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Implementation of a new patient education programme for renal recipients: Developing a widened concept of patient tailoring

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Title: Implementation of a new patient education programme for renal recipients: Developing a widened concept of patient tailoring

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Keywords:

Qualitative research, individual tailoring, patient education, implementation, knowledge translation

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Abstract

Objective

To understand how a new patient education programme for renal recipients becomes situated and adapted when it is implemented in daily hospital teaching practice. The analysis focuses on how the programme's principles of individual tailoring and patient involvement are enacted, and the knowledge that is produced.

Design

Qualitative observation study. 19 teaching sessions were observed, resulting in 35 pages of data written observation notes

Setting

A Norwegian University hospital. The study included the TX post, the medical post and the outpatient clinic.

Participants

10 newly transplanted patients receiving the education programme, and 13 nurses trained in the new programme participated in the study.

Results

The new programme emphasizes patient involvement and individual tailoring, which is based on an initial mapping of the patients' knowledge. Results show that many patients have difficulties of identifying their own knowledge needs, and in turn to create a basis for individual tailoring. Patients and nurses develop a widened practice of tailoring, which entails actively engaging with the patients' knowledge about his life and experiences in order to translate generalized knowledge into meaningful knowledge within the frame of the patient's life world. Individual tailoring is however also limited, as the nurses balance between concerns of patients' individual needs and responsibilities by virtue of being health system representatives.

Conclusion

The concept and practice of individual tailoring should be extended. Our results illustrate that individual tailoring is a comprehensive practice which includes verbal, practical and emotional involvement in the patient's life world. The patient's knowledge about his life world should constitute the basis for individual tailoring.

Strengths and limitations to this study

- Qualitative observations of naturally occurring teaching sessions allows for detailed and in depth investigation of complex adaptations to implementation
- While the study's small scale limits generalization, the study discloses important issues in patient education, individual tailoring, and implementation that could be further investigated.
- Few participants had additional conditions or special needs, which perhaps prevent understanding about particular needs in groups with additional conditions or challenges

Keywords:

Qualitative research, individual tailoring, patient education, implementation, knowledge translation

Word count: 4122

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IMPLEMENTATION OF A NEW PATIENT EDUCATION PROGRAMME FOR RENAL RECIPIENTS: DEVELOPING A WIDENED CONCEPT OF INDIVIDUAL TAILORING

1. INTRODUCTION

About 300 patients per year receive kidney transplantations in Norway. Patients who go through kidney transplantation have to acquire knowledge about immunosuppressive medication, graft surveillance, and the benefit of specific lifestyle behaviour in order to reduce rejection episodes, graft loss and the negative consequences of lifelong immunosuppressive medication [1, 2]. The benefits of individually tailoring patient education have been increasingly documented [3-5]. However, the term ‘individual tailoring’ is used to describe many different approaches, which apply various notions of what individual tailoring means, and its purpose. Much research has focused on improving patients’ adherence to medication [6, 7], while less research have investigated what kind of knowledge that patients achieve by individual tailoring in patient education.

In a recent publication in BMJ Open, Poland et al [8] describe that patients build ‘individually relevant knowledge of their condition’, which in turn ‘support a situated understanding’. Their description provides valuable understanding about the kind of individual knowledge that patients need and how it may help them. It does however not investigate *how* individuality of knowledge is achieved in patient education. To understand the development of such knowledge is however important in order to advance patient education to meet patients’ need for individual knowledge.

This article presents a study of the implementation of a new patient education programme for newly transplanted renal recipients. The main difference between the new and old patient programme was that the new program emphasised stronger individual tailoring, patient centring, and an extended number of training sessions. The new programme was based on evidence of significant benefits related to tailoring the patients’ education [9].

We conducted an observation study, which is an underexploited approach to investigating patient education, and which enables detailed studies of naturally occurring education implementation processes. An intervention developed in an experimental context cannot be

1 transferred to a real world setting without contextual adaption [10]. Such adaption is not
2 necessarily a threat to accurate implementation, as often assumed, but a precondition for
3 implementation[11]. However, implementation also presupposes critical awareness about how
4 this adaption comes about and elements that are added to or removed from the "original"
5 intervention through the implementation process [12]. The overall question that we explore is
6 *how the new patient education programme is situated and adapted when implemented in the*
7 *daily teaching practice in the hospital.*

15 1.2. Background

16 The work reported here is a sub-study outgoing from the evaluation project '*Evaluating and*
17 *monitoring evidence based implementation of a structured, tailored education program for*
18 *renal transplant recipients*'. The overall goals of the evaluation project were to 1) improve the
19 quality of patient education, and 2) to understand and evaluate processes involved in the
20 implementation, as well as changes in practice following the implementation of the
21 intervention. The evaluation project included seven sub-studies which investigated both the
22 pre - and post implementation phase of the new education programme. The pre-
23 implementation phase addressed identification and analysis of the current situation and the
24 development of an implementation plan regarding competence enhancement of the new
25 patient education program (sub study 1-3) [13, 14]. The post implementation phase focused
26 on the delivery of the new patient education programme to the patients (sub study 4-7) and
27 included both the perspectives of patients and staff. The current paper presents sub study 4
28 (see Figure 1).

29 **Figure 1.** Overview of the sub-studies in the research project *Evaluating and monitoring*
30 *evidence based implementation of a structured, tailored education program for renal*
31 *transplant recipients*

32 The evaluation project was inspired by the FORECAST-framework [15], which is a formative
33 evaluation framework for programme implementation and evaluation. Implementation is seen
34 as a dynamic and two-way process, and continuous collaboration and mutual influence
35 between the implementation teams and the project stakeholders are emphasized. The
36 implementation process should be flexible, and feedback loops are used to secure continuous
37 evaluation and adaption.

Patient involvement

The project and research question was developed on basis of literature revision, discussions in the researcher group and clinical experience. A user representative from The Norwegian Association for Kidney patients and Organ transplanted took part in the discussions. Patients were not involved in the recruitment to and conduct of the study. Results will be disseminated to study participants through the journal published by. The Norwegian Association for Kidney patients and Organ transplanted and through oral presentations.

1.2. The new patient education programme

Development of the new education program involved studies of educational theory, a review of previous research on patient education, knowledge about transplantations and clinical experience [1, 16]. A randomised controlled trial (RCT) was conducted prior to implementation, which identified that the customised patient education program increased levels of knowledge, compliance and self-efficacy, and higher quality of life-scores compared to the control group which received standard care [9].

Compared to previous education programmes used in the hospital, the new programme emphasizes patient centring and individual adaption. In order to ensure individualization of the knowledge, the method of “academic detailing” is used. “Academic detailing” is a strategy based on learning principles and includes identification of baseline knowledge and needs (measured by knowledge questions), definition of evident training areas, a skilled instructor, encouragement of active participation, repetition and elucidation of key areas, and feedback on behaviour change [17].

The new program consists of five one-to-one teaching sessions with a trained nurse, lasting about 40-60 minutes. Three different departments are involved: the TX-post, the medical post and the outpatient clinic. The first two sessions are held at the TX post, and the first session is held during the first week after transplantation. Most patients are discharged directly to the outpatient clinic where three more sessions are held. Patients needing special care or more follow up on medications and self-surveillance, are admitted to the medical post and receive additional sessions.

During the five sessions, essential information on the three knowledge areas of medication, rejection, and lifestyle is provided. These areas are also covered in the standard written information handed out for all renal recipients post-transplant, which is used as a basic tool

for the sessions. Under each of the predetermined themes, the content is contextualized and further detailed based on each patient's needs and life situation. The patients also receive a diary in which medications, temperature, fluid balance and urine is registered.

2. METHODS

2.1. Study design

Ethnographic observation emphasizes the collective aspects of human life and practices, and explores shared behaviour, customs and beliefs [18]. It allows the researcher to investigate naturally occurring practices as they unfold in specific contexts [19], and provides thick descriptions of these practices, as well as the contextual circumstances that impinge on them. Ethnographic observation is thus a fruitful method for studying implementation as an encounter between the new intervention and the already existing daily practice in a hospital, especially when it comes to complex interventions such as patient education.

2.2. Data collection

Observations

10 patients were included in the study. Two or three sessions in each patient's teaching programme were observed: one at the TX post, one at the medical post in cases where patients were admitted there, and one at the outpatient clinic. We observed a maximum of three sessions per patient (see Table 1). All five sessions of the programme were observed at least once. A total of 19 teaching sessions were observed; ten at the TX post, one at the medical post, and eight at the outpatient clinic.

Table 1. Number of observations per patient

| | Number of patients | Number of observations |
|---|--------------------|------------------------|
| | 1 | 3 |
| | 7 | 2 |
| | 2 | 1 |
| N | 10 | 19 |

2.3. Participants

Nurses

A total of 13 nurses were included: one male and nine female. Eight worked at the tx post, one at the medical post, and four at the outpatient clinic. One nurse had less than one year of experience working with renal recipients, five had one to five years, two had six to ten years and four had more than 10 years of experience.

Patients

The TX nurses enrolled patients in the study. Selection criteria was that the patients were not in need of a translator, and that the patient was fit enough to participate in regular teaching sessions. With these exceptions, all patients were asked. The nurses however remarked that patients with severe additional conditions were more likely to say no. In the following we will refer to all patients as 'he' due to an overweight of mail patients (see Table 2).

Table 2. Included patients: sex and age

| Age | Female | Male | N |
|-------|--------|------|----|
| > 40 | | 1 | 1 |
| 40-60 | 1 | 3 | 4 |
| 61-80 | 1 | 4 | 5 |
| N | 2 | 8 | 10 |

2.4. Observation strategy

The observations were conducted by a researcher (IL) with competence and experience in ethnographic observation and qualitative studies of communication of knowledge. Due to little knowledge about renal transplantation and the daily practice at the hospital before the observations she visited each post for one or two whole days.

Observations notes were written during and directly after observations. An open approach was emphasised in the earliest observations, in order to identify key topics for further observations. Subsequent observations specifically addressed issues like: nurses' and patients' definition of the sessions' purpose, communication, the structuring of the sessions, patient

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3 participation and communication of needs, as well as how material artefacts were involved in
4 the sessions. The observations resulted in a total of 35 data written pages of observation notes.
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7 8 **2.5. Data analysis**

9 Data analysis began shortly after data collection and involved several phases. The first phase
10 involved detailed reading of the data and identification of topics for further analysis, guided
11 by the research question of how the programme was adapted and situated during
12 implementation in the clinic. Topics such as communication, knowledge, patient involvement
13 and patient participation were addressed. Topics and quotes from the data were presented to
14 the researcher group, and generated feedback which narrowed down topics for further
15 analysis. In the second phase two of the researchers (IL and EE) deepened the analyses by
16 working with excerpts of the observation notes. Further discussions with the researcher group
17 resulted in the identification of two main topics: 1) a widened concept of knowledge tailoring,
18 and 2) challenges and limitations for knowledge tailoring in daily practice.
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28 **3. RESULTS**

29 **3.1. Involving patients and mapping individual needs**

30 As described, the new programme emphasized principles of individual tailoring and patient
31 centring. During the observed sessions, the nurses often attempted to map the patient's needs
32 by starting the conversation with a question. Sometimes these questions were quite general,
33 for instance how the patient was doing in the department, or how he was feeling about his
34 situation this day. However, more often the questions were related to the educational content.
35 For example, the nurses often started the session by asking if the patient had read the written
36 material that they had received, if he had any questions about it, or if there was anything in
37 particular that he wanted to talk about in the session.
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45 Opening sessions with a question was a method to map the patient's knowledge. However, it
46 also reflected the new programme's core principle of patient centring by inviting and
47 encouraging the patient to take ownership of the situation and of his own knowledge needs
48 and interests.
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53 The ideal of patient centeredness were also reflected in other, more subtle ways. For instance,
54 the nurses often presented the purpose of the teaching sessions emphasizing care: i.e. "We are
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3 going to talk a little bit about how you are going to take care of yourself now that you have
4 had the transplantation” or “the goal is to enable you to live normally after the
5 transplantation”, thus setting the patient perspective as a frame for the session. Some nurses
6 also used non-verbal communication to convey the patient’s centre role, for instance by
7 letting patients walk first into the room and waiting to take their place until the patient had
8 chosen a place to sit.
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14 The patients, however, were often acting reserved. Most patients confirmed that they had read
15 or looked through the information material, but very few had any follow-up questions or
16 formulated any particular interests. Many were silent and acting expectantly, seemingly
17 waiting for the nurses’ initiative. That is, despite the nurses’ attempts to map the patients’
18 needs by inviting them to take an active patient role in the situation, it seemed it was often
19 difficult for the patients to respond as intended. In turn, it became difficult for the nurses to
20 structure the session based on an initial mapping of the patients’ needs and interests as
21 intended in the programme. Consequently, in many of the observed sessions, the nurses had to
22 find an alternative approach to the teaching sessions, which often was to use the written
23 material. Hence, the sessions were often structured by the three predetermined topics of
24 medication, rejection and life style in the written material.
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33 That is, in many observed sessions it was not possible to tailor the sessions as intended by the
34 patients’ needs and knowledge. Instead, many sessions took a more standardized form,
35 structured by the written material.
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38 **3.2. Widening the concept of patient tailoring: including the patient’s life** 39 **world**

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42 When patients refrained from taking an active, knowledge seeking role in the sessions it could
43 be interpreted as a lack of knowledge or interest. Accordingly, when the nurses structured the
44 sessions based on the standard written material, it could be seen as inaccuracy in
45 implementation. However, studying our data in depth revealed a more complex dynamic.
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51 When the nurses started talking about the predefined topics, the patients would often respond
52 with interest and follow-up questions. A pattern in our material was that their response was
53 often explicitly related to their daily life at home. I.e. one patient was particularly interested in
54 the information about chickenpox, as he told the nurse that he had children at home who had
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3 not yet had chickenpox. Another patient was particularly interested in the information about
4 medication and traveling, and told the nurse that he had a summer house in South Europe
5 where he used to go with his children and grandchildren.
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9 This suggests that the patients' difficulties of formulating knowledge interests or needs were
10 not related to lack of such, but to difficulties in assessing and utilizing the generalized
11 information material as basis for identifying their own knowledge needs and interests.
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15 We also found that the nurses actively used the information they had or acquired about the
16 patients' lives as a tool to individualize the teaching. For example, weight gain and loss of
17 bone density is a known side effect of to the medication. A general advice in the
18 information material is that patients should exercise regularly. This generalized knowledge
19 was individualized by a nurse with the following formulation, based on her knowledge about
20 the patient's life at home: "You can take your dogs for an extra walk and make sure to get
21 some extra exercise". In another session, the nurse used her knowledge about the patient's life
22 to individualize the generalized knowledge about increased risk of skin cancer, asking the
23 patient: "When you are on your boat, do you make sure that you use sunscreen?"
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32 Also, the nurses expressed attention to patients' general condition, state of mind, and personal
33 style of communication. They adapted to the patients, both explicitly and implicitly, for
34 instance by shortening the session if a patient seemed tired or unwell, or by actively tuning in
35 to the patient's way of communicating. For example, a nurse could lower her voice and tempo
36 with a reserved patient, while acting more outgoing and humorous with another patient. The
37 nurses also responded to patients' knowledge interests or particular needs by making
38 arrangements outside of the sessions, for instance by offering to provide information material,
39 or scheduling appointments with specialists or home care during visits at home on behalf of
40 the patient.
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48 Our data is rich on examples of how tailoring of the education programme involves a more
49 complex and comprehensive practice than an initial mapping of the patient's knowledge about
50 the content of the education programme. Observation of the teaching sessions suggests that
51 patient tailoring involves actively engaging with the patient's life world. The term life world
52 originates from phenomenology and refers to our horizon of experiences, which constitute the
53 background on which all things appear meaningful [20]. Applied here, the term illustrates
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3 how the patients and nurses use the patients' daily life, work, family, and interests, as well as
4 the patients' behaviour and communication as a primary frame of reference for the teaching
5 sessions.
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9 **3.2. Limits to individual tailoring**

10 In some observations patients concluded that a certain part of the programme content was not
11 relevant to them. For example, one of the patients, a young man, told the nurse that he was
12 determined not to have children, and that information about precautions regarding
13 reproduction was irrelevant for him. Several patients also commented that having lived with
14 medication regimes for many years prior to the transplantation, they were already familiar
15 with the importance of compliance detailed instructions or repetition. A few patients explicitly
16 opposed to certain parts of the information, like one patient who repeatedly said things like:
17 "you needn't be a rocketeer to understand that", "that's self-explanatory", or "that's
18 unproblematic."
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27 In cases where patients told the nurses that they had existing knowledge, or that they felt some
28 knowledge was irrelevant to them, the nurses would not easily accept this as sufficient basis
29 for tailoring the session. For instance, in the case with the man not wanting children, the nurse
30 first suggested that he might change his mind later on. When the patient denied this, the nurse
31 insisted that the knowledge nonetheless could become useful in the future and that the patient
32 should know about the precautions. A similar response was given to an underweight patient
33 who had already explained to the nurse that she wanted to gain weight. The nurse gave the
34 information about diet as usual, but added: "now, you are slim, so there is no concern, but you
35 should know about it anyway". When a patient found some of the information excessive or
36 irrelevant, the nurses often responded with formulations like "repetition does not hurt", or "it
37 can become relevant in the future". This may be interpreted as while the patients' knowledge
38 about their lack of knowledge was considered an important basis for tailoring, their
39 knowledge about what they already know or did not need to know was not regarded as a
40 sufficient basis for tailoring.
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51 This suggests that there are certain limits to the tailoring, constituted by responsibility for
52 patient safety and health economy placed upon the nurses as representatives for the health
53 care system. The nurses were thus seen as performing a balancing act between the
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3 intervention's principles and other responsibilities by virtue of their role as representatives for
4 a larger system.
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8 **4. DISCUSSION AND CONCLUSION**

9 **4.1. Discussion**

10 Previous research has shown that tailored patient education increases learning for patients
11 with chronic conditions [5, 9]. While the principle of individual tailoring suggests a process of
12 developing individualized knowledge, there is little insight into how such individualized
13 knowledge can be achieved in patient education settings. Our results suggest that individual
14 tailoring is enacted as a comprehensive practice which entails actively engaging with the
15 patients' knowledge about his life and experiences in order to translate generalized knowledge
16 into meaningful knowledge within the frame of the patient's life world.
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24 The new patient education programme in this study used academic detailing as an approach to
25 secure individual tailoring and patient centeredness. We observed that the nurses attempted to
26 involve patients, and map knowledge needs by encouraging patients to define their own
27 knowledge needs. However, in many cases the patients were not able to take the active role
28 and articulate their own knowledge needs. In a review of patient reported barriers to shared
29 decision making, Joseph-Williams et al [21] conclude that knowledge alone is not sufficient
30 for patients to take part in health related decisions, but that patients must also be granted
31 power by health care providers. Our results suggest that one way of granting patients power to
32 participate, in this case in articulating their own needs for knowledge, is precisely a question
33 of knowledge. Our study illustrate that patients find it difficult to identify and articulate their
34 knowledge needs only in relation to the generalized content in the programme. However,
35 when knowledge is presented within the frame of their own life world, patients are able to
36 identify and articulate their knowledge needs. Hence, our results suggest that patient
37 involvement should not depart from the generalized programme content, or from patients'
38 knowledge about it, but from the patients' knowledge about their life and experiences.
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50 For instance, mapping the patients' knowledge in relation to the programme's content seems
51 to be problematic in practice. The problem, we suggest, is tied to a narrow underlying concept
52 of knowledge, where knowledge is seen as something that is external to the patient; that can
53 be mapped and measured by questions with right or wrong answers, and that can be
54 transferred from the health care practitioner to the patient. Such a knowledge view aligns with
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3 what Wieringa and Greenhalgh [10] call an ‘objectivist approach to knowledge’, which they
4 and others [11] find is a common view of knowledge in medical and health care models for
5 translating knowledge between people and places. When individual tailoring is based on such
6 a knowledge concept, tailoring is understood as selecting knowledge (of the content) or more
7 repetition, based on the initial mapping of what the patient lacks knowledge about.
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12 Hence, individual tailoring is a question of ‘delivering’ the right knowledge to the patient, but
13 it does not involve a translation of the knowledge. Whilst this notion of knowledge and
14 tailoring is relevant in some learning situations, i.e. in teaching patients about signs of
15 rejection or medicine regimes, our study illustrates that it is an insufficient concept of
16 tailoring to encompass the complex practice that individual tailoring involves.
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22 As our study shows, individual tailoring involved translating knowledge from a generalized to
23 a personalized form by relating it to the patient’s own life world. One way to understand the
24 process is to view the process of knowledge translation as ‘meaning production’ [11] – in this
25 case it implies that instead of viewing knowledge as an object (content) that is transferred
26 from one place or person to another, the process of translation indicates a processes of re-
27 creating the content in light of the patient’s own life world.
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31 Moreover, the process is not just a matter of delivering content, but a complex practice which
32 involve verbal, practical and emotional engagement with the patient’s life world.
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37 Such a concept of knowledge and knowledge translation opens up for a widened
38 understanding of patient tailoring, which encompass the complex practice of verbal, practical
39 and emotional engagement with the patient’s life world in a process of creating individualized
40 and meaningful knowledge for the patient.
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45 The principle of individualization is maintained in the teaching sessions, based on an
46 extended knowledge concept. However, the nurses have to balance this principle with issues
47 of patient safety and health economics. These issues are tied to statistical knowledge about
48 risk for rejection, graft loss and other complications. It is also tied to economic knowledge
49 about the expenses of non-compliance and possible consequential complications. Thus, when
50 the nurses limit individual tailoring, it is an act of balancing between individualized and
51 generalized knowledge, where the generalized, statistical knowledge become prioritized [22].
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3 This might be an important barrier to individual tailoring and implementation of patient
4 centred interventions.
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7 **4.2. Conclusion**

8 The primary question that we explore in this article is how a new patient education
9 programme becomes situated and adapted when implemented in the daily teaching practice in
10 the hospital. Our analysis focused on how the programme's core principles of patient
11 centeredness and individual tailoring become enacted in practice. A strength to this study is
12 that the methodology enable in depth studies of complexities in implementation and in
13 individual tailoring in patient education settings. While the study's small scale limits
14 generalization, the study discloses important issues that may have implications to the practice
15 and study of patient education, as well as the study of implementation.
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23 For instance, when the nurses develop alternative approaches to individual tailoring, it might
24 have been understood as inaccuracy in implementation. In depth analysis depict however that
25 their adaptations are actually what retain the programme's core principle of individual tailoring
26 and patient involvement in encounter with the implementation context. In fact, the enactment
27 of these principles in practice opens up for a widened understanding of individual tailoring
28 which departs from knowledge about the patient's life worlds.
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34 The widened concept thus challenges a notion of individual tailoring based on the patients
35 knowledge about the programme's content, and suggests that individual tailoring should be
36 understood as a multifaceted practice in which individualized and meaningful knowledge is
37 recreated within the frame of the patients' life worlds. As such the results are relevant to
38 health personnel who teach patients, as well as to researchers interested in further developing
39 and improving patient education.
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45 We also observe that the context of the hospital, and the nurses' role as representatives of the
46 health care system place competing concerns upon them, which may cause limitations to the
47 individual tailoring. That is, contextual aspects may impinge on the individual tailoring. But it
48 is also an important insight in the study of implementation, as it illustrates how contextual
49 aspects may cause incorrect implementation. As such, our study strengthen the argument that
50 implementation processes should be studied with critical awareness about how adaptations to
51 the intervention are made, and what causes them [10, 11, 23].
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Author contributions

MA, KHU, AW and EE designed and led the project. IL conducted observations, the first analysis of data and drafted the manuscript. All authors gave feedback on analysis and contributed to revise the manuscript.

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Competing interest

None

Data sharing statement

This is a qualitative study and therefore the data generated is not suitable for sharing beyond that contained within the report.

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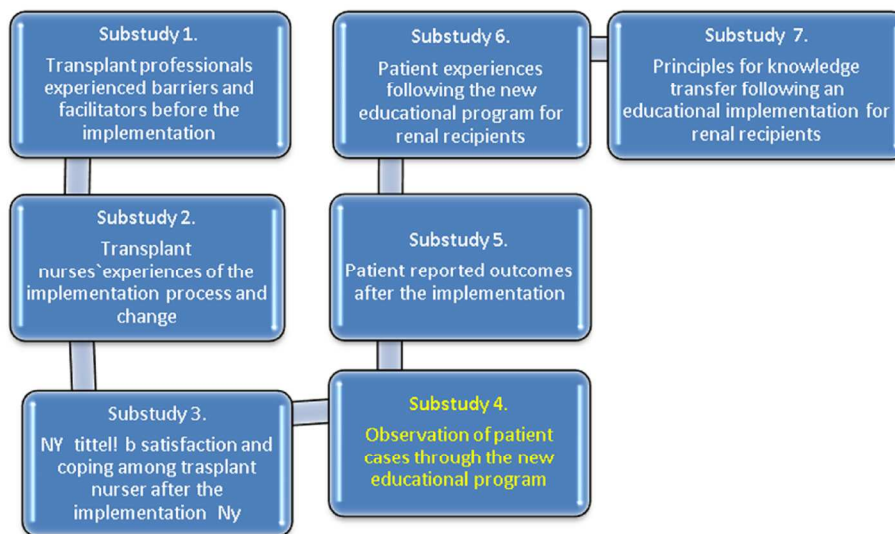


Figure 1. Overview of the sub-studies in the research project Evaluating and monitoring evidence based implementation of a structured, tailored education program for renal transplant recipients

566x317mm (300 x 300 DPI)

Review only

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BMJ Open

How does a new patient education programme for renal recipients become situated and adapted when implemented in the daily teaching practice in a university hospital? An ethnographic observation study

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Title: How does a new patient education programme for renal recipients become situated and adapted when implemented in the daily teaching practice in a university hospital? An ethnographic observation study.

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Abstract

Objective

To understand how a new patient education programme for renal recipients becomes situated and adapted when implemented in daily hospital teaching practice. The analysis focuses in particular on how principles of individual tailoring and patient involvement are adapted.

Design

Ethnographic observation study. 19 teaching sessions were observed, resulting in 35 pages of data written observation notes

Setting

A Norwegian University hospital. The study included the TX post, the medical post and the outpatient clinic.

Participants

10 newly transplanted patients receiving the education programme, and 13 nurses trained in the new programme participated in the study.

Results

We observed that the nurses attempt to implement the programme's core principles of individual tailoring and patient involvement as intended, but that patients found it difficult to formulate their knowledge needs and interest. Patients and nurses developed an approach to individual tailoring and patient involvement which used knowledge about the patients' life and experiences as basis for translating generalized knowledge into knowledge that is individualized and meaningful for the patient. The individual tailoring was however also limited, as the nurses balanced between responsibilities for the programme's principles of individual adaptation and patient involvement at the one hand, and responsibilities of safety and economy from a health systems perspective on the other hand.

Conclusion

Individual tailoring is observed to be comprehensive practice which includes verbal, practical and emotional involvement with the patient's life world. This extends the notion and practice of individual tailoring as selecting among predefined, generalized knowledge based on an initial mapping of the patients' knowledge. While the adaptations to individual tailoring could have been seen as inaccurate implementation, in depth analyses discloses that the extended approach to individual tailoring is in fact what retains the programme's core principles in the implementation context.

Strengths and limitations to this study

- Ethnographic observations of naturally occurring teaching sessions allows for in depth investigation of complex adaptations to the implementation context
- While the study's small scale limits generalization, the study discloses important issues in patient education, individual tailoring, and implementation that could be further investigated.
- Few participants had additional conditions or special needs, which perhaps prevent understanding about particular needs in groups with additional conditions or challenges

Keywords:

Qualitative research, individual tailoring, patient education, implementation, knowledge translation

Word count: 4 181

How does a new patient education programme for renal recipients become situated and adapted when implemented in the daily teaching practice in a university hospital? An ethnographic observation study

1. INTRODUCTION

About 300 patients per year receive kidney transplantations in Norway. Patients who go through kidney transplantation have to acquire knowledge about immunosuppressive medication, graft surveillance, and the benefit of specific lifestyle behaviour in order to reduce rejection episodes, graft loss and the negative consequences of lifelong immunosuppressive medication [1, 2]. The benefits of individually tailoring patient education have been increasingly documented [3-5]. Much research has focused on improving patients' adherence to medication [6, 7], whereas questions regarding what kind of knowledge patients achieve by individual tailoring in patient education have received less attention.

In a recent publication in BMJ Open, Poland et al [8] describe that individual tailoring help patients build 'individually relevant knowledge of their condition', which in turn 'support a situated understanding'. This clarifies that individual tailoring is not merely a question of individually adapted education, but that patients need to develop individualized knowledge. It does however not address the question of how individuality of knowledge is achieved in patient education. To understand how patients achieve such individualized knowledge is however crucial in order to advance patient education to meet patients' need for individual knowledge.

This article presents an ethnographic observation study of the implementation of a new patient education programme for newly transplanted renal recipients. The question that we investigate is how the new patient education programme is situated and adapted when implemented in the daily teaching practice in the hospital. Our results focus in particular on how the new programmes' principles of individual tailoring and patient involvement are practiced.

The main difference between the new and old patient education programme was that the new program emphasised stronger individual tailoring, patient involvement, and an extended number of training sessions. A randomized controlled trial (RCT) was conducted prior to implementation, which identified that the customized patient education program increased

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3 levels of knowledge, compliance and self-efficacy, and higher quality of life-scores compared
4 to the control group which received standard care [9].
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8 An intervention developed in an experimental context cannot be transferred to a real world
9 setting without contextual adaption [10]. Such adaption is not necessarily a threat to accurate
10 implementation, as often assumed, but a precondition for implementation[11]. However,
11 implementation also presupposes critical awareness about how this adaption comes about and
12 elements that are added to or removed from the "original" intervention through the
13 implementation process [12]. We used ethnographic observation to investigate adaptations in
14 the implementation of the new programme. The method is well suited to study the
15 implementation of multifaceted interventions such as patient education programmes as it
16 allows for detailed descriptions and in depth studies of naturally occurring interaction [13].
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23 24 1.2. Background

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26 The work reported here is a sub-study outgoing from the evaluation project '*Evaluating and*
27 *monitoring evidence based implementation of a structured, tailored education program for*
28 *renal transplant recipients*'. The overall goals of the evaluation project were to 1) improve the
29 quality of patient education, and 2) to understand and evaluate processes involved in the
30 implementation, as well as changes in practice following the implementation of the
31 intervention. The evaluation project included seven sub-studies which investigated both the
32 pre - and post implementation phase of the new education programme. The pre-
33 implementation phase addressed identification and analysis of the current situation and the
34 development of an implementation plan regarding competence enhancement of the new
35 patient education program (sub study 1-3) [14, 15]. The post implementation phase focused
36 on the delivery of the new patient education programme to the patients (sub study 4-7) and
37 included both the perspectives of patients and staff (see figure 1). The current paper presents
38 sub study 4, which investigates how the programme becomes situated and adapted in the
39 implementation context of individual teaching sessions with patients and nurses.
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50 **Figure 1.** Overview of the sub-studies in the research project *Evaluating and monitoring*
51 *evidence based implementation of a structured, tailored education program for renal*
52 *transplant recipients* [14]
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3 The evaluation project was inspired by the FORECAST-framework [16], which is a formative
4 evaluation framework for programme implementation and evaluation. Implementation is seen
5 as a dynamic and two-way process, and continuous collaboration and mutual influence
6 between the implementation teams and the project stakeholders are emphasized. The
7 implementation process should be flexible, and feedback loops are used to secure continuous
8 evaluation and adaptation.
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14 **1.3. The new patient education programme**

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16 The new program consisted of five one-to-one teaching sessions with a trained nurse, lasting
17 about 40-60 minutes. Three different departments were involved: the TX-post, the medical
18 post and the outpatient clinic. The first two sessions were held at the TX post, and the first
19 session was held during the first week after transplantation. Most patients were discharged
20 directly to the outpatient clinic where three more sessions were held. Patients needing special
21 care or more follow up on medications and self-surveillance, were admitted to the medical
22 post and received additional sessions.
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28 During the five sessions, essential information on the three knowledge areas of medication,
29 rejection, and lifestyle were provided. These areas was also covered in the standard written
30 information handed out for all renal recipients post-transplant, which was used as a basic tool
31 for the sessions. Under each of the predetermined themes, the content was contextualized and
32 further detailed based on each patient's needs and life situation. The patients also received a
33 diary in which medications, temperature, fluid balance and urine was registered.
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38 Development of the new education program involved studies of educational theory, a review
39 of previous research on patient education, knowledge about transplantations and clinical
40 experience [1, 17].
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44 Compared to previous education programmes used in the hospital, the new programme
45 emphasized patient centring and individual adaptation. In order to ensure individualization of
46 the knowledge, the method of "academic detailing" was. "Academic detailing" is a strategy
47 based on learning principles and includes identification of baseline knowledge and needs
48 (measured by knowledge questions), definition of evident training areas, a skilled instructor,
49 encouragement of active participation, repetition and elucidation of key areas, and feedback
50 on behaviour change [18].
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2. METHODS

2.1. Study design

Ethnographic observation emphasizes the collective aspects of human life and practices, and explores shared behaviour, customs and beliefs [19]. It allows the researcher to investigate naturally occurring practices as they unfold in specific contexts [13], and provides thick descriptions of these practices, as well as the contextual circumstances that impinge on them. Ethnographic observation was thus a fruitful method for investigating in depth how the new programme was adapted and situated when encountering the implementation context.

2.2. Data collection

Observations

10 patients were included in the study. Two or three (of five) sessions in each patient's teaching programme were observed: one at the TX post, one at the medical post in cases where patients were admitted there, and one at the outpatient clinic. We observed a maximum of three sessions per patient (see Table 1). All five sessions of the programme were observed at least once. Inclusion of 10 patients was considered sufficient to capture a detailed material containing variances and patterns in how the new programme was taught and received. Data collection ended as planned, as the material was considered providing in depth insight into the implementation process and rich on relevant examples.

A total of 19 teaching sessions were observed; ten at the TX post, one at the medical post, and eight at the outpatient clinic.

Table 1. Number of observations per patient

| | Number of patients | Number of observations |
|---|--------------------|------------------------|
| | 1 | 3 |
| | 7 | 2 |
| | 2 | 1 |
| N | 10 | 19 |

2.3. Participants

Nurses

A total of 13 nurses were included: one male and twelve female. Eight worked at the tx post, one at the medical post, and four at the outpatient clinic. One nurse had less than one year of experience working with renal recipients, five had one to five years, three had six to ten years, and four had more than 10 years of experience.

Patients

The TX nurses included patients in the study (see Table 2). Selection criteria was that the patients were not in need of a translator, and that the patient was fit enough to participate in regular teaching sessions. With these exceptions, all patients were asked. The nurses however remarked that patients with severe additional conditions were more likely to say no. As such, the material includes only a few patients who had additional conditions or needed special follow-up.

Table 2. Included patients: sex and age

| Age | Female | Male | N |
|-------|--------|------|----|
| > 40 | | 1 | 1 |
| 40-60 | 1 | 3 | 4 |
| 61-80 | 1 | 4 | 5 |
| N | 2 | 8 | 10 |

2.4. Observation strategy

The observations were conducted by a researcher (IL) with competence and experience in ethnographic observation and qualitative studies of communication of knowledge. Due to little knowledge about renal transplantation and the daily practice at the hospital, she visited each post for one or two whole days prior to observations. She also spent time at the departments between scheduled observations and took part in formal and informal gatherings, such as meetings and lunches. This was done to make the researcher more familiar with the daily practice at the departments, but also to be available for nurses' questions and to create an atmosphere of trust around the project.

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3 Observations notes were written during and directly after observations, and contained
4 description of situations, quotes, and more theory driven reflections and preliminary analysis.
5 As the researcher was unfamiliar with the setting and content of the education programme, an
6 open approach was emphasised in the earliest observations. In subsequent observations, key
7 topics for further observations were identified and pursued. These observations specifically
8 addressed issues like: nurses' and patients' definition of the sessions' purpose,
9 communication, structuring of the sessions, patient participation and communication of needs,
10 as well as how material artefacts were involved in the sessions. The observations resulted in a
11 total of 35 data written pages of observation notes.
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18 19 **2.5. Data analysis**

20 Data analysis began shortly after data collection and involved several phases. The first phase
21 involved detailed reading of the data and identification of topics for further analysis, guided
22 by the research question of how the programme was adapted and situated during
23 implementation in the clinic. Topics such as communication, knowledge, patient involvement
24 and patient participation were addressed. Topics and quotes from the data were presented to
25 the researcher group, and generated feedback which narrowed down topics for further
26 analysis. In the second phase two of the researchers (IL and EE) deepened the analyses by
27 working with excerpts of the observation notes. Further discussions with the researcher group
28 resulted in the identification of two main topics: 1) a widened concept of knowledge tailoring,
29 and 2) challenges and limitations for knowledge tailoring in daily practice.
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38 39 **2.6. Patient involvement**

40 The project and research question was developed on basis of literature revision, discussions in
41 the researcher group and clinical experience. A user representative from The Norwegian
42 Association for Kidney patients and Organ transplanted took part in the discussions. Patients
43 were not involved in the recruitment to and conduct of the study. Results will be disseminated
44 to study participants through the journal published by. The Norwegian Association for Kidney
45 patients and Organ transplanted and through oral presentations.
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51 52 **3. RESULTS**

53 This study inquires how a new patient education programme becomes situated and adapted
54 when implemented in the daily teaching practice in the hospital, with special attention on how
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3 the programme's core principles of patient centeredness and individual tailoring is practiced.
4 We find that when implemented, the programme's approach to individual tailoring and patient
5 involvement is insufficient. As a response, the nurses and patients develop an extended
6 approach to individual tailoring and patient involvement which includes the patient's life
7 world. We also find that the implementation context constrain individual tailoring and patient
8 involvement.
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14 **3.1. Involving patients and mapping individual needs**

15 As described, the new programme emphasized principles of individual tailoring and patient
16 involvement. During the observed sessions, the nurses often attempted to map the patient's
17 needs by starting the conversation with a question. For example, the nurses often started the
18 session by asking if the patient had read the written material that they had received, if he had
19 any questions about it, or if there was anything in particular that he wanted to talk about in the
20 session. Opening sessions with a question was a method for mapping the patient's knowledge,
21 but it also reflected the new programme's core principle of patient involvement, as it invited
22 the patients to take ownership of the situation and of their own knowledge needs and interests.
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30 The patients, however, were often acting reserved. Most patients confirmed that they had read
31 or looked through the information material, but very few had any follow-up questions or
32 particular interests. Many were silent and acting expectantly, seemingly waiting for the
33 nurses' initiative. That is, despite the nurses' attempts to map the patients' needs by inviting
34 them to take an active patient role in the situation, it seemed it was often difficult for the
35 patients to respond as intended. In turn it became difficult for the nurses to structure the
36 session based on an initial mapping of the patients' knowledge. Consequently, in many of the
37 observed sessions, the nurses had to find an alternative approach to the teaching sessions,
38 which was often observed to use the written material; structuring the sessions by the three
39 predetermined topics of medication, rejection and life style.
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47 Thus, in many observed sessions it was not possible to tailor the sessions as intended by the
48 patients' needs and knowledge. Instead, many sessions took a more standardized form,
49 structured by the written material.
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3.2. Including the patient's life world

When patients refrained from taking an active, knowledge seeking role in the sessions it could be interpreted as a lack of knowledge or interest. Accordingly, when the nurses structured the sessions based on the standard written material, it could be seen as inaccuracy in implementation. However, when nurses started talking about the predefined topics, the patients would often respond with interest and follow-up questions. A pattern in our material was that their response was often explicitly related to their daily life at home. I.e. one patient was particularly interested in the information about chickenpox, as he told the nurse that he had children at home who had not yet had chickenpox. Another patient was particularly interested in the information about medication and traveling, and told the nurse that he had a summer house in South Europe where he used to go with his children and grandchildren. Seeing this, suggests that the patients' difficulties of formulating knowledge interests or needs were not related to lack of such, but to difficulties in assessing and utilizing the generalized information material as basis for identifying their own knowledge needs and interests.

We found that the nurses actively used the information they had acquired about the patients' lives as a tool to individualize the generalized knowledge in the material. For example, a general advice in the information material was to exercise regularly to counteract weight gain and loss of bone density, which are known side effects of the immunosuppressant medication. This generalized knowledge was individualized by a nurse, based on her knowledge about the patient's life at home: "You can take your dogs for an extra walk and make sure to get some extra exercise". In another session, a nurse used her knowledge about the patient's life to individualize the generalized knowledge about increased risk of skin cancer, asking the patient: "When you are on your boat, do you make sure that you use sunscreen?"

Nurses also attended to patients' general condition, state of mind, and personal style of communication. They adapted to the patients, for instance by shortening the session if a patient seemed tired or unwell, or by actively tuning in to the patient's way of communicating. For example, a nurse could lower her voice and tempo with a reserved patient, while acting more outgoing and humorous with another patient. The nurses also responded to patients' knowledge interests or particular needs by making arrangements outside of the sessions, for instance by offering to provide information material, or scheduling appointments with specialists or home care during visits at home on behalf of the patient

Our data is rich on examples of how individual tailoring of the education programme involves a more complex and comprehensive practice than an initial mapping of the patient's knowledge about the content of the education programme. Observation of the teaching sessions suggests that patient tailoring involves actively engaging with the patient's life world. The term life world originates from phenomenology and refers to our horizon of experiences, which constitute the background on which all things appear meaningful [20]. Applied here, the term illustrates how the patients and nurses use the patients' daily life, work, family, and interests, as well as the patients' behaviour and communication as a primary frame of reference for individualizing the education.

3.3. Limits to individual tailoring

In some observations patients concluded that a certain part of the programme content was not relevant to them. For example, one of the patients, a young man, told the nurse that he was determined not to have children, and that information about precautions regarding reproduction was irrelevant for him. Several patients also commented that having lived with medication regimes for many years prior to the transplantation, they were already familiar with the importance of compliance detailed instructions or repetition. A few patients explicitly opposed to certain parts of the information, like one patient who repeatedly said things like: "you needn't be a rocketeer to understand that", "that's self-explanatory", or "that's unproblematic."

In cases where patients told the nurses that they had existing knowledge, or that they felt some knowledge was irrelevant to them, the nurses would not easily accept this as sufficient basis for tailoring the session. For instance, in the case with the man not wanting children, the nurse first suggested that he might change his mind later on. When the patient denied this, the nurse insisted that the knowledge nonetheless could become useful in the future and that the patient should know about the precautions. A similar response was given to an underweight patient who had already explained to the nurse that she wanted to gain weight. The nurse gave the information about diet as usual, but added: "now, you are slim, so there is no concern, but you should know about it anyway". When a patient found some of the information excessive or irrelevant, the nurses often responded with formulations like "repetition does not hurt", or "it can become relevant in the future". This may be interpreted as while the patients' knowledge about their lack of knowledge was considered an important basis for tailoring, their

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3 knowledge about what they already know or did not need to know was not regarded as a
4 sufficient basis for tailoring.
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8 **4. DISCUSSION AND CONCLUSION**

9 **4.1. Discussion**

10 Whereas the study includes a limited number of participants, it discloses important insights to
11 further develop individual tailoring in patient education. The methodology enable in depth
12 studies of complexities in implementation and in individual tailoring in patient education
13 settings.
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19 The use of FORECAST and feedback loops provided continuous adaptation throughout the
20 entire implementation process and awareness about individualized knowledge. Still, one
21 might question whether the FORECAST framework fully captured the complexity of the
22 implementation process. Although the model ensures continuous adaptation and modification
23 of the intervention, it tends to presuppose that the knowledge to be implemented is a package
24 that can be traced thought the implementation “pipeline” and to which the implementation
25 process owes some kind of fidelity. Our results demonstrate that a more flexible framework is
26 needed that considers knowledge as a process of continuous interaction, an –ing rather than a
27 thing.
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35 Previous research has shown that tailored patient education increases learning for patients
36 with chronic conditions [5, 9]. The principle of individual tailoring suggests a process of
37 developing individualized knowledge, which has been shown to be important for patients [8].
38 Our results suggest that individual tailoring is enacted as a comprehensive practice which
39 entails actively engaging with the patients’ knowledge about their life and experiences in
40 order to translate generalized knowledge into meaningful knowledge within the frame of the
41 patient’s life world.
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48 The new patient education programme in this study used academic detailing as an approach to
49 secure individual tailoring and patient involvement. We observed that the nurses attempted to
50 involve patients, and map knowledge needs by encouraging patients to define their own
51 knowledge needs. However, in many cases the patients were not able to take the active role
52 and articulate their own knowledge needs, which in turn left the nurses without a basis for
53 further individualization of the programme.
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4 In a review of patient reported barriers to shared decision making, Joseph-Williams et al [21]
5 conclude that providing patients with knowledge is insufficient, and that patients must also be
6 granted power by health care providers to enable them to take part in health related decisions.
7 Our results illustrate that the formulation of individualized knowledge seems to be crucial for
8 the empowerment of patients. More precisely, it seems from our results that presenting
9 patients to generalized knowledge of medication, transplant rejection and lifestyle does not
10 help them identify their own knowledge needs. Relating the knowledge to their own life world
11 however helps patients to articulate knowledge needs, and in turn to develop individualized
12 knowledge about medication, transplant rejection and lifestyle.
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20 Seeing the patient as part of the wider context that makes up the patients' life world, would
21 include the patients' families, homes, work places and local society. The stories told by the
22 patients often involved their closest family; that is, spouse, children and grandchildren. It has
23 been shown that family members and other caregivers provide important support to patients
24 with chronic conditions. This indicates that involving family in patient education might be
25 beneficial. It may help the patients and their families to integrate knowledge about
26 medication, rejection of graft and life style in their daily life. Family involvement in patient
27 education could also counteract caregivers' feelings of being unprepared and having
28 insufficient knowledge [22].
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36 While involving family could be valuable, it can also be practically challenging as the patients
37 receive the programme while admitted to the hospital. A benefit of educating patients while
38 admitted to the hospital is that it allows the nurses to observe the patients progress in learning
39 the medical regime and the registration of body fluids. However, as illustrated in our results,
40 development of individualized knowledge of how to live with the regimes required to keep
41 the organ and maintain good health, seems to be related to the patients' daily life outside of
42 the hospital. Having the general knowledge of how to prepare medication and register body
43 fluids might be a different kind of knowledge than the individualized knowledge needed to
44 develop good habits and long term adherence.
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52 As such, patient education should seek to help patients identify possible situations in their
53 daily lives where they may utilize and adapt the generalized knowledge provided by the
54 information material. Moreover, as the individualized knowledge seem to be tied closely to
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3 experiences in the patients' lives, it might be valuable if the education take place in, continue,
4 or become repeated when the patient has returned home and have gained experience in living
5 their life with a transplanted organ.
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9 When nurses limit individual tailoring, we see it as an act of balancing between
10 responsibilities for correct implementation on the one hand, and for patient safety and health
11 expenses on the other hand. That is, when they insist on teaching certain topics although the
12 patients find it irrelevant or unnecessary, they are prioritizing statistical knowledge about risk
13 for graft loss and other complications, as well as economic knowledge about the expenses of
14 non-compliance and possible consequential complications over the patients' own knowledge.
15 Previous research have also identified that it may be challenging for patients with chronic
16 disease to make their individual knowledge heard by health care personnel. Health care
17 personnel's reliance on biomedical, economic or statistical knowledge over the individual
18 knowledge of the patient may be an important barrier to individual tailoring and patient
19 involvement [22, 23].
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28 29 **4.2. Conclusion**

30 Our results indicate that individual tailoring should help patients identify how and when
31 generalized knowledge about medication, rejection and lifestyle is relevant in their daily life
32 outside the hospital. As such, the observed practice extends the notion of individual tailoring
33 as selecting topics based on an initial mapping of the patients' knowledge of the generalized
34 information.
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39 It can be further asked if developing knowledge that is meaningful within the frame of their
40 own life may help patients with maintaining the new regimes of medication and lifestyle in
41 the transition to home, and thus improve long term compliance. Another possible question to
42 pursue is whether incorporating patients' daily life and family into patient education
43 programmes can contribute to individual tailoring.
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49 While the approach to individual tailoring that was practiced during implementation of the
50 new patient education programme could have been understood as failed implementation, the
51 ethnographic approach allowed for in depth analyses which disclosed complex adaptations to
52 the implementation context. As such, our study strengthen the argument that implementation
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processes should be studied with critical awareness about how adaptations to the intervention are made, and what causes them [10, 11, 23].

Author contributions

MA, KHU, AW and EE designed and led the project. IL conducted observations, the first analysis of data and drafted the manuscript. All authors gave feedback on analysis and contributed to revise the manuscript.

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Ethical approval

The study was assessed and approved by the Data Protection Office at Oslo University Hospital (2014/5573). All participants were informed about anonymity, confidentiality, publication and their right to withdraw from the study at any time without any consequences. All participants signed letters of informed consent.

Competing interest

None

Data sharing statement

This is a qualitative study and therefore the data generated is not suitable for sharing beyond that contained within the report.

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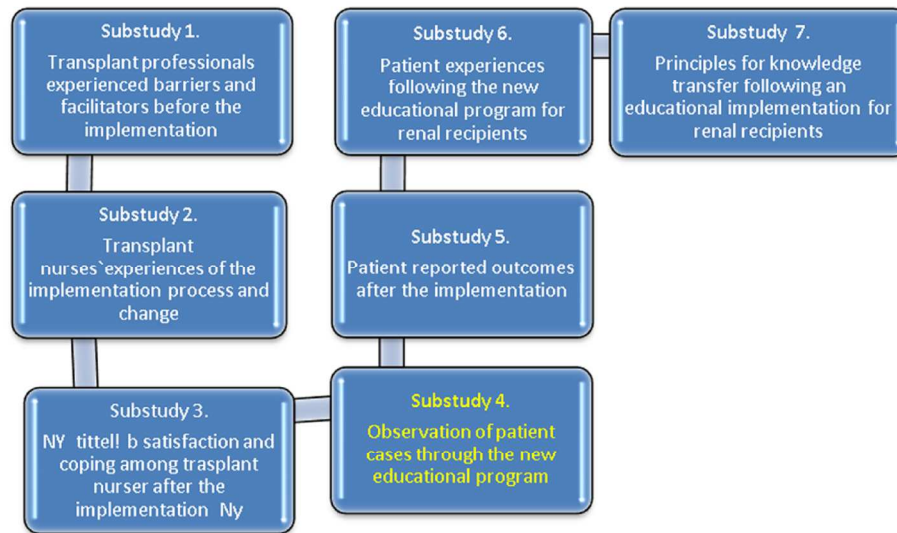


Figure 1. Overview of the sub-studies in the research project Evaluating and monitoring evidence based implementation of a structured, tailored education program for renal transplant recipients

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Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

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| <p>Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p> | 1/1-4 |
| <p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p> | 1/19-56 |

Introduction

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| <p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p> | 3/96-98 |
| <p>Purpose or research question - Purpose of the study and specific objectives or questions</p> | 3/103-107 |

Methods

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| <p>Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p> | 4/121-124 6/187-192 |
| <p>Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p> | 7-8/229-236 6/196-203 |
| <p>Context - Setting/site and salient contextual factors; rationale**</p> | |
| <p>Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p> | 7/211-223 |
| <p>Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p> | Not relevant |
| <p>Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p> | 7/228-246 |

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| 1 2 3 4 5 | Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study | 7-8/228-246 |
| 6 7 8 | Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results) | 7/211-225 |
| 9 10 11 12 | Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts | 8/238-246 |
| 13 14 15 16 | Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale** | 8/249-258 |
| 17 18 19 20 | Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale** | 8/249-258 |

Results/findings

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| 23 24 25 26 | Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory | 8-9/263-267 |
| 27 28 29 30 31 32 33 | Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings | 10/297-305, 312-315, 317-327 11/337-344, 346-356 |

Discussion

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| 36 37 38 39 40 41 42 43 | Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field | 12-13/367-439 |
| 44 | Limitations - Trustworthiness and limitations of findings | 12/363-365 |

Other

| | | |
|----------------|---|--------|
| 46 47 48 | Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed | 15/483 |
| 49 50 51 | Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting | 15/473 |

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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3 **The rationale should briefly discuss the justification for choosing that theory, approach,
4 method, or technique rather than other options available, the assumptions and limitations
5 implicit in those choices, and how those choices influence study conclusions and
6 transferability. As appropriate, the rationale for several items might be discussed together.
7

8 **Reference:**

9 O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative**
10 **research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
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