

FAMILY PERSPECTIVE ON A FAMILY CARE PROGRAM

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This study aimed at assessing the family's perspective on a family care program to better understand the challenges and potential capacities for changing the health care model. A qualitative study was carried out to assess the Family Health Program in the city of São Sebastião, Brasília, Brazil. Data was collected through direct systematic observations of the workflow developed by the program's team, and through focal groups with family members. The discourse of the collective subject was used in data analysis and showed that health prevention and promotion actions and the relationship between providers and consumers were positively evaluated while access to health services, drugs and providers was negatively evaluated. There is no assurance of comprehensive and continuous care to the family, which points to the need of reviewing the strategies of health service organization for more effective involvement of the community to meet their health needs.

DESCRIPTORS: primary health care; family health; consumer satisfaction

LA ATENCIÓN A LA SALUD DE LA FAMILIA EVALUADA POR EL PROPIO USUARIO

Este estudio tiene como objetivo analizar la evaluación del usuario sobre la atención a la salud de la familia, con la finalidad de verificar las dificultades y potencialidades para transformar el modelo de atención a la salud. Se trata de un estudio de caso cualitativo, realizado en una Unidad de Salud de la Familia, en San Sebastián, Brasilia-DF, Brasil, cuya recolección de datos consistió en la observación del proceso de trabajo desarrollado por el equipo y grupos focales con usuarios. Los datos analizados, utilizando la técnica del Discurso del Sujeto Colectivo, demostraron que las acciones de prevención y promoción de la salud y la relación de profesionales y usuarios fueron evaluadas positivamente; y, el acceso a los servicios de salud, a los medicamentos y a los profesionales fue evaluado negativamente. Las acciones desarrolladas no garantizan la atención integral de la salud de la familia y señalan la necesidad de revisar las estrategias de organización del servicio, sobre todo las que posibiliten la participación de la comunidad para resolver sus necesidades.

DESCRIPTORES: atención primaria de salud; salud de la familia; satisfacción de los consumidores

A ATENÇÃO À SAÚDE DA FAMÍLIA SOB A ÓTICA DO USUÁRIO

Este estudo teve como objetivo analisar a ótica do usuário sobre a atenção à saúde da família, a fim de verificar as dificuldades e potencialidades para a transformação do modelo de atenção à saúde. Trata-se de estudo de caso qualitativo, realizado em uma Unidade de Saúde da Família, a de São Sebastião, Brasília, DF, cuja coleta de dados consistiu da observação do processo de trabalho desenvolvido pela equipe e grupos focais com usuários. Os dados analisados, utilizando-se a técnica de Discurso do Sujeito Coletivo, demonstraram que as ações de prevenção e promoção da saúde e a relação profissionais-usuários foi avaliada positivamente e o acesso aos serviços de saúde, aos medicamentos e aos profissionais foram avaliados negativamente. As ações desenvolvidas não garantem a integralidade da atenção à saúde da família e apontam para a necessidade de se reverem as estratégias de organização do serviço, sobretudo aquelas que possibilitem a participação da comunidade para o alcance de suas necessidades.

DESCRIPTORES: atenção primária à saúde; saúde da família; satisfação dos consumidores

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INTRODUCTION

The Family Health Strategy (ESF) is a priority approach for the reorganization of primary care based on the Brazilian National Health System (SUS) principles. This strategy should be implemented using management and health practices that are equitable and involve the community, provided by a multidisciplinary team and delivered to populations in defined linked areas with the use of highly effective and complex, low-density technologies⁽¹⁾. It should be integrated to a network of services to assure comprehensive care to individuals and their families and provide referral and counter-referral from the primary care level to more complex levels of attention.

In the Federal District, Brasília, the Family Health Strategy is currently known as the Healthy Family Program (in Portuguese, PFS). Ten years after its implementation, as seen nationwide, PFS has been meeting significant challenges locally. Difficult access to care, discontinued attention and lack of comprehensive care are some of the problems faced, calling for a profound reevaluation of this complex program⁽²⁻⁴⁾.

It is thus crucial to evaluate the PFS as part of a process of critically assessing the services provided based on the participation of the involved actors, especially those users who can more clearly and reliably articulate their opinions on care delivered to them^(2,5-9). In this sense, the evaluation made by the very population attended by PSF team aims at providing input for rethinking professional practices and implementing actions for the improvement of service organization.

Studies as such have incorporated into the evaluation process a subjective dimension that allows to assessing quality of PSF services, including user's satisfaction assessment⁽⁶⁻⁹⁾. However, it should be noted that most studies have adopted mechanist and functionalist approaches, overlooking priority issues for service evaluation⁽⁷⁻⁹⁾.

Acknowledging these limitations and the special need to broaden the analyses and go beyond the simple appraisal of PSF user's satisfaction, an evaluation process has been proposed to explore cultural and behavioral changes: representations of the health-disease process, appropriate care practices and health management strategies⁽⁸⁻⁹⁾. Also, it should further examine the meaning of family, which is regarded as a social agent of change from a wider perspective.

Hence, this evaluation should allow users to actually expressing their subjective views about the

care service⁽⁷⁻¹¹⁾, giving them an opportunity to freely discuss their feelings and perceptions about several different dimensions: general needs (deficiencies, health-related necessities); cognitive (perception about care service); relational (respect, listening, reception); organizational (access to services, drugs, providers); and professional (quality and competence)⁽⁸⁻⁹⁾.

The purpose of the present study was to provide input to consider the inclusion of user subjectivity in the assessment of health service quality and to examine family care from the user's perspective to identify critical challenges and potential capacities for improving care and ultimately reorganizing the care model.

USER SATISFACTION: A BRIEF REVIEW

Since 1960s in Europe and the US and mid-1990s in Brazil, user satisfaction approach has been applied in health evaluation studies⁽¹²⁻¹³⁾. This approach focuses on the different dimensions involved in health care, from doctor-patient relationship to the quality of facilities and care delivered by health providers.

The concept of quality has enabled to better define measurement variables of service quality with the inclusion of a non-specialized outlook; i.e., users' view⁽¹³⁾. Several models have been designed for user satisfaction assessment and most are based on the assumptions of user perceptions concerning their expectations, values and needs at the different dimensions of health care⁽¹²⁻¹³⁾.

When forming their opinion about services, users take into consideration one or more combinations of the following aspects: an ideal service; a notion of care service they ought to have; their past experiences in similar services; and a minimum subjective level of service quality to be achieved to be acceptable⁽¹²⁻¹³⁾.

Recognizing the inherent complexity of user's assessment process of service quality, the World Health Organization (WHO) introduced a surrogate for the concept of satisfaction: responsiveness. This proposed concept intends to examine how governmental actions meet people's expectations and demands⁽¹²⁾ and is based on the assumption that health systems should promote and maintain people's health, treat them with dignity and facilitate their involvement in decision making regarding their health care, treatment and other management.

More recently, due to a concern to actually take into consideration users' status in health services and systems and, more importantly, to allow them to express their status, the concept of humanization was included in the design of health services evaluation studies⁽¹⁰⁻¹²⁾. This concept focuses on human, individual and ethical dimensions of care and user's rights and empowerment. Although new and not yet strong, this proposal calls for the inclusion of a health-related social/cultural dimension in the evaluation process, especially in qualitative studies.

METHODS

It was opted to conduct a qualitative study as it allows capturing subjects' perceptions, beliefs and values on an array of situations routinely experienced at PSF. The PFS unit in the city of São Sebastião, Federal District, was studied since it met the inclusion criteria: large staff in the metropolitan area; at least six months of operation; and primary care team available (one doctor, one nurse, three nursing assistants and five health workers).

A two-step data collection was carried out. First, data was collected from a focus group discussion. There were two sessions, on average an hour and half each, where a coordinator and an observer met with members of 10 families who attended the PSF for at least a year and lived in the five microareas studied. The focus group participants were selected by drawing and had the following profile: 60% were females, 40% males; 50% had complete and 50% had incomplete elementary schooling; 60% were homemakers, 30% unemployed and 10% were retired.

The focus group discussions were guided based on the following statements: "Tell us how you perceive the PFS"; and "Tell us about the pros and cons of care provided at the PFS". The discourse of the collective subject (DCS) approach was applied in the analysis⁽¹⁴⁾. Key expressions of central ideas were first identified in each speech and then central ideas were singled out and grouped. Each group was named and a summary central idea was designated. Finally, DCS were constructed for each group as shown above.

The second step of data collection included non-participant observation of the work process developed at the PSF unit. Two trained investigators collected the data and recorded it on a log book.

The following aspects were observed over a two-week period (30 hours): user's reception,

screening, medical and nursing visits, procedures, home visits, campaigns and educational lectures. Over the first week, there were 20 hours of observation (morning and afternoon), and over the second week, 10 hours (morning and afternoon). The study investigators deemed this amount of observation time sufficient as it provided information on how the work was developed at that service.

This step was intended to assess the quality of care, the relationship between providers and users, access to care service and management effectiveness. To further explore the reality of care, i.e., PSF everyday operation, this data was cross-examined with DCS.

The study was approved by the Federal District Local Health Department (SES/DF) Research Ethics Committee and all subjects signed a free informed consent form after the objectives, methods, risks and benefits of the study were discussed.

RESULTS AND DISCUSSION

DCS 1 showed that users, when referring to PFS, first focused on the *health representation*. This representation should be well understood as it guides users' attitudes and practices toward health care⁽⁸⁻⁹⁾.

Health comes first. If you have good health, you sleep well, get up in the morning feeling good, and eat well. Health is not having body pain or headaches, is having a healthy body, it is not getting too tired and feeling well for work. Health is wealth. It does not mean only doctors and drugs. You have to be concerned about your eating, cleaning your house and your children. (DCS 1)

This discourse reveals that users have sought to incorporate into their life the broadened, SUS-proposed concept of health as a component of quality of life. Health is not only understood as an absence of diseases, a long-lasting concept that generally intended to keep a healthy, productive body. The WHO, in an effort to broaden the understanding of health, has proposed the concept of health as complete physical, mental and social well-being. But this concept has been largely criticized for not considering it a process involving economic, social and cultural factors.

In fact, while health providers have been promoting a change in the way people take care of their health, many efforts still focus on the biomedical model with a strong mechanist or at most systemic emphasis that affects health practice⁽¹⁵⁾. Such approaches fail to facilitate the complex human processes of life, health, care, cure and death.

There is a need to advance actions of health prevention and promotion as well as to reinforce the idea of health as a social right based on the utilization of all technologies available for health prevention, promotion, treatment and rehabilitation⁽¹⁶⁾.

DCS 2 illustrated the *family representation*, which is the main goal of PFS team work.

The family is the beginning of life and it comprises children, parents and siblings. It is a priority and symbolizes it all. I believe that if you have a family, you have love and harmony with the others. The family is a whole, it gives you love, affection, and care. It also can give you a better life. The family comes to your rescue during hard times, and helps you when you find yourself in a predicament and having a disease. We have to communicate with each other and if we have other problems, we have to forget them. (DCS 2)

Users described the family as a core social institution traditionally formed by a father, a mother and children and its role is to provide affection, care and help to its members. However, it has changed due to recent trends of reduced family size, fragile marital bonds and multiple arrangements other than that of the conventional nuclear family. This is above all a result of single-parent families commonly headed by single women. These trends have raised questions about the centrality and future of the families in modern societies as well as their responsibilities and social roles.

Focusing on the family is a breakthrough toward changing the health care model. Yet it calls that providers take an in-depth, contextualized approach. To begin with, family should not be regarded as a biological, natural or set body but rather a product of historical forms of human organization. In addition, the family can be approached in multiple ways and the health team should find the best approach that will allow them to take on roles that can communicate with each other and be complementary to produce a comprehensive care⁽¹⁷⁾.

Users evidenced their *representations about PFS team providers* in DCS 3:

The health team is also our family because they help us when we find ourselves in a predicament. Nursing staff provide us medicines, care, and cleans us and takes us to the toilet. This is all very important. However, there is god, there is the family and there is the doctor. The doctor is actually made by god; when you hand it to the doctor, you actually do so quite knowingly because he studied for that. (DCS 3)

Users have quite positively evaluated the health team and in particular show an affective bond because they realize they can count on the team's

help. The nursing team is regarded as a caretaker; the doctor is considered made by god, i.e., someone gifted to save lives and who has knowledge to manage health problems.

The representation of the doctor as a key element for managing problems is based on the hegemonic medical model. It makes it difficult to accept common knowledge, which is vital to promote the family role in health care through practices that do not involve medicalization.

DCS 4 addresses the evaluation of *practices developed by PFS team*:

We come here when we have bronchitis, for testing, checking blood pressure, prevention. Here they can cure flu, a small condition but when the problem is more serious, they send you to a hospital. That team that comes to your home they visit those who are in more need, they always come when it is serious, they have never come to my home. Doctors, nurses and health workers pay you a visit. The doctor has not been paying visits lately as he is quite busy. Yet the times they came to my home, it was very good, it was great for me. The team also gives lectures, they gave explanations, showed a movie. I liked it because they gave a lot of details. Another activity developed was the prostate campaign, I enjoyed it very much. (DCS 4)

In regard to the work developed at the PSF unit, DCS 4 evidences it is intended to the management of low-technology medical conditions. During the study observation it was verified that the work team spends most of its time in internal medicine, prenatal, growth and development visits which are prescheduled and organized on free demand. These visits are short, lasting no more than 15 minutes, and focus on complaints with little room for discussion between users and providers. Besides, there are also groups of high blood pressure and diabetes patients who have an opportunity of undergoing procedures for disease management.

Home visits, particularly paid to those patients with special needs, were positively evaluated. It was observed that health workers pay home visits, identify family problems and then discuss them with the team. They are welcome in the community and people tell them their problems and seek clarification about their care.

Users also positively evaluated lectures and disease prevention campaigns. It was found that lectures addressing hygiene care, healthy eating, environment and waste management, family planning and newborn care are delivered in simple language but attendance is low and educational resources are poor. Users had a positive attitude toward disease

prevention campaigns since they perceived it as an important opportunity of health management.

These findings indicate that PSF actions aim at managing health problems with low technology; they take most of the providers' time, especially the doctor's; and there are also educational and group management activities, which are highly important for improving primary care. However, it becomes clear that, for improving care quality, quality actions with effective involvement of users and based on the assessment of their actual needs and demands are required.

In DCS 5 users pointed out *flaws in the program organization*:

Here at PSF we are not seen on the same day but we make an appointment to be seen later. But there is a problem, if you are dying and do not have an appointment, you will not be seen. PSF's major flaw is shortage of drugs. The government usually issues a notice informing that drugs are available but when you get to the unit you do not get any drugs, you try and try but you end up buying at the pharmacy. It does not help to be seen and do not get any drugs, we get only part of the treatment. Another huge problem is to get test results. Blood test results are not available because the equipment is out of order, it cannot be so. Also, PSF health team does not manage it all, they are so few to attend so many users and they do not have the required resources for their work. We need a hospital to improve health (DCS 5).

With respect to program organization, it was pointed out difficult access to care chiefly because of bureaucracy obstacles to get to be seen. Everyday about 10 patients with scheduled visits are not seen. Several users had their visits rescheduled for a month later, some complained they had to come for the third time to wait for an opening. A large number of users also tried to get home visits and others complained of long wait at the unit and other services of higher complexity.

Another issue pointed out in DCS 5 was difficult access to drugs. It evidences that the Brazilian Ministry of Health drug aid program for promoting comprehensiveness has not been adequately meeting people's needs.

In addition, DCS 5 shows users have difficult access to testing. Apparently the difficulty to manage health conditions requiring high technology has made users believe they need a hospital in their area. This belief prevents users from appreciating PSF and health prevention and promotion actions as well. And, lastly, users reported difficult access to providers as there were too many people to be seen.

Access to many services (visits and tests) and drugs is limited. There is a clear need for PFS to

improve the program's comprehensiveness with sustained coordination of family-related health practices (not seen at the unit) to ensure the required delivery of continuous, global services and providers and organizations, all articulated in time and space. Comprehensive care necessarily requires the integration of services through care networks considering the interdependence of actors and organizations as they do not have by themselves all resources required for managing users' conditions during their life cycles⁽¹⁸⁾.

DCS 6 focus on the *relationship between providers and users*:

I was welcomed at PSF and very all served, they all treat me well. This team is very good in welcoming and providing people care, affection and attention. The doctor is excellent, I like him a lot. I cannot complain and I appreciate a lot their care. (DCS 6)

Users revealed that the team providers are kind and affectionate in both reception and care. Humanization of care was assimilated as a core component of work. This concept brings in the notion of dignity and respect to human life, underscoring the ethical dimension of the relationship between patients and health providers⁽¹⁹⁾.

In DCS 7, users expressed their *perceptions about the program* by comparing care provided at PFS and other health care units:

I thought that at PSF one would be better served than in other health care units but it is even better. In basic health units, you are no one. Some doctors see you but do not even look at our face, they do not check your pressure, do not put on the meter, they just write it down and send us away. See, I thought that was disrespectful. (DCS 7)

Users reveal PFS team providers have a humanized and caring attitude, which makes them feel treated with dignity and respect. The above findings indicate PFS has the potential to ensure humanization of care by establishing a bond between providers and users.

This was a right gained as a result of the process of strengthening democracy and people's empowerment granted in the 1988 Brazilian Constitution, which stipulated that health services should preserve people's autonomy and ensure their access to health information.

FINAL CONSIDERATIONS

The study findings show that representation of health as absence of disease based on the

biomedical model still prevails among health services users. It evidences a need of PFS to strongly focus on a broader concept of health, which includes the understanding of basic human biological, psychological and social needs for health promotion.

As for health practices developed at PFS, they focus on the management of health conditions requiring low technology. Users positively evaluated health prevention and promotion actions including home visits, educational lectures and disease prevention campaigns. These are valuable tools but more creative strategies are needed for improving care quality.

Users' satisfaction regarding service organization is very low, mostly because of difficult

access to services, drugs and providers, which are key for health management. Care provided was perceived as humanized, caring and respectful, which indicated that bonds can be developed between providers and users as they are crucial for family care.

In conclusion, PSF has made some advances in family care but its actions need to be redirected for bringing about change to the care model, with an effective involvement of users for meeting their needs. People's empowerment should be sought in the process of program management as a requisite for quality policy and technical actions and the development of a cultural identity in the community, opening up new horizons for gaining the right to a healthy lifestyle.

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