be the optimal treatment. After transplantation, adherence to immunosuppressive drug therapy and other

medical advice is important for staying healthy, keeping the graft, and retaining good function and quality of life [3–5]. Consequently optimal translations of health information are crucial. In medicine, knowledge translation (KT) is often seen as a 'pipeline' of knowledge. This implies a somewhat simplistic and linear link between communicating health information and its uptake and application by in patients. However, KT is not only a scientific and technical process, but also requires that both healthcare providers and patients are able to make sense of new medical knowledge in their particular socio-cultural contexts [6,7].

Recent theories in the sociology and history of knowledge have emphasized the performativity of knowledge, i.e. how knowledge must be understood as an act rather than just as a source of information [8]. In this literature, then, knowledge is construed as a practice. One approach to the performativity of knowledge sees thinking/cognition as a craft or a practice in itself. The Canadian philosopher Bernard Lonergan was an early representative for this kind of practice-based view of knowledge [9,10]. Lonergan

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underscored that knowledge is a 'cognitional technology'; here, knowledge is knowing, and is therefore something one does. He developed an empirical method based on the idea that true knowledge can only be obtained by attending to three supplementary processes involved in the act of knowing: sensation, interpretation and judgement. Sensation is instrumental in the act of gathering data; however, in contrast to positivist views, Lonergan sees this only as the point at which the process of knowing starts. To make sense of one's data, one must confront one's sensations by actively querying what the data are about—in other words, interpreting the data. Through this creative and interpretative process, one ultimately reaches a judgement. Hence, knowing is not a simple activity, but an assemblage of processes [9,10].

In 2012, our research team implemented a tailored patient education programme in the context of renal transplantation at the National Transplant Centre in Norway [11–13]. We found that, even when health information was tailored to each patient's knowledge, the patient's competence in finding, understanding and using health information remained challenged [14,15]. In their literature review of patient education for patients with end-stage renal disease Skelton et al. also found the patients' competence challenged underlining the need for a more motivational transplant education in order to let patients make effective decisions about own health [16]. We developed a new project to investigate health literacy in the context of renal transplantation. In this project, patients reported a need to be more thoroughly prepared for their transplantation, in order to make use of health information relevant to their life and situation [17,18]. Consequently, a new health communication intervention was developed. Rather than focusing on the specific content of the health information, the intervention targeted the knowledge management skills of patients—their ability to search for, interpret, evaluate and act upon relevant health information. In the context of health communication, the reasoning processes through which knowing is practised and knowledge is produced are rarely taken into account. However, such processes, as described by Lonergan, are vital to obtaining a richer understanding of KT in health communication. The aim of the present paper was to explore processes of knowing in the translation of a new health communication intervention for patients awaiting kidney transplantation.

2. Methods

We applied an ethnographic research approach using field observations and in-depth interviews to explore processes of knowing in the translation of the new intervention. An ethnographic approach allowed us to study the collective aspects of human life and practices, and shared behaviour, customs and beliefs [19]. The intervention was two-fold, consisting of a short patient information film demonstrating a transplant pathway, followed by a patient–nurse counselling session. The study was conducted in a nephrology department at a large university hospital in Norway, employing approximately 30 dialysis nurses and providing haemodialysis treatment and care to approximately 100 patients each year.

2.1. The intervention

The aim of the intervention was to strengthen the patients' capacity and role as knowledge actors and to empower patients to become active users of health information (Fig. 1). First, the patients were given electronic access to a five-minute film demonstrating a realistic kidney transplant pathway at the transplant centre. After watching the film each patient participated

in one counselling session with a trained dialysis nurse, developed around Lonergan's model of knowing [9,10]. All counselling sessions were observed by an external researcher and took place during November 2018–March 2019 at the dialysis units, and lasted between 20–60 min. The sessions were conducted during or following one dialysis treatment aiming to stimulate reflection based on data gathering (what kind of information do I need?); understanding (how do I understand the information given to me?); judgement (how do I judge the value of this information? Useful or not useful?); and deliberation (how should I act upon this knowledge? What kind of behavioural change does it imply?). A conversation guide was used to facilitate reflections around how to approach health information, make contextual meaning of health information, and act upon the knowledge in different real-world situations (Table 1). Motivational interviewing (MI) techniques were used as communication tools [20]. The nurses' role was that of facilitator, involving the patient in decision-making rather than acting as an expert; core communication methods, such as open-ended questions, reflective listening, affirmations, and summarizing and eliciting change talk were employed in the sessions. Prior to the intervention, the dialysis nurses attended a two-and-a-half-day workshop that included MI theory and simulation training for utilizing MI techniques, and instruction in Lonergan's model. During the intervention period one nurse led six MI-sessions with six patient being on self-dialysis (performing the dialysis without assistance from the staff). Another nurse led two MI-sessions with two patients receiving traditional hemodialysis treatment. The third nurse led one MI-session with one patient receiving traditional hemodialysis treatment.

2.2. 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. Due to few patients being at the waiting list during the inclusion period we consecutively asked all patients being available to participate. Inclusion criteria for nurses consisted of having more than two years' nursing experience in the dialysis department within patient education for patients awaiting kidney transplantation. Two head nurses at the department recruited the nurses.

Nine male patients awaiting a kidney transplant were included, six of whom were on self-dialysis while three received traditional haemodialysis treatment. Their ages were between 35 and 82 years, and 3 of the 9 patients had previously undergone kidney transplantation.

Four female dialysis nurses were included in the study and attended the MI-workshop, but one was unable to perform MI-conversations with the patients because of a busy period at the dialysis unit. All the nurses had more than five years' nursing experience within the field of nephrology, including longlasting experience with patient education and counseling of dialysis patients awaiting kidney transplantation.

2.3. Data collection

All nine counselling sessions were observed by one, experienced researcher, whose fieldnotes consisted of descriptions, quotes and theory-driven reflections.

The interviews with patients and nurses were conducted 1–3 weeks after the intervention, with a duration of 19–60 min. The nurse interviews lasted between 22 and 53 min.

The patient interview guide focused on the value of the intervention, the health information seeker's role and their relation to the health personnel (Table 2). The nurse interview guide

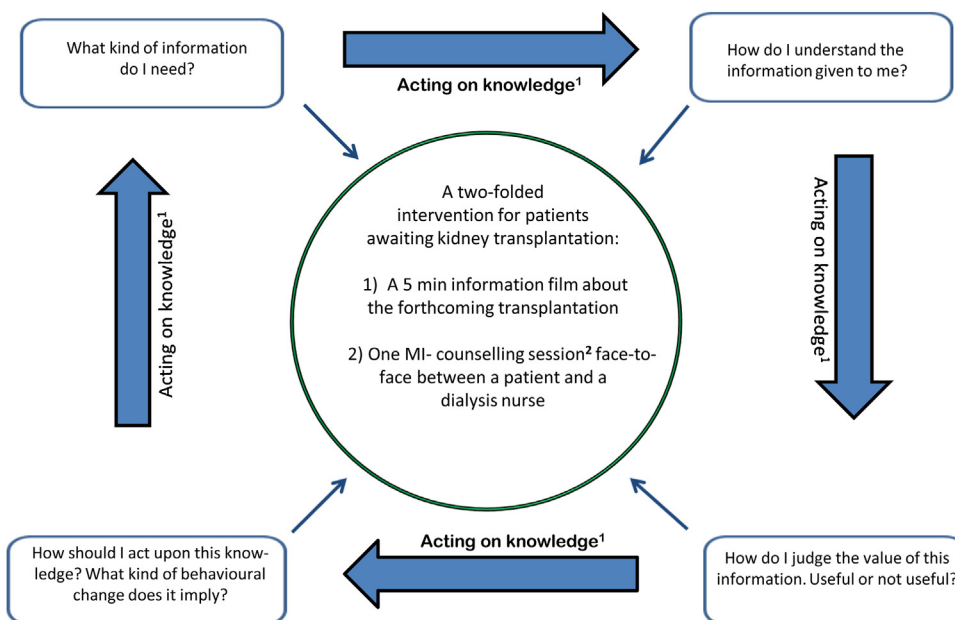


Fig. 1. Acting on knowledge in a new health communication intervention for patients awaiting kidney transplantation. Engebreetsen, N.K. Vøllestad, A.K. Wahl, H.S. Robinson, K. Heggen, Unpacking the process of interpretation in evidence-based decision making, *J. Eval. Clin. Pract.* 21 (2015) 529–531. doi: 10.1111/jep.12 [19]. W.R. Miller, S. Rollnick, *Motivational Interviewing: Helping People Change*, Guilford Press, New York, 2013.362.

Table 1
 The nurse-patient conversation guide.

The guide included the following guiding questions to reflect upon:
1. What is important for you to know in relation to waiting for a kidney transplantation? How do you consider going through a transplantation with the knowledge that you now possess?
2. How do you picture yourself finding answers to your questions?
3. How do you consider your role in finding answers to your questions?
4. Could you tell me how you experience and understand the information that you have received from health personal in relation to going through a transplantation?
5. How do you consider this information to be useful for your every-day life? Do you think it has been adapted to your needs?
6. What has the information meant to you and how has this affected your every-day life and how you feel?

Table 2
 Interview guide-nurses.

Interview guide-nurses
1. The aim of the intervention was to prepare the patient to utilize relevant knowledge prior to kidney transplantation. What is your experience with the intervention?
2. What do you think about the benefits of the chosen method (film and MI-motivating conversation) for the intervention?
3. How did you experience your own competence in carrying out the intervention?
4. What do you think about the patients' experience of the intervention?
5. How do you think the intervention contributed to changing patients' skills to find and assess relevant knowledge related to the transplant?
6. If you do not feel that the intervention was helpful, what would you say is the reason for that?
7. To what extent do you think the intervention could make the patient better equipped to interact with healthcare professionals? Can you tell us about something that was discussed in connection with this during MI?
8. Do you think that the intervention can affect communication and the relationship between patient and healthcare professional? In what way? Can you give examples?
9. The main goal of the project was to develop an intervention that strengthens the patient's knowing processes and understanding of organization and patient course in connection with transplantation. To what extent do you think we have reached the goal related to: <ul style="list-style-type: none"> • the transplant process, roles in the hospital system. Examples? • meeting points for teaching / information. Examples? • the patient's role, rights and responsibilities. Examples?
10. How do you think this intervention fits into everyday practice? What are possible barriers to introduction? Is there anything you would have done differently?

concentrated on aspects related to their competence in performing the intervention, perceptions of the value of the intervention and perceptions of the patients' experiences of the intervention (Table 3). All interviews were audio-recorded and transcribed verbatim.

2.4. Analyses

As noted above, Lonergan developed a four-step model of the interpretational processes involved when combining and applying

Table 3
Interview guide-patients.

Interview guide-patients	
1.	What is your experience of the intervention (the film and the MI conversation) you participated in at the dialysis department?
2.	To what extent has the intervention been useful to you in the waiting period before transplantation (to absorb knowledge about having a kidney transplant, to prepare for having a kidney transplant)?
3.	If the intervention was not useful to you, what do you think is the reason for it?
4.	How did you experience the film about the transplant process? And the MI-conversation?
5.	How do you now view your own role as a patient and your knowledge about the health care system (responsibilities, rights, organization, meeting points for information)? Has the intervention meant anything to this, your role and understanding? Can you give examples?
6.	What was important to concerning the intervention when it comes to collaborate with health professionals (expectations, communication, other . . .)?
7.	To what extent has your relationship with healthcare professionals changed as a result of the intervention? Can you give examples?
8.	How prepared do you feel now to undergo a kidney transplantation?
9.	How has the intervention been useful or not useful for finding relevant health information? In what way? Can you give examples?
10.	In terms of understanding and evaluating the information you have received, have you found it useful? In what way? Can you give examples?
11.	What do you think about dealing with your own illness in everyday life now that you have undergone the intervention? Any examples?

knowledge [9]. Engebretsen [10] further developed this model, adapting it for evidence-based decision-making in medicine and healthcare services, particularly through highlighting the process of interpretation of knowledge. Engebretsen's adapted model describes the following stages of knowing: 1) recording of data (sensation); 2) interpretation of data (understanding); 3) weighing of interpretations (judgement); and 4) choice of action (deliberation). This four-step model of knowing is highly relevant for both healthcare providers' and patients' decision-making processes.

Data analysis was conducted in a cross-disciplinary research group representing both medical and humanities perspectives. The group was part of a larger project aiming to rethink the field of the medical humanities as a cross-disciplinary intersection between the humanities and medicine in the context of KT.

First, three researchers (MAH, AKW, KHU) representing the medical encounter read the text in light of the four-step model. The texts from the three data sources (nurse interviews, patient interviews and fieldnotes from the observations) were read in light of the three different perspectives provided by the study design. Summaries were then made of each interview and observation to obtain an overview of the knowledge-managing processes that emerged in the text.

Summaries and sections of the original text were then presented to the cross-disciplinary research group. The group discussed the material based on the perspectives of their respective disciplines, but in light of Engebretsen's four-step model of knowing.

The text was then re-read by the three medical researchers (MHU, AKW, KHU), bringing new perspectives into the ongoing analytical process.

3. Results

Three knowing processes were identified: i) Knowing as meaning-making; ii) Knowing as acquiring confidence; and iii) Knowing as accessing professionals' and peer experts' knowledge.

3.1. Knowing as meaning-making

[The patients] The film and the conversation triggered a form of knowing for the patients, including reflections on and preparing for transplantation. Patients linked their understanding, valuing and judgement of information to the overall goal underlying their kidney transplantation: to keep the graft and avoid rejections. One patient said 'I appreciated the film because it visually demonstrated the transplant centre, the different units and the transplant staff. That was very useful'. Although the patients had the basic knowledge, the intervention seemed to provide more in-depth

insight. Another patient explained, 'I started to reflect on things that I hadn't really thought about. They had been in the back of my head, but were not really clear to me. It was about life after the transplantation. You have to relate to issues about lifestyle, eating habits and restrictions—that it is extremely important to take the pills and so on'. The dialogues revealed a form of shared KT between the nurse and the patient, as both parts contributed to the knowledge process: the nurse asked knowing questions relevant to the individual patient, and the patient reflected back based on his actual situation. This, in turn, made these shared knowing processes and KT a social act.

[The nurses] The nurses experienced the patients as becoming more aware of their own knowledge needs, and in that sense the nurses expressed enthusiasm for the intervention. The intervention also made them listen more carefully to the patients, and the nurses particularly valued how patients were able to reflect consciously about their health. One nurse explained: 'To create a space for that particular conversation, I think that it is very meaningful. That's the most important goal and the dream for the patients, of course, to be able to talk about their situation. Being able to think about it and reflect on it made the patients more conscious. I think it prepared them'. Moreover, the nurses were also positively surprised by the patients' high level of reflection: they experienced the patients has having precise thoughts, expectations and knowledge about their situation.

[The observer] The observations revealed that the nurse-patient dialogues generally focused on knowing processes related to dialysis and transplantation information. The questions circled around the patients' information needs, their understanding of this information, their judgement of the information, and how they acted on the information. The most vital information for the patients was knowing when the transplantation would happen.

3.2. Knowing as acquiring confidence

[The patients] The intervention seemed to give patients confidence and make them more relaxed. While the patients reported having previously experienced difficulty asking questions of healthcare professionals—not knowing which questions to ask, or what kinds of information they needed—the intervention helped them enter into dialogue with the nurses; reflect on actual challenges; and act upon knowledge related to their pre-transplant situation. As one patient remarked, 'The worst thing is the vacuum that nobody speaks to you. This [the intervention] was something new and interesting to me. The combination of watching the film and talking to the nurse afterwards—that was a good process. It made me feel prepared, and knowing what will come'. The patients felt they were being considered individually. In this way, the

patients' felt that their role became more like active knowledge actors.: 'It is important to get that signal that my role is to take the initiative to ask questions. What they say is that we would like you to be active—and that invitation is very important to me'.

[The nurses] The nurses expressed some ambivalence concerning the MI conversations because they found it difficult to perform the technique and did not feel confident practising it. 'I think the MI-technique was difficult', one nurse said. She continued: 'I think it's a complicated method, in a way. One must be very careful not to say the wrong thing. It is quite demanding for the nurse to perform'. They also found their role somewhat threatened, as they did not consider 'knowing' dialogues with the patients a natural part their professional role (i.e. overseeing dialysis treatment, checking and recording patients' vitals, and teaching patients how to operate dialysis machines); moreover, they argued that a lack of time made it difficult to follow-up on patients' personal issues. The nurses also felt constrained by a lack of knowledge about the post-transplant phase: 'If I had a patient conversation about what happens after the transplantation, then I first would like to know what is really going on at the transplant centre'. According to the nurses, their main focus was to care for the patients during the pre-transplant phase; as such, they found it difficult to fully relate to the 'knowing' conversations and experience professional confidence.

[The observers] To some extent, the dialogues revealed shared knowledge between the actors, as the nurses asked knowing questions and the patients reflected on these based on their individual needs and contexts. However, while the patients were intuitively engaged in the intervention, the nurses seemed somewhat reserved towards the conversations they had with the patients.

3.3. *Knowing as accessing professionals' and peer experts' knowledge*

[The patients] The patients viewed information provided by experts like nephrologists and dialysis nurses to be most important. The dialogues also revealed a strong loyalty to the experts' advice, even when it entailed changes to patients' routines of daily living. One patient explained, 'The nephrologists follow us closely and tell us if something is wrong. They check results from blood tests and suggest what to do to improve our health. That makes me feel safe. This is a very important factor'. Sharing experiences with other patients suffering from kidney disease was also meaningful to the patients: this provided a different kind of information, since it was based on patients' own experiences. For example, patients would learn from other patients about the metallic taste of the pills they would need to take following their transplant—this kind of information helped prepare the patients for the transplantation. In comparison, knowledge accessed from other sources, like the Internet, was not immediately trusted as significant information.

[The nurses] Knowing was also accessed via the opposite channel: from patients to health professionals. The nurses gained new knowledge about their patients during the conversations because of the MI techniques being used (i.e. open-ended questions, reflective listening and a conscious focus on individual needs). The nurses appreciated knowing directly from their patients, in particular when exploring what kind of information was needed by the patient. One nurse reported, 'It was a bit strange, but for me a good experience. I experienced getting to know the patient better. I became more familiar with how the patient thinks'. Additionally, the nurses considered it important to learn how the patients reflected on their own situation. For example, one patient focused on his diet in the conversation, as his main concern was what to eat after being transplanted.

[The observer]. Accessing professionals' and peer experts' knowledge seemed to be vital for initiating the knowing processes in the patients.

4. Discussion and conclusion

4.1. Discussion

We will discuss the findings from two different perspectives: a philosophical perspective using Lonergan's model of knowledge management, and a sociological perspective to shed light on the performances taking place between the different actors in the intervention.

With regards to our findings concerning 'knowing as meaning making', both the patients and the nurses appreciated the new intervention. The film and the conversation provided them with a sense of meaning concretely relevant to the actual context (the pre-transplant situation) and to the knowledge actors (the patients awaiting transplantation and the nurses caring for the patients during this time). According to Engebretsen, Lonergan underlines the quest for insight as the work of active, inquiring intelligence [10]. The findings revealed that questions like 'what kind of information do I need?' and 'how do I understand the information given to me?' seemed to explicitly place the patient at the forefront, as the main character.

The nurses expressed their surprise concerning the knowledge and understanding demonstrated by the patients. This, in itself, is an interesting discovery, leading one to wonder how we may understand this in light of KT. It seemed like there was a discrepancy between the nurses and the patients: the parts interacted, but the premises of the interaction seemed to differ. This makes the fictive figure of the 'ignorant patient' a kind of 'ghost' in our data. The ignorant patient is the one who is assumed to actually need the intervention. He is also a figure evoked by the actual patients, to whom they may present themselves in opposition—as skilled, competent and in control. This fictive figure of the ignorant patient may help us enlighten the findings [21], as it may have arisen out of a norm in the study setting: the healthcare professionals representing the experts and the patients representing those who lack vital information. If this is indeed the case, it reflects traditional thinking within medicine, i.e. that professionals rely more on biomedical knowledge than on patients' individual knowledge and experience. Such thinking can be a barrier for patients' individual knowing processes—which has been documented in prior research within kidney transplantation [14–16,22,23] and within treatment of chronic conditions [10,24,25]. Our findings indicate that the patients' opportunity to act as individual knowledge actors was particularly negatively influenced by this approach. This remind us about the importance of being aware of the phenomenon. It also demonstrated the slowness of the paradigm shift within patient education.

Our findings centring around 'knowing as acquiring confidence' indicate that the intervention opened a space in which the patients could ask relevant questions and add it to their existing knowledge. In this space, the patients could also perform their competence—they could display it and exhibit it—and it seemed they felt confident with becoming engaged and visible performers. In such, the intervention seem to have different attributes compared to existing patient education and counselling programs [16].

The nurses appreciated the intervention, in that it satisfied the patients' needs. However, they seemed somewhat sceptical towards integrating a new conversation technique in a traditional dialysis nurse role. A sociological perspective may help explain this: from a performative perspective, the nurses were given the opportunity to perform as competent nurses and were thus presenting what their competency and profession entailed. They pointed to boundaries, and delineated the parameters around their tasks as professionals. Williams and Calnan [26] reflect on how patients traditionally have become increasingly subjected to control by a patriarchal medical profession. Our findings spotlight

the importance of self-conscious questioning and active interactions between patients and healthcare providers in processes of knowing.

Lastly, with regards to ‘accessing professionals and peer experts’ knowledge’, the patients considered it vital to receive knowledge and information from trusted sources. Lonergan emphasizes the importance of acknowledging data and recognizing it as significant, and from this making individual and situated judgements [10]. Additionally, the nurses’ attitude, to some extent demonstrated what Lonergan underlines when it comes to KT. The nurses acknowledged that the intervention increased their awareness concerning different data sources and that merging these was important for knowing.

One study limitation was our inability to recruit female dialysis patients, despite concerted efforts to do so (e.g. by extending the data collection period). This was due to random factors occurring during data collection: for example, one female included in the study was excluded temporarily from the transplant list for medical reasons and thus did not meet the inclusion criteria, while another included female was later excluded due to language issues. In addition, while four nurses were ultimately included in the study, one was unable to hold the planned counseling sessions because of a busy period at the dialysis unit. Probably the voices of one more participant would have added variations and nuance to the data and helped situate the results. Another limitation was that the nurses to some extent lacked skills in MI-counseling when performing the conversations. The MI-technique is time consuming to learn (20) and coping with it requires thorough experience and training. We think that extended MI- training for the nurses ahead of the study would impacted positively on their self-efficacy of the MI-skills and probably reduced the nurses scepticism towards the new conversation technique. Finally, one important aspect of ethnographic research is the researcher’s involvement with the participants. When researchers interact with participants biases may occur and present limitations. To reduce possible biases all nine counselling sessions were observed by one experienced researcher, whose field notes consisted of descriptions, quotes and theory-driven reflections.

Despite these limitations, we think the study’s broad methodological approach, conducted at a large dialysis department in Norway, provides transplant professionals and patients awaiting kidney transplantation with valid and significant knowledge. As the intervention was not patient-specific, the findings can also be transferred to patient education and counseling contexts in general.

4.2. Conclusion

The findings support active interactions between healthcare providers and patients in processes of knowing, including approaches of self-consciousness and critical questioning in both actors. Findings indicate that is important to understand which factors are at play, what motivates and engages patients, but also what may hinder knowing processes and KT in clinical contexts. Such knowledge is rarely highlighted within research, but vital for KT in a clinical setting. The results of our findings can be useful for developing evidence-based interventions to enhance communication and improve outcomes for both transplant patients, but also in general for patient suffering from chronic conditions.

4.3. Practice implications

We recommend more evidence based practice within the field of patient education and counseling to strengthen the patients’ ability to act upon relevant health information while awaiting

kidney transplantation. These recommendations are also highly relevant to patient education and counseling contexts in general.

Author Statement

The manuscript entitled Processes of knowing in the translation of a health communication intervention for dialysis patients awaiting kidney transplantation, has been reviewed and approved by my co-authors. The authors hereby declare that they have no competing financial interests

Ethics

The study was approved by the Norwegian Ethics Committee for Health Research (#2017/2224).

Funding

We acknowledge the support of the Centre for Advanced Study in Oslo, Norway that funded and hosted our research project “The Body in Translation: Historicising and Reinventing Medical Humanities and Knowledge Translation” during the academic year of 2019/2020.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.pec.2020.09.009>.

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