

Research Paper

Micro Level Impact of the Right to Health – A Qualitative Study of Patient Perceptions

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ABSTRACT

Background: Health is unequally distributed across the Swedish population, even though it has ratified Human rights declarations pointing out The Right to the Highest Attainable Standard of Health for all. The meaning of these declarations is condensed in The Right to Health-concept and specified in the so called AAAQ-framework, which highlights equal Accessibility, Acceptability, Availability and scientific Quality of care as indicators for analyzing a state's fulfillment of such declarations.

Methods and findings: The aim of this qualitative interview study was to examine whether patient perspectives on health care encounters would shed new light on the focal points specified in the AAAQ-framework, i.e., complement macro analyses on a state's fulfilment of human rights declarations. Interviews were carried out with 55 patients in a socioeconomically challenged suburb, and analyzed in accordance with established standards for thematic content analysis. Two main themes with six subthemes were identified in this descriptive phase. The patient narratives centered on health care prerequisites for good care, but patients' own responsibility was also brought up. Most noticeable was the importance given to staff's ability to respectfully acknowledge the meaning of individual patient characteristics, and the negative effects on patients' wellbeing of its opposite (authoritarian and impersonal staff attitudes). The results

from the descriptive phase were then deductively interpreted in relation to the AAAQ-framework. The interpretative analyses revealed that human rights inspired policies are not enough for the realization of The Right to Health as patients' experiences of different hospitals varied significantly, despite identical policies. In addition, it underlined the importance of all four AAAQ-indicators, i.e. that scientifically appropriate care (Availability and Quality) is vital, yet that the meaning of The Right to Health-concept is not realized unless a health care experience includes emphatic encounters adapted to the individual patient's capacities and disease experience (Accessibility and Acceptability).

Conclusion: The analysis of patient perspectives on health care experiences highlighted the significance of respectful and personalized treatment. In addition to providing functioning health care facilities, a vital part of health care quality work is securing empowering care encounters. Even though human rights inspired state regulations and health care policies are imperative, specific strategies to secure their implementation on the health care micro level is needed, e.g. staff training in communication skills as well as follow up mechanisms measuring patient satisfaction and levels of participation.

Keywords: Patient RIGHTS; Patient participation; Health care quality; Access and evaluation; Guideline adherence

Key Points

- The Right to Health is not simply a one-directional delivery from government regulations, to health care policy and the patient, but depends – for its impact on the patient level – on the health care services ability to embrace patients' individual characteristics.
- What The Right to Health means varies between different populations as its connotations are determined by marginalization indicators such as socioeconomic status, language capabilities and so forth.
- Specific human rights focused training is recommended for all health care staff as the realization of The Right to Health depends on their ability to appreciate the concept's meaning, e.g. acknowledge patients' right to participate in decisions pertaining to health.

Introduction

Although Sweden is a welfare country with generally high health status, health is unequally distributed across the population. Some suburbs have higher unemployment, lower educational levels and socioeconomic statuses compared to other parts of the city as well as significantly lower health

status¹. When this gap in health became particularly obvious in a socioeconomically challenged suburb of Gothenburg, Sweden, a political decision was made to build a local daycare hospital with the purpose of improving access to health care². The idea of making special efforts to secure universal health coverage for marginalized communities stems from The Right to Health-concept explained in the International Covenant on

Economic, Social and Cultural Rights, i.e., from international human rights doctrines directed towards questions of equality and non-discrimination in health care³.

The Right to Health-concept is used for analyzing how well a country meets the health needs of its different inhabitants⁴. The AAAQ-framework (Accessibility, Acceptability, Availability and Quality of care) captures its different elements and has been described as a tool for identifying problem areas, and for seeking inspiration for planning and organizing health care services so that they are characterized by the spirit of The Right to Health⁵. The Quality-element refers to a government's responsibility to offer health facilities and services that are scientifically and medically appropriate, while Availability concerns the human and material resources of such facilities (i.e., that well-equipped health clinics with trained staff are available to the whole population). Accessibility refers to different groups' ability to effectively use existing facilities, e.g. physical accessibility, economic affordability, information as well as non-discrimination. The last element, Acceptability, strengthens the essence of the other as it further emphasizes people's right to culturally and ethically appropriate health care encounters and treatment. In sum, the AAAQ-framework demonstrates what, in this case, Swedish authorities have assured its inhabitants when ratifying human rights doctrines referencing The Right to Health, i.e. that people are entitled to health care that is scientifically sound, properly equipped and that they will be met with respect and consideration of both their health needs and general worldviews⁶.

The Right to Health-concept and the AAAQ-framework are usually used for analyses of macro state activities, e.g. on law making, public health policy and strategies, countrywide collection and analysis of health data, government expenditures, and so forth⁵. Yet, micro-level events such as patient participation facilitated by genuine two-way communication between health care staff and patients are described as vital signs of the impact of rights based approaches for improving health equity^{6,7}. This implicates that records of government activities and examinations of official hospital documents need to be complemented by studies of patient perceptions of health care experiences with special attention given to "vulnerable and marginalized groups"⁸. This study responds to this need in its examination of patient narratives through the lens of the AAAQ-framework, the aim being a broadened and deepened understanding of micro level aspects of The Right to Health, in a socioeconomically challenged community.

Methods

This qualitative interview study is part of a larger study that focused on hindrance and possibilities when living with a chronic disease, either COPD grade 3-4 or Diabetes Mellitus. The interviews in this concrete study focused on how patients in the catchment area of the new local hospital perceive, understand and describe care encounters. Sampling was guided by epidemiological data indicating that socio-economic conditions and living habits such as smoking, obesity and decreased mobility, are major contributory factors to ill-health^{1,9,10}. Thus, individuals

with life-style disease, either COPD or diabetes mellitus, were recruited from the local hospital where the population generally has a low socioeconomic status and a migratory background. Within this assemble purposive, maximum variation sampling was used with regard to participant gender, birth country, age, psychosocial background and physical function¹¹. The inclusion criteria were: over 18 years, and with no obvious psychiatric diagnosis. Fifty five (55) patients were included with the following characteristics: 30 male and 25 female, age range 20-82 years, mean 70 years, 58% had low education (nine or less years) and 54% were born outside Scandinavia.

The face-to-face interviews took place either at patient homes or the clinic, were conducted during 2011-2014 and lasted between 20 and 80 min. The main interview question was: "Please describe your perceptions of what the care given at the hospital means to you and what help patients expect from the health care professionals?" During the interviews, a dialogical validation was performed. Similar questions were asked in different contexts to ensure that patients' views were fully captured. The interviews were recorded and transcribed verbatim. Twelve (out of the fifty five) patients were interviewed through an interpreter. Quotations from the interviews are inserted in the Result section, where quotes from COPD patients are labeled C (1-31) and quotes from Diabetes patients are labeled D (1-24).

The computer software Excel, extended with sorting functions in Visual Basic, was used in the coding process. Dialogical inter-subjectivity was employed: the authors analyzed the interviews separately and then compared their findings. This was an ongoing process of reflection and discussion between both authors throughout the analysis, involving a movement back and forth between the whole text and its parts. Any inconsistencies were discussed, and common descriptions were formulated. The interviews were read through several times to obtain a sense of the whole.

In the first phase of the analysis interview data was subjected to manifest thematic content analysis. The text was divided into meaning units with each meaning unit being related to the same central content. Thereafter, the meaning units were condensed and labelled with codes. The codes were sorted and abstracted into six subthemes, illuminating threads of meaning running through the codes¹², exemplified in Table 1.

This part of the analysis was performed in several steps without predetermined categories, focusing on the identification of themes and subthemes' reflecting what patients' considered being fundamental to their health care experience. In addition, a specific analysis was conducted where differences and/or similarities in theme patterns between foreign-born and Swedish-born patients were checked. The six subthemes were then abstracted into two main themes, in accordance with an inductive, qualitative research process (Table 2).

In the second phase a deductive (latent) thematic analysis was performed in relation to the AAAQ-framework^{13,14}. Interview excerpts categorized under the six subthemes were analyzed in relation to accounts of what the framework's different aspects

Table 1: Example of inductive identification of meaning units and themes in the descriptive analysis.

Meaning unit	Condensed meaning unit	Code	Subtheme	Theme
When I was here last week Thursday, I was very sick. But the nurse telephoned me in my home the following day to check on me...Just like that, what hospital does that?	Last week I was very sick. The nurse checked on me -what hospital does that?	Acknowledgement	Nearness and convenience	Health care prerequisites

Table 2: Patient perspectives on care encounters.

Themes	Subthemes
Patient contribution	Shared responsibility Patient characteristics and capabilities Interdependence of technical skills and empathy
Health care prerequisites	Straightforward and individually adapted information Nearness and convenience

and The Right to Health-concept are meant to capture⁶⁻⁸. These subthemes structure the study results presented below.

Results

Patient contribution

Shared responsibility

In line with judicial aspects of The Right to Health patients, in their thoughts about health and health care, clearly expressed the view that the provision of medication, treatment, medical equipment and information about disease as well as health promotion advice is the responsibility of the health care sector. Yet, they also highlighted their own constructive agency in using these health care deliveries, and their own ability to influence their health and take responsibility for the consequences of their choices. The individual's own responsibility was a theme when deliberating upon care encounters: these were not only apprehended as taking place between patients and health care staff, but as the individual's encounter with his or her own capacities and sense of responsibility. To be attentive to symptoms, to accept the disease and not blame destiny or the society was thus described as part of taking responsibility for one's life. In addition, the power of the staff did not, in the respondents view, extend to actually make people adhere to treatment strategies and other advice given, i.e. the individual's capacity was described as an important resource for health.

Each person has their own responsibility. It is good that the nurse gives precise information early on. Then the person is prepared for, well, there will be consequences if you do not do 'this and that'. I need sufficient resources and tools to be able to handle the situation. // When the nurse says 'cut down on smoking', 'do not drink alcohol', 'be more physically active' and I do not pay attention to this, then it is not the responsibility of the nurse. [D6]

Who's responsibility? ... It is after all the persons themselves that create their own destiny. And you influence your destiny. [D13]

While assessments of the implementation of The Right to Health often focuses on state responsibility, this part of the

interviews shows that patients see themselves as valuable assets for improving their health status. This subtheme can therefore be interpreted as an indication of that the realisation of The Right to Health should not be seen only as a one-directional delivery 'state—health care system—patient'. Rather assessments as well as implementation strategies should, with advantage, appreciate the importance of mutuality and the facilitation of each entity's ability to be an active agent in health care delivery, expressed in e.g. the Alma-Ata Declaration where patients are explained to not only be "mediators and beneficiaries but as actors in driving the system itself"⁶.

Patients characteristics and capabilities

The supplementary analysis where interviews between Swedish born and foreign born patients were compared showed no differences in the perception of disease. In the interview parts relevant to this subtheme the important dividing line between patients was rather their respective personal attitude towards life. In this case it was possible to detect a clear pattern in the data where self-esteem was a major point of reference for respondents when they reflected over their attitude towards the disease. Those, who described general satisfaction with life, did not seem to give the disease a prominent role. Similarly, those that appeared to have low self-esteem and depressive symptoms did not attribute these to the disease but to earlier experiences in life. In sum, the importance ascribed to being sick was interpreted in relation to the general perception of one's life, present and past.

At first it was difficult to accept having diabetes, but – really – it is not that difficult or uncomfortable. As a human being I have not changed. [D16]

Contrasting...

No, my life has always been bad, with or without diabetes. [D18]

The respondents thus related differences in disease experience to personality rather than ethnicity. They specifically stressed that they wanted to be comprehended as individuals and not primarily as representatives of an ethnic group, and some respondents even claimed this to be one of the positive

aspects of the local hospital. They stated that they in this context did not feel stigmatised as immigrants as the staff treated them justly and showed willingness to help.

I do not consider myself as a foreigner; the staff treats me as any patient. I have equitable healthcare, medical staff were really helpful. [C19]

This suggests that an aspect of accomplishing non-discriminatory (Accessibility) and culturally appropriate health care services (Acceptability) is health care staffs' ability to acknowledge patients' individual life stories with no automatic generalizations concerning the importance of, e.g. birth place. These parts of the patient narratives too connect to statements that patient participation is central to the implementation of The Right to Health¹⁵ as the meaning of different patient characteristics cannot emerge if patients' active voices are not being heard.

Health care prerequisites

Interdependence of technical skills and empathy: The interviewee did not ask the respondents to compare the care given at the local hospital to encounters at other hospitals, yet when portraying the local hospital quit a few respondents did so. Concerning quality aspects respondents' clearly expressed that they expected to meet nurses and doctors with up-to date knowledge at the local hospital, as they defined this, combined with attentive staff, as central to their health care experience. However, dominating the patient narratives was how flexible, sensitive the staff at the local hospital was, that they showed the capacity to listen and engage in genuine two-way communication.

I get my medication, they check my lab status, and I feel that they know what is going on with this COPD, you know. ... Always when I meet one of the nurses or doctors, they are always very caring and take my problems seriously and you always feel well taken care of ... You feel a little safer, a little bit more secure. [C7]

I believe very much in the doctor, because he listens to everything. And that is not common. That is absolutely amazing. And the nurses...have been my salvation [starts crying] Ugh, now I'm like that again. [C3]

The positive experiences from the local hospital were also referred to seemingly insignificant details such as a smile, as being greeted at arrival and spontaneously being offered help, e.g. that a physician offered a glass of water to a patient that was coughing in the waiting room. These kind gestures were frequently mentioned as important factors for feeling welcomed, acknowledged and respected.

You see, the best medicine for me is when the nurse laughs, when she smiles. [D24]

Respondents portrayed the staff-patient encounters at the local hospital as empowering in the sense that they felt acknowledged and taken seriously, while visits to the central hospital meant, from their point of view, being another patient in the crowd.

I went to a large hospital previously and of course, there I was just one among 100 others but then when I moved here everybody recognizes me; I feel very welcome when I come here. [D17]

Quite a few stories from the larger hospitals include tales of stressed out staff, and some respondents claimed to have been tossed around without proper information about test results and care planning, that they had been sent home before they were feeling better and that the whole experience affected their wellbeing in a negative way.

In the health care system, they do not understand anything. You have to fight, be rude, and defend yourself. It is like they say: "Be silent, don't criticize, we are treating you. Here is your medicine...Thanks and goodbye." It should be evident that if you are treated well it has an effect on you. [D19]

One respondent even described the long waiting hours, the anonymity and the perceived nonchalance as conveying the message that he lacked human dignity. Other respondents expressed a disappointment with the doctors' ability and willingness to listen and take into account their experiences, and yet another respondent pointed out the computerization of health care as a hinder for real contact. Some even described the doctors at the central hospital as oppressive and disempowering.

If a doctor is dominant and tries to make decisions for the patients, it feels a bit dangerous and he is like a dictator. They should only do their job and don't judge. [D12]

These narratives connect the study to statements putting forward that an insufficient implementation of The Right to Health result in health care that is "impersonal, top-down, and dominated by experts"¹⁶. While the study confirms that staff competence is vital (Availability and Quality) it also elucidates its interdependence with softer values, expressed in e.g. the Acceptability-element's emphasis on medical ethics. In the same breath as respondents describe their appreciation of accurate medical professionalism they mention the importance of a kind and considerate communication style. The interview quotations illustrate what has been demonstrated in earlier studies: that care encounters, that are medically flawless but lack in respectful acknowledgement of the individual, can result in a disempowered mindset which is counterproductive to recovery and improved health^{16,17}.

Straightforward and individually adapted communication

Information, a core aspect of the Accessibility-element, was specifically discussed by the respondents and they mentioned both individual face-to-face communication and patient training programs. In both cases patients underlined the value of a pragmatic approach, as well as adequate and within reach information. The impact of different communication styles was again something that the respondents dwelled on, at length. They emphasized the importance of dialogue, of an honest and straightforward communication style, and some specifically rejected being pitied.

They should not pity anyone. They should be distinct: "If

you do not do this the consequences will be...” Honesty: telling it the way it is, not cosmetics. [D2]

The need to adapt both content and quantity of information and the modes for transmitting it to each patient’s unique life situation was once more emphasized. A concrete example was when a respondent put forward that the staff should keep in mind that patients with chronic diseases repeatedly need basic or updated information.

I wish the nurse asked me more, she thinks I know everything. Some things they said in the beginning, I have no idea. Then they need to repeat that information again. [D17]

The respondents stated the importance of staff competence in understanding and taking into account a patient’s level of emotional vulnerability and how it may affect the possibility of receiving and digesting information. Another respondent specifically pointed towards the fact that *not* absorbing detailed information could be a coping strategy for some patients. Health care staff, she said, should incorporate this into their information strategies and e.g. distribute the information over time:

The staff should take into account that you get a shock when you find out that you have diabetes. [C13]

Foreign born respondents underscored the possibility to communicate in a language they felt comfortable with, if necessary through an interpreter. This was described as a prerequisite for positive care encounters, i.e., to be able to express questions, worries, thoughts etcetera and to receive explanations and information both about the diagnosis and health care in their first language.

In line with other studies focusing on patient information^{18,19} this part of the interviews suggests that the Accessibility-element, from a patient perspective, centres on adaptation of information to the needs of the individual, regardless of whether it concerns language difficulties or vulnerabilities connected to their diagnosis. This subtheme implies, referencing the Availability- and Quality-elements, that a well-equipped hospital of good quality includes access to interpreters as well as comprehensive and integrated strategies regarding the role information and communication styles play for patients’ recovery and wellbeing.

Nearness and convenience

This subtheme presents examples of what physically accessible health services mean to socioeconomically challenged populations. The geographical nearness of the local hospital was mentioned by many respondents as very important for their health care experience. Many rely on public transportation and especially severely affected COPD patients described the short distance between their home and the local hospital as a prerequisite for being able to make use of health services. The importance given to the Accessibility-element was thus confirmed when patient narratives were examined, yet these narratives also contributed with details concerning how its meaning may vary depending on socioeconomic position and severity of disease.

Patients also depicted the appointment guarantee given

by the local hospital as an important basis for their sense of security. The possibility of having a specific doctor and nurse, and the fact that they were readily available, was highly valued. So were the follow-up calls, which are standard care at the local daycare hospital.

To me, it has been a very positive experience here at the local hospital. The closeness. // The nurse said that now as we have met, “you can just call me and if I’m off duty, there will be other staff to take your call” [C10]

When I was here last week on Thursday, I was very sick. But the nurse telephoned me at home the following day to check on me ... Just like that! What other hospital does that? [C 28]

This indicates that the meaning of functioning health care facilities, aspects of the Availability-element, to these patients included the sense of security that devoted staff and continuity of care can give. The local hospital’s specialized COPD care team, which collaborates with the central hospital in the region, was also mentioned with appreciative words. If needed the COPD care team makes home visits after discharge from hospital for inpatient care and this too was mentioned as something that created a sense of safety and security.

The COPD team have been here [at home] after I was hospitalized and it has been a great comfort to me. [C7]

A diagnosis, e.g. COPD, that makes it difficult to travel long distances, combined with a low income demands alternatives (e.g. geographical nearness and convenience technology) in order for health care to be reasonably accessible, even in a welfare state like Sweden. This is yet another example of how the meaning of Accessibility can differ depending on the individual’s life situation, which in turn indicates that analyses of a state’s fulfilment of The Right to Health need to consider variations within populations.

Discussion

When a country’s fulfilment of The Right to Health is assessed the focus is often on state activities such as law making, public-health strategies, collection and analysis of relevant data, government expenditures, and so forth. When viewing the AAAQ-framework through the lens of patient perspectives on health care encounters we learn that their implementation happens when health care staff has time to listen, and to be empathic enough to grasp and adapt to the patients’ momentary needs. Qualitative studies allow for patient perspectives to become visible and are therefore valuable complements to more common macro analyses of The Right to Health-related strategies.

The respondents’ concerns regarding attentive and respectful staff-patient interaction was obvious in different ways in all the themes and subthemes identified in the analysis: the interviews provided detailed examples of the need to adapt care to the individual’s life situation in order for it to be helpful. In this, the results link up with statements regarding patient participation being a core component of The Right to Health^{6,15}, which – in addition – is consistent with empowerment theories that stress

the importance of recognizing the individual's own abilities²⁰⁻²². However, even though the AAAQ framework was a valid guide for structuring the rights based analysis of the health care encounter, we also learned that it did not provide practical guidance about what needs to be done for patient participation to take place. This is a clear weakness given the great value the respondents attached to their ability to get their 'voice' heard in health care.

The study results confirm statements that medical skills cannot be separated from emphatic skills when realizing The Right to Health¹⁹, i.e., that the whole human rights paradigm is "grounded in the dignity of the human person"²³. It shows how the four AAAQ-elements are interdependent, that scientifically appropriate care (Availability and Quality) is vital, yet that the meaning of The Right to Health-concept is not realized unless a health care experience includes emphatic encounters adapted to the individual patient's capacities and disease experience (Accessibility and Acceptability).

In addition to providing functioning health care facilities, a vital part of health care quality work is therefore securing empowering care encounters. Even though human rights inspired state regulations and health care policies are imperative, specific strategies to secure their implementation on the health care micro level is needed, e.g. staff training in communication skills as well as follow up mechanisms measuring patient satisfaction and levels of participation. The study also demonstrates that human rights inspired policies are not enough as patients' describe how their experiences of different hospitals varied significantly, despite identical policies. All hospitals in Sweden abide to the same regulations, which is why this variety indicates that regulations and policies need to be complemented by courageous and committed local work that provides hospital leadership and health care staff with knowledge and practical skills. Follow up mechanisms, e.g. indicators for measuring the level of human rights implementation, as well as distinct, local human rights strategies including staff training in communication skills seem to be necessary for securing that The Right to Health is actually fulfilled at a health systems micro-level, in daily health care encounters. How different state legislations and health policies play out for vulnerable groups is of particular importance as health services need to reflect their limitations in resilience and range of possible strategies, if attempted universal health coverage is to truly include them.

In *The General Comment No. 14* it is stated that inability to fulfil The Right to Health needs to be distinguished from unwillingness to do so⁶. In a welfare state like Sweden inability is not probable, which is why non-fulfillment can be interpreted as institutional unwillingness. Even though a complete fulfilment of this right may not be possible, the negative reports from the larger hospitals need to be taken seriously. The fact that the interviews picture the homely, welcoming and kind atmosphere at the local hospital as a unique and distinctive experience calls for consideration. Questions need to be asked concerning staff accountability as well as what is lost when patients' health care experiences include memories of a diminished sense of human dignity and being put in a state of despair.

Limitations

Most patients showed great satisfaction with the care provided at the local daycare hospital, yet the conclusions must be cautiously interpreted. The interview study should be understood as providing examples of patient perspectives, but as the number of respondents is limited in qualitative studies the results cannot be interpreted as indisputable facts and cannot be used for statistical conclusions. Even though the researchers declare no personal interest in the results, interview bias is always a possibility in qualitative studies. Furthermore, when using interpreter, there is a potential interpreter bias as these may summarize and misapprehend information. In order to counteract this, we used adequately qualified and trained interpreters. Often studies exclude respondents who not speak the native language, but in this setting it is not relevant to do so.

Ethics

The project in itself is a reflection of the integral ethical ambitions of a rights based approach to health care, i.e. it acknowledges the idea that ethical aspects are fundamental to health care improvement that aims to level out health inequalities. In addition, ethical approval for the study was obtained from the Regional Ethical Review Board in Gothenburg (209-11; 414-13). All participants received verbal and written information and gave informed consent to participate.

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