

Patient involvement in Greenland hospital-care: A qualitative study of the patient perspective

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ABSTRACT

This article deals with drivers for and barriers to patient involvement in Greenland hospital-care, from the patients' perspective.

Data were generated in 2019, via semi-structured research interviews and field observations. At the National Hospital in Nuuk, participants were purposively included to ensure variation regarding diagnosis, age, sex, socio-demographics, and place of residence. A number of 11 patients participated in individual interviews. Concurrently, observations of bed-side care situations and interactions between health professionals and patients were conducted, and informal conversations were held with eight patients. Findings were analysed using Malterud's systematic text condensation, and constituted the following themes: "Patient characteristics"; "Interaction with staff members"; and "Personal experiences and prerequisites for information and care".

One of the main findings was that personal expectations, confidence in the quality of hospital-care, language skills, conditions around family support, and taboos concerning not being able to take care of oneself, impacted patients' opportunities for involvement.

It is concluded that patient involvement cannot be accomplished by simply focusing on patients' health competencies. To ensure that hospital-care is provided in partnership with patients and families, it is equally important that health professionals develop new skills, and that the healthcare system is re-organised towards a more patient-oriented approach.

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Introduction

This article deals with patient perspectives on surgical treatment pathways and care delivery in Greenlandic hospital-care. The aim is to identify patient-related drivers for and barriers to patient involvement.

In Greenland, the National Health Services aim to involve patients in the prevention and treatment of illness, thus promoting self-care [1]. The vision is to make good quality healthcare accessible to all citizens that is adapted to the population's cultural background and lifestyle. Consequently, there has been increasing focus on involvement of citizens and patients. The question is, however, how the political visions of patient involvement are being implemented and do actually function in clinical hospital-care practice – from the patients' point of view.

Patient involvement includes patients' rights and opportunities to influence their healthcare. The concept of patient involvement is defined as:

"... Specifically to the rights and benefits of patients to have a central position in the healthcare process ... The

benefit is expected to be a better patient outcome due to the improved interaction between the healthcare provider and the patient"

[2]

According to the above definition, patient involvement predominantly deals with the way patients' own perspectives are being integrated into treatment and care decisions, with a view to improved collaboration and increased self-management during treatment, hospitalisation and rehabilitation. To ensure this, a more patient-centred approach has been suggested, where patients' preferences, needs and values are used actively in treatment and care decisions. In continuation hereof, patient involvement may also be seen as an integrated element of person-centred care [3]. Thus, it represents a caring practice that is respectful of and responsive to individual patients' preferences, needs, and values, and one that ensures that clinical decisions are guided not only by biomedical evidence or tradition, but also by patients' values [4]. However, many factors may influence the actual opportunities and conditions for patient involvement [5], of which some are contextual.

Kalaallit Nunaat – the country of the Greenlanders

Greenland is the world's largest island with 2.166.086 km² of which 85% is covered by ice and only 15% is inhabited (along the coast). The population consists in approximately 56.650 individuals of whom 15.000 live in the capital Nuuk. Besides an additional three cities, there are 18 towns and 120 villages. Greenlandic is the official language, and Danish the second; both languages are used in healthcare. There are no roads between the towns along the coast, so travel is by dog sledge, plane, helicopter or boat, at times when the sea is not frozen. Consequently, because of the climate and infrastructure, the Greenlandic health services operate under significant logistical challenges.

The organisation of healthcare

In 1992 the Greenland Home Rule Government took over the responsibility for health services from Denmark. Approximately twenty years later in 2010, the largest healthcare reform to date was launched, to address a number of persistent administrative, financial, and health professional challenges: recruitment and retention of educated health professionals, change in settlement pattern from settlements to cities and towns, increasing demands of health services in the population, and increasing numbers of individuals suffering from chronic lifestyle diseases. However, there were also positive factors such as improved infrastructure, longer life expectancy, and increased use of telemedicine which impacted the need for a radical healthcare reform.

Currently, the Greenlandic health services are organised in five regions, all of which have affiliated hospitals, health centres, nursing stations, and rural consultancies in cities, towns, and settlements [1]. Given this infrastructure and the country's topography, patients can travel for several days across huge distances if they need treatment at the national hospital in the capital of Nuuk. To these patients, such clinical pathways may involve several transitions and contacts with health professionals from various parts of the healthcare system. So, while such organisation may bring about efficient utilisation of medical resources, it also carries a risk that the primary goal of the effort – the patient – is left out of influence on their care, which may result in a suboptimal outcome.

Aim

To study patient perspectives on drivers to and barriers for patient involvement in Greenlandic hospital-care

Methods and materials

To capture patients' perceptions on their treatment pathways and care delivery we applied a qualitative approach in the form of individual semi-structured research interviews [6,7] and field observations [8,9].

Data were generated during in 2019 at the – so to speak – end of the patient-pathway at the National Hospital in Nuuk, on a surgical ward, a surgical day-care unit, and a surgical out-patient clinic. Under supervision, two Greenlandic clinical nurses conducted face-to-face interviews and made field observations in close cooperation with the author LS. The nurses were Bachelors of Science in Nursing and were thus acquainted with qualitative research methods. In addition, the nurses completed a short educational course focusing on the interview methodology. The feasibility of the interview and observation guides was tested in close cooperation with LS, who personally attended the initial four interviews and was present at the hospital, during the whole study period.

Interviews

The interviews took place during patients' acute or elective admission or during follow-up, at the hospital ward or the out-patient clinic, and always in private. Eleven patients – six females and five males – participated in one interview each. The participants were purposively included to ensure variation regarding their diagnosis, age, sex, and socio-demographics, including place of residence. Patient characteristics, sociodemographic variables, pathways, and interview language are presented in [Table 1](#). Eight patients were hospitalised when interviewed, while the remaining three were either about to be discharged, in transfer between hospitals, or visiting the out-patient clinic. Additional four patients were invited but did not participate in the interviews; one was discharged before the scheduled interview, and three preferred to participate in informal conversations instead of being formally interviewed. Those three patients are presented in the "Observations" section.

The interviews followed an overall semi-structured guide that was adapted to be used before, during or after the patient's treatment ([Table 2](#)), and were held in three languages at the participants' choice: Greenlandic (four); Danish (five); a mix of Greenlandic and Danish (one) and English (one). All interviews were digitally recorded. Interviews held in the Greenlandic and English languages were translated into Danish and

Table 1. Overview of interview participants.

ID	Pathway	Age	Gender	Admission	Treatment	Profession	Residence	Language
1	Discharged	45	Female	Elective	Surgery	Teacher	Small town	Danish
4	Hospitalised	60	Female	Acute	Plaster dressing	Self-employed	Small town	Danish
7	Hospitalised	67	Female	Acute	Surgery	Pensioner	Town	Danish/Greenlandic
8	Hospitalised	82	Male	Acute	Observation	Pensioner	Denmark	Danish
10	Hospitalised	58	Male	Acute	Surgery	Fisher/hunter	Residence	Greenlandic
11	Hospitalised	20	Male	Acute	Surgery	Student	Town	English
13	Hospitalised	43	Female	Acute	Antibiotics	Housewife	Town	Greenlandic
14	Transfer	58	Female	Acute	Surgery	Kitchen manager	Small town	Greenlandic
15	Hospitalised	44	Female	Acute	Surgery	Blue collar worker	Residence	Greenlandic
16	Out-patient clinic	29	Male	Acute	Surgery	Self-employed	Town	Danish
17	Hospitalised	77	Male	Acute	Wound care	Pensioner	Small town	Danish

Table 2. Semi-structured interview guide.**OVERALL INTERVIEW TOPICS**

- Patients' description of their pathway
- Patients' perception of being included in treatment decisions
- Where in the process the patients experience that final decisions are made
- Patients' knowledge of consequences and side effects of treatment
- Patients' experiences of whether they have had the opportunity to express concerns and doubts about side effects and consequences for treatment

INTERVIEW GUIDE – BEFORE TREATMENT

- Please tell me in your own words,
- *What has happened until now that you are here?*
 - *Have you been part of any decisions until now?*
 - *Have you been told what you think you need to know?*
 - *Do you know what is going to happen now?*

INTERVIEW GUIDE – DURING TREATMENT

- Please tell me in your own words,
- *What has happened during your stay at the hospital?*
 - *What have you learned about your disease and treatment?*
 - *Have you been involved in any decisions concerning your treatment plan?*
 - *Can you talk to the staff members about your personal concerns?*

INTERVIEW GUIDE – BEFORE DISCHARGE

- Please tell me in your own words,
- *Were you involved in deciding anything when your discharge was planned?*
 - *Do you feel ready for your discharge?*
 - *Do you feel better now than when you were hospitalised?*
 - *Do you know whom you can turn to, if you need any help after your discharge?*

subsequently, as for the interviews held in Danish, transcribed verbatim.

Participants in observations

Concurrently, participant observations of bed-side care situations, interactions between health professionals and patients, and informal conversations with patients were conducted [8]. Handwritten field notes were taken immediately after the observations, each comprising a description of the observation and the observer's initial impressions of the situation, and reflections.

A total of eight patients participated in observations which involved interaction with staff members in various clinical situations and informal conversations with

the observers. Patient characteristics, sociodemographic variables, pathways, and notes are presented in Table 3, where it is shown that two patients were hospitalised and one was on the point of being admitted to hospital. Of the remaining patients, two were about to be discharged, one was to undergo day surgery, and two were about to visit the out-patient clinic.

The translated interview transcripts and field notes were analysed using the methodology of systematic text condensation (STC) [6]. All transcripts were read systematically while listening to the audio recordings, to check the quality of the transcripts, generate overall impression of the data, and define preliminary findings. This was followed by a de-contextualisation of the transcripts into meaning units, which was coded in groups. Subsequently we re-contextualised the material into a multi-vocal first-person narrative, before an analytic text was created, and a novel understanding of the research topic was achieved.

The initial steps of the STC analysis were conducted after the first five interviews, and the final interviews were focused according to the preliminary findings. Subsequently, in-depth STC analyses were performed for all transcripts, and findings were thoroughly discussed in the study group to ensure transparency of the analysis process and validation, while keeping the study aim in mind. This procedure was repeated for the field notes. The subsequent critical discussion focused on the content of the total dataset which was structured into themes. Finally, possible interpretations were discussed across the themes, to identify both patterns and variations in the material.

Ethics

The study was conducted in accordance with the Helsinki Declaration's rules on voluntariness and anonymity [10], and the International Council of Nurses' Code of Ethics for Research [11]. Permission to undertake the study was obtained from the Health Management in Greenland (Nanoq – ID: 8,954,580) and the Health Science Ethics Committee of

Table 3. Overview of participants in observations.

ID	Pathway	Age	Gender	Admission	Treatment	Profession	Residence	Note
2	Hospitalised	48	Male	Acute	Surgery	NA	Small town	Has complications and prefers to focus on recovery.
3	Discharge	60	Female	Acute	Plaster dressing	NA	Small town	Does not feel well, is pale and worried.
5	Discharge	27	Female	Elective	Surgery	NA	Town	Agrees to participate in an interview, but is discharged.
6	Hospitalised	64	Male	Elective	Surgery	Farmer	Residence	Does not wish to be interviewed; prefers informal conversation.
12	Day surgery	19	Female	Elective	Surgery	Student	Small town	Does not wish to be interviewed; prefers some company instead.
18	Admission	55	Male	Elective	Surgery	Pensioner	Small town	Does not wish to be interviewed; we are allowed to observe his interaction with the staff members
19	Out-patient clinic	64	Female	Follow-up	No	NA	Town	
20	Out-patient clinic	53	Male	Follow-up	No	NA	Small town	

Greenland, National Medical Board KVUG 2018–22 (Nanoq – ID: 8,883,192).

All participants were informed orally and in writing about the project in either Greenlandic (Appendix 1) or Danish language in accordance with their choice. The participants in observations gave oral consent to participate, and the participants in interviews gave written consent. Person-sensitive data is stored in accordance with the provisions of the Data Protection Act for Greenland [12]. To ensure anonymity of the participants in this relatively small study population, we have refrained from presenting quotations with personal information that could potentially be associated with specific participants.

Results

Initial findings

The initial analyses showed that the participants generally expected that their interaction with the health professionals would take place on the staff members' initiative, rather than on their own. Therefore, and even though some held important experiences with their disease and suggestions concerning improvements of their care, they did not take any initiative themselves; instead they waited to be contacted. This seemed due to a somewhat pending approach, where the patients expected to be invited to enter into a dialogue with the health professionals. On the other hand some patients expressed that they had difficulties in accepting not being able to take care of themselves, which may be the reason for trying to neglect their need for personal care. In both situations the hospital setting and their personal expectations and experiences impacted the conditions for their involvement, in terms of processing information and taking part in decisions around their care.

The Following themes emerged from the STC analyses: "Patient characteristics"; "Interaction with staff

members"; "Personal experiences with and prerequisites for information and care".

Patient characteristics

Table 2 and Table 3 illustrates the variation in pathways, age, living conditions, education, language, and nationality in interviews and observations. Among the 11 interview participants, ten had acute admission to hospital for either observation, surgery, plaster dressing, wound care, or antibiotics. Five were male and six were female. Age ranged from 29–82 with a mean age of 53 years. One patient was unemployed and three were pensioners, while six were either self-employed or employees. Four of the participants lived in the capital where the national hospital is situated, while six lived in either small towns or settlements along the coast, and one lived abroad.

Among the eight participants in the observations two were acutely and four were electively admitted to hospital, for either surgery or plaster dressing, while two were in follow-up after treatment. Four were male and four were female; ages ranged from 19–64 with a mean age of 49 years. Three were, respectively, student, farmer, and pensioner; the professional status of the remaining five was unknown. Two lived in capital, while six lived in small towns along the coast.

Interaction with staff members

Being informed created understanding and gave the patients a sense of being involved in decisions:

Patient (P): They informed me and asked me. We discussed the various things they could put into my hip.

Interviewer (I): So you got the choice? And you made the decision?

P: Yes, but I had to, because I was in such pain every day – 24/7.

However, to some patients it did not seem appropriate to participate in such decisions:

Observation/ field note: The patient (an elderly man living in a rural area, who had already been at the hospital for half a year) explains to me that in Greenland, you live in circumstances that in many cases cannot be influenced, and where the only possibility is to be patient and not make excessive demands. At the hospital the doctor knows what is best, so therefore he does what the doctor tells him to do.

In such cases entering into a dialogue with the health professionals required an invitation:

P: When I talk to the health professionals, I tend to be reluctant with some of the things I would actually like to say. But I am happy when they approach me.

This need for an invitation could also be present, even if the patient suspected that some error had occurred:

P: Yesterday when we talked to the doctor, he said that my blood percentage was low and that I should have antibiotics and saline. But I did not get saline.

I: ... Well, even if the doctor said this to you?

P: Yes, even though the doctor told me, it wasn't done, but I didn't tell the nurse either.

However, some patients did have solutions and suggestions on their minds that they wished to share:

P: ... I even went down there [to the hospital] several times: "you know what, it [the plaster dressing] hurts, I think it needs to be replaced".

When such suggestions were rejected, it did not always seem understandable to the patient:

P: I talked to the physiotherapist and to the occupational therapist: 'I do not need to come to XX [name of a regional hospital] to get physiotherapy. We have up and down hill, we have mountains where I live. Can't I just try to go home? But no I cannot. [They say that] ... I will also get to know something in XX which I will not get to know here. I do not know what it is.

Personal experiences and prerequisites for information and care

Besides their diseases, the patients also brought their personal life experiences with them to the hospital. This contributed to their competences for being involved as in the following, where the patient's inner knowledge of her body led to a shared treatment decision:

I: Do you feel that you have been involved in deciding to have an operation?

P: Yes, I know my body really well, because I am as physically active as I am, with mountain hikes in the summer and jogging in the winter. For the last two

months, I have felt that I am not using my body like I am used to do.

A shared language represented a main prerequisite for dialogue and information. However, to the patient it was not in all cases necessary for obtaining a feeling of being taken good care of:

P: One of the staff members speaks only Greenlandic and I cannot talk to him, but he takes good care of me.

In all cases, the constitution of a trusting relationship was fundamental to the experience of quality of care:

P: At first, I was a little sceptical and nervous about the nurse changing the bandage, but I could easily see that she had done this many times before. I myself thought that the wound looked a little ugly. But that a professional, who knows what such a thing should look like, said to me that it looked fine, was a relief. When she had finished cleaning my wound I had to tell her that she was cute. I was so grateful that she washed the wound and showed it to me.

Trust in healthcare was not always present from the beginning, but it could be build up along the treatment pathway:

P: I was very nervous about having surgery and going under anaesthesia and all that. There was a [swearing] ... good anaesthesiologist ... Her brother did something similar to me for a living you know, and she just talked about that while I was lying there shaking all over. She did everything she could to make me feel comfortable, and so did the surgeon. All my fear and paranoia – it simply disappeared. "Do you have something you want to ask about?" Nah, not really.

I: So you actually felt really safe there?

P: Definitely on the day of surgery, yes, definitely.

Not all patients expected any psychosocial support during their admission:

P: They say if I have any questions I can just call – if I need anything, they will come. But what [things that] has to do with my private (life) is not their concern, I think.

On the other hand, being far from home without family and friends was perceived as difficult to many patients, and the experience of loneliness could even activate previous traumatic experiences:

P: I feel lonely here, by myself, right? ... And I come to think of the time when I was "injured" [uses a Greenlandic term for sexual abuse] 25 years ago. Lots of thoughts come up. And that's why I'm kind of a little emotional.

Social problems were also experienced during the admission, for which patients in some cases sought assistance outside the ward:

P: When I was admitted I could not work and did not receive a salary. I have therefore not been able to pay my bills. It has occupied my mind a lot and I have been afraid of what would happen if we were put out on the street. Such thoughts have made me worried

I: Have you contacted the staff regarding these concerns?

P: No. On my own I found out about Sana-Social [the hospital social workers], so I went over to talk to them.

A contributing factor to not seeking assistance on one's own seemed to be that some patients experienced difficulties in accepting their need for assistance:

Observation: The patient seems embarrassed, especially when the conversation with the nurse approaches the fact that he is receiving home care, because he is not able to take care of his home anymore.

Discussion

Involving citizens in the prevention and treatment of illness, and the promotion of self-care are topics of growing interest in the Greenlandic healthcare services, but the debate has been dominated by professionals and politicians, with only a very little input from the patients themselves [13]. In the present study, patient perspectives on barriers to and opportunities for

patient involvement in hospital care have been investigated, leading to the following discussion of findings organised by analytic themes.

Being a guest in a foreign environment

Firstly, the patients rarely seemed to perceive themselves as active participants in their own healthcare pathway. Rather, most of the hospitalised patients saw themselves as visitors in a somewhat unfamiliar environment, and only a few saw themselves as co-players. There may be several reasons for this: One is that Greenland healthcare experiences many logistic challenges because it is provided across sparsely populated and remote areas [14]. While approximately a third of the citizens lives in the capital and might have some familiarity with the national hospital, the remaining two thirds of the population live in smaller towns and villages where there is much more restricted, heterogeneous medical expertise and resources available. As a consequence, access to healthcare or even to information about healthcare opportunities may vary substantially depending on place of residence [1,15]. Further, a tendency on the part of both patients and health professionals towards the belief that the professional, biomedical kind of knowledge is more valuable than the patients' perspective, may reinforce this mechanism of patients



distancing themselves from the responsibility of making decisions [16].

From an everyday-life perspective being in good health can be described as being in a state of bodily unawareness, while disease and treatment on the other hand may bring about an increased bodily awareness. Further, from a sociological-phenomenological perspective, disease and treatment and especially admission to hospital represents a rupture of the habits and routines of the individual patient's everyday life conduct including his or her coping strategies. All human action has a cultural form that is based on already established habits and routines, where peoples' everyday life is created and recreated in a constant interaction between their living conditions and their handling of these conditions [17]. In this way, one could say that the patients bring their embodied culture with them to the hospital [18].

Communication is not just language

Secondly, language barriers severely affected the communication between patients and health professionals. Healthcare in Greenland has for many years been challenged by the country's isolated position, great internal distances, and a small population, all contributing reasons for the increasing centralisation of healthcare. In addition, and although half of the nurses are now born in Greenland, where they train and qualify as Bachelors in Nursing, there are persistent challenges in terms of sufficient recruitment of doctors and nurses [19]. As a result, many health professionals come from other countries (especially Denmark) on short-term contracts. Even though, as part of Greenland's independence process, Naalakkersuisut, Greenland's Home Rule Government, assumed responsibility for the health service in 1992, the official language in healthcare is still Danish. Consequently, because the provision of care and the exchange of health information is not possible without a shared language, communication is often mediated by a professional interpreter. However, not simply the interpretation but also the way communication takes place between patients and health professionals may play a role. Referring to Curtis [20], Grove [21] stresses that differences in mutual expectations of the situation may also impact the understanding. For example, while a patient who seeks medical assistance may have only a vague assumption of what can be done to alleviate his or her condition, the health professional may assume that the patient expects a specific treatment. In such cases, besides providing a direct and accurate translation of what is said in the consultation, it becomes incumbent on the interpreter to reconcile

not only the patient's but also the health professional's expectations, in order to achieve a shared focus for the conversation. Further, we experienced that some of the Greenlandic patients wished to be interviewed in Danish language, even though the interviewer spoke Greenlandic language fluently. The Greenland language represents a fundamental prerequisite for the development of identity and social relations, and the language is continuously developing. However, Greenlandic terms for many new or "Western" concepts and words are not existing. This also applies to many of the concepts and expressions related to healthcare, which may explain why some patients found it easier to express themselves about their healthcare in Danish during the interview. Further, the finding illustrates that lack of expressions related to healthcare in the Greenlandic language will make those patients who do not speak or understand the Danish language especially vulnerable and dependent of an interpreter [21]. On the other hand, although it is essential to share the same language so that health information can be provided and exchanged,, our findings also showed that some patients actually perceived that the care they received was of good quality, despite not sharing the same language as the health professional. To the attentive health professionals, the patients' embodied culture became visible also in the light of their personal habits, language, food preferences, and appearance. This is why patient-centred care could be provided for some patients without a shared language – simply because the health professionals were aware of the patient's appearance and needs, and by showing empathy and human understanding [22].

Being alone on the hospital

Most patients stayed alone at the hospital without any presence of their relatives. To be separated during times of illness may represent a significant emotional strain for both relatives and patients. In addition, it can be difficult for relatives to follow the patient's treatment trajectory at the hospital from a distance [23]. As a support to patients, relatives are of great significance not only during hospitalisation but also as informal caregivers during rehabilitation or chronic/palliative care at home. Further, or most likely because of this fact, relatives may need support themselves, too. In a study of relatives in cancer care in Greenland, Augustussen and colleagues found considerable dissatisfaction with the lack of inclusion in care and care decisions [23]. It is therefore important that relatives are included as the significant resource they represent in the patient's pathway, and further, that they are

seen, heard, and supported as human beings themselves, along the way.

Patient or partner?

Besides repeatedly expressing a need for better information, some patients also had ideas regarding improvement of their treatment and care. Bringing their own everyday life and culture with them to the hospital, the patients also brought their personal experiences, resources, and knowledge. Some knew their bodies very well and had knowledge and ideas they wished to share but did not share with the health professionals. Some were used to taking care of themselves and their families under harsh conditions and now found it hard to accept that they needed assistance. Some had previous traumas for instance in relation to being abused that became re-activated in the current situation. In all cases, a trusting relationship between patients and health professionals needed to be established or re-established. When asked during the interviews, most actually had unanswered questions they would have liked to ask, or opinions, they would have liked to share. This also applied to those patients who preferred not to be directly involved in medical decisions, or whose medical condition put restraints on their energy levels. Still, it seemed that the very act of being asked provided them with some sense of being involved. The concept of health literacy combines personal competencies and resources to determine a patient's ability to find, understand, and use information to make health decisions [24], and the ability to communicate, maintain, and act on these decisions (health competencies). At the present, and despite free and tax-financed healthcare, there is rising inequity in health in Greenland [19]. However, a reduction in inequity will not be accomplished by simply focusing on the individual patient's level of health competences, as healthcare is provided in unequal power relations. The Greenlandic healthcare system itself will also have to develop new competences, in a professional as well as organisational level, to ensure that Greenland healthcare is provided in partnership with patients and families.

Methodological considerations

A qualitative approach with interviews and field observations constituted a rich empirical material, which proved sufficient to achieve the required information power [6]. Furthermore, thematic analyses (STC) sufficiently guided the analyses. According to the study aim, we wished to gain insight into as many perceptions as

possible. To improve representativeness, we included the participants as diversely as possible. In many cases we succeeded to obtain diversity, while in other cases recruitment to interviews turned out to be more difficult. In these cases, we included the participants who preferred informal conversations including observations, which also broadened our perspectives.

It is a strength that individual patients participated from all over Greenland with variation in age, gender, education and living conditions, who were undergoing various sorts of primarily surgical treatment at the largest hospital in Greenland. It is also a strength that analyses of both interviews and observations showed overlap in attitudes and personal viewpoints, regardless of the participants' age, geographical, and socio-economic background.

However, given that the study was conducted at only one part of the patient course, namely at the national hospital, the findings must be interpreted in the light of this circumstance. Further exploration of a regional perspective on patient involvement in hospital care would therefore be most relevant.

Initially, we wished to include the patients' relatives in interviews and observations to investigate their perspectives. Therefore, it represents a methodological limitation that no relatives participated, as we did not have either the opportunity to study the relative perspective, or observe interactions between patients, relatives and health professionals.

In conclusion

In investigating drivers for and barriers to patient involvement in Greenland hospital-care, we identified factors that both positively and negatively affected patients' opportunities for involvement. These related to patients' expectations, their interaction with and confidence in hospital-care, their language skills, conditions around family support, and taboos around not being able to take care of oneself during illness. This study, which is among the first to highlight a patient perspective may provide decision-makers and health professionals with important insights into what it is really like to be a patient in Greenlandic hospital-care. However, as healthcare is provided in unequal power-relations, patient involvement will not be accomplished by simply focusing on the individual patient's health competences. The healthcare system itself will have to develop competences for involvement, on both a professional and organisational level, to ensure that patients are actually given the opportunity to become involved.

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Disclosure statement

The authors declare that there are no competing interests.

Data availability statement

For data protection reasons, the original data material is not available.

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Appendix1: Information about the study in Greenlandic language

Kalaallit Nunaani napparsimaveqarfimmi nakorsianik peqataatitsineq

Takorluugaq "Akisussaasutut aamma ineriartoriusutut peqqinnissamik isumaginnittoqarfiup, innuttaasoq peqataatinnisaanut ukkatarinnittoq, pitsaaliuinermut passussinnermullu aammalu nammineq isumassuinissamut paasisimasaqalernissamut siuarsaasoq"-mik qulequtalerlugu Kalaallit Nunaani Peqqinnissamut Isumaginnittoqarfiup anguniagaraa.

Napparsimanermi katsorsartinnerullu nalaani napparsimasut qanigisaasullu nappaat pillugu qanorlu

katsorsarneqarsinnaaneramik paasisutissanik tunineqartarnissaat aammalu katsorsaanermit aalajangigassanut peqataatitsinissamut peqqissaasuniit taperserneqartarnissaat kissaataavoq. Uani suliniummi sulisaaseq iluarsartuullugu pilersaarusiarsavarput.

Suliniut ingerlanneqassaaq uku ikioqatigalugit Grønlands Center for Sundhedsforskning, Ilisimatusarfimmi aamma Nuummi Dronning Ingrid Napparsimaviani, piffisami uani 1.-11.2018–31.10.2020.

Suliniuummi akisussaasuvoq lektor, ph.d Lene Seibæk aamma professor, ph.d Lise Hounsgaard

Grønlands Center for Sundhedsforskning, Peqqissaanermik Ilisimatusarfik, Ilisimatusarfimmi