

WHY IS IT BETTER AT HOME? SERVICE USERS' AND CAREGIVERS' PERCEPTION OF HOME CARE

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ABSTRACT: The objective was to analyze service users' perspectives regarding the attendance of their needs by the Home Care Service. This is a qualitative study, with a descriptive and exploratory approach, undertaken between February 2014 and July 2015. A total of 15 service users and 15 caregivers participated, from the Home Care Service of eight municipalities in the Brazilian state of Minas Gerais. The results indicated that the profile of the population attended is mainly older adults. The reasons for admission are diverse, and relate to the chronic nature of the health conditions. The team seeks to undertake the activities taking into account the service users' natural and radical needs. Attendance in the home is presented as the best option due to the comfort of the home, the link with the family and with the team, and to the fact that this overcomes the barriers to accessing other points in the healthcare network. It is possible to understand that, in the service users' perspective, care provided in the home presents new relationships which broaden access, autonomy and quality of life for the service user.

DESCRIPTORS: Home Care Services; Health Services Needs and Demands; Patient Satisfaction; Public Health Policy; Needs Assessment.

POR QUE É MELHOR EM CASA? A PERCEPÇÃO DE USUÁRIOS E CUIDADORES DA ATENÇÃO DOMICILIAR

RESUMO: O objetivo foi analisar as perspectivas dos usuários sobre os atendimentos de suas necessidades pelo serviço de Atenção Domiciliar. Trata-se de estudo qualitativo, com abordagem descritiva e exploratória, realizado entre fevereiro de 2014 e julho de 2015. Participaram do estudo 15 usuários e 15 cuidadores da Atenção Domiciliar de oito municípios de Minas Gerais. Os resultados indicaram que o perfil da população atendida é majoritariamente de idosos. Os motivos de admissão são diversos e remetem à cronicidade. As equipes buscam realizar as atividades considerando as necessidades naturais e radicais dos usuários. O atendimento no domicílio é apresentado como melhor opção pelo conforto do lar, vínculo com a família e com a equipe, e pela superação quanto às barreiras de acesso a outros pontos da rede de atenção à saúde. Foi possível compreender que, na perspectiva dos usuários, o cuidar em casa apresenta novas relações que ampliam o acesso, a autonomia e a qualidade de vida do usuário.

DESCRIPTORES: Serviços de assistência domiciliar; Necessidades e demandas de serviços de saúde; Satisfação do paciente; Políticas de Saúde Pública; Determinação de Necessidades de Cuidados de Saúde.

¿POR QUÉ EN CASA ES MEJOR? PERCEPCIÓN DE USUARIOS Y CUIDADORES DE LA ATENCIÓN DOMICILIAR

RESUMEN: Estudio cuyo intuito fue analizar las perspectivas de los usuarios acerca de los atendimientos de sus necesidades por el servicio de Atención Domiciliar. Es un estudio cualitativo, de abordaje descriptivo y exploratorio, realizado entre febrero de 2014 y julio de 2015. Participaron 15 usuarios y 15 cuidadores de la Atención Domiciliar de ocho municipios de Minas Gerais. Los resultados apuntaron que el perfil de la población atendida es de ancianos en mayoría. Los motivos de esa opción son variables y se asocian a la cronicidad. Los equipos buscan realizar las actividades considerando las necesidades naturales y radicales de los usuarios. El atendimento en domicilio es presentado como mejor opción a causa del confort del hogar, vínculo con la familia y con el equipo, además de la superación de dificultades de acceso a otros puntos de la red de atención a la salud. Se constató que, en la perspectiva de los usuarios, cuidar en casa presenta nuevas relaciones que extienden el acceso, la autonomía y la calidad de vida del usuario.

DESCRIPTORES: Servicios de asistencia domiciliar; Necesidades y demandas de servicios de salud; Satisfacción del paciente; Políticas de Salud Pública; Determinación de necesidades de cuidados de Salud.

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● INTRODUCTION

The aging of the population, the epidemiological transition and the crisis in the health care model have required efforts on the part of managers and health professionals, with the aim of seeking effective alternatives for meeting the population's health needs. Faced with this demand, home care is indicated. This is defined as "actions for promoting health, preventing and treating diseases, and rehabilitation: provided in the home, ensuring continuity of the care, and integrated into the Health Care Networks" (HCN) ^(1:10).

The Brazilian National Policy for Home Care (*Política Nacional de Atenção Domiciliar*) was instituted by Ministerial Ordinance N. 2,029 of August 24, 2011, and was modified by Health Ministry Ordinance N. 2,527 of October 27, 2011, Ordinance N. 1,533, of July 16, 2012, and by Ordinance 963, of May 27, 2013: which regulate Home Care (HC) in Brazil. At the time of writing, HC is regulated by Ordinance N. 825, of 2016 ⁽²⁾.

HC proposes care which is individualized and contextualized with the subject's context, and is capable of promoting the service user's health condition ⁽³⁾. Receiving care from the HC professionals may mean – for the service user – a possibility for improvement, for prolonging of life lived with quality, and for understanding of their clinical status – besides "promoting people's recovery, their relations with life, the understanding of the future perspectives, and their autonomy in taking care for their own health" ^(4:183).

The service user's participation in the therapeutic plan is a differential between care provided in hospital and care provided in the home. The service's implementation contributes to attending patients in their own homes, through comprehensive and humanized care, as well as the process of education in health promotion both for the patient and for the family, seeking quality of life for both ⁽⁵⁾.

Nevertheless, there is a paucity of literature discussing the other views of service users attended in the Home Care Services (HCS). In general, studies emphasize: the patient's autonomy; the comfort of the home; the closeness of family members and the relationship with the health team professionals; self-confidence and quality of life ⁽⁵⁻⁶⁾; meeting needs ⁽⁷⁾; and maintenance in the family and community as a therapeutic environment ⁽⁸⁾. Few studies are to be found which discuss the health needs of service users attended in HC.

In the present study, the authors used the concept of need as "a conscious desire, aspiration or intention, directed at all points to a certain object, and that motivates the action as such" ^(9:170). This object is a social product. In the light of this conceptualization, the author presents two types of needs: the natural and the radical. Natural needs relate to the conservation and perpetuation of life (food, shelter, sexual-related, related to social context and cooperation, and to self-conservation and to the preservation of the species). Radical needs are truly human ones, relating to liberty, autonomy, self-realization, self-determination, moral activity and reflection ⁽⁹⁾.

In order to discuss health needs, the authors adopted the concept classifying them as: living conditions – the way of living translates into different health needs; access to technologies – contributes to maintaining helpful prolongation of life; the creation of bonds between the health professional or team and the service users, and the growing degrees of autonomy that each subject must have in order to lead her life ⁽¹⁰⁾.

In the light of the above, this study's objective was to analyze the service users' views regarding the attending of their needs by the Home Care Service.

● METHOD

This article is the result of a qualitative study, of the descriptive and qualitative type, undertaken between February 2014 and July 2015. It presents the findings of the needs analysis phase of the multicentric study entitled "Home Care in Health: effects and movements in the offering and requirements in the SUS in the State of Minas Gerais", undertaken by research groups from six State Universities in Minas Gerais.

The study's scenarios were HCS in Minas Gerais, in municipalities which were in conformity with Ministry of Health Ordinance N. 963 of 2013⁽¹¹⁾, which defined the National Home Care Policy, through the "Better at Home" (*"Melhor em Casa"*) program.

A total of 19 municipalities in Minas Gerais, which offered Home Care Services linked to the Better at Home program, accepted to participate. Data was produced through visits undertaken to the municipalities, interviews held with the managers, and accompanying the work of the home care teams, during which times the service users were approached. This approach took place in all the municipalities, although interviews were held with service users and/or caregivers in only eight of them. In the other municipalities, the service users declined to participate in the study or found it impossible to participate in data collection.

The data collection instrument was defined as interviews following a semistructured script, with questions on sociodemographic data (sex, age, educational level, type and conditions of housing, income) and on the attendance in the Home Care Service (time, reason, experience in relation to attendance, availability of equipment and products, the care provided, contact with the team and needs met).

The empirical material in this phase totaled 06 hours, 15 minutes and 21 seconds of recordings, referent to 30 interviews: 15 with service users, and 15 with caregivers. Each interview lasted an average of 18 minutes 46 seconds. In the presentation of the results, each participant received a code made up of the letter M, corresponding to municipality (M1 to M8), U to designate 'user', or C to designate 'caregiver'.

Once the material had been collected, thematic content analysis was undertaken, in accordance with Bardin⁽¹²⁾. The authors proceeded to a transversal reading of the empirical material, emphasizing the registration units and the units of meaning. The collected data were analyzed in categories which were grouped analogically in order to define these units.

The participants were informed about the study, and its objectives and purposes were clarified for them. The study was approved by the Research Ethics Committee in October 2012, under Opinion N. 129,275.

● RESULTS

The analysis of the empirical material gave rise to the emergence of two categories: 'Profile of the service users and activities undertaken in the home'; and 'Access: Home Care and health needs'.

Profile of the service users and activities undertaken in the home

The participants in this study were under the care of an HC team and were aged between 38 and 89 years old. Most service users were older adults and lived in their own homes. Only one user lived in a rented property.

The patients interviewed had distinct clinical profiles which allowed Home Care to be included in modalities HC2 and HC3, in accordance with the regulations in this area. Reasons for admission to the HCS were: wounds; respiratory problems; antibiotic use; use of ventilatory support; gout; and hyperemesis. Wounds and ambulation problems were the most frequent reasons, this last being caused by various issues: lack of strength in the legs; fractures; the patient having cancer of the spine, in the final phase of chemotherapy, and traumatic injuries to the femur.

Duration of attendance in the home varied between weeks and years. Service users classified as in the HC2 profile tend to use the service for a shorter period, as when their situation is stabilized, they are referred to primary care. In the case of users classified in the HC3 profile, use is long-term and habitually continuous, as a result of their clinical needs.

The findings indicate that basic human needs are met in the home care. These needs refer to restoration of the health condition, and were mentioned as essential care for maintaining life. In this

regard, the participants indicate a set of actions linked to activities of daily living (ADL) undertaken in the home; hygiene; bathing; eating; changing clothes; checking vital signs, blood sugar levels, cleaning wounds and changing dressings; administration and preparation of medications; changing of position, and physiotherapy exercises. The reports which follow depict this understanding:

Hygiene – such as having a shower, changing dressings, giving the medication at the right time and talking with him and cheering him up, you know [...]. (M8 C1)

Um, cleaning, hygiene, drugs [...]. (M5 U1)

Well, having a shower, changing clothes [...]. (M2 U1)

The service users and caregivers are accompanied by the professionals in accordance with the requirements for, and frequency of, the care. Participation in the therapeutic plan and the patient's autonomy when undertaking her own ADL varied in accordance with the complexity of the case and the caregivers' involvement. In this regard, the interviewees reported undertaking some forms of activity alone, such as care for their own wound, participating in the care plan and taking their medications. Some users reported receiving help from other people for daily care.

[The service user applies a dressing to the gluteus using a mirror] I put a mirror there and do it... Because then it leaks, and we cut a disposable nappy so that we can put it there, do you understand? We make suggestions, you know, because sometimes the person isn't accustomed to dealing with this, and we improvise something. (M4 U1)

All of the care, what I eat, what I don't eat, how I take my medications, at the right times, you know? What time I take the insulin, what time I take my drugs, they control these nicely, and always remind me, you know [...]. (M2 U4).

They give me all the advice I need for caring for him. What experience I have today, is due to them. It is they who explain everything that I have to do, and explain everything, how I have to do the procedures. (M8 C2)

The team works in advising the service users and caregivers. In addition to this, there is the creation of bonds between the health team, the service users and the family members. It was observed that most have the support of informal caregivers for the home care. It was identified that grandchildren, children, sisters, parents, nephews/nieces and neighbors may all help.

The participants recognize that the work of the HC team is based in warmth, respect and the forming of bonds that contribute to ensuring the continuity of the care, through the guidance and training of the service users and caregivers. These are elements which make up the dimension of the bond in the attendance to their health needs, and are expressed in the participants' reports as a positive evaluation of the service and of the professionals.

The attendance is very good, whether it is on the part of the nutritionist, the speech and language therapist or the physiotherapist, or the doctor. They give a lot of attention, a lot of attention indeed, to the patient. (M1 C1)

They're very nice people, all of them are very tender, very attentive, and they don't turn up in a rush, that old hurry to get away. They stop and talk with you and all that. (M1 C2)

The team is very good, they're very polite and very attentive. The nurses come and change the catheter, all the nursing team comes / (+) and that's just as true for the doctors as for the physiotherapist. I am not alone! (M5 C1)

In the reports, it is possible to capture the feeling of gratitude and satisfaction with the program. These feelings are related to the availability of telephone contact for moments when there are doubts or complications. The team presents itself as available for attending the service user and establishes a feeling of support for the family and for the service user. This support ranges from constructing the care plan through to support and guidance at times when there are complications or doubts.

Access: Home Care and health needs

The user's access to the services is an element of the structural dimension of the attendance to the health needs. When this access is fragmented and piecemeal, challenges are posed to the comprehensive care. In some reports, the participants mentioned difficulties for accessing the health care network, in particular the primary care services and urgent or emergency care services.

For me, it is lack of interest you know, because the health unit is nearby, less than five minutes away from them here; they don't come, because they don't want to. (M6 U1)

Over in YYY, there is an urgent care center, and I have their number, so I phone in to say: "What do I have to do?" (M6 U1)

It took two months for the health unit to come here. They only came in December. So it got worse and worse, and we were caring for them in their homes you know, as far as we knew how to do. It was only when it became much worse that they came. (M4 U1)

On the other hand, inclusion in the HC was recognized by the participants as a condition that facilitates access to the health network. As a result, the following were indicated as advantages of being included in the program: the ease of obtaining transport to emergency or hospital units, in the event of a complication or worsening of the patient, and taking specimens for laboratory analysis in the home.

Lots and lots. Taking blood, if I am in pain, transport, they do everything. [...] I make a telephone call to the Center. [...] When I need anything, I call them. The aspect of the ambulance and transport, that is very good too. (M6 U1)

When they need to take fluids for tests, things like that, they come here at home / the laboratory people come here, and take everything just right/ with good care, I can't complain (M5 C2)

When you need to call them, we call them, and they come to get you and take you to hospital. [...] When he is not being treated at home and needs to get to hospital, then we make an effort and take him. (M8 U1)

As far as I can tell, this is not just with me [...]. Recently, I needed to go to the doctor, you know, to see him, to see if he can do some surgery, so I went with the HCS ambulance. (M4 U1)

They are always here. They come and do blood tests, urine tests. They are always here. (M1 C1)

Moreover, in relation to the set of needs linked to access to the health services, the participants associate the lack of home care and exposure to risk of contamination in the hospital and in the urgent/emergency care units as conditions which have been minimized through the possibility of being attended in the home.

It's because I went to the Urgent/Emergency Care Unit and wasn't treated there. The girl there asked if I wanted to receive inpatient treatment or to come home. So I said: "Ah, in that case I will go home, because that's better, isn't it". (M3 U1)

It is better than staying there in the Urgent/Emergency Care Unit, where it is really cold, trembling, and waiting to catch some bacteria you know. (M3 C1)

I think that what they did was wonderful, because many people don't have this privilege, to stay home – because of the infections that you have in hospitals. (M8 U2)

It is much better at home than in the hospital. Because in the hospital, you are stuck there for 24 hours, if you don't have anyone to stay with her, you can't leave the place – not even to have a shower. But at home, I stay here, I care for her, have a shower, have a coffee, I have lunch at the right time. (M7 C1)

The reports allow one to recognize that the attendance in the home is presented as better because of the comfort of the home, the bond with the family and with the team. It is ascertained that the home care service meets the needs from the historical-philosophical-anthropological point of view, provided through the soft, soft-hard and hard technologies.

I'm very well monitored, they give me a lot of attention, sometimes I'm in a real mess, and they come

and talk with me, encourage me to eat, because sometimes I don't want to eat you know – because the chemo takes away your taste, and my son ends up inventing all sorts of things for me to eat. (M6 U1)

They assist me, they show concern for me, you know, I never thought that that would happen. [...] I give thanks to God and for the services provided by these professionals, which are fundamental, as the team, and as friends. (M2 U4)

God, it was the best thing that ever happened, because you can't continuously be carrying an elderly person here there and everywhere, you know? (M4 C1)

Ah, I feel really comfortable, you know? Much more comfortable, because going to the doctor is very comfortable for me, you know? As a result, I feel more at home, you know? I am much more relaxed, I don't get all worried (+) I know that I am being well cared for, you know? (M5 U1)

The team provides products, equipment and medications. The list of these items included varies in accordance with the proposal for each municipality. However, some costs fall to the family, but this did not represent a hindrance to maintaining the HC.

They always provide the materials and things, such as support for saline when they come here, and when there isn't any more, we make arrangements to get some from the Family Health Program, but it is very little. (M8 U1)

It was the doctor you know, they recommended him, and the prefectural government arranged it for me. As for the BiPAP machine, my son bought it for me. They all put some money together and bought the BiPAP for me. (M2 U4)

Some days ago, I had run out of material: so I bought some, I was buying it (+) (+) but we can't afford it, because we need so much gauze, and hydrogel too, hydrogel wasn't available in the public network/ and he needed to use it (+)(+) so we went and bought it. (M5 C2)

It cannot be denied that costs have risen for the patient, whether direct or indirect, subsequent to inclusion in the home care program. These costs constitute the dimension of the living conditions in the taxonomy of the health needs and result from the use of drugs, diets, and products for care – most of which are due to the chronic nature of the health problems.

● DISCUSSION

The study's results indicate that the profile of the population attended in the home care is of a more elderly public, which requires longer duration of stay in hospital, considering the fragility of their health. For this type of patient, the presence and work of the caregiver is considered fundamental.

In HC, the caregiver with a link to the family is the actor responsible for providing care in the home, and a model termed as the informal care system, which is associated with the caregiver-service user bond⁽¹³⁻¹⁴⁾. This relationship of care has the undertaking of nonprofessional care as a characteristic – undertaken free of charge by family and friends for carrying out the activities⁽¹⁴⁻¹⁵⁾.

The team works in guiding the service users and caregivers, establishing links to the health team, the service users, and the family members. It is observed that the majority have the support of informal caregivers (grandchildren, children, sisters, parents, nephews/nieces and neighbors). When one associates the living conditions with the context of the care provided to the service user receiving HC, it may be observed that the guidance, support, bond, and home take on a meaning of meeting their health needs, which transmits a feeling of safety and care to the service users.

The findings indicate that the actions undertaken in the home aim to meet the basic human needs, providing comfort and satisfaction and reestablishing the balance of the biopsychophysiological functions. These needs are essential for maintaining life and are common to all individuals. However, how these are satisfied depends on the context of the subjects' insertion, and how they are approached is not limited to the individual dimension⁽¹⁶⁾.

The satisfaction with the care provided in the home reveals an aspect of the needs which refers to

the realization of the human condition itself – which needs warmth, shelter, tenderness and protection. In this regard, one can assert that the HCS contributes to meeting the user's natural needs, which entail more than just recovery of health – a condition for survival – through reaching the dimension of the natural being. It is understood that the work in the HCS is part of a complexity of human work in the search to meet these needs⁽¹⁷⁾.

This study's results allow one to grasp that the HCS has adopted a work process which encompasses the idea of meeting the health needs of the population attended, as with the other human needs. The health needs are socially and historically determined. They are situated between nature and culture, that is, they do not relate only to preservation of life, but the undertaking of the project in which the individual, a point between the particular and the generic, is progressively humanized⁽¹⁷⁾. As a social practice, the care is organized in order to meet the health needs. However, the care practices may or may not correspond to the social groups' concrete needs.

In the specific case of HC, the results indicate that the services have organized their processes in such a way as to meet the health needs partially. The partiality is due to the services' low capacity to articulate with other points of the network in order to guarantee a complex of actions for meeting the needs in order to have "good living conditions"; to have access to and to be able to use all health technology capable of improving and prolonging life; to create affective/effective bonds between each service user and a team and/or professional and to allow each person to have growing degrees of autonomy in her way of leading her life.

In relation to access, it is emphasized that it is understood as a process that goes beyond the number of services in existence and the accessibility to the various levels of the care network. It includes the quality of the care provided, through humanized and welcoming care, provided rapidly and when needed⁽¹⁸⁻¹⁹⁾.

In this sense, the results indicate that meeting the service users' needs is related to access to the other points of the care network. Entrance to the HCS is seen, in the view of service users and caregivers, as a way of avoiding barriers to access, in particular to the specialized services for diagnosis and consultation. Thus, Better at Home, (the Program) opens doors to the other points in the care network. In this way, the program's user becomes differentiated from the set of the users of the health system.

The findings indicate that meeting the health needs presupposes access to the technologies, as much those which relate to the equipment and products as those which indicate the cheerfulness of the relationships established in the home care. These last are represented in the data by the references to the bonds, the embracement, the listening and the promptness that the teams produce in conjunction with the users and caregivers. This set of technologies is used in mediating the work in the HC, resulting in an intermediary field which contributes to meeting both the natural needs (social contact and cooperation) and the radical needs (autonomy, self-realization, reflection and others).

For nursing, it is important to recognize that the issue of the needs must be central to guiding the actions and analyzing the health practices. The health services which are organized focusing on the population's needs tends to be more efficient, as they allow the complementarity between objective and subjective aspects which are valued, as well as the expression – by the subjects – of meanings attributed to their modes of life, health and suffering⁽²⁰⁾.

With this understanding, thinking about the issue of health needs and how these guide the work in this field requires one to reposition the subjects involved in this process, for a broader understanding of their wishes and expectations in relation to the health services. Thus, the relationship of balance between offering, demands and needs is a presupposition for rethinking that care is provided better at home, depending on how this triad is organized.

One limitation of this study is that it did not include, in this phase, investigation of the professionals from the health teams, it being important to undertake further investigations for broadening the scope of our investigation to include the views of these actors.

CONCLUSION

The study's findings suggest that the home care services have contributed to meeting the users' needs, whether these are linked to the typology of the health services or even to the natural and radical human needs. This statement is evidenced in the services analyzed and it is understood that it can be applied to other contexts whose characteristics are similar to the scenarios of the present study.

HC is indicated as an important point in the health care network for the service users and caregivers, in spite of the structural challenges to meeting fully the demands presented in the home care.

It is important to emphasize the recognition of HC as a means of overcoming the difficulties in accessing the other points of the health care network, indicating that it meets a set of needs referent to the offering of care. Accordingly, receiving HC facilitates attendance in other points of the network, whether this is for diagnostic-therapeutic purposes or guaranteeing transport and products for continuous care.

Thus, it was possible to understand that Better at Home is not simply a matter of the configuration of a new care space. It is, above all, a matter of new relations which broaden the service user's access, autonomy and quality of life. It is reasserted that HC also needs to be consolidated and have its role recognized as a powerful mode of care, which produces other forms of caring focused on the service users' needs; and that because of this, it produces autonomy.

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