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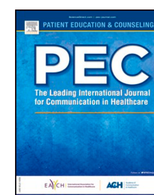

“When I feel safe, I dare to open up”: immigrant and refugee patients’ experiences with coproducing healthcare

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ABSTRACT

Objective: Interest in the coproduction concept in healthcare is increasing. According to coproduction, services are, unlike goods, always coproduced by a user and a service provider. This study explored how immigrants and refugees perceive the coproduction of their healthcare service in clinical encounters.
Methods: We conducted semi-structured interviews with thirteen patients with varied backgrounds and health problems. Participants were purposefully recruited in an interdisciplinary clinic for immigrants and refugees at a Danish University Hospital. Interviews were transcribed, anonymized, and analyzed using meaning condensation.
Results: Patients emphasized the importance of a safe space where they could be themselves and feel supported. This encouraged them to be open and assume an active role in the coproduction of their health. A stable therapeutic alliance based on kindness and kinship helped them find strength and take responsibility for their own health.
Conclusions: This study improves our understanding of how immigrants and refugees experience the coproduction of healthcare services. Further studies, evaluating long-term outcomes of coproduction efforts, are required.
Practice implications: Providing a safe space in which health professionals have time to listen and empathically validate immigrant and refugee patients’ lived realities, can enable patients to open up and become agents of their own health.

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1. Introduction

Immigrants and refugees are at risk of receiving lower-quality health care in their recipient country. Language and cultural differences, discrimination, lack of knowledge about the healthcare system, and difficult living conditions contribute to this problem [1–4]. Increased patient participation, otherwise considered a key driver for improving the quality of care [5,6], can be difficult to obtain with immigrants and refugees. They are often hesitant to take an active role in consultations and health care professionals are less likely to support their involvement [7,8]. New approaches are needed for improving the quality of healthcare service for this vulnerable and complex group of patients.

The coproduction of healthcare services enables new perspectives. It refers to a collaboration between users and professionals who unavoidably create public service together [9]. A recent model for healthcare coproduction [10] (Fig. 1) describes how healthcare service is coproduced in a clinical setting. In their relationship, patient and health professional progress through multiple levels of

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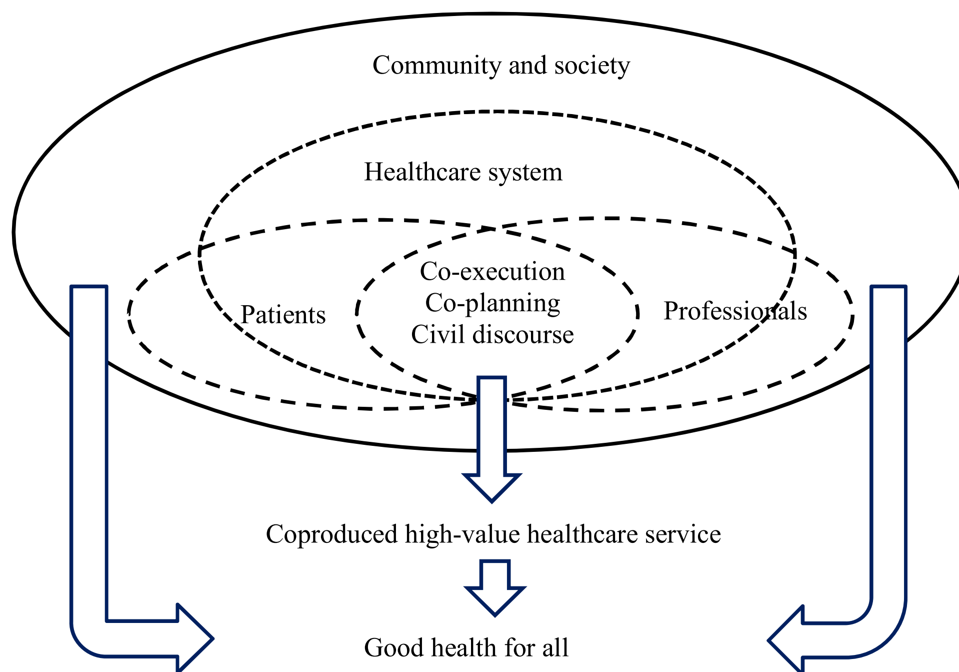

Fig. 1. Conceptual model of healthcare service coproduction [10].

coproduction (civil discourse, co-planning, and co-executing), which require increasing levels of mutual trust, effective communication, and understanding of one another's expertise, capabilities, and values [10]. Patients and professionals bring different types of knowledge to the shared work of coproducing the service: the health professional science-informed practice, skills, and experience; patients their life-experience knowledge and skill, their interest in their own health, and access to support [11]. Within the "patient-person" and "professional-person" relationship, they make decisions and take action to contribute to the health of the patient [12]. Yet, this shared work of coproduction on the individual level depends on how it is facilitated by management and applied by professionals [13]. Clinicians should learn how to enable the patients' self-care and to recognize the patients with limited ability or desire to participate actively in coproduction [10].

Coproduction is the co-planning and co-delivery of tailored health interventions to enhance individual well-being and improve health outcomes [14]. It is particularly suitable for heterogeneous and marginalized groups such as immigrants and refugees. Yet, their experiences with how they contribute to coproducing healthcare have not been studied. Therefore, we aimed to describe coproduction as experienced by immigrant and refugee patients in the clinical encounter. We will use the term "patient" to refer to persons who are also immigrants and refugees.

2. Methods

2.1. Research design

In this qualitative interview study, we explored immigrant patients' lived experiences with and views on coproduction of healthcare service with health professionals. We applied principles of hermeneutic-phenomenology to capture these phenomena. Hermeneutic phenomenology is concerned with the life world of human experience. It pays attention to seemingly trivial aspects of experience that often are taken for granted [15].

2.2. Research context

Data were collected at an outpatient clinic for immigrant and refugee patients at a Danish university hospital. The interdisciplinary team at the clinic, consisting of nurses, doctors, and social workers provides ambulatory coordinated care for immigrant and refugee patients with long-lasting, complex, and unexplained symptoms [16,17]. General practitioners or other hospital departments refer patients to the clinic. Health professionals at the clinic use communication tools specifically designed for the use in the clinic. These tools include a list of all the health and non-health related problems of a patient, a family tree, and the life story and provide an overview of living conditions and overall life situation. The information obtained using these tools form the basis for a shared action plan with agreed-on priorities and responsibilities between the patient, the clinic, and, if necessary, other health and social care professionals. Consultations at the clinic usually last around one hour, which is above average for outpatient consultations [18]. Trained medical interpreters are used in about 85% of consultations, as most patients at the clinic have limited language proficiency [16].

2.3. Participants and data collection

We conducted semi-structured interviews [19] between September and November 2020. Participants were recruited among patients who had attended the migrant clinic for a minimum of one year. Purposive sampling was used to ensure a balance of female and male participants from different countries of origin [20]. Of 20 patients, that were asked, 13 agreed to participate (Table 1). Due to Covid-19 restrictions, eight interviews were conducted via telephone with participants in a separate room at home. Trained interpreters participated via video in six interviews.

The semi-structured interview guide (Appendix A) was informed by the conceptual model for healthcare service coproduction [10] and included questions on patients' experiences in different clinics, tools, and approaches used in consultations, patient contributions to

Table 1
Characteristics of participants.

#	Gender	Age	Country of origin	Time in Denmark (years)	Time in the clinic (years)	Interpreter used	Location	Length of interview (minutes)
1	Male	60	Irak	30	12	Arabic	Clinic	35
2	Female	56	Thailand	23	1	No	Phone	21
3	Female	37	Palestinian in Lebanon	32	3	No	Phone	25
4	Female	31	Irak	25	2	Arabic	Clinic	23
5	Male	39	Syrien	5	2	Arabic	Patient´s home	37
6	Male	62	Iran	33	3	No	Phone	22
7	Female	50	Somalia	24	6	No	Clinic	19
8	Female	51	Thailand	17	1	No	Phone	23
9	Female	23	Irak	20	2	No	Phone	24
10	Female	36	Syrien	5	1	Arabic	Phone	26
11	Female	50	Kongo	10	2	Swahili	Phone	25
12	Male	39	Nepal	10	3	No	Phone	51
13	Female	33	Somalia	8	2	Somali	Clinic	34

care, and the relationship with health professionals. Interviews were conducted in Danish by the first author, a doctoral student with a background in Public Health and long experience with qualitative data collection. She had no other relationship with the migrant clinic. Interviews were digitally recorded and transcribed verbatim.

2.4. Data analysis

First, the interviews were read and listened to simultaneously to gain an overall impression. Second, we organized the emerging meaning units according to van Manen's interrelated lifeworld existentials of lived space, time, body, and relations [21]. These existentials belonging to everyone's lifeworld opened for a deeper understanding of for example how participants experienced the clinical space, the longer consultations, themselves in the situation, or the relationship with health professionals. Third, in an iterative process, we clustered meaning units and generated themes according to the study objective [22]. Finally, these themes were described and illustrated by quotations, which illustrate the essence of the patients' experiences. We used NVivo software [23] to ensure transparent coding and analysis of data. Credibility was further secured by discussing the analysis with the second author and refining the final themes with all authors. An example of the analysis is provided in Appendix B.

2.5. Ethics

The study is part of a research project registered with and approved by the Danish Data Protection Agency in the Region of Southern Denmark (journal no: 19/16130). According to Danish law, approval from the Regional Committee for Health Research Ethics of Southern Denmark was not required. Patients were informed about the research project and invited to participate by their health professional. If they agreed, their verbal consent was recorded together with the interview. All interviews and citations were anonymized.

3. Results

The patients' perspectives on their clinical encounters with health professionals at the migrant clinic clustered around three main themes. Fig. 2 shows the themes and the directionality of patients' experiences in the co-created healthcare service (full arrows). The dotted arrows indicate that this process in practice is not strictly linear but iterative. The themes are described below and exemplified by interview quotations.

3.1. Entering a safe space

The atmosphere in which patients were received was crucial for their co-productive relationship with their health professionals. Often, they had previously found themselves stuck and trapped in the healthcare system due to their long-lasting and complex health issues. With the patience and tolerance of the professionals, the patients described having found a "safe space" in which they could be themselves. As one patient said:

> "I feel treated as a human. They always have a smile on their lips and a big heart. We [immigrant patients] have many problems and when we talk about our inner struggles, we often get emotional. Here, they [health professionals] know how to deal with us and our different reactions." (#1)

Patients repeatedly mentioned a sense of security from knowing that there was someone who genuinely *had their back;* a person who would protect, defend and support them. The holistic and interdisciplinary tools used in the clinic (problem list, family tree, and life story) helped them feel "heard" and it contributed to the creation of a safe space in which their diversity was accepted. In that setting, they could gradually reveal their health-related issues as well as their background story and life situation. As a patient said:

> "She [nurse] listens to me and understands me. Here, I have room to explain how I feel and talk about all my problems. I feel that we [immigrants and refugees] otherwise often have to fight to get a place to be heard." (#7)

A repeated issue from the interviews was a sense of relief among patients when their symptoms, diseases, and treatment options were explained in a way they could understand. By fully understanding their health conditions and associated options, they were able to more actively participate in decisions regarding care and treatment. Moreover, a better *understanding of what is going on* also had an important stress-relieving effect. Thus, they were better able to care for themselves. As one patient said:

> "The first time I came here, we talked about all my symptoms. Until then, I had no idea what was wrong with me. I had so much pain in my body and my bones. They explained to me what all my pain was about and what I could do about it." (#11)

3.2. Feeling encouraged to take a shared active role

The safe space and the possibility of a trusting relationship with health professionals encouraged the patients to open up and share not only their health issues but also secrets, feelings, and life-related problems. One patient commented:

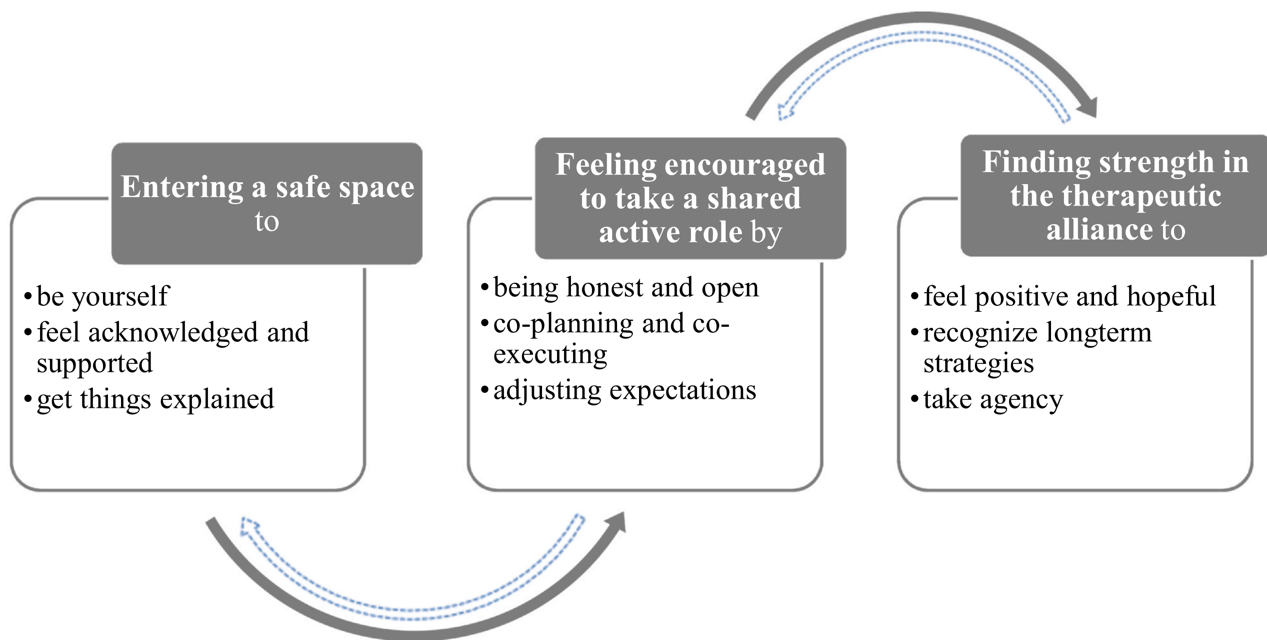

Fig. 2. Immigrant and refugee patients' experiences with coproduction in their clinical encounters.

"In the beginning, it was so difficult for me to talk about my problems, but over time I could really feel that she [nurse] wants to help me. I can see, she also gets sad, when I am sad." (#9)

Some patients mentioned that initially, it was unfamiliar and sometimes painful for them to open up, especially about sensitive topics such as mental health, sexuality, or trauma. Yet, most of them agreed on the importance of honesty. They realized that their honesty and openness allowed the health professional to understand what might help and support them in self-care efforts. As a patient said:

"My contribution is to be honest and tell all about my situation. This is something I have not tried in a long time because it is so hard for me to share my problems with others, but if I am not open with them they do not have a chance to figure out how to help me." (#7)

The safe space with open, trusting communication enabled patients to take a more active role in the planning and execution of actions as part of their own healthcare service. They started to see the meaning behind medical practices and realized how they might contribute to improving their own health. A female patient who had repeatedly refused a necessary lung examination said:

"I listen to her [doctor] and really take her advice to heart. It requires effort on my part, but I do it happily. I had skipped that lung scan several times because I was so afraid of it. However, she convinced me and explained everything to me. I would not have done it without her by my side." (#10)

In addition, participants mentioned that they had learned to reframe their expectations for recovery and of the healthcare system. This applied especially to patients with chronic and/or psychological health issues. One patient commented on having to keep a migraine diary as a tool to document her migraine attacks:

"When I started, I thought they could fix my migraine in three months. After one year, I was really stressed. Why did it take so long? I am tired of filling in forms but now I know that I have to go through it to find the medicine that works for me. Now I know things take time." (#3)

3.3. *The therapeutic alliance as motivation for change*

Seeing the same nurse, doctor, or social worker over time created a strong bond of trust between patient and professional. The resulting mutual understanding was perceived to be of value to the patients and reduced the stress around the consultations. The following quote illustrates how vital this continuity of care was for the patients:

"She [nurse] knows everything about me and I know a lot about her. It is so important to always see the same person. We have such a good relationship that she only has to look at me to know how I am doing." (#7)

Consultations and the collaborative partnership with their respective health professionals made patients feel positive and hopeful, or, as one patient put it, "coming here is like having one's batteries charged" (#1). Several patients could only let go of their worries and frustrations during consultations. They would not even share some of their most sensitive concerns with close family or friends. Patients did not hesitate to contact their nurse or doctor for advice or urgent matters as the following comment illustrates:

"Her [doctor] door is always open. When I need her, I can easily get in touch with her. She has never shown me that she does not want to talk to me. That feels so good." (#3)

The feeling of *a door that is always open to me* was important for the patients. Several referred to past situations in which they felt rejected or burdensome, further contributing to a passive approach to their own care. A patient, who experienced serious physical and psychological stress symptoms over imminent deportation of herself and her children, remembered:

"At that time, I tried to tell my story to my [previous] doctor, but he did not really listen or ask many questions. At some point, I simply chose not to talk about it anymore." (#13)

Feeling supported by the health professionals, patients took agency for their own health and life situation. Patients felt empowered and began to think of long-term solutions and take responsibility for healthier lifestyle choices. As one patient proudly said:

"They show me what I can do myself to get better. I always look forward to coming back and telling them what I have achieved. All these things have made a big difference in my life." (#11)

Thus, the supportive consultations allowed patients to contextualize and personalize the medical advice they received for their own life and health situation. Several patients were able to transfer the positive energy and hope from the consultations to their everyday life. In this way, the safe space at the clinic, the relationship with the health professionals, and the invitation to contribute actively helped patients reach a turning point in their life:

"They [health professionals] can see how hard I work to get better. I have gained so much hope and power. I am looking forward to getting better again and enjoying life with my children." (#3)

And another patient:

The way they [health professionals] treat me has given me hope. My life makes sense again. (#11)

4. Discussion and conclusion

4.1. Discussion

We interviewed a varied group of immigrant and refugee patients with long and complex healthcare needs that offered insight into varied conditions and experiences relevant for service coproduction in clinical encounters. Basic to coproduction was a safe space in which patients could be themselves, feel supported, and acknowledged. In this "space", empathic and understandable explanations of symptoms, disease, and treatment facilitated their engagement and active coproduction. When feeling safe, patients could open up and resume an active, shared role in the planning and creating of their own healthcare. The therapeutic relationship with their health professionals helped them mobilize the strength to reorient themselves towards long-term solutions and take agency for their own health and life. **These themes were important for participants irrespective of their ethnic background, their age and time spent in Denmark as we compared the participants' perspectives based on age, home country, and how long they had lived in Denmark. Language proficiency influenced their ability to articulate their experiences, which could interpreters compensate for.**

Supportive relationships that encourage self-care are essential for coproduction [24]. The healthcare service is composed of a relationship and some actions, which are coproduced by the patient and professional. The quality of this relationship influences the quality of the service. A trusting relationship between patient and professional is particularly important for immigrant and refugee patients given their vulnerability. This often requires dedicated support and flexible individualized approaches [25,26].

Our study corroborates the previously described importance of a safe space, which has been described in studies from varied settings [27,28]. **While others have studied coproductive relationships between various patient groups and health professionals [29–31], this is the first empirical study to report focus specifically on the role of a safe space in coproduction**. Creating a safe space involves a setting where patients feel they are genuinely listened to and that their symptoms and illness are understood. Feeling safe includes meeting professionals who empathically validate a patient's experiences and who motivate patients to share useful information and get involved in their own care [32,33]. In fact, sharing useful information is a major contribution to the coproduction of the service. Enabling that sharing is sometimes limited by the 'deficit'-focused approach often used in medical training. It does not prepare them for detecting the coproduction capacity of their patients [34]. Moreover, many refugee patients have been previously traumatized so it can be particularly painful for them to share their stories [35]. Health professionals who proactively welcome and seek the "voice" of their patients create an atmosphere in which patients feel safe to speak up [27,36].

Surprisingly, when reflecting on their communication behavior in the clinic, patients did not focus much on issues around language and the need for interpreting services. This was unexpected as the use of skilled interpreters has elsewhere been mentioned as critical for patient participation [27,37,38] and the quality of care and health outcomes [39]. A possible explanation for this might be the fact that in the migrant clinic – unless a patient is very much fluent in Danish or refuses to use an interpreter – professional interpreters are present via video in most consultations by default. Those who did mention the importance of interpreters noted that it is especially difficult to express feelings and emotions in another language.

Patients stressed the importance of understanding a health professional's motives behind the clinical tools that were used, such as the problem list and the basis of the reasoning behind suggested medical practices and treatments. Another study on coproduction with refugees [40] found that participants felt alienated by formal text-heavy action plans that were created for them because of the format. When meaningful to them, patients were able to coproduce their own care by being open and honest, by actively taking part in the decisions of their care, and by aligning their expectations of their recovery and the actions of the healthcare system. Tools that support coproduction with immigrants and refugees include a list of all of the patient's problems or a reconstruction of a patient's life story and family tree offering an overview of a patient's health and life situation [41]. By focusing on what multifaceted, proactive patients already are doing to contribute to the coproduction of their own health, these patients, despite being at a disadvantage in society, can become empowered [29].

Participants valued empathy, genuineness, and accessibility by their health professionals. These attributes facilitated the therapeutic relationship that allowed them to digest complex information, manage bad news, respond to challenges about their behavior, or cope with dependency and vulnerability [42]. The coproduction in such an alliance expresses the kinship of a shared humanity. It meets the needs of the patient, generates individual well-being, and fosters the individual capacity to resolve problems in the future [9]. An interesting finding in this regard was the mutual understanding between patient and professional ("She [nurse] knows everything about me and I know a lot about her"). The therapeutic alliance reached beyond the classic roles of *patient* and *professional* and turned into a kinship of human persons built on kindness, authenticity, and mutual vulnerability [42]. Recognizing and using these relational dynamics in the coproduction of service offers the opportunity to jointly pursue efficiency and patient-determined goals resulting in better health outcomes [29]. After all, coproduction endorses a person-centered perspective, which in turn enhances patient satisfaction but also health outcomes [14,43].

An important strength of this study is the recruitment of immigrant and refugee patients, who often are underrepresented in research studies constituting a 'hard to reach' study population. Participants were open and offered rich insight into their experiences. The strong trust relationship with the health professionals who recruited the participants strengthens the validity of the results. **On the other hand, we cannot exclude that patients' dependency on their health professional affected our results. We tried to compensate this by assuring patents that participation would not affect their treatment or therapeutic relationship with their health professional.** We also believe that the overall lack of social contexts due to Covid-19 restrictions motivated them to participate. Nevertheless, we cannot exclude that participants might have withheld information that they did not feel comfortable sharing.

COVID-19 restrictions forced us to conduct eight out of thirteen interviews over the telephone. Thus, we could not react to non-verbal communication clues that might have arisen or been noticeable during in-person interviews. These limits, however, do not influence the interpretation of transcribed interviews. The second and third co-authors work at the migrant clinic. They explicitly questioned their subjectivity in the interpretation of the data [44]. During interviews, the first author paid particular attention to avoiding leading questions. Finally, we used trained interpreters whom patients were familiar with, paying tribute to the importance of interpreters for the validity of qualitative data [45]. These interpreters were thoroughly informed about the purpose of the study and the content and structure of the interview in advance.

We were interested in the experiences of specific patients in a unique best-practice setting, being aware that they might differ from other patients' experiences in the same setting. They represent the most complex of immigrant patients with long-lasting, multifaceted health issues and they are a *case* of a group of patients with similar challenges who are studied in a particular clinical context [46]. Thus, they offer a rich source of knowledge because of their many experiences with the healthcare system. These are certainly relevant for other healthcare settings that struggle with involving immigrant patients in healthcare decisions and activities. Moreover, themes such as the importance of a safe space and kindness for coproduction seem useful for any group of patients.

4.2. Conclusion

Our analysis indicates that immigrant and refugee patients can coproduce their healthcare when feeling safe and genuinely respected and supported by trustworthy health professionals. Their experiences show that they coproduce by sharing their stories, engaging in decisions, design and co-creation of their healthcare, ultimately taking responsibility for their own health and life situation. We hope the perspectives presented in this paper can encourage healthcare organizations and health professionals to better understand the added value of coproduced healthcare also for indirect outcomes such as feeling cared for, listened to, and encouraged to take responsibility. Further studies are needed to evaluate the long-term outcomes of coproduction and to test the validity of our findings in different healthcare settings and with different groups of patients and professionals.

4.3. Practice implications

Our study has several practice implications for health professionals and management. Immigrant and refugee patients value a welcoming atmosphere in the clinical setting. Health professionals can proactively create this safe space for patients through simple acts of kindness such as proactive listening and empathic validation of life experiences and views. Moreover, health professionals should foster trust, encourage patients to rely on their strengths and capacities, and respect their decisions. Healthcare managers should recognize the long-term value of coproduction and prioritize sufficient consultation time for interpreting services and the creation of coproductive relationships between patients and health professionals.

Informed consent and anonymization

Participants consented to participate in the study at the beginning of the interview and their consent was recorded. I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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CRediT authorship contribution statement

Christina Radl-Karimi: Conceptualization, Methodology, Former analysis, Writing – original draft. **Dorthe Susanne Nielsen:** Methodology, Former analysis, Supervision, Writing – review & editing. **Morten Sodemann:** Supervision, Writing – review & editing. **Paul Batalden:** Supervision, Writing – review & editing. **Christian von Plessen:** Conceptualization, Methodology, Supervision, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Semi-structured interview guide

Semi-structured interview guide for patient interviews.

Overall research question: How do immigrant patients experience coproduction in the clinical encounter?	
Preliminary question	Can you tell me about your overall experience at the migrant clinic? (Can you give an example?)
Comparison of migrant clinic to previous experiences in the healthcare system	How do you compare your experiences at the migrant clinic with other places in the healthcare system? (Can you give an example?)
Experience of civil discourse	What is important to you when you come to a consultation at the migrant clinic? With "important", I mean the way health professionals communicate with you and treat you. (Why? Can you give an example?)
Experience of co-planning of care	
Health professional and patient contribution to co-executing the planned care	

Experience of relationship **Concluding question**	- In the migrant clinic, interpreters are used in most consultations. What does it mean for you to be able to speak in your native language in health consultations? At the migrant clinic, they use tools such as the problem list, family tree and life history to plan your course of care. (Explain if necessary) How did you experience these communication tools? What is it your nurse/doctor/social worker helps you with? When you look out relationship as a partnership, in which both sides help/contribute, what would you say, are your contributions to improve your health? How would you describe the relationship to your nurse/doctor/social worker? (Can you give an example?) How do you feel after leaving one of your consultations at the migrant clinic?

Appendix B. Translated example of the analysis

Translated example of the analysis

Gaining a general impression	**Meaning unit** What is being said/observed?	**LS, LB, LT, LR***	**Condensation** What does it mean?	**Synthesizing** Emergence of key themes
	I feel they [the health professionals at the MHC] have our backs. I feel they are sincere and support me and therefore I seek security with them. I also trust them and speak honestly. (#5) Here, I have time and I can be myself I can talk about my problems and many different things. There is so much attention and I feel safe here. (#7) It has been so important to feel accepted, to be seen as a human being and taken seriously and not ignored. (#2) She [nurse] listens to me and understands me. Here, I have room to explain how I feel. I feel that we [immigrants] otherwise often have to fight to get a place to be heard. (#6) I really appreciate that she [nurse] will also help me with things that are not exactly within her area of responsibility, but which mean a lot to me. (#4)	LS, LR LS, LB LB LR, LS LR	Feeling supported creates trust Patients feel there is time to be listened to and a place where they can be themselves	Entering a safe space
	In the beginning, I couldn't tell everything. But over time, I could feel that she [nurse] wanted the best for me. I can see in her eyes that she gets upset when I'm upset. (#9) I think my contribution is that I tell it all. I do not have any secrets. I tell about my life and about how I feel. And then they have an easier time helping me. (#11) What I can do is be honest. I have to be honest so they can help me. It's something I haven't tried in a long time because it's hard to come out with its problems to others. (#9) When I started here, I thought it would take 3 months and then I would be done. And then, 1 year went by and then I got stressed that it takes so long, but now I understand that these things take time. (#3) I try to be open and tell about my situation and accept the help they offer. It's important that they can see how I really feel. To get the help I need, I need to show openness. (#7) I take her [doctor] advice very seriously. I listen and listen. It requires an effort on my part but I do it with happy. For example, that scan. I was so scared to do it. I wouldn't have done it without her help. (#10)	LR, LT LR LR LR, LT LR	Patients know that they have to open up if they want help, even though it is difficult for them. Taking advice, understanding the meaning of healthcare activities	Feeling encouraged to take a shared role

* LS=lived space, LB=lived body, LT=lived time, LR=lived relation.

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