Difficult patients in primary health care: between care and order

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This study was aimed to understand nurses and doctors ethical deliberation related to difficult patients in Primary Health Care (PHC). It used a comprehensive approach, based in the methodological theoretical framework of deliberative Bioethics, using semi-structured interviews and practical wisdom as the analytical category. Seventy PHC professionals in São Paulo were interviewed between 2002 and 2010. The results show that intermediary courses of action tend to a trade-off between two values: care and planning. In the case of extreme courses of action, nurses tend more to care and doctors to planning. We conclude that difficult patients are common in PHC and health professionals tend to have courses of action in order to assist them without disturbing the routines of services, of other professionals and of users.

Keywords: Professional practice. Nurse patient relation. Physician-patient relations. Primary Health Care.

Introduction

Meeting difficult patients in complex encounters in Primary Health Care (PHC) is a common situation and creates a stressful moment for both the practitioner and the user[1]. The practitioners in PHC estimate that between 15 and 60% of PHC users are deemed "difficult"[2]. Physicians working in Health of the Family Strategy (HFS) report daily clinical encounters with these patients, about one of every six visits, even though the impact in practice is more related to the emotional intensity than to the frequency of these encounters[3]. Those circumstances may be the origin of ethical problems, as they involve conflict of values. In spite of the influence of the intuition and subjectivity of the topic, there are common components that are roadblocks in the rapport of practitioners and users in PHC: features from the patient, the physician and the environment, working conditions, communication skills and rapport [1]. Also worth of note are the interaction among age, sex and ethnicity of professionals and patients[4].

Research usually focuses in alternatives and techniques to deal with this situation, forgetting that they involve conflict of values and basic duties of the profession[1,3,4]. The present research sees the situation of the difficult patients in PHC from the perspective of this conflict of values. Nursing, as a social practice combines care-technique and care-ethic. In the former, the main value is order or planning, while on the latter the main value is care[5].

Following this perspective, this paper deals with the following issues: In which way the values "care" and "order" are imbricated in the nurses' and doctors' practice in PHC. How these professionals deliberate in this value conflict? Which is the tendency of the courses of action? In this way, the article has the objective of understanding the ethical deliberation of nurses and physicians when facing difficult patients in PHC.

Difficult patients have associated marks such as mental disturbances, being polysymptomatic, chronic pain, unattended expectations and persistent lack of satisfaction with the care they receive, even as heavy users of health services[3]. There are also medical and behavioral issues determining the condition of difficult patients:

lack of interest in self-care; excess of demands; manipulative behavior; conflictive families, multiple complaints[1]. This kind of heavy users (heartsink patients) that are one type of difficult patients, make repetitive visits to health services with multiple, unspecific symptoms and oftentimes they express complaints that are impossible to treat [1]. They are usually described as awaking a set of negative feelings (exasperation, defeat, aversion) in the practitioners, due to inappropriate behavior in the clinical settings[2]. The difficult clinical encounter situation in PHC is aggravated in the circumstance of the lack of psychosocial skills in the professionals[3]. Not withstanding the variety of typologies of difficult patients, this study opted for choosing the heavy demanding (heartsink) users, to analyze the trends in the process of deliberation of the professionals.

Methodology

Comprehensive approach research, grounded in the theoretical and methodological framework of deliberative bioethics, using as empirical foundations the discourses of nurses and doctors of the Primary Care Health Units in the city of Sao Paulo. These discourses were gathered during the nine years of fieldwork (2002-2010) in funded research projects that looked in depth into the interface of bioethics and PHC, focusing in "how" and "with what kind of" foundations the professionals use to cope with the ethical problems in PHC. The analysis of this array of discourses came from qualitative studies using the same methodology and performed by the same researcher, thus allowing for a synthesis pointing to new findings[6].

Data collection using semi-structured interviews, followed criteria of representativity, social variables and sufficiency to achieve the objectives as to answer the research questions. The interviews used hypothetic scenarios with ethic issues, asking for recommendations about how the team should act in the situation. In this article a "vignette" was analyzed, describing a case of a user that disturbed the Unit's routine, a behavior that lead to the PHC practitioners to label a patient as difficult.

This vignette was:

> Mr. C, hypertensive and diabetic patient is usually making demands that disturb the Health Unit's routine. The Doctor and the Nurse in which team he is listed, try their best to provide care, but they are every day closer to give up in their efforts. What would you recommend to the team?

Due to the findings of previous studies[4,7-9], the situation when patients disturb the routine was considered as good setting to analyze how deliberation occurs when there is conflict between the values Care and Order. The theoretical and methodological framework of deliberative bioethics understands ethics from the vantage point of the moral language of facts, values and duties. It encompasses deliberation, hermeneutics, responsibility and practical wisdom through the deliberation process. This framework analyzes the discourse, identifying the values and courses of action used to cope with this situation[10].

The MaxQDA 11 software was used for organizing the data set. To make explicit the values in conflict and the courses of action used in ethical dilemmas, the analysis performed the following techniques (among others): fluctuating reading of discourses to grasp the general meaning of information, a detail of the initial analysis through in-depth reading of discourses to be codified and segmented following empirical categories, detailing of information with the distribution of the courses of action according to the procedure prescribed by the theoretical and methodological framework of deliberative bioethics[10].

In this way, data was organized for deliberation about values and duties: the identification of the main ethical problem present in the vignette and its recommendations; acknowledgement of the proposed courses of action; their influence to determine a trend in solving the conflicts; clarifying the empirical crosscutting categories present in the foundations of the courses of action.

Data analysis allowed to establish the relationship among findings and to show the trend that the courses of action point out, as they are expressed in the discourses, using the category "practical wisdom" as a starting point. The analytical categories are those that encompass basic social relationships and may be used as beacons for comprehension of the object under study in general terms[11]. The study

used the analytical category Practical Wisdom (*Phronesis)* as a hallmark of the well-performed deliberation, leading to reflective action and allowing for well-weighted, thoroughly analyzed activity. As Deliberation is a concept formulated by Aristotle, Practical Wisdom was also understood under his perspective as Gracia remarks[10,12-15].

The term Practical Wisdom in its origins is not univocal and may also mean caution and carefulness. However, in deliberation-based ethics, Practical Wisdom is understood as wisdom directed to the human good, to decisions that are the "best" in a certain circumstance.

A practically wise (prudent) decision should open an array of possible outcomes, specifying how they contribute or hamper the realization of the conflicting values. This was a directive in the analysis of the courses of action of the discourses, taking as prudent or wise those that were conducive or impeded in the least possible way the two conflicting values in the situation that was explained to orient the interviews. Due to the fact that in deliberative bioethics, moral duty implies to make possible values, those characteristics of the facts make the world a place where life is feasible with dignity for human beings.

The Ethics Committees from the School of Public Health of the University of Sao Paulo (COEP 084/10) and the Secretary for Health of the municipal administration of Sao Paulo (427/2004 CEPSMS) approved the research projects.

Deliberation

To deliberate is an open way of jointly thinking about uncertain situations, in order to manage in a responsible and wise fashion, the facts, the values and duties. Deliberation is a concrete and objective procedure that evaluates ethical problems, including the circumstances of the situation and the consequences of possible outcomes, to arrive at the best alternative for managing the case through moderation and reasonable action[10, 12-15].

Through deliberation, moral judgment is built putting together facts, values

and duties, weighing different points of view, based in experiences and knowledge, resulting in choices of courses of action in a morally conflictive situation, thus conducing to a more practical, wise and responsible life[10, 12-15]. In this sense, deliberation points to feasible outcomes to realize values in practice, taking into account facts and duties.

Throughout deliberative processes the ethical judgments are composed in the following moments: cognitive (facts, guided by cognitive logic); evaluation, estimates or preferences (of the values) and volitive (about duties). This is the more specifically moral moment, as it includes the act of will (autonomous), the predisposition and the willingness to make real the values in projects of a fair and happy life[13].

The facts are pieces of data from perception, objective, material and observable. The values are based in facts, because only what is observed can be estimated. In this sense it can be said that there are no pure facts, they are always collated with values that are individually gained through intuition and at the same time socially construed, as they do not depend exclusively on personal preferences, but as a need that everyone should feel, such as may happen with values as liberty, solidarity and beauty.

The values give contents to duties, which are the formal aspect of moral obligation. In specific situations of daily real life, duties, as well as values, may enter into conflict; in that moment we do not know how to act to make real the values or at least to make less harm to them, and there is when there is a need to use deliberation to find moral outcomes, the varied courses of action, the feasible options that make reality the values in the case found to be a ethical problem. Extreme courses of action are those that accomplish only one of the values in conflict, while intermediate courses achieve the maximum or damage the less the values in conflict as wise outcomes. It is among them that the optimal course of action for every conflict is to be found[10, 12-15].

Results

The study compiled discourses from 70 individuals, among them 34 nurses

and 36 physicians from PHC services; Health of the Family Strategy (HFS); traditional Basic Health Units (BHU); Teaching Health Centers (THC). Regarding nurses, one was male and the rest female; with ages varying between 22 and 53 years and time in the job from 1 to 30 years. The physicians were 14 male and 22 female, ages between 27 and 57, time in the job from 11 months to 36 years.

Courses of action

The practitioners proposed different courses of action to cope with difficult patients in PHC. They can be grouped in: educational actions; to involve the social and family network; to use the professional authority to keep the order; humane management; humane clinic; to use the professional and care network. The educational actions included as courses of action: to modify the guidelines to suit the patient; to check what the patient has truly understood; to explain vantages of being responsible in the treatment; to raise awareness about the gravity of illness; to talk about the co-responsibility in health, the part of the practitioners and the part corresponding to the users. While suggesting the use of the social and family network as a course of action, a nurse stated: "we know that there is a network, that she may count on a much wider network, because there are other families, relatives, other persons she may count on and she may solve, so there is this lingering feeling that it may be easier to give up" (cseE35).

"Using professional authority to keep order" brings up courses of action going from adequate to exaggerated. Within the exaggerated and authoritarian use of professional power there are several courses of action: to rebuke and punish the user, to make the consultation and refer to other unit; to stop any disturbance to avoid discomfort in other users; to say "no" to users sometimes; to keep an eye on the patient; to call the attention of the users explaining that treatment is also of their own account. Adequate use of professional authority to keep order and oftentimes to put together order and care, is present in the following courses of action: to explain the routines; to make clear that users also have duties including respect for the team;

to give service with boundaries, explaining the routines of the Unit; to give service putting time limits to avoid disrupting routines; to give service explaining the Unit's routine; urgencies will be always solved.

Punishments include to deny prescriptions when the user has lost the previous ones (psf M10); to give a scheduled time to other user more prone to adhere to treatment (cse M35). Speaking loud to patients should be done cautiously to avoid being rude (psf M6) or disrespectful or using cusswords (psf M1; psf M10; psf E2). A humane healthcare includes management and clinical aspects. Humane management consists in: to open schedules to facilitate the patient attendance; to review the professional activity; to keep in mind the manager's responsibility with the health practitioners; to be careful with the professionals' burnout. Regarding this course of action, one of the physicians remark: "it is hard to be at ease here, even going to the bathroom is difficult, I have a dry mouth [...] we can hardly leave the consulting room, every time we open the door, someone comes in, looking for something, demanding" (psf M10).

Another physician speaks about the overload due to the number of patients: "it is not just one patient, there are several, it's time to stop working and talk to see what is happening, why you give up on this or that patient" (psf M11).

Practitioners speak about how important is the *sprit de corps* and joint work to cope with burnout: "we are getting sick, stress abound, lots of responsibility, what would happen if we don't have our colleagues' collaboration?" (ubs M29)

Regarding humane clinic, discourse showed the following actions: the professional must invest in self knowledge; to avoid labeling users; to expand clinical approach; to have a individualized therapeutic project; to invest in the rapport; to incentivize self-care; to foster users' trust in treatments; to stimulate users' self-esteem; to perform active listening; to have empathy with chronic conditions illnesses; to grieve with the patient; to expand the clinical aspects of the Nursing practice; to create liaison.

Regarding the avoidance of labeling, there is a concern related to the Community Health Workers (CHW) in HFS disseminating those nicknames in the

community and bringing discredit to the health service. That is why a nurse argues for avoiding these practices even internally in the team:

> […] sometimes there is a lingo […] a tempting one because tit can spill out, so we need to keep vigilance, because the community health workers may disseminate those catchwords in the community, so when we perceive this inside the team […] we try to stop it as best as we can because we need to be respectful to the needs of everyone (psf E3).

Expanding the clinic approach includes to explore more the users' life:

> To get to know better the life of that person when outside of the health unit, to know why is he here every single day […] who is his family […] if he has means […] his financial side […] (ubs E23)

To empathize with the condition of the chronically ill means to weigh the burden of taking lifelong medication and the need of changing lifestyles:

> Because it is difficult to accept that you are diabetic, that you have hypertension […] he says that his illness is here and will finish him but […] even though he is not making efforts to improve his status (psf E8). I know that no man is prepared to spend the rest of his life solving problems (cse E33).

Regarding the classification "to use the professional and care network", discourses showed that courses of action were: to shift practitioners; to refer to other professionals in the Basic Unit; to involve other Unit's sectors; to visit the families in their homes to get to know them; to try new approaches; to refer to other groups in the Unit; to unify languages in the behavior of the team and the Unit; to exchange positions in the care process; to discuss the cases in the team, to involve the community health worker; to give mutual support within the team. The HSF structure is prone for home visits:

to find what's missing […]what's happening when making home visits
[…] to discover the intra-family dynamics and discovering the source of
the problem of the client and try to solve it (psf E6)
do house diagnosis […] to get to know the house, the family, who are
they, how are they, if they also adhere to this treatment (psf E12).

The interchange of roles among the professional is geared not only to alleviate the workload but also to promote the team cohesion:

[…] so as not overloading one team member who is usually the nurse,
so with this turnover the patient goes to the doctor, then the nurse […]
if needed. We have a joint presence of the whole team in those difficult
moments (psf E).

Mutual support is seen as a way of sharing responsibilities and coping with the weariness coming from facing difficult patients in PHC:

working together is teamwork not centered in the doctor's office visit,
even because many concurrent things in these illnesses may be well
discussed and not only with the nurse or the doctor (cse E32).

Trends in the courses of action of the practitioners

To analyze the trends in the courses of action based in the deliberation, it was used the following questioning as the basic ethical issue: "How to give care to a difficult patient without compromising the order and routine of a Basic Health Unit?" Order and care are the conflicting values that lie the foundations of the ethical and technical components of Nursing.

The extreme courses are to keep order forcing the user to adapt to the routine of the facility (ordering) and give services to the user each time that she/he demands attention (caring). Within this array (figure 1) there was a distribution of the courses of

action based in the representation of each category in the alternatives found in the discourses.

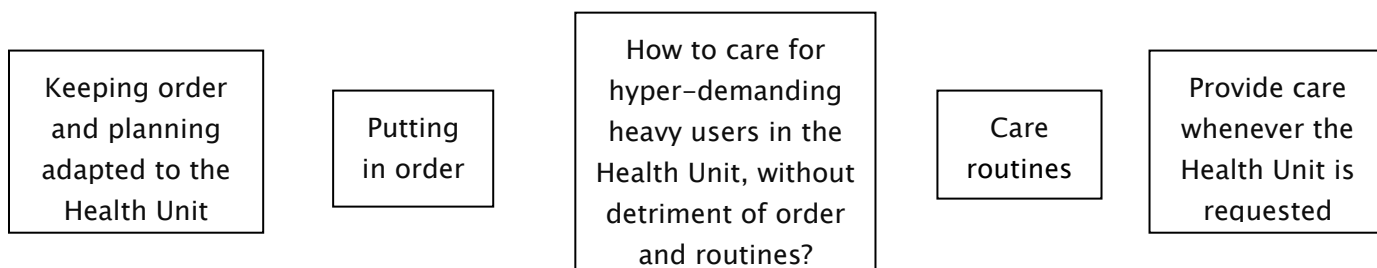| Keeping order and planning adapted to the Health Unit | | Putting in order | | How to care for hyper-demanding heavy users in the Health Unit, without detriment of order and routines? | | Care routines | | Provide care whenever the Health Unit is requested |

Figure 1: Ethical Problems, Values in Conflict, and Extreme Courses of Action

Closer to the extreme course geared to preserve order we found actions such as: to rebuke and punish the user; to explain the routines; to clarify the duties and the need for respect that the user needs to give to the team; to call the attention of the user to the dependence of the treatment to his/her own responsibility; avoid disturbance to other users; to know when to say 'no' to the patient. In this polar extreme the medical discourses are predominant. In the polar extreme of care we found those that stand for ensuring care every time it is sought; to give urgent care always; to refer to other professionals in the Health Unit; to shift responsibilities in the team. In this extreme the nurses' discourses are more prevalent.

In the middle ground between these two extremes we found those that achieve the two values. Those middle ground courses may be the optimal to cope with the situations: to give care and refer to other facility; to give care with limits explaining the service's routines; to give negotiated time-limited care in order to keep the routines; to open schedules to facilitate users' attendance. In this middle ground the nurses' discourses are more frequent. The course "to give care and refer to other facility" is more related with the order-keeping extreme, because it implies the avoidance of the user. There is a doctors' discourse and a nurses' discourse:

He doesn't follow rules, no way [...] right? just send him to a specialized

service (psf M6)

Here is a Health Unit, you need to make an appointment, usually a doctor [...] so, you better go to the Emergency Room in the hospital to see if someone may see you there (ubs E28).

In the intermediate courses there are also those that contribute to make effective the values of order and care, because they expand the clinical approach, foster empathy and dialogue with the user, promote teamwork, work on the self-esteem and self care.

Here is a discussion of a case in the team:

We need to work to avoid that, not to get to this point, we need the team working with everyone in their own limits [...] we don't have that moment to speak to each other, to express the negative and see the positive points. That moment should always happen to stop stress (psf E3).

Doctors, nurses and auxiliaries need to sit down and discuss the best way to study this case, the best way for the team and also for the patient (psf E7).

Expanding the clinical approach in the nurses' consultation and active listening showed themselves to be pathways for self esteem and self care, based in the comprehension of the real situation of the user:

May he be a lonely person? He does not have self esteem, because he is jobless, because he is retired, always there is a reason (psf E11)

To perceive how this patient is being approached [...] in the best way, but may this "best way" be what the professionals, i.e. doctors and nurses think is the best way possible for this patient? The patient's approach is wrong, so it needs to be revisited (psf M4).

It is worth of note the importance of the CHW in dealing with this case:

> it is much more responsibility of the CHW in relation to the patient […] the CHW does not give up […] to request from the doctor, from the nurse, from the auxiliary […] because when she gives up, the team will abandon the patient because, when the doctor or the nurse will remember of this case? […] they will remember only when the patient comes again to seek attention and disturbing the routine (psf E14)

Discussions

The courses of action as proposed by doctors and nurses to cope with difficult patients are similar to what has been identified in other studies[1,4,7]. Some researches approaching the issue of difficult patients explored the professional point of view[4]; they placed the responsibility in the patients' behavior, blaming them for the illness[7]; tried to reveal why those patients create bad feelings in the practitioners[1]. Several reasons were pointed out for these behaviors related to the practitioners or the patients; workload; professional satisfaction; psychosocial attitudes, counter-transference; co-morbidity; social situation[1], family context[8].

The research in family physicians in the USA showed that collaborative strategies (vs. opposition), adequate use of power (vs. inadequate use of power or violation of limits of each party) and empathy (vs. compassion weariness) as ways of coping with these cases[3], results that are similar to those of this article.

In the collaborative strategies, the USA study stated the prioritization of the patients' concerns; to involve the patient in the decision making process, clarifying through candid, consistent, objective and fair information; teamwork using referrals to other professionals; supported self care, establishing feasible goals. Adequate use of power was geared towards the compliance between the patient and the institutional normative.

Several recommendations were suggested, such as shortening the due

dates for procedures, with more time for the visit, improving the records in the file; setting boundaries with clear rules, restricting the number of requests and a maximum time for each visit. Empathy appeared as a strategy to encompass the psychological aspects, the emotions, the compassion as well as firm, patient-centered and reinforcing the positive aspects[3].

The use of professional power in caring for PHC users is specially worth of attention as the users are in their own territory and environment. Both the professionals and the users may exert power in different levels, not withstanding the predominance of the professionals, and especially of the physicians. The users exert their power through the information they chose to share with the team or some of its members and with their decisions whether to adhere or not to treatment plans. The professionals, on the other hand, may exert power in deciding what is going to be offered to the users and controlling the flow of the conversation through questions. That is why difficult patients may be seen as a nuisance, leading to misuse of professional power[1]. This misuse of the professional power appeared in the findings of the present study under the fashion of punitive aspects. Self-knowledge of professionals was remarked as a possible course of action. The professionals may ask themselves several questions when facing a difficult patient: Why do I think that this is a difficult patient? Which are my biases and prejudices? What is my agenda for action regarding this patient today?[3]

The results showed the need of investing in the rapport s a way of coping with the situation of difficult patients to improve the relationship of the practitioners and the users. In that direction, several guidelines may help: the target of changes should be the practitioner-user relationship and not one of them separately; the emotional experience of the patient deserves an explicit attention in the clinical interaction; the patient's perspective should guide the clinical encounter[3]. In other words, there is the need of shifting the focus from the disease to the patient as an individual, with a personal biography, within a collaborative interaction.

A Danish study show how emotional reactions and behaviors of the nurses

facing difficult patients include "persuasion", "commitment" and "alienation". The same professional, depending upon the situation and the moment, may use any of those strategies. Persuasion strategy includes from counseling to threats. Alienation or taking distance is a way of callousness. Commitment means that the professional will not give up, even knowing that the patient is not adhering to the recommendations[3].

A research in a Family Health Center in Chile done in difficult patients with multiple consultations, the findings resulted in the conclusion of considering this situation as a showcase of the weakness of the biomedical approach[16].

Regarding the trends of the courses of action of doctors and nurses, several differences were found. The nurses' course of action tend more to the trade-off of both values and whenever this is not possible, the discourses show pathways to make reality both values. The lexical order between the values of care and order[5] appears in the results as nurses in extreme courses tend more to the care polar extreme. Physicians are closer to the pole of keeping order and routine of the Unit.

Final considerations

Caring for difficult patients is a frequent occurrence in PHC and may be the source of over using services, lack of satisfaction with the care received and professional weariness. They feel themselves incapable of providing for the needs and requests of those patients and when they perceive the lack of satisfaction that the patients experience, tend to refer them to specialized tests, that are seldom needed.

In the present research, nurses and doctors were inclined towards courses of action that were well suited to care for difficult patients, using a wide comprehensive approach, without disturbing the Unit's routine, the team's dynamic or the other users care process. The highlighted courses of action encompassed case discussions in the teams, new approaches and strategies for more friendly care and using the diverse resources present in the Unit and the region.

Professionals tend to use their powers in an inadequate fashion when they feel

themselves challenged by the users, when they question the provider, don't follow prescribed conducts, or disregard norms. This inadequacy also showed some shortcomings in the practitioners' performance due to the lack of mastery of the tools and means to achieve the desired outcomes, and especially the psychosocial skills to understand and cope with difficult relations and the communicational skills to keep open dialogues about their experience in these situations.

There is a need for transitive actions to build inside the training process the relational skills both in the initial education as well as in lifelong training to create more assertive relations, and breaking apart from the paternalism and authoritarianism pattern of behavior that does not consider the user as an adult in a relation that needs to be horizontal, friendly and with a comprehensive vision. There is a fertile ground for these developments as the nurses and physicians acknowledge the importance of the rapport, of the expansion of the clinical approach and of empathy.

There is also a need to strengthen the practitioners as they need to cope with the hardship of the contact with the difficult users in PHC, creating times and spaces for sharing experiences, analyzing cases and to forecast assertive ways to deal with these situations.

The scenario under study is a frequent occurrence in PHC, although very few publications, and especially Brazilian studies have analyzed this topic and its significance for the professional practice when dealing with difficult patients.

Collaborators

Elma Lourdes Campos Pavone Zoboli ccordinated the research projects, carried out the data collection, and prepared the first proposal of this article. Deisy Vital dos Santos and Mariana Cabral Schveitzer prepared the final version and participated on an equal basis in the discussion of the results, drawing up and revision of the text.

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