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Patient Participation in Healthcare Practice in Greenland: Local Challenges and Global Reflections

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Abstract

Various kinds of user and patient involvement are spreading in healthcare in most Western countries. The purpose of this study is to critically assess the actual conditions for patients' involvement in healthcare practice in Greenland and to point to possibilities for development. Patients' perspectives on their own conduct of everyday life with illness and their possibilities for participation when hospitalized are examined in relation to the conditions in a hospital setting dominated by biomedical practice. On a theoretical level, it is argued that the concept of 'participation' is preferable to the concept 'involvement' in healthcare. The study shows that there are several interconnected areas for development: the structural frames of hospital practice, including professionals' possibilities for handling patient participation, and the agency of the patients conducting their everyday lives when hospitalized. Consequences of the biomedical hegemony are discussed in relation to WHO's broader approach to disease, illness and health and the still existing postcolonial traces of power and hierarchy. Finally it is argued that patient participation during hospitalization will promote the patients' conduct of everyday life, the cultural knowledge of the professionals, and the democratization of the healthcare sector. Such changes might be connected to a more encompassing democratic societal development – in Greenland as well as globally.

Key concepts: Patient participation, patient involvement, conduct of everyday life, biomedical hegemony, chronic illness, rehabilitation, democratization and Greenland.

Greenland as the Context of the Study

The current healthcare system in Greenland was established during the Danish colonization of the country (1721 – 1953). With the end of colony-status, Greenland was integrated as an administrative region within Denmark and underwent rapid modernization. In the span of a few generations the country went from being a largely nomadic hunter society to becoming partially industrialized on the model of Western societies. The population was concentrated in a number of towns with factories, administrative services and educational institutions, and in several smaller towns and settlements where production is low-tech and partly used for self-subsistence. Institutions based on economic rationality and individualism replaced the communal organization of social life, which had been necessary for survival in the hunter society. However, the practices, norms and values of the hunter society, dominant only a few generations ago, continue to influence the modes of thought and practice in contemporary Greenland, while some features of the postcolonial society are not quite overcome (Petersen, 1993).

The 56,000 inhabitants are spread in 17 towns and 54 settlements distributed along more than 2.000 km of coastline with no roads connecting them. Nuuk is by far the biggest town with 17.000 inhabitants. All transportation is by ship, flight or helicopter, which is exhausting, expensive and often time consuming. Internet and telephone communication are well functioning and accessible for most people.

The healthcare system holds doctors, therapists and nurses in regional hospitals in the five largest towns. In the smaller towns and settlements there are medical personnel with varying degrees of qualifications. Telemedicine is being established, but is not yet functioning everywhere. Lack of professionals and turnover by short-term professionals from Denmark is a current problem everywhere in the healthcare system. Thus, the availability of treatment depends on the competences of the current staff at any given time (Deloitte, 2010).

The situation with many professionals from outside Greenland causes communication problems between patients and professionals, who do not speak Greenlandic and are not familiar with Greenlandic culture and practice. Many Greenlanders, particularly elderly people from towns and settlements, are cautious and reserved in expressing their wishes and needs, having grown up in a time when this was seen as a virtue and a necessity for living in a small and isolated society (Elsass, Christensen, Falhof & Hvolby, 1994a, 1994b; Petersen, 1993; Lyng, 2000). The withdrawnness is often misunderstood by professionals coming from outside of Greenland. In addition to this, the official language of the healthcare system is Danish which many patients do not master.

The Status of ‘Involvement’ in Present Greenlandic Healthcare

Within the last three to four decades patient involvement in healthcare practice has been put on the agenda in most Western European and North American countries¹ along with a

¹ The idea of the initiative has carried different names: ‘involvement’, ‘participation’, and ‘engagement’. The subject has been called: ‘user’, ‘citizen’, ‘client’, ‘patient’. Sometimes relatives are also treated as relevant subjects.

development in disease patterns with larger numbers of populations living with chronic diseases due to better treatment, and longer duration of life. The agenda for involving patients during hospital care has many sources: WHO's human rights, various ethical demands, patients' legal rights, the development of professional practice related to quality, economic calculations, and more. There is a swarm of understandings of what interests 'involvement' of patients should serve in practice which inform different initiatives, from tools for patient involvement in professional decision making (e.g. European Commission, 2012; Stacey et al., 2014) to professional attempts to recognize patients' complex and diverse problems in everyday life with illness (e.g. Armstrong, Herbert, Aveling, Dixon-Woods, & Martin, 2013; Barello, Graffigna, & Vegni, 2012). It seems that the agenda tends to be set by the professionals and thereby be disease-oriented. At the same time, many research- and evaluation reports find that the outcome of patient involvement is unclear, only partially experienced by patients and found difficult to practice by the professionals (e.g. Holen & Ahrenkiel, 2011; European Commission, 2012; Brorholt, Nielsen, & Kjellberg, 2015). There is a need for clarification of what patient involvement should be in practice in order to serve the patients' interests.

In Greenland current health strategies have incorporated the intentions of patient involvement from Danish strategies, but general and systematic initiatives for creating structures for this in healthcare practice seems not to be object for much debate yet. It is the purpose of this study to investigate what is going on concerning patient involvement and participation in actual health practice in order to point to new and unseen possibilities for development, instead of simply copying the strategies from Denmark. Such insight might also contribute to discussions of patient involvement and participation in healthcare practice in Denmark and other countries.

Theory and Methods

Theoretical Point of Departure

'*Conduct of everyday life*' is a theoretical concept for everyday life as it is organized and lived by any person any day. This concept is part of a social psychological frame of reference (Holzkamp, 1998; Dreier, 2008). It captures the basic idea that people live in and move across different *contexts*, for instance: Their home, work, leisure time activities – and hospitals, when they receive in-patient care. The different *structural frameworks* contribute to shaping the courses of action that are available to individuals. The concept, 'conduct of everyday life', emphasizes that human beings strive to construct a coherent everyday life in relation to the real possibilities open to them. Individuals organize the *activities* of everyday life, *relations*, and *uses of time*, within and across the contexts in which they live, and they do this from a *first person perspective* on what is relevant and meaningful. Looked at in this way, illness is an event that intervenes in a person's ongoing life and activities. What remains central is to make this life hang together, now with an illness. The concept 'conduct of everyday life' shifts the focus from professional practices in professional contexts to the life that the professional efforts should support, namely the everyday life that the individual person lives in various contexts. Everyday life is thus not relegated to a secondary place outside of professional practice. The concept of 'conduct of

everyday life' also helps to characterize persons as actively engaging with the conditions of their lives and the possibilities that they see in them – an aspect that is often overlooked when the patient is only looked at from an institutional perspective.

Within this theoretical framework healthcare is a universal welfare resource and a set of practices for the common good in which all actors are participating including patients, relatives and professionals, but also administrators, managers and researchers. All participate in a dynamic interaction, each from their own position as a social actor, and each with their own perspective on the common practices. Thus, the concept of 'participation' brings an insight that captures more, and is more informative than the concept of 'involvement' generally used in healthcare practice. Involvement centers on the individual, while participation at the same time captures both the engaged and contributing individual and the relevant structural conditions.

Based on these theoretical reflections, the main research question of the study presented in this article² is: Which opportunities and problems influence the relations between, on the one hand, cultural-historical, structural and institutional conditions for providing professional support to patients in their everyday lives with illness and, on the other hand, patients' historical and cultural preconditions for managing the everyday life with illness?

Design and Methods

The study was conducted by the first author between 2010 and 2013 as ethnographic fieldwork in an in-patient ward in the national hospital in Nuuk and in healthcare centers in towns and settlements. Methods included participant observations, individual and couple-interviews, focus group interviews and document analysis (policy documents, institutional procedures, medical records, and more). 13 patients were interviewed during hospitalization in the national hospital. Five of these were visited in their homes in Nuuk, towns and settlements up to three times during a period of two-three years. In three cases the patient's life partner participated in the interviews. The institutional context was studied as part of the conditions for the patients' everyday conduct of life with illness. In this connection, 13 nurses and other medical personnel were interviewed. The study was conducted in accordance with the relevant hospital authorities and the participants. All data about persons are anonymized and their names are pseudonyms.

Analysis

The analyses were closely related to the research question mentioned above. The relations between institutional practice and the patients' conduct of everyday life were revealed, how the different practices affected each other, and what possibilities and problems they did hold for providing positive professional support evaluated in the patient's own everyday perspective. The interview material was structured according to their contexts in everyday life, such as home, work, leisure-time activities, and hospitalization. The material from the interviews was supplemented by material from the participant observations, the focus-group interviews, the interviews with the healthcare professionals, and the documents (i.e. institutional procedures and patients' medical records). The analytic focus was on the patients' life conditions, the meaning of the conditions for the

² Aagaard 2015; Aagaard 2017.

patients, and how this affected their possibilities for handling their life in meaningful ways (for this way of analyzing, see Holzkamp, 1998, and Jartoft, 1996).

In the following case, we reconstruct a patient's and her relative's perspectives on their own conduct of everyday life with illness at home and hospitalized, followed by analyses of professional practices in a hospital context.

Juliane and Kurt's Story

Juliane lived with her Danish husband Kurt in a little town in northern Greenland. They had retired from work and now enjoyed a simple active life, close to nature and surrounded by family and friends. Yet, their two young grandchildren had no parents and were dependent on the support of Juliane and Kurt. The couple also had a close relation to their daughter in Denmark, whom they missed.

Juliane and Kurt thus managed to conduct their everyday life with the aforementioned concerns in and across a whole range of contexts all rooted in the small town, and through the whole they tried to create a relevant and meaningful life as seen from their own perspectives. The embodied cultural values formed in this context they carried with them into their meeting with the healthcare system's individual- and body-focused practices.

Juliane suffered from a kidney disease which led to recurrent hospitalization in the national hospital Queen Ingrid's Hospital (QIH) in Nuuk. This had the consequence that Juliane, and also Kurt, had, each in their own way, yet another context to integrate into their conduct of everyday life: The hospital, the people there, activities related to treatment and in-patient life, and new time schedules. They had to manage traveling, family care (at times from distance), being separated, and they were eventually forced to live by themselves, thus lacking their network of family and town.

Positive Experiences of the Healthcare System

Juliane suffered many complications to the kidney disease, such as bleedings, which caused acute hospitalizations. On one occasion, the doctor sent Juliane to a hospital in Denmark to have the actual problem solved in a permanent way – to 'improve her quality of life', as noted in the medical record. On another occasion, the doctors gave Juliane and Kurt a thorough explanation of the effects of the disease on Juliane's body, which made it possible for them to estimate their possibilities and plan their future conduct of everyday life. These examples show that when health professionals relate to the perspectives of patients and relatives on their illness and treatment, the latter are placed in a better position to organize their everyday lives.

Problematic Experiences of the Health Professional Initiatives

The doctors had prepared Juliane and Kurt for the fact that Juliane would, at some point, need permanent dialysis in Denmark³. This information prompted urgent discussions between the couple on their common conduct of everyday life; on whether they should move to Denmark in order to be close to a specialized hospital (and their daughter), or stay in Greenland for the sake of the grandchildren. These questions continually incorporated evaluations of how activities were and would be conducted, of relations, and of timing. Juliane and Kurt did not agree on this issue, and they never reached a joint decision. As a

³ Dialysis treatment is not offered in Greenland.

consequence Juliane, in poor condition, approached the end of her life in QIH in Nuuk, where she could neither be transferred to the hospital in Denmark nor sent to her local hospital. After several weeks in QIH, the doctors announced that she was dying, and she risked dying alone in the hospital far from her home and family. In the end, thanks to her daughter's coming to see her, Juliane became strong enough to be transferred to her local hospital, where she died two months later surrounded by family.

Kurt had tried several times to enter into dialogue with the health professionals about the problem of where to live and the consequences for their daily conduct of life. But more often than not he was turned down. The practice of the healthcare system is disease-oriented. The patients' and their relatives' perspectives and knowledge of their conduct of everyday life are not viewed as being as relevant as knowledge of disease and medical treatment. Within this practice it is considered a rational use of resources to down-prioritize the relatives. This led to the situation in which doctors and nurses overlooked the fact that there was an important discussion going on between Juliane and Kurt about when to move to Denmark. This discussion was set in motion by doctors' information about Juliane's coming need for dialysis in Denmark. But since the doctors did not connect their disease-oriented knowledge with its significance for Juliane's and Kurt's conduct of everyday life, they also failed to discover that Juliane and Kurt had different opinions about how to use that knowledge. It might have been used to develop possible future scenarios: For example, about when Juliane should expect to need dialysis in Denmark, and the consequences of staying in Greenland without dialysis.

Health professionals have a general medical knowledge and practical experience of the typical course of a disease. Furthermore, they often have more knowledge than the patients about the provisions and possibilities within the healthcare system. When this knowledge is not related to the patients' knowledge and considerations about possibilities in their everyday life, this disconnection might have dramatic consequences for the patients. Juliane and Kurt's story is about insufficient possibilities for participation in communication with health professionals about disease-related questions and the consequences that choices of treatment would have for their conduct of everyday life. Their story is also about a lack of possibilities for including their prospective engagement as an element in their communication with health professionals.

The empirical material on which this article is based includes more cases and further examples of difficulties related to involvement/participation.

Other Patients' Perspectives on their Possibilities for Participation

Some patients experienced the diagnostic process as lacking sufficient receptiveness to their own experiences of symptoms. Some cancer patients, for example, experienced that their own observations about symptoms in the form of deviations from their everyday life were overlooked by health professionals, who instead interpreted symptoms solely on the basis of their own prior medical understanding of the disease.

Other patients felt that they had been made into passive recipients of a course of treatment. They did not feel that they were given space in the communication, but on the contrary withheld questions and alternative views due to the time pressure that they experienced in the hospital ward. Some experienced the courses of treatment as irrelevant, and later found their own (perhaps insufficient) ways to handle the problem in their conduct of everyday life.

Many patients experienced a lack of professional attention to their needs and possibilities in future life after a hospital stay. It seemed to them that the professionals tended to focus on the immediate situation and its constraints. In this way, patients' recovery, and the development of a new conduct of everyday life with illness, was held back, and patients' motivation for this development was not supported.

Finally, some patients felt that they were placed in situations that increased the communication difficulties already referred to. This can be seen as a result of cultural differences in forms of conduct of everyday life. In healthcare practice the professionals deal with a range of patients who conduct their everyday lives under a wide variety of conditions, and who have different ways of handling everyday life and illness due to these conditions and their perceptions of them. The professionals are thus confronted with the patients' various culturally shaped views of the need for professional support, but often seem to be blind to the cultural differences. Patients' values and practices – for instance embedded in a factory worker's way of life, or that of a fisherman and hunter – may be at odds with the values and practices of the health professionals who are often more highly educated and often come from Denmark or other Scandinavian countries. In such a situation it can be difficult for patients to make their own viewpoint count in their interactions with professionals. They feel that the possibility for equal participation depends on the sharing of a way of life, which is very often not the case (Ramhøj, 1991). At the same time linguistic difficulties in communication between Greenlandic-speaking patients and Danish-speaking professionals may play a role in accentuating unequal levels of participation. These circumstances can thus produce a kind of twofold inequality with both cultural and linguistic aspects.

When a Person Becomes a Patient: Structural Conditions

The Law and Personnel

Recent strategies in the healthcare sector are directed at raising efficiency and simultaneously improving the quality of healthcare provision within the existing economic limitations (DSI, 2014, p. 29). For instance, Danish-inspired initiatives are being implemented, but have not yet been evaluated. The Cancer Plan for Greenland 2013 emphasizes the involvement of patients in their courses of treatment as important for the quality of the healthcare services they receive (DSI, 2013). However, systematic initiatives or guidelines are yet to be developed.

The great amount of professionals who come from outside of Greenland have the necessary medical competences, but many lack cultural insight and linguistic abilities. Interpreters are used, but they are often meagerly qualified, have varying degrees of medical knowledge (Curtis, 2001), and often lack the means to build bridges between the organizational culture and the patients' culture. These cultural and linguistic challenges have consequences for the treatment and care of patients.

Practical Procedures

When people like Juliane are admitted to QIH, there are already a series of procedures waiting for them. The first is an admittance talk with a nurse or another healthcare worker in Danish, Greenlandic, or via an interpreter. The interview follows an admittance schema focusing narrowly on the current health problem.

During Juliane's first hospitalization, with cervical cancer, the most important step, after talking to a doctor and being examined, was the laboratory testing. Appointments were made, results analyzed, new discussions with doctors took place and a decision was made leading to a course of treatment. The procedures and routines were concerned with instrumentally managing the disease and the treatment; Juliane's and her husband's concerns with how the treatment would affect their everyday conduct of life counted for little in this context.

The procedures are mostly taken over from hospitals in Denmark. They are adjusted to the technical and practical situation in Greenland, including the linguistic differences, patterns of residence, transport, and the services that take over healthcare provision after discharge. Possible cultural differences between the two countries do not appear to be regarded as important. Inter-professional discussions and teamwork usually take place without the participation of patients and relatives.

The process that patients are guided through during hospitalization, and the fact that procedures and actions are so clearly limited to a disease-oriented practice, fits with Järvinen and Mik-Meyers' analysis of the 'production of a client' (2003). The pattern that they reveal in their analysis of the processes, in which clients of social welfare institutions meet 'the system', fits in principle with the processes that take place where people meet 'the system' at QIH. Here, people like Juliane meet standardized routines designed to reveal and treat a precise range of specified diseases. This aspect of healthcare practice overshadows the particular person's individual situation and perspective on that situation.

"Human problems are translated into 'the language of the system', and the individual's situation is explained using the institution's fixed diagnoses and knowledge frameworks; clients are made to fit categories that mirror the provisions and courses of action that the institution has available" (Järvinen & Mik-Meyer, 2003, p. 10).

Thus, practice in such welfare institutions depends on the institutions' previous choices of specific health problems to be treated.

The organization of work at QIH reflects initiatives that are politically legitimated. The relevant knowledge-frameworks and values (including assumptions about what counts as knowledge) on which healthcare work is based will always dominate in practice. At QIH all health professionals regard their primary task as one oriented towards disease.

Professionals' Possibilities for Handling Patient Participation

The professionals' working lives are occupied every day with the strictly structured procedures of a disease-oriented practice. On top of this, health professionals have many tasks related to the education and training of students and new staff. Programs concerned with how patients should handle life with an illness after their discharge have not yet been firmly established. The question of rehabilitation is currently not addressed by a general initiative but is only a part of specific courses of treatment by occupational therapists and physiotherapists – a theme we will return to later.

Since there are currently no structures or guidelines for patient participation, it remains up to the professionals whether or not the patients' perspectives are included in practice, and if so, how, when and to what extent. Within the current organizational culture, staff hierarchy, and disease-oriented approach, patient participation remains limited. The

disease-oriented focus binds staff to a mode of biomedical thinking and its underlying knowledge base. Exact and objective information from an external perspective on the patient is prioritized. Patients' and relatives' participation is regarded as subjective, providing internal perspectives that are not relevant for the disease-oriented procedures.

The difficulties of communication and the quality of the interpretation have consequences for how professionals engage with patients' problems, and how patients themselves engage.

Healthcare assistants, most of whom speak Greenlandic and account for much of the care staff at QIH⁴, are often those that have most contact with the patients and learn about their lives and perspectives. They are often familiar with the way of life and related cultural values characteristic of small towns and settlements through personal experience or family and friends. Doctors and nurses do not, however, request that knowledge. In the hierarchy of staff and medical knowledge, the knowledge of the less formally qualified healthcare assistants may be overlooked or not highly valued. Furthermore, healthcare assistants are not always able to argue for their viewpoints in Danish, which is the language of the majority of the higher-educated staff. Following the dominant values of healthcare practice in the hospital context, healthcare assistants themselves also often regard their knowledge of patients' everyday lives as irrelevant.

In conclusion, the actions and perspectives that characterize health professionals' daily healthcare practices reflect the dominant institutional biomedical approach to treatment and the form of knowledge on which this is based. The specific biomedical understanding of knowledge is maintained by the hegemony of medical practices and the staff hierarchy.

Discussion

The Western Model for Greenlandic Hospital Provisions – a Problem and a Possibility

Patient Participation and First Person Perspectives

Recent health strategies include a focus on patient involvement. In the Cancer Plan for Greenland 2013 this is expressed as follows: “*By being included, patients gain greater knowledge and understanding of their own disease and its treatment. This can contribute to raising patients' sense of security and active participation in the course of the disease and the decision-making process*”. (DSI, 2013, p. 33).

‘Involvement’ is closely linked to current medical practice and implies the communication of information to patients and relatives. Moreover, where different treatments are available the patients are asked about their preferences. The rationale is that by understanding the diagnosis and treatment more thoroughly, these actors will become better at following advice and instructions, making the treatment and rehabilitation more effective. In this

⁴ According to staff records from 2013 from the department of statistics at QIH about 1/3 of the care staff in the medical section of QIH were healthcare assistants, while the rest were nurses. According to an internal statistic from the Projects Department (from 2014) about 1/3 of nurses could speak Greenlandic, while the rest were Danish speakers. The staff numbers are relatively small, which means that small staffing turnover can produce large changes in these ratios.

disease-oriented approach ‘patient involvement’ still refers to communication that goes top-down from the professional to the patient. This approach is similar to many – but not all – dominant approaches in healthcare practice in other parts of the world (e. g. Stacey et al., 2014; Barelo et al., 2012).

As the empirical findings in this article shows, however, there is a need for purposeful collaboration for change and a potential for development. The professionals can expand their attention and practices by including patients’ first person perspectives and knowledge of their lives with illness and treatment. This form of involvement could provide for an equal participation and contribution in dialogues on diagnosis, treatment and the future. It might result in a purposeful collaborative transformation, changing work procedure and at the same time changing the participants’ knowledge, in and through this process (see Stetsenko, 2008).

Rehabilitation and the Question of Knowledge

This study shows that inhabitants in Greenland who become patients seem to be satisfied with receiving specialized bio-medical treatment that contributes to survival or a longer and perhaps better life. But patients’ reflections on hospital practice and their conduct of everyday life with illness show a need for better possibilities to participate during hospitalization in dealing with needs that extend beyond the narrow treatment of a disease. Within the terminology of the World Health Organization (WHO), such needs are related to disabilities. Disability is defined as an umbrella term for impairment, activity limitation and participation restrictions (WHOa). Disabilities require forms of rehabilitation, the lack of which causes problems as this study has shown. According to the WHO ‘*rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels and to maintain independence and self-determination*’ (WHOb). This approach pays attention to both the biological, psychological and social needs of the patient (WHOc). As revealed by this study, some patients do not get relevant support in relation to their rehabilitation process. The lack of support affects their conduct of everyday life in and across different contexts. Issues around rehabilitation remind us that it is necessary to incorporate first person perspectives and the knowledge of patients and relatives in processes of diagnosis and treatment, and in decisions about the future. As discussed in this study, the lack of patient participation and rehabilitation, points to the need for developing specific provisions for rehabilitation.

The study also raises questions about which forms of knowledge are regarded as necessary to promote the best treatment and rehabilitation. Patients’ and relatives’ knowledge of everyday life with illness and treatment include more and other forms of knowledge than just bio-medical. Both knowledge of one’s own body and practical action in different contexts, and knowledge about cultural and historical contexts are of relevance. In the health professionals’ clinical practice these forms of knowledge are drawn on in varying degrees and often arbitrarily. But such knowledge is consequently not included in evidence-based thought and practice, which today is regarded as decisive for quality (Schwandt, 2004). Similarly to what our findings indicate, Thomas Schwandt argues that forms of knowledge such as those named above are necessary for the development of clinical and rehabilitation practices (Schwandt, 2004). Patients’ specific knowledge can contribute to improving hospital provisions, which may become more relevant and effective in those areas where their effects should be appreciable: In patients’ and

relatives' conduct of everyday life in the different contexts they belong to (Schwandt, 2004; Borg, 2002, 2011). Such a shift in knowledge perspectives requires that patients' knowledge be recognized as necessary for successful courses of treatment and rehabilitation.

Issues of Culture and Language

An important precondition of a broader and more equal approach to patient participation is establishing possibilities for educating more Greenlandic-speaking health professionals with experience of life in Greenland. The possibility for patients to express themselves in their own language, and to be understood, is important for the knowledge that health professionals can gain in a talk with the patient. When Greenlandic-speaking patients express themselves in Danish, their communication can be influenced by the values embedded in the Western-influenced healthcare system because the dominant language in that system incorporates the system's view of disease and health, patient involvement, etc. As it is also shown in much anthropological and linguistic research, words and concepts of a language express deeper aspects of culture (Roepstorff, 2003). The way that patients express themselves in their own language reflects aspects of their worldview and life values. The chance to articulate wishes and needs in one's own language influences the content of this communication, giving it more substance, weight and meaningfulness (Alexander & Szanton, 2003). For example, when Greenlandic patients during hospitalization express wishes for a walk in nature or socializing with fellow patients around singing and story-telling, it is meant as a way to relieve suffering and promote wellbeing through fellowship and meaningful activities, in spite of illness. For European professionals, such activities reflect private preferences and have no significance for health and treatment. In a Western-influenced healthcare system 'health promotion', in this connection, is related to physical health rather than to wellbeing.

The education of Greenlandic health professionals means however that the issue of culturally specific conduct of everyday life returns in a new way. During their Danish- or English-language education, Greenlandic-speaking health professionals often appropriate a way of life that differs from many of their compatriots'. They may also be born into such a way of life. This can mean that they, like professionals from outside of Greenland, are (or become) blind to the various living conditions of many patients, and to patients' ways of meaningfully handling these conditions. Alternatively, the professionals may actively distance themselves from these modes of conduct and thought because they have appropriated different life practices and values.⁵ Therefore, the issue of linguistic capacities in the involvement of patients in health practice is closely connected to the professionals' awareness of their own culturally specific conduct of everyday life and its values. Issues around the quality of interpretation also belong to this discussion. Word for word translation is insufficient in those situations where a culturally grounded meaning is necessary.

⁵ Due to the small size of the population most inhabitants of Greenland will have some insight into, or experience of, different ways of life according to occupation, place of living, leisure-time activities, and more. But due to the difficult conditions in which a hunting- or fishing way of life in the settlements now has to be lived, this way of life is also given a low cultural status from the perspective of formally educated, economically wealthy people living in the towns (see also Poppel, 2007; Hendriksen, 2013).

Global Reflections

One of the most serious challenges in the area of health politics – in Greenland and globally – is the spread of Western, specialized, biomedical treatment practices dominating the handling of illness and health (Schwandt, 2004). There are, however, other important forces at play. Since the middle of last century the WHO has laid out well documented strategies for development, including prevention and health promotion⁶, that build on a broad concept of health, which has been influential worldwide. Furthermore, WHO's rehabilitation strategies are not only supported by biomedical perspectives, they include other ways of understanding 'disability'⁷. Disability is exactly what characterizes the kind of problems related to everyday living with diseases that many persons in this study are fighting to overcome and that appear to remain unsolved. WHO uses a bio-psycho-social model for understanding functioning, disability, and health; the model attaches importance to human activity and is also concerned with patient and citizen participation in different contexts (WHOa). Using WHO's bio-psycho-social model challenges the bio-medical understanding of illness and disease globally (WHOa), but are seldom raised within institutions such as hospitals.

There are some other developmental issues concerning citizen participation in the Greenlandic hospital context that are comparable to developmental issues in health institutions worldwide. Countries like Greenland find themselves in a postcolonial phase of development. The relation between Greenland and Denmark, which began when Denmark appropriated Greenland as a colony in 1721, is currently under discussion. Today Greenland is no longer a colony, but part of a cooperating commonwealth. However, the relation between the population in Greenland and Danes who 'represent' the earlier colonial power is still sometimes marked by a lack of mutual understanding. In the large former colonies in Asia, Africa, and the Americas, there are millions of people who live with similar tensions.

Globally, many examples exist of how basic structures, norms and values, necessary for running institutions, are imported from the former, colonizing powers. A biomedical approach to health and disease, developed in the West, and now influencing Greenland, is an example. Import of ideas and practices continues, driven forward, among others, by actors who identify themselves as Greenlandic. Developments toward autonomy are taking place, but the old problems continue to arise occasionally.

Given that many patients in Greenland experience an insufficiency of dialogue with Danish professionals, it is possible that (over and above the problem of cultural conduct of life) this reflects the fact that the hospital as an institution is dominated by a distinctly Western culture, the development of which the population of Greenland has had very little influence upon.

⁶ E. g. 'Global Strategy for Health for All at the Year 2000', WHO 1981, 'Ottawa Charter for Health Promotion', WHO 1986, and 'Health21. The health for all policy frameworks for the Who European Region', WHO 1998.

⁷ 'Functioning' is the central concept in WHO's International Classification of Functioning, Disability and Health (WHOa). This concept is defined as an interactive and relational concept in a systematic bio-psycho-social model.

The essential issue of involving citizens' values and resources in developing initiatives that will benefit citizens more broadly, is recognizable from a number of different policy areas worldwide, for example in peace and conflict research, as works by Richmond (2009) suggest. Here, evaluations of peace processes after conflicts show that citizens' own everyday cultural and historical understandings of peace are seldom taken into consideration. Instead, Western peace negotiators' focus on the institutional and inter-state levels of action carries weight. The results of this have been evaluated as lacking and short-sighted (Richmond, 2009).

The study of the situation in Greenland has raised the general question of whether the healthcare service, as practiced today, is culturally the most suitable framework to meet the needs of all the citizens. The study indicates that inadequate communication, which can be marred by differences of cultural ways of life, may be connected to the failure to problematize the values embedded in the 'colonial', Western model of healthcare. As described above this model involves a disease-oriented approach and a knowledge hierarchy that - contrary to the espoused intentions - stands in the way of professionals (both Danish and Greenlandic) inquiring into patients' cultural knowledge concerning solutions to their health problems – an obstacle that leads in the end to a situation where patients continue to be treated with cultural insensitivity. This study suggests that problems of hierarchy and power that result from the postcolonial situation today remain alongside cultural differences in conduct of everyday life. The complex picture this is leading to does not however quite capture the dichotomizing logic implied in Richmond's descriptions. There are various features of the communication difficulties noted in the Greenlandic study, but in most contexts they are – in line with Richmond's analyses – influenced by both power and hierarchies.

An analysis carried out using the concept of conduct of everyday life opens the way to solutions that build on the involvement of patients/users as participants contributing to the practices of the relevant institutions, regardless of their nationality. An important question in healthcare and other institutions is how to organize a democratic form of development where citizens' values in everyday life are taken as a starting point in their own right (Richmond, 2009). It is widely recognized that genuine democratic influence on national development involves respect for citizens' values and for their own perspectives on the future. There is growing recognition that democratic institutions provide the best means to realize this. This implies institutions that promote users to influence their development. Views of how to achieve this are many and sometimes ambiguous. It is not sufficient to establish institutions to provide services. If the provisions are to meet citizens' different needs, the institutions must create opportunities for the citizens to contribute through participation with their various insights, values and resources, all of which must be attached importance in their own right (Richmond, 2009). Many different political and strategic initiatives are necessary to meet this goal. Within the frameworks of healthcare institutions this kind of development has some prerequisites: Primarily that there exist positive expectations concerning patient participation from the side of the hospital organization and the professionals, and that communication between professionals and patients that gives the patient the opportunity to understand and take part in what is going on in the health practice he or she meets. This kind of involvement of patients in healthcare practice is what political strategies aim at. But as discussed earlier, one-way information communicated to patients about professional initiatives is not enough. Another requirement is that professionals actively search for patients' own ways of

handling their everyday life with illness or disabilities as an indicator of what kind of professional support is meaningful in individual cases. This again requires willingness from the side of politicians, administrators, and professionals to continuously modify the established practices and take responsibility for making changes based on what citizens regard as improvements (Richmond, 2009). The establishment of possibilities for citizen participation in such processes and developmental contexts – on different strategic levels – is a precondition for democratization.

All of the development suggestions sketched in this article aim to improve patients' possibilities for democratic participation in the Greenlandic hospital system. The suggestions are also likely to have relevance to discussions and solutions in other parts of the world. A key point is that professionals' learning about patients' different cultures and life situations, and patients' learning about the healthcare system's provisions and potential for development, are equally important and continuously determine each other.

Patient participation in a hospital context as described here contains constructive possibilities for citizens to take control of their own everyday lives and of the democratization of the institution. At the same time, democratization of the healthcare system is a contribution to the democratization of society. Patient participation is thus not just an 'ethical demand'. Giving citizens concrete possibilities for participation in the development of society's institutions, including healthcare institutions, is also a collaborative contribution to a country's democratic development.

References

- Aagaard, T. (2015). Hverdagsliv med sygdom—patienters kulturelle perspektiver på sundhedspraksis i Grønland (Everyday life with illness—Patients’ cultural perspectives on healthcare practice in Greenland). *Inussuk—Arktisk forskningsjournal*, 1, 1–221. <http://naalakkersuisut.gl/~media/Nanoq/Files/Attached%20Files/Forskning/Inussuk/DK%20og%20ENG/Inussuk%201%202015.pdf>
- Aagaard, T. (2017). “Patient involvement in healthcare professional practice in hospital – A question about knowledge”. *International Journal of Circumpolar Health*, 76: 1, 1403258, <http://www.tandfonline.com/doi/full/10.1080/22423982.2017.1403258>
- Alexander, N., & Szanton, D. (2003). *Towards the Intellectualization of African Languages*. A Workshop Proposal to the Ford Foundation, From the Project for the Study of Alternative Education in South Africa. Unpublished.
- Armstrong, N., Herbert, G., Aveling, E.-L., Dixon-Woods, M., & Martin, G. (2013). Optimizing Patient Involvement in Quality Improvement. *Health Expectations*, 16 (3), 36–47. DOI: <http://onlinelibrary.wiley.com/doi/10.1111/hex.12039/full>
- Barello, S., Graffigna, G., & Vegni, E. (2012). Patient Engagement as an Emerging Challenge for Healthcare Services: Mapping the Literature. *Nursing Research and Practice*, 2012(2012), 1-7. DOI: <https://www.hindawi.com/journals/nrp/2012/905934/abs/>
- Borg, T. (2002). *Livsførelse i hverdagen under rehabilitering – Et socialpsykologisk studie*. Ph.d.-afhandling. Aalborg: Institut for Sociale Forhold og Organisation. Aalborg Universitet. (Conduct of Everyday Life During Rehabilitation – A Social-Psychological Study. Ph.D.-dissertation. Aalborg: Institute for Social Studies and Organization. University of Aalborg).
- Borg, T. (2012). Viden i praksis. I: Thorgaard, K., Nissen M., & Jensen; U. J. (red.), *Viden, virkning og virke*. Roskilde: Roskilde Universitetsforlag. (Knowledge in Practice. In: Thorgaard, K., Nissen, M., & Jensen, U. J. (Eds.), Knowledge, Impact and Activity. Roskilde: Roskilde University Press).
- Brorholt, G., Nielsen, K. V. L., & Kjellberg, P. K. (2015). *Borgernes sundhedsvæsen – Frontpersonalets perspektiv*. København: Det Nationale Institut for Kommuner og Regioners Analyse og Forskning. (The Citizens’ Healthcare System – The Perspective of the Front Personnel. Copenhagen: The National Analysis and Research Institute of Municipalities and Regions).
- Curtis, T. (2001). *Kommunikation mellem læge og patient i Grønland - En kvalitativ undersøgelse af interaktionen mellem parterne i den tolkede konsultationsamtale*. København: Statens Institut For Folkesundhed. Afdeling for Grønlandsforskning. (Communication Between Doctors and Patients in Greenland – a Qualitative Study of Interaction Between Parties in Interpretive Consultation Discussions. Copenhagen: TheDanish Institute of Public Health. Department of Greenlandic Research).

- Deloitte. (2010). *Grønlands sundhedsvæsen – udfordringer for fremtiden. Økonomi- og strukturanalyse af det grønlandske sundhedsvæsen*. Nuuk: Grønlands selvstyre, Departementet for Sundhed. (Greenland's Healthcare System – Challenges for the Future. Economic and Structural Analysis of the Greenlandic Healthcare System. Nuuk: Government of Greenland, Ministry of Healthcare).
- DSI - Departementet for Sundhed og Infrastruktur. (2013) *Kræftplan for Grønland*. Nuuk: Naalakkersuisut/Grønlands selvstyre. (Ministry of Health and Infrastructure. (2013). *Cancer Plan for Greenland*. Nuuk: Naalakkersuisut/Government of Greenland).
- Dreier, O. (2008). *Psychotherapy in Everyday Life*. New York: Cambridge University Press.
- DSI - Departementet for Sundhed og Infrastruktur. (2014). *National Sundhedsstrategi 2014-2017*. Nuuk: Naalakkersuisut/Grønlands selvstyre. (Ministry of Health and Infrastructure. (2014). *National Health Strategy 2014-17*. Nuuk: Naalakkersuisut/Government of Greenland).
- Elsass, P., Christensen, H. P., Falhof, J., & Hvolby, A. (1994a). Grønlændere på hospital - En interviewundersøgelse af patienter og behandlere vedrørende informationsudveksling, tilfredshed og behandlingspræferencer. *Ugeskrift for Læger*, 156(12), 1794-1797. (Greenlanders in Hospital – An Interview Study of Patients and Providers Concerning Exchange of Information, Satisfaction and Treatment Preferences. *Weekly Journal for Medical Practitioners*, 156(12), 1794-1797).
- Elsass, P., Christensen, H. P., Falhof, J., & Hvolby, A. (1994b). Grønlænderes sygdoms- og sundhedsopfattelse - En sammenlignende interviewundersøgelse af patienters og behandleres opfattelse af sygdom og sundhed. *Ugeskrift for Læger* 156(12), 1800-1804. (Greenlanders' Conceptions of Illness and Health – A Comparative Interview Study of Patients' and Providers' Conceptions of Illness and Health. *Weekly Journal for Medical Practitioners*, 156(12), 1800-1804).
- European Commission, Directorate-General for Health and Consumers. (2012). *Eurobarometer Qualitative Study – Patient Involvement. Aggregate Report*. DOI: http://ec.europa.eu/health/sites/health/files/systems_performance_assessment/docs/eurobarometer_patient_involvement_2012_en.pdf
- Hendriksen, K. (2013). Grønlands bygder – økonomi og udviklingsdynamik. *Inussuk – Arktisk forskningsjournal*, 2013(3), 1-392. (Greenland's Settlements – Economics and Dynamics of Development. *Inussuk – Arctic Journal of Research*, 2013(3), 1-392). DOI: <http://naalakkersuisut.gl/~media/Nanoq/Files/Attached%20Files/Forskning/Inussuk/DK%20og%20ENG/Inussuk%203%202013.pdf>
- Holen, M., & Ahrenkiel, A. (2011). 'After all, you should rather want to be at home'. Responsibility as a means to patient involvement in the Danish health system. *Journal of Social Work Practice*, 2011(3), 297-310. DOI: <http://www.tandfonline.com/doi/abs/10.1080/02650533.2011.597177>
- Holzcamp, K. (1998). Daglig Livsførelse som subjektvidenskabeligt grundkoncept. *Nordiske Udkast* 26(2), 3–31 (Conduct of Everyday Life as Founding Concept of a Science of the Subject. *Nordic Outlines* 26(2), 3-31).

- Jarftoft, V. (1996): Kritisk psykologi: en psykologi med fokus på subjektivitet og handling (Critical Psychology: a psychology with focus on subjectivity and agency). I: Højholt, C. & Witt, G. (red.): *Skolelivets socialpsykologi: Nyere socialpsykologiske teorier og perspektiver*. København: Unge Pædagoger.
- Järvinen, M., & Mik-Meyer, N. (2003). At skabe en klient. I: Järvinen, M., & Mik-Meyer, N.: *At skabe en klient: Institutionelle identiteter i socialt arbejde*. København: Hans Reitzel. (To Create a Client: Institutional Identities in Social Work. Copenhagen: Hans Reitzel).
- Lynge, I. (2000). *Psykkiske lidelser i det grønlandske samfund*. Århus: Afdeling for Psykiatrisk Demografi, Institut for Psykiatrisk Grundforskning, Psykiatrisk Hospital i Århus, Universitetshospital i Århus (Psychiatric Illnesses in the Greenlandic Society. Aarhus: Department for Psychiatric Demography, Institute for Psychiatric Basic Research, Psychiatric Hospital in Aarhus, University Hospital of Aarhus).
- Petersen, R. (1993). Samfund uden overhoveder - og dem med. Hvordan det traditionelle grønlandske samfund fungerede og hvordan det bl.a. påvirker nutiden. *Grønlandsk kultur- og samfundsforskning* 93(1), 121-138. Nuuk: Ilisimatusarfik/Atuakkiorfik. (Societies Without Chiefs and Those With. How the Traditional Greenlandic Society Functioned and how It i.a. Influences Today's Society. Greenlandic Culture- and Society Research 93(1), 121-138. Nuuk: University of Greenland/Atuakkiorfik).
- Poppel, B. (2007). Nogle forskelle mellem levevilkår i byer og bygder: og input til en diskussion om bygdernes fremtid. *Samfundøkonomen* (1), 19-24. Grønland og nordatlantiske regionaløkonomier. (Some Differences Between Living Conditions in Towns and Settlements: and Input to a Discussion About the Future of the Settlements. The Economist (1), 19-24. Greenland and North Atlantic Regional Economies).
- Ramhøj, P. (1991). *Livsform og alderdom*. København: Akademisk Forlag. (Life Mode and Old Age. Copenhagen: Academic Publishing).
- Richmond, O. (2009). A Post-Liberal Peace: Eirenism and the Everyday. *Review of International Studies*, 35(557), 580.
- Roepstorff, A. (2003). Clashing Cosmologies: Contrasting Knowledge in the Greenlandic Fishery. In: Bubandt, N., Kull, K., & Roepstorff, A. (Eds.): *Imagining Nature*. Aarhus: Aarhus University Press.
- Schwandt, T. A. (2004). *Evaluating Holistic Rehabilitation Praxis*. Oslo: Kommuneforlaget Oslo (Municipality Publishers Oslo).
- Stacey, D., Légaré, F., Col, N. F., Bennett, C. L., Barry, M. J., Eden, K. B., Holmes-Rovner, M., Llewellyn, T. H., Lyddiatt, A., Thomson, R., Trevena, L., & Wu, J. H. C. (2014). Decision Aids for People Facing Health Treatment or Screening Decisions (review). *The Cochrane Collaboration*. DOI: http://www.cochrane.org/CD001431/COMMUN_decision-aids-to-help-people-who-are-facing-health-treatment-or-screening-decisions
- Stetsenko, A. (2008). From relational ontology to transformative activist stance on development and learning: expanding Vygotsky's Cultural Historical Activity Theory (CHAT) project. *Cult Stud of Sci Educ* 3:471-491

WHO (a) International Classification of Functioning, Disability and Health (ICF). DOI: www.who.int/classifications/icf/en.

WHO (b) Rehabilitation. DOI: <http://www.who.int/topics/rehabilitation/en/>

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