Confidentiality and privacy of information about patients treated by primary health care teams: a review

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Abstract

As part of the treatment process, a multi professional primary health care team has access to the health information of a user. Such access raises questions regarding the confidentiality of this information and the privacy of the user. The present study uses a review of literature as a basis with which to discuss this issue. A search was performed of the SciELO, Lilacs and BVS databases using the fixed descriptors: secrecy, privacy and confidentiality. While earlier articles discuss the issue in the context of a professional code of conduct, excluding community health agents from access, the most recent study, concerning the care of HIV patients, is more embracing. It can be concluded that confidentiality is an arrangement between the health team and patient, creating new perspectives for the activities of community health agents and regarding access to and the role of the medical records system.

Keywords: Primary Health Care. Health Team. Privacy. Confidentiality. User embracement.

Resumo

Sigilo e privacidade das informações sobre usuário nas equipes de atenção básica à saúde: revisão

No atendimento à saúde, a equipe multiprofissional de atenção básica tem acesso às informações de saúde do usuário como parte do cuidado. Diante disso, é oportuno levantar a questão do sigilo e da privacidade das informações no trabalho de equipe. O artigo faz revisão da literatura, com o objetivo de discutir o tema. As consultas foram realizadas nas bases de dados SciELO, Lilacs e BVS, utilizando sigilo, privacidade e confidencialidade como descritores fixos. Os artigos mais antigos reportam o assunto ao código profissional, que exclui os agentes comunitários de saúde do acesso às informações; os mais recentes introduzem o acolhimento, ao tratar do cuidado de portadores do HIV. Conclui-se que a confidencialidade é uma pactuação entre a equipe e o usuário, abrindo novas perspectivas para a atuação dos agentes e para o papel e a acessibilidade do prontuário médico.

Palavras-chave: Atenção básica em saúde. Equipe de saúde. Privacidade. Comunicação sigilosa. Acolhimento.

Resumen

Sigilo y privacidad de las informaciones sobre el usuario en los equipos de atención primaria a la salud: revisión

En la atención de la salud, el equipo multi profesional de atención primaria tiene acceso a las informaciones de salud del usuario como parte del cuidado. Esta realidad pone en discusión la cuestión del sigilo y la privacidad de las informaciones cuando se trabaja en equipo. Este artículo es una revisión de literatura con el objetivo de discutir sobre el tema. Las consultas fueron hechas en la base de datos de SciELO, Lilacs e BVS, al utilizar como descriptores fijos: sigilo, privacidad y confidencialidad. Los artículos más antiguos reportan el asunto al código profesional, excluyendo los agentes comunitarios de salud del acceso a las informaciones, mientras que los más recientes introducen el acogimiento para hablar del cuidado de los portadores del VIH. Se concluye que la confidencialidad es un pacto entre el equipo y el usuario, abriendo nuevas perspectivas para la actuación de los agentes y para el acceso y papel de los registros médicos.

Palabras-clave: Atención primaria a la salud. Equipo de salud. Privacidad. Confidencialidad. Acogimiento.

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In classical health care models, confidentiality and privacy of information are part of the doctor-patient relationship. It was an issue present in deontological codes of professional classes in charge of assisting patients in their demand for health services. With the increasing introduction of multidisciplinary health teams, especially in primary health care – such as it is the case of the family Health Strategy (ESF, Portuguese acronym) - the way to ethically handle confidential and private information must be reconsidered, as the sharing of such information in primary health care is essential to enable the team to be accountable for the longitudinal care of users, who do not depend exclusively on a single professional. Considering this new scenario, how can we preserve user confidentiality?

Confidentiality and privacy refer to how professionals must handle pieces of information gathered during medical care. Confidentiality concerns the attitude required of professionals to handle information resulting from this relationship. The three attributes – secrecy, privacy and confidentiality – are professional obligations when handling information [1]. In addition, these three attribute are also rights of users.

Primary health care teams, which also include community health agents, access and handle a lot of information on users. Thus, it is appropriate to discuss how to respect the secrecy and privacy of such information while working in a multidisciplinary team. The exchange of information between users and professionals is, in principle, related to the trust created in their relationship. According to Teixeira [2], this relationship depends on the quality of access and how users are received in the service, both marked by the establishment of a relationship based on user embracement, or yet, marked by the absence of such relationship.

According to Franco, Bueno and Merhy [3], user embracement is a step of the health service “production process”. And this process allows the connection between users, professionals and services, leading to the establishment of “accountability” and consequent solution of health production processes. In this user-embracement context, privacy of user information shared among the health team is agreed upon as a confidentiality “pact”.

Therefore, an agreement among health team members and users in regard to the handling of secret and private information must begin at the moment of embracement and continue all throughout the treatment, so as to establish a bond based on ethical precepts of respect to autonomy and to users’ uniqueness as well as of adequate information handling.

Thus, this study aims to review and analyze publications on the theme. Also, based on the results obtained, this study aims to discuss the issue of secrecy and privacy in user information handling in cases in which a multidisciplinary team is involved in primary health care.

Method

The study is characterized as exploratory literature review. A useful tool in this investigative methodology is a *literature map of the research on a given topic* [4]. The literature review aims to gather studies on a given topic, as well as to present, analyze and compare such studies so as to deepen the understanding regarding the theme in question. By capturing data and comparing it to their hypotheses, researchers can discuss the results based on the points in which similarities and differences are identified [5,6].

Papers available in several databases were referred to, such as those found in the Scientific Electronic Library Online (SciELO), the Latin-American and Caribbean System on Health Sciences Information (Lilacs) and the Virtual Health Library (VHL), using “secrecy”, “privacy” and “confidentiality” as descriptors browsed one at a time together with other descriptors: “user embracement”, “bond”, “team”, “Family Health Strategy (ESF)”, “Family Health Program (PSF)”, “primary health care” and “care”.

The inclusion of the selected papers was based on the following aspects: qualitative studies on primary health care conducted between 1995 and 2013. Papers were excluded when they were quantitative studies, monographs, thesis, dissertations, had an out-of-context thematic, were hospital network studies or literature reviews.

Results

During literature review, only eight studies fulfilled the inclusion and exclusion criteria. Some authors repeat themselves in more than one paper, and most of them recommend that secrecy and privacy in primary health care be part of the bioethics discussion agenda more clearly. To analyze the results, the papers were organized as follows, considering the year, name, volume and number of the publication, title of the paper and respective authors.

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Chart 1. Summary of the results found during literature review

Year	Publication	Volume (number)	Title	Authors
2004a	Saúde e Sociedade	13 (2)	The information in community health agents and patient relations in the Family Health Program	Fortes PAC, Spinetti SR [7]
2004b	Cadernos de Saúde Pública (Reports in Public Health)	20 (5)	Community health agents and patients' privacy	Fortes PAC, Spinetti SR [8]
2004	Cadernos de Saúde Pública (Reports in Public Health)	20 (6)	Bioethics and primary care: an outline of ethical problems experienced by nurses and physicians in the Family Health Program, Sao Paulo, Brazil	Zoboli ELPC, Fortes PAC [9]
2008	Saúde e Sociedade	17 (2)	Opening of privacy and the secrecy of HIV/Aids information concerning women assisted by the Family Health Program in the City of São Paulo, Brazil	Abdalla FTM, Nichiata L YI [10]
2008	Revista da Escola de Enfermagem da USP (Journal of USP School of Nursing)	42 (3)	Women living with AIDS and Family Health Program professionals: disclosing the diagnosis	Ferreira FC, Nichiata LYI [11]
2009	Saúde e Sociedade	18 (1)	User's perception on the Family Health Program in regard to privacy and confidentiality of information	Seoane AF, Fortes PAC [12]
2009	Ciências e Saúde Coletiva	14 (Supl. 1)	Ethical relationship in Primary Health Care: the experience of medical students	Ferreira RC, Silva RF, Zanolli MB, Varga CRR [13]
2011	Polis e Psique	1 (Thematic issue)	Secrecy in STD/Aids Care: from the doctor's office to organizational processes	Bellenzani R, Mendes RF [14]

The results found by Fortes and Spinetti [7] show the health team's concern in relation to user privacy management conducted by community health agents (ACS, Portuguese acronym), as they are not professionally regulated nor do they have a code of ethics to follow. Professionals in the team understand that ACS should only convey simple and general information to users. Thus, it is not within their competence to have access to information regarding each patient's pathology.

Physicians and managers believe access to medical records regards only the professional-user relationship, thus should not be granted to ACS. On the other hand, the team believes ACS should transmit patient information to physicians, even though patients might ask ACS not to tell physicians. Another concern that emerged was the issue related to preserving the privacy of ACS themselves, as ACS reside in a neighboring community, or even in the community where patients reside, which makes them practically the patients' neighbors.

Based on the results found by Fortes and Spinetti [8], the information given to ACS within a health care unit must be defined by management and be limited to administrative and organizational aspects of the task. Since ACS do not have health training, it is not their role to provide patients with information about diseases. Thus, the information provided by agents to users must be limited to aspects previously defined during the training sessions conducted by the team.

As a result, the data in medical records must not be opened to ACS, as they contain private information about users. Note that agents understand it is not within their competence to supply information on pathologies, treatments, medication and exam interpretation. It is also clear to them they play a supporting and intermediate role when it comes to users' access to health services. However, the better understanding of users' health would help agents play this role more efficiently.

A study published by Zoboli and Fortes [9] identified and organized three sets of ethical problems experienced in primary health care: user-family relationships; 2) relationships within the team; 3) relationships with the organization and the health system. By analyzing the discourse of physicians, the authors found difficulties to define daily routine situations in primary health care. The authors also stressed that ethical conflicts are subtle, unlike crises experienced in hospitals.

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Zoboli and Fortes [9] also indicate that the bound seen as a working tool in Family Health Structure makes room for closer relationships, which, in turn, may generate professional doubts, which may lead to uncomfortable and awkward situations. Thus, secrecy becomes an important issue, considering it is more difficult to preserve privacy in home health care. In addition, this health care service modality makes it more difficult to define which pieces of information must be shared with the team. The authors warn that this situation affects mainly ACS, once they reside in the community and are often neighbors of the families receiving health care services.

Another important issue identified by the authors regards the thin line of conduct for professionals adopting a persuasive attitude in regard to therapeutic proposals to users – which might be ethically defensible – as opposed to a coercive attitude which does not consider users' leading role in their recovery process. In this way, physicians and other team members must have as their motto the production of health, autonomy and the guarantee of rights to users.

A study by Abdalla and Nichiata [10] mentions as results four sets of issues on secrecy and privacy, related to women living with HIV: 1) disclose of the HIV diagnosis to users; 2) user embracement and bond in privacy opening; 3) disclose of the HIV diagnosis to members of the Family Health Program team; 4) team discussion of the case and information secrecy.

User embracement was mentioned by professionals as being essential to build the bond. The establishment of this bond requires time and patience on the part of the team, as well as the establishment of a confidentiality agreement, that is, a pact between professionals and users. User embracement begins when the bond is established, and it is perceived by professionals as a moment to listen and identify users' needs.

Based on what professionals reported during the focal discussion group, the authors observed that when the team does not find out about the HIV diagnosis by means of exams and referrals, it is often revealed by users themselves. When concrete cases of women with HIV were discussed by the team, there were differences of opinion among the professionals in regard to information secrecy. According to the authors, one of the physicians advocates for the *democratization of ideas, once the Family Health Program is team-oriented* [15]*.* By "democratization" this physician refers to the need to reconsider secrecy and privacy in teamwork. Despite being concerned with secrecy once they live within the users' area, ACS argue that these situations must be discussed as a team. However, everyone agrees that the condition required for this discussion to happen is users' consent so that information on their diagnoses can be shared within the team [10].

Based on interviews made with six women with HIV who are users of a specialized health care service (SAE, Portuguese acronym), as well as considering ethical discussions on privacy and autonomy, Ferreira and Nichiata [11] propose two analytical categories that indicate the reasons for SAE users to reveal, or not, their HIV diagnoses to one or more professionals in the Family Health Program (PSF, Portuguese acronym). The following situations favor diagnosis disclosing: when the diagnosis is made in the unit, when sharing resulting from the diagnosis itself occurs; 2) when the information is relevant to treatment, as users feel they will receive better care as HIV-positive patients; 3) when a bond is established with the professional(s), especially the ACS. Trust in ACS is established as a result of ACS clarifying doubts and providing information on patients' rights as users of the system; 4) when patient is certain of the absence of pity on the part of the professional.

However, the authors identified situations in which users do not disclose their diagnoses to Family Health Program professionals: 1) when they feel fear and insecurity resulting from some improper attitude on the part of the professional; 2) when they lack information or are misinformed of the role of the Family Health Program; 3) when they are suspicious of a possible breach of confidentiality by the Family Health Program professional; and/or 4) when they use another service and believe they do not need to be taken care of by the Family Health Program team.

A study by Seoane and Fortes [12] show the point of view of primary health care users on important issues related to the work of ACS in communities and as part of the Family Health Care team. It becomes clear that ACS are perceived as facilitators of users' access into the service, and none of the testimonials expressed any discomfort about this. Often it is the agent that promotes the link between users and the remaining team members, acting as an intermediary in access to residential users.

Nonetheless, when it comes to information provided to the ACS, there is some difference of opinion among users. Some believe that information to this professional must be limited and aspects regarding their pathology must not be disclosed. Others do not mind reporting health issues to ACS and are aware that whatever they had mentioned to ACS may be shared with the team of professionals.

Ferreira, Silva, Zanolli and Varga [13] study the perception of medical students regarding ethical relationships involved in health care internship activities in communities. Three categories can be perceived when their speeches are analyzed: importance of ethical and professional education considering the reality of primary health care (PHC); 2) confidentiality of information in the development of medical professional secrecy; 3) interpersonal relationships in the ethical development of medical students. From the beginning, the learning of ethical relations at this level of PHC is perceived as important by students who, despite that, show difficulty defining situations in which information sharing would be required.

A study by Bellenzani and Mendes [14] assesses how secrecy is handled in work processes involving specialized HIV/Aids services. The authors show that the professional team considered secrecy and privacy extremely important themes when it comes to offering quality and humanized services. Given the nature of the health care provided, the service was concerned to include other types of care, so as to avoid a biased classification and user stigmatization by the population of the municipality, which is considered small.

Contrasting to the testimony of professionals on the importance of secrecy, during the observation of daily routine services, it was possible to identify situations of professional disrespect to users' right to secrecy. Such disrespect was noticed both when users sought health care and when physicals were conducted. This might have been caused by lack of organization in the service, as well as by insufficient training to handle sensitive situations such as this one, which might lead the professional to inadvertently reveal aspects related to users' sexual privacy or that of third parties (even when they are not present). This might expose users to moral judgment by those receiving the information, who might even be a family member.

The study made it possible to perceive that the notion of secrecy on the part of professionals was limited to not revealing the names of those who were HIV-positive. However, the delivery flow of serological test results and other work routines such as the use of user transportation made by vehicles identified with the logo of the DST/Aids program left gaps that could have exposed patients to embarrassing situations and even to breach of secrecy and privacy, even though that might have happened indirectly.

Discussion

The analyses of the bibliographic data selected in the literature led to three major themes interrelated to secrecy and privacy of information: the first one regards patients' medical records; the second is related to community health agents and the third one regards user embracement as a bond-establishing tool.

As for the first aspect, patients' medical records, the analysis showed the importance of its completion by team members, the type of information they must contain and who may access them. The second aspect, related to ACS, allowed the identification of the importance of accurately defining which pieces of information must be collected and which ones must not, as well as how to transmit or communicate this information to the team and establish team access level to medical records. The third major theme, user embracement, was identified as a user-oriented tool to promote bonding. User embracement was identified as the timely moment to work issues related to information secrecy and privacy and, thus, deemed the ideal context to agree on secret and private information shared by the multidisciplinary team.

The first studies [7,8] advocate agents should not be granted access to medical records or to information related to user pathologies, arguing the ACS are not actually health care professionals as they lack a professional code of ethics which legally requires their secrecy. The analysis and exclusion of ACS when it comes to access to information is characterized by a legal perspective regarding a professional code. Medical students found out the positive value of learning ethical relations in practice. However, they have difficulty defining how to handle primary health care information, as their professional imagery is guided by those deontological obligations established in the professional code [13].

More recent studies show another point of view [1, 11, 15] as they address, for instance, how to handle information of HIV-positive patients. In such case, professionals do not assume the legal approach provided in the professional code of ethics. Instead, they adopt a user embracement approach, working as facilitators of a reliable environment, which is required between users and professionals.

By analyzing the literature, it was possible to perceive the need of a more adequate approach in regard to the handling of information needed in the work of the multidisciplinary team in charge to caring for users. This is the case of primary health care, a service which is characterized by teamwork practices that depend on the active participation of ACS. In this way, agents are team members who, during their home calls, have access to confidential information either through observation or through conversations with users. They often know more about the general state of users than health professionals themselves. Thus, the issue of confidentiality must be mentioned and discussed in team meetings, so as to allow the construction and agreement of accountability when it comes to shared information.

The legal perspective of the professional code of ethics is insufficient to discuss this problem in cases in which the work is carried out by a multidisciplinary team and a longitudinal life care approach is used. In such cases, the only way to handle the issue of confidentiality is through an environment that promotes embracement, trust and bonding. The legal perspective focuses on obligations set forth in the professional code, whereas the user embracement approach focuses on user welfare and rights, so as to define and agree on information sharing.

Ultimately, users own the rights to their medical records, and they should know and define who can have access to them in primary care. Since primary health care is team-oriented and has a broader view of health, medical records can and should include all information deemed essential to users' longitudinal care, even though this information might not be directly medical-related. Thus, agents may bring in relevant information related to users' care and, for this very reason, these pieces of information must be included in the medical records. Thus, with proper consent granted by the interested user, ACS may have access to medical records and help completing them. However, all this must be discussed by the team as a permanent means of education. In addition, it must be agreed upon in the construction of professional accountability, which also includes agents.

In this sense, the National Policy for Primary Health Care of 2012 establishes permanent education as the response to the requirement for *a great capacity to analyze, intervene, and allow autonomy to promote the establishment of transforming practices, change management and the strengthening of links between work concept and execution* [16]. The challenge and the requirements regarding secrecy and privacy of information in a multidisciplinary primary health care team are the necessary links to bring the health care model proposed closer to the broader concept of health and teamwork, as well as to transforming health care practices. This perspective allows for the identification, discussion and handling of critical aspects of this new model, among which are secrecy and privacy of information within a multidisciplinary team, *encouraging innovative experiences in care and health care management* [17].

Final Considerations

The results of the systematic review showed that the discussion on secrecy and privacy of information in primary health care had a gradual transfer of the legal professional code perspective - focused on individual professional obligations – to a user embracement approach - focused on the rights of users and on the work of a multidisciplinary team. In primary care, if part of a broader view of health and teamwork is considered, this leads to a new perspective which allows professionals to consider different paradigms to address the issue of confidentiality aiming practical aspects such as medical record completion and purpose, as this document may include information about the patient which might not be strictly medical-related, as well as its consequent access by ACS. This different focus on secrecy and privacy analysis in primary health care reveals diverse perspectives between professional ethics and bioethics to address ethical issues: The former is more focused on obligations set forth in the area's respective professional code, whereas the former is not characterized by a legal perspective, as it considers other contextual and subjective elements to discuss the issue.

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Participation of the authors

José Roque Junges was responsible for the design, analysis, discussion and correction of the article; Micheli Recktenwald coordinated the collection and reading of the articles, organization of the material, discussion and writing of the article; Noéli Daiãm Raymundo Herbert, Andressa Wagner Moretti, Francine Tomasini and Bárbara Nicole Karlinski Pereira participated in the collection and reading of the articles, discussion and writing of the article.

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