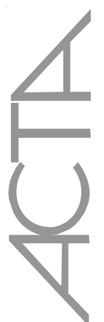

Nurses and primary care service users: bioethics contribution to modify this professional relation*

Enfermeiros e usuários do Programa Saúde da Família: contribuições da bioética para reorientar esta relação profissional

Enfermeros y usuarios del Programa Salud de la Familia: contribución de la bioética para reorientar esta relación profesional

Elma Lourdes Campos Pavone Zoboli[1]

ABSTRACT

Objective: To identify ethical issues experienced by nurses during their clinical practice in primary care settings and to explore ways to improve the nurse-patient ethical relationship. **Methods:** This qualitative descriptive study was conducted through semi-structured interviews with 17 registered nurses from a Family Health Program in São Paulo City, Brazil. Data were analyzed through content analysis. **Results:** Ethical issues in primary care settings are not serious and do not demand immediate attention. Ethical issues in these settings can be easily resolved through good nurse-patient relationship. **Conclusion**: The main ethical principles of autonomy, justice, and beneficence may contribute to better citizenship and health promotion.

Keywords: Bioethics; Ethics, nursing; Family health program; Primary health care; Nurse-patient relations; Public health.

RESUMO

Objetivo: Identificar problemas éticos vividos por enfermeiros na atenção básica, com vistas a contribuir para aprimorar a relação profissional-usuário. **Métodos:** Estudo de ética descritiva, empírico, qualitativo no Programa Saúde da Familia de São Paulo, com entrevistas semi-estruturadas e análise de conteúdo. **Resultados:** A dimensão ética na atenção básica lida com situações corriqueiras da prática cotidiana É urgente o redirecionamento da sensibilidade dos enfermeiros para a percepção da sutileza dos problemas éticos nas relações com os usuários na atenção básica. **Conclusão:** A ponderação e especificação dos princípios da autonomia, não maleficência, justiça e beneficência, enriquecidas por outros enfoques da bioética, podem contribuir para a construção da cidadania e promoção da saúde.

Descritores: Bioética; Ética de enfermagem; Programa saúde da família; Atenção primária á saúde; Relações enfermeiro-paciente; Saúde Pública.

RESUMEN

Objetivo: Identificar problemas éticos vividos por enfermeros en la atención básica, con miras a contribuir para perfeccionar la relación profesional-usuario. **Métodos:** Estudio de ética descriptiva, empírico, cualitativo realizado en el Programa Salud de la Familia de Sao Paulo, con entrevistas semi-estructuradas y análisis de contenido. **Resultados:** La dimensión ética en la atención básica lidia con situaciones rutinarias de la práctica cotidiana. Es urgente el redireccionamiento de la sensibilidad de los enfermeros para la percepción de la sutilidad de los problemas éticos en las relaciones con los usuarios en la atención básica. **Conclusión:** La ponderación y especificación de los principios de la autonomía, no maleficencia, justicia y beneficencia, enriquecidas por otros enfoques de la bioética, pueden contribuir en la construcción de la ciudadanía y promoción de la salud.

Descriptores: Bioética; Ética de enfermería; Programa salud de la familia; Atención primaria de salud; Relaciones enfermero-paciente; Salud pública.

* *Study carried out Family Health Program in São Paulo City, Brazil.*

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INTRODUCTION: BIOETHICS AND PRIMARY CARE

Proposed as a bridge, bioethics increases the space for limits and exceptions, and relegates everyday issues. Hence, bioethics can be perceived much more as a wall and become isolated from the ethical issues that involve most people's everyday lives, as well as most health care services and professional activities. Therefore, the lack of published studies in bioethics, focused on primary care, comes as no surprise, due to its particularities and specificities. These particular characteristics arouse ethically significant issues, different from those experienced in the hospital. The actors (users, workers, professionals, administrators), the environment, the type of encounters and relationships between the heath staff and users, the composition and team work have different characteristics than those of hospital health care [1].

Hence, if studies and reflections performed in and about hospital health care are transferred, in a non-critical way, to primary care, bioethics issues will, most likely, be inadequate. Not to mention the equivocated management of situations that generate ethical issues, since one health setting would have been undertaken as a model for others. This means that the particularities of other settings were disregarded. Hence, studies should be performed to identify ethical issues specific to primary care, especially considering basic health units[2-4].

Based on these motivations, this study was performed to identify ethical issues experienced by nurses of the Family Health Program and the foundations that guide their decisions in these situations[5].

This article discusses the results concerning relationships with users and their families, from the nurses' perspective, with a view to contribute to the construction of bridges between health care and work, between welcoming and technique in nursing practice. Bioethics provides ethics to new professional relationships and dismisses any voice of domination in relationships. This is because it realizes and legitimates the plurality of roles and voices with a view to avoid disqualification of people due to the exercise of power. The combination of active hearing, attentive look, genuine reflection, knowledge, and technical competency enables respectful professional relationships, which promote human rights, freedom, and dignity[6].

METHODS

The study sample consisted of 17 nurses from family health teams in the City of Sao Paulo. The sample size was determined according to the criteria of representativeness and variability that would permit to approach the statements about the investigated issue considering its multiple dimensions, thus saturating it. The project was approved by the Institutional Review Board at the University of Sao Paulo Public Health College.

This is a empirical, qualitative, descriptive ethics study, which consists of a factual investigation of the moral conduct by means of scientific procedures and methodologies, with a view to learn about how people reason and act. Since bioethics regards scientific rather than philosophical tasks, one of the functions involved is to identify and characterize the ethical issues experiences in health care practice.

By means of semi-structured interviews, participants were asked to report a situation they had experienced in which they considered that ethical issues had been dealt with. Participants were then asked to list the issues. After transcribing the recorded statements, thematic category analysis was performed according to Bardin[7]. Content analysis revealed three domains regarding situations that generated ethical issues: relationships with users and their families; staff relationships; and relationships with the organization and health system.

Since this study is performed based on descriptive ethics, the terms ethical issue and dilemma were differentiated. Dilemma involves "the situation of having to chose between two contradictory propositions"[8]. By extension of its etymological meaning, the dilemma expression is applied to the "mutual opposition of two philosophical theses so that accepting or rejecting one, along with its corollaries, means denying or confirming the other without the possibility of being refuted by the principles professed by the two supporting parties"[8].

On the other hand, an ethical issue addresses the ethical aspects, questions, or implications of "common" occurrences, trivial to health care practice, and do not necessarily constitute a dilemma, as previously described[9]. Ethical issues always comprise value conflicts, evidently, and values are based on facts. However, the actors involved in the cases are the ones who select the ethical issue that afflicts them and which they want to discuss. This is not an expert's prerogative[10]. Hence, the following enunciation of ethical issues is presented according to that stated by the participants.

RESULTS: THE ETHICAL DIMENTION OF THE USER-NURSE RELATIONSHIP IN THE FAMILY HEALTH PROGRAM (FHP)

The nurses reported the following ethical issues regarding their relationships with users and families: difficulty to establish limits to the professional-user relationship; staffs' prejudgment toward patients; professional's disrespect against users; unclear clinical indications; prescribing drugs that the user cannot afford; prescribing expensive drugs that are just effective as inexpensive ones; user's request for procedures; how to inform users so to achieve treatment compliance; omitting information from users; health care professionals' access to information regarding users' intimate family and married life; difficulty to have privacy in domiciliary care; disclosing users' diagnosis to their family members.

Results show that ethic issues in the primary health care

setting result from ordinary health care concerns. A study performed in Israel[3] reported the 10 most common ethical issues reported by community health nurses, which included: conflict between users' and their families' needs; providing care to offensive users; reporting incompetent actions by physicians or nurses; professionals' insulting or rude behavior toward users; omitting information form users due to family pressure; administrating wrong treatments or with questionable validity; and causing embarrassment to users that refuse the treatment.

This evokes the subtlety that can surround ethical problems in primary health care[9]. Primary health care, mainly concerning the Family Health Program (FHP), mainly concerns chronic situations, and is offered through time, with mid- and long-term results; equivalent to a movie. Regarding hospital care, the momentarily encounter occurs in acute episodes that require immediate results, comparable to a photograph[1]. This constancy and apparent simplicity of encounters with primary health care users imply specificities and particularities regarding the form that ethical issues emerge, which could make their recognition difficult. In addition, the ethic issues that most appear are the most controversial, like abortion, euthanasia, cloning, etc.

It appears that these primary health care particularities also explain the difficulties implied in establishing limits in professional-user relationships: "*the limit of the professional-family relationship, professional-patient, for me, is an ethic dilemma (…)we do out part and we don't have to mind other businesses (…) I think we are, indeed, responsible, we have, indeed, to do something.* (E2)

Autonomy is often mistakenly confused with independence, which would imply that respect to the autonomous person is limited to not interfering in their decisions and choices. Individualism is the foundation of this understanding and thus spreads the rationale of interpersonal responsibility, domesticating the capacity of indignation in face of inequities, and reducing ethics to defensive aspects, in detriment to its affirmative and creative dynamism. Health care consists of practicing ethical proximity, and therefore demands contiguity, availability, and concern for others, addressing their pain. However, though it is impossible to help others from a distance, proximity should not mean affective dependence that obscures personal identity. Nurses cannot take the other's place and speak for him/her. There should be some distance in health care, so that individuals can take responsibility and make their own decisions, from either edge of the relationship; nurse and user. Moments of strong proximity should be balanced with others of respectful distance[11].

The rude and offensive behavior of the health staff toward users could compromise autonomy respect and promotion, which presupposes a dialogue relationship between tow people that recognize each other as subjects. Though a violent and aggressive behavior might not make the relationship unfeasible, it at least threatens a relationship that aims at users' autonomy. From one side, users seek the solution to a health problem they consider important; and, from the other, the health workers are often restricted by procedures, norms, and service routines, or, yet, to their technical expertise regarding what is best for the user. Considering the failure to meet interests and needs, negotiation, made effective through respectful speech and qualified listening, becomes essential. This is especially true because, sometimes, health care professionals do not understand the users' needs as a health issue[12]. Communication is indispensable to health care, since, in addition to being the main means of education, it is the resource to establish trust and attachment between users, health care professionals, and the service[13]. However, the most important aspect in this regard is not the ability to make logical arguments, rather, it is the dialogue of presences, that is, meeting individuals that are willing to speak, look within, find acceptance, and mutually improve[11].

The FHP characterized by the bond and co-responsibility regarding health. Program actors (nurses, physicians, community health agents, and administrators) identify the profile for this work as: "committing"; "becoming involved"; and "seeking social equity" [14]. These attitudes evoke the idea of alterity (otherness): "being able to consider others in the plenitude of their dignity, rights, and, overall, their differences". This implies to replace and value the understanding of the self in relation to the other, considering the latter's singularity and uniqueness. Overcoming injustice situations necessarily comprises going through changes in one's understanding toward others, while breaking with modern rationalism and individualism[15].

The user's autonomy cannot be judged and specified without taking nonmaleficence and justice into consideration, as it is evidenced in this procedure request: *"There is a case of a HIV-positive patient and his exam has been repeated 3 or 4 times. But he still doesn't believe it, he's in denial (…) his exam is going to be repeated again, the doctor thought it is better because (…) he won't eat, he won't take his drugs, he won't do anything"* (E11)

Naturally, patients have the right to autonomously accept their therapeutic project along with the health team. However, in this negotiation, obligations concerning nonmaleficence and justice principles: not impair and effectively and efficiently use health resources, so as to avoid waste and promote appropriate use; should also be considered. This should be observed especially in situations of scarcity, as in the Brazilian health system. The user asks for a new draw for the HIV test, and his request is answered based on the possible harms of denying him this right. However, it is acknowledged that health staffs often work with limited quota of laboratory exams, as in this case. In exceptional situations, the benefits of renovating users' belief regarding their doubtful diagnosis justify repeating exams, though unnecessary and implying unfair costs to the health system[5]. This view apparently exceedingly considers the

individual perspective due to the important character of autonomy and freedom of choice, which marks North American bioethics. The ethical justice principle should be founded by health care directed to promoting autonomy and co-responsibility. Thus, unnecessary procedures should be refuted so that scarce resources can be equally distributed.

It appears that concerns regarding the users' conditions to buy the prescribed drugs exceed the biological aspect of the complaint-conduct model. Hence, it is possible to exchange values and conceptions with a view to health co-responsibility: "*If I am to prescribe an ointment (…) I have to know if it is available at the health unit's pharmacy and if she can afford it. Because there is no use in writing the prescription if she just puts it away and doesn't use it. So there are natural things…* (E11)

Autonomy, in the Latin-American reality, should be rethought more dialectically, considering vulnerability, especially concerning its social dimension. Respect to autonomous people, therefore, should not be limited to passive attitudes of simple not invading the other's autonomy. In fact, more should be done so that, with mutual help, face deficiencies and build autonomy[16]. Only the capacity to transcend and understand the other's pain can provide the sensitivity that would generate the readiness to overcome contradictions and the system producing this pain followed by the denial of others[15].

The vulnerability principle directly challenges nurses in terms of their responsibility to establish symmetrical relationships with health service users. It obliges professionals and institutions to protect, and care for all citizens equally. Moreover, this principle exceeds the logic of demanding people's rights, to announce the solicitude logic of people's obligations[17]. It has the purpose to complement the ethics of rights, founded on individual freedom and developed over the reinforcement of autonomy, with and ethics of responsibility established on otherness and cultivated on solidarity.

Health care humanization requires guarantees regarding the right to information, one of the key elements for users to be able to make substantially autonomous decisions about their health. The relationship of trust, bond, and co-responsibility determine nurses' obligation to recognize and give information in a comprehensible way, that is, simple, approximating, intelligible, loyal, and respectful[18]. Therefore, it is surprising that the nurses' concern was regarding how they should provide information to obtain patient compliance, and not how to transmit information to assure clear and substantially autonomous decisions.

Some statements reiterate concern regarding the "friendship", that many times is established between professionals and users due to the particularities of health care in the FHP, which provide access to information outside the clinical domain, entering intimate aspects of the family dynamics: *(…) suddenly appears in the middle of a nurse visit (…) stories of adultery (…) unwanted pregnancy or doubtful paternity (…)*" (E5).

Clearly, this situation implies the obligation to preserve confidentiality[19], since otherwise, users usually would not feel comfortable with sharing such private and potentially embarrassing information. Nevertheless, approaching intimate family life aspects generates certain discomfort, as shown in this study.

The FHP with domiciliary visits and community health agents enhances the closeness between families and neighbors, which poses new challenges for preserving confidentiality:

"*(…) sometimes (…) during the visit, there are other people (…) neighbor (…) you end up talking with the patient, but other people also have access to what is happening with that person"* (E10)

"(…) *the community agents (…) have access to the patient form and talks about the neighbor, who has a certain problem* (…)" (E3)

Sharing information with families is expected, due to the caregiving and protective role **[20]**. However, each user has the responsibility to what information from their private domain they wish and authorize to be revealed to his or her family, neighbors, or close friends, even if they are health care professionals.

DISCUSSION: BIOETHICS' PERSPECTIVE FOR THE USER-NURSE RELATIONSHIP IN THE FHP

The situations experienced by FHP nurses cannot be characterized as dilemmas. Rather, they represent ethical aspects regarding the everyday health care setting. They are different from critical situations that require immediate solutions, faced in the hospital setting. These particularities could result in the difficulty to recognize them, with possible harms to health care, mainly concerning attachment and health co-responsibilization; FHP guidelines. Hence, it appears that to work with primary health care, professionals, in addition to redirecting their daily clinical practice, should re-evaluate their sensitivity regarding understanding, perceiving, and considering significantly ethical or problematic situations. Professional education, marked by hospital-centered approaches and experiences in highly specialized environments also affects nurses' ethical rationale.

Nurses showed they respect users' autonomy by preserving their confidentiality and privacy. They also showed they are able to consider and effectively balance this prima facie principle with the similarly obligated nonmaleficence principle, mainly when considering risks to the health and life of third parties or the community.

However, it appears that nurses are not well prepared to deal with light relational technologies, like communication, welcoming, attachment, and qualified hearing.

Users should have access to information so they can

make substantially autonomous decisions and make health care citizenship effective. Nevertheless, this will only be possible when nurses master the skills to carry out communicative, dialogue-based, emancipatory processes.

Health care actions, which mark nursing care, should be founded on user autonomy. Further, it should be acknowledged that it still often requires mutual effort and solidary solicitude. Though vulnerable, caregivers and service users, together, are capable of major transformations. However, if isolated, they will only be able to maintain what already is established in the society.

FINAL CONSIDERATIONS: BIOETHICS' PERSPECITVE FOR NURSING IN THE FHP

Making the FHP effective is not limited to a new technical-service staff composition or a reformed basic health unit. If the construction of the Single Health System is a process of ethical turmoil, since it demands attitude and cultural changes of the multiple actors involved, the FHP expands and deepens the path of this ethical spin and reinforces the need for ethical sensitivity and commitment with otherness.

Nursing practice in the family health care team should be marked by humanization, health care, citizenship, and the respect to human dignity and freedom. Moreover, it should be founded on understanding that life conditions determine families' health-disease-care process – and thus require the effort from nurses to transform this process with a view to promoting health and building autonomy.

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