

Original Article

A Critical Lens on Patient Decision-Making: A Cultural Safety Perspective

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ABSTRACT

Background: Involving patients to make decision is a fundamental principle of patient's rights. It is also one of the components of cultural rights. Health professionals have undeniable role in this field through patient participation. "Power" is something that highlights this role. **Objectives:** This study aimed to explore the existing power imbalance between patients and practitioners and its influence on patient autonomy and cultural rights, based on cultural safety perspective. **Methods:** A critical ethnography was conducted in a nephrology ward. Data collection was started by observation to build a primary record undertaken over 7 months and continued by interview about 6 months. Data were analyzed using the reconstructive analytical approach, developed by Carspecken. **Results:** Two main themes from high-level coding were emerged one: suspense of uncertainty, information desperation, and alienation by the health care. Two: misunderstanding of patient participation, professional centrism, and abstract participation. **Conclusion:** The medical praxis has drawn a glass wall between patients and health professionals and divided them into two groups of "self" and "others". The current dominant culture of medical centers could not provide an appropriate setting for ethical decision-making based on cultural right. This paternalistic view is a threat to the public discursive ethics and the cultural safety of patient as well in the medical and health-care settings.

KEYWORDS: *Critical ethnography, Cultural safety, Decision-making*

INTRODUCTION

Patients have right to determine their own destiny, actively manage the treatment process, and make free decisions.^[1] However, the ethical decision-making in practice requires certain features.^[2] As Fraenkel and McGraw asserted, the essential components to make an ethical decision would be informing patient, encouraging him to contribute to treatment, responding his questions properly, and respecting his rights.^[3] Cultural safety as about a new concept which originally presented in New Zealand makes appropriate atmosphere to achieve and assure these rights by balancing the power between patients and health professionals.^[4] Health professionals including nurses and physicians have played a key role in achieving to the medical information, and "power" is something that highlights this role.^[5] Cultural safety perspectives of professionals led to cultural autonomy

of patients. It means that patients could plan, pursue, participate in, and evaluate their own choices in health-care system.^[4]


Cultural safety and its emphasis on the "self-consciousness" of professionals has challenged their ideas of power and stressed the need for careful attention to patient's beliefs, values, personal experience, and cultural right.^[6] Camerini and Schulz contended that even in countries where people have common historical and social roots, microcultures have their own manners, customs, and beliefs which have a major impact on their decisions and ideologies.^[7] Furthermore, Tahrekhani and

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Abedi emphasized to help family member for making logical decision, especially in crisis situations.^[8] Douglas quoted from Payne that in culturally safe care, nurses realize that patients and families must participate in decision-making regarding their health.^[9]

Despite the paradigm shift in the last decade,^[10] our experience reveals that in the most situations, practitioners are still the main agent to make decision. According to the literatures, this approach roots in power relation between patients and medical teams.^[11,12] As regards cultural safety challenged the power inherent in the health professionals' role, we decided to address the medical relations in cultural safety perspective.

In this way, we founded the critical ethnography as an appropriative method as it enables us to not only study and understand the context but also to critique and potentially make change. It defines health as a sociopolitical phenomenon widely influenced by the issues of power and dominance.^[13] We have tried to portray that how knowledge and access to information can put somebody in a privileged position in a health-care setting using this genre of ethnography.

Objective

We conducted this study to explore and review the process of medical decision-making and patients' autonomy, by focusing on access to information and patient participation, through the cultural safety perspective.

METHODS

We applied the ethnographic research to better understand all factors that shape the individuals' experience of interactions in the health-care provision or intervention system. On the other hand, we searched to understand issues of power and politics associated with the challenges facing patients and professionals. As a result, we used the critical ethnography to explore of these challenges.^[14] Carspecken's critical ethnography is a widely held research strategy for scholars in nursing practice.^[13] For Carspecken, procedure of the critical ethnography has five stages as follows: compiling the primary record, preliminary reconstructive analysis, dialogical data generation, describing system relations, and system relations as explanations of findings.

Out of all stages, we applied just first three stages, with reference to his recommendation for the novice researchers.^[15]

Stage one: Building a primary record: In this stage, observation was performed during 7 months of continuous attend in three shifts: morning, afternoon, and night. We selected the nephrology ward in one of the largest hospitals

of Tehran University of Medical Sciences (TUMS) as the field or site of our study. Nephrology ward as a social site which involves all activities and interactions is chosen due to the chronic nature of the hospitalized patients' diseases. Thus, these patients have experienced multiple admissions in that ward which is helpful in understanding and recognition of the dominant culture.

Observations were concentrated on the complex interactions among all actors that lead to the production of culture. These data were monological because there was minimal dialog with the actors. We observed all actions that involve decision-making process, such as the reaction of professionals to the questions asked by patients and their families, the way patients obtain information, and the way of informing patients at the time of conducting treatment procedure, such as biopsies and catheter insertion. Observer was known as researcher for all the actors in the field.

Stage two: Preliminary reconstructive analysis: Preliminary reconstructive method is consisted of three intertwined activities: low-level coding, initial meaning reconstruction, and horizontal analysis. We started to reconstruct the meaning by reading the primary record and beginning the low-level coding process. The codes had little abstraction level and were so close to the original record. They were multi-access codes which mean any person familiar with the field was able to reach them by seeing or hearing.

In other words, we get the nearest possibilities in a hermeneutic process, it is horizon analysis. According to Carspecken, horizon analysis consists of subjective, objective, and normative-evaluative claims. These claims help us to achieve meaningful acts and high-level codes. Claims help us to understand the reasons that actors give for their actions. High-level codes were based on explicit meaning reconstructions and horizon analysis.^[16]

For example: a patient commented: "I search all the time a doctor or a nurse to get the answer, but no one here answers me. I am following and searching, they (medical teams) just do the laboratory test and scans with no response about what are my illness!" A low-level coding was extracted of this quote as: I search all the time to get the answer. According to low-level coding, the objective claim was: I am following and searching, the objective claims were: patient is sad of no news about the laboratory tests and scans/lake of information makes patient worry, and the objective claim was: I am following and searching. Finally, "information desolation" was extracted as high-level code.

Stage three: Dialogical data generation: Semi-structured interviews were designed based on obtained

observational data. For example, we observed that patients had little knowledge about their diagnosis or care plans, then asked them “how could you access to information?” and asked question from practitioners that “how do you get information to the patients?” or “what is the meaning of patient participation?”

We interviewed five nurses, five physicians, six patients, and two families or relatives of the patients. Each interview lasted approximately 40 min. Interviews were analyzed by the same method used for the observation. Interviews not only presented new information but also confirmed observations. Emerged themes were obtained from merging high-level codes.^[15]

Ethical considerations

Ethics approval was acquired from the Ethics Committee of the TUMS and Health-Care Institutions (IR.TUMS.REC.1395.2812). The signed consent was obtained from the manager and head nurse of nephrology ward for observation. All participants voluntarily completed and signed the informed consent form for the study. We ensured them that their provided data would be managed confidentially and reported anonymously. Moreover, they were free to either participate in or withdraw from the study.

Data trustworthiness

Carspecken recommended strategies to validate findings in each stage. In observation stage, we used flexible observation schedule. It means that the main researcher selected an actor in a time and observed her/his to encounter other actors as a first priority. Then, she observed the reactions of other people in interaction with that person as a second priority. Important events have been recorded as a third priority. To reduce Hawthorne or observer effect in this stage, we used the prolonged engagement.^[17] In an endeavor to use the peer review debriefing, we inscribed observations in a low-inference vocabulary.

In interview, we conducted the member checking and peer review debriefing to establish validity of the inquiry. Moreover, since the result of an ethnographic study is highly affected by the relationship between researcher and participants, observer stated her values, views, and opinions both before and during the study and shared those with research group (reflexivity). The statement enabled research team to examine the analysis process.^[15]

RESULTS

Two main themes were emerged in this ethnographic research: suspense of uncertainty, in order to access to information, and misunderstanding of patient

participation to practitioner’s attitude toward patient participation.

Suspense and uncertainty

How hospitalized patients obtain information could be likened to a sense of suspense and uncertainty. Patients have no awareness of the current situation and consequently are unable to visualize the future happenings. The theme of suspense and uncertainty is the combination of two high-level codes of information “desolation and alienation” with the treatment process.

Information desolation

Patients and their family are in a permanent struggle to obtain information during hospitalization. The subject of their questions is diagnosis, test results, treatment plan, medications, discharge time, and home care. The term of “desolation” describes patients’ distress into taking medical information. In some cases, the distress forces patients to resort to unprofessional help:

Observer: *I saw patients that ask cleaners about biopsy procedure, diabetic regime and even lab results.*

However, it is not the case for all patients. In other words, patients are aware that only professionals could answer their main questions. A patients’ mother expressed her feeling regarding this matter: “*There are some residents that can answer my questions about my daughter, but I like to ask their professor to feel more relaxed and sure*” (interview 3, family).

Accessing professors is also a challenge due to their 1-h presence in the ward. At this time, patients’ families have to leave the rooms and professors begin to visit patients’ quickly. It should be noted that professors play both a therapeutic and educational role. Patient visits are like a classroom for residents. Patients are quiet and physician talk like a teacher in class room.

Patients and their families, who did not manage to get answers, ask nurses for help. Nurses give general answers, and if patients need detailed answers, they would be referred to physicians or answer to questions based on the personality. Only respondent decides how to answer a question. For instance, some nurses choose certain information to share (observation 3). As a nurse commented, “*I never talk about patients’ disease and always mention positive aspects of their situation*” (interview 1, nurse).

Personal choice of information devalues its validity and results in patients’ deprivation of knowledge. Ambiguous responses and wrong management of information by practitioners confuse patients and families. In such situations, the patient avoids decision-making due to the fear of making wrong decisions based on ambiguities.

For example, as a patient said, “*I don't have any opinion, because I don't have knowledge. If an error occurred, they (health professionals) told that it was your fault*” (observation 5). Since the information is censored, the conditions for making free decisions are not met. Patients simply confirm the decisions taken and inadvertently reinforce the power of practitioners.

Alienation from the treatment process

Alienation from treatment process is another barrier to patients' decision-making. First of all, we should note that alienation from treatment process or limited knowledge about future happenings, measures taken, and exact diagnosis was not of equal value for all the patients. In other words, some patients, elderly patients, in particular, were unaware of this issue, and they were not necessarily unsatisfied.

As doctors explain the situation, they constantly say: “as you wish” and their posture was not as such an active listener. Our observation showed that if patients are not interested in knowing, professionals disregard informing patients, and some patients are discharged after being hospitalized for several days without even knowing the final diagnosis. It has been neglected that sharing information with such patients prepares them to accept treatment and cooperate with practitioners.

The professionals' attitude while sharing information is another cause of alienation. According to our observation, doctors and nurses give information only when it is necessary for conducting procedures and deemed appropriate. In this case, patients' permission is not based on awareness but on trust in physicians' diagnosis. For instance, a patient (male 67/primary education) went to operating room for fistula procedure. After half an hour, he came back alone. A nurse looked in wonder and asked: why are you back? He said: they cannot insert a fistula into my hand. I should wait for a few days. A few hours later, his nurse went to his room to medication. He asked in a gentle voice: why did you take me to the operating room? The nurse was shocked and asked: did not you know why you were there? He answered: no, you said I have to go and I went. The nurse said: I said you should go and you did! Who signed your consent form? Was not the doctor here yesterday? He explained and you filled the consent form and signed it!! The patient responded: yes, I signed it myself but I did not understand what he said. The doctor said it is necessary for your dialysis. I did not know I have to go to the operating room. Will they anesthetize me? (observation 5).

The current way of providing information, more than revealing concern for patients' rights, shows disregard

and negligence in implementing roles and guidelines issued by the Ministry of Health, Treatment and Medical Education.

Patients are dealing with suspense and uncertainty throughout their hospitalization. Their little amount of information is the result of their search for information in hallways, clinics, other units, and pavilion. Our observations indicated that the most dominant way of obtaining information is corridor consultation that discourages patients and their family members to participate in treatment, and there is a risk of misconceptions and receiving incomplete information.

Misunderstanding of patient participation

Limited understanding of patient involvement means that practitioners do not accept patient participation due to a kind of professional centrism. Their misunderstanding about patient participation is what we explained as abstract patient participation.

Professional centrism

Health professionals compared patients' knowledge with themselves. In other words, limitations in knowledge are the first reason for disregarding patient participation. One of the residents declared: “*Generally it's impossible to involve patients in scientific argument because they are not knowledgeable. What could they say?*” (interview 3, residence). Physicians believe that they are merely eligible group to have authority to make decisions.

Abstract participation

Abstract participation happens when professionals assume that patients are involved in treatment process due to misunderstanding of patient participation. For example, practitioners believe that patients signing consent form is their participation. As a physician declared: “*why aren't they involved? They know what is going to be done. They sign the consent form and it's in their file*” (observation 4). Physicians are unaware that participation is consulting before decision-making and filling the consent form is agreeing to a made decision. In other words, the practitioners pay attention to “consent” and not to the “informed consent” that is referred to the guidelines of the ministry.

As a nurse stated: “*We explain everything to them. We do nothing without their consent. For example, when I go to inject blood, I explain the reason, and if they disagree with the procedure, I won't insist*” (interview 1).

All our observations confirm that there is no doubt that professionals do not insist on doing things. However, this fact does not show their democratic spirit and

belief in patient participation. As mentioned before, the way of transferring information is a critical factor in decision-making. We never have encountered a situation that all the possible options are explained for patients and by asking a question ensure their awareness of provided information. It should be noted that involvement is optional and filling the consent form is obligatory and would not be considered a thorough patient involvement.

DISCUSSION

The findings of this ethnography indicate that patients are facing two major challenges for accessing to information and making ethical decision. (1) Sense of suspense and uncertainty and (2) misunderstand of patient participation by practitioners. In both cases, health professionals are the authority and have the power and patient tries to escape the despair.

According to cultural safety, the current trend is an indication of the imbalance of power between patients and practitioners and ignoring patient's identity and culture in decision-making.^[11] Our study showed that knowledge as the core element of patient-professionals relationship is appeared to be powerful and inflexible that neglects patient's beliefs and needs and replaced them with disease. However, cultural safety recognizes patient's right in decision-making as well as medical information.^[18]

Stacey *et al.* introduced the concept of "decisional conflict" as the gap between what physicians believe patients should know and what patients want to know. Presenting information, regardless of patients' identity and values, is likely to cause confusion and could not facilitate decision-making.^[19] Our study reveals the negligence of practitioners in patients' personal differences and dealing with all the patients the same. While patients' need for information is different according to their lifestyle and beliefs, the presupposition of "one size fits all contexts" is neglecting personal differences.^[20] In addition, patients who decide based on their personal values and beliefs easily accept the consequences of their decisions.^[19]

The findings also showed that professionals inform patients improperly and also answer their questions inefficiently. The exclusion of information by practitioners is confirmed by other studies and introduced as the major obstacle in decision-makings.^[7] Access to information is being emphasized both during the process of decision-making and after that. Patients and their families should be able to share decisions with practitioners and receive additional information.^[21]

A noteworthy result of this study is patients' alienation to treatment process and their passive reaction to this issue. Peek *et al.* argued that the main reason for patients' inaction is practitioners' attitude as authorities. Their self-righteous attitude causes patients to feel incompetent and afraid of making decisions regarding medical affairs.^[22] Patients' lack of confidence in decision-making is due to the issue of information access and practitioners' attitude as gods in white that results in patients' dependence on practitioners.^[23]

Forgettable role of nurses in completing and correcting information is one of the many findings of this study. The holistic care strategy and its regard for patient autonomy and empowerment consider a special place for nurses. In fact, nurses as a facilitator should ensure patient autonomy to access quality health care in a manner that accommodates their cultural values, beliefs, and behaviors and confirm patients to make a decision on personal beliefs and identity.^[19] Blumenthal-Barby *et al.* introduced nurses as members of a supportive network that should provide answers for uncertainties.^[24]

The above-mentioned issues and physicians' belief in superiority which is called elitism have resulted patient noninvolvement in decision-makings. Politi *et al.* contended that physicians' academic excellence could not be the only justified reason for medical decision-makings due to their limited knowledge of patient's preferences. In fact, they decide for the disease and not the patient. Such attitude results in patient's inferiority.^[25]

Abstract participation is another result of this study. Surprisingly, practitioners deny patient noninvolvement. Joseph-Williams *et al.* emphasized this issue and believed it to be the reason for patient suppression. They stated that professionals do not accept patients who ask too many questions and interfere. In their view, these patients are not good patients and will be marginalized.^[26] Coulter and Ellins emphasized that instead of providing patients with information, practitioners believe to know everything better and by having a patriarchal look tries to control the situation.^[27] Despite considerable efforts made to enable patients to be involved in decision-making, the current trend has left patients with more needs. Health professionals take advantage of patient's desperation and impose its decision.

As our study revealed, the current dominant culture of medical centers could not provide an appropriate setting for ethical decision-making based on cultural right. Biomedical paradigm of medical centers leaves no place to value patient's individuality, culture, and

identity. Decision-making as an indicator of power is done by health professionals and is solely based on its knowledge and identity.

In addition, medical praxis has drawn a wall of glass between patients and practitioners and divided them into two groups of “self” and “others”. Practitioners as “self” believe their knowledge to be superior to patients as “others”. This view would shift power from patients to practitioners and practitioners and deprive patients of the autonomy, with no opportunity to be involved and make decisions.

It could be noted that current medical knowledge has focused on patient’s body and provision of services by practitioners is a threat to patient’s cultural safety.

A limitation of this study is the weakness of written language in describing interactions which were based on nonverbal connections such as facial expressions, posture, and gesture.

CONCLUSION

Given the ethnocultural diversity of Iranian context which is referred to as a cultural mosaic, we suggest further research in areas regarding patient’s right based on cultural safety approach as it can be applied to Iranian culture and be efficient in improving the quality of medical services. In addition, cultural safety training may be one mechanism to reduce disparities in public health system. Hence, further work needs to be undertaken to transform power relations and understand patient autonomy and informed ethical decision-making.

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Conflicts of interest

There are no conflicts of interest.

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