



FAMILY CARE AND THE FAMILY HEALTH STRATEGY FROM THE PERSPECTIVE OF THE USER WITH CHRONIC HEALTH PROCESS

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ABSTRACT

Objective: To know how the user who is dependent on care and who has a chronic health process affected by a chronic non-communicable disease has been taken care of by the family and by the professionals of the Family Health Strategy. **Methods:** Descriptive, qualitative study, carried out in a Basic Health Unit and in the homes of users who have a chronic health process, in the city of Belo Horizonte. Eight users, 18 years of age or older, who had some chronic disease, dependent on mild care, participated in the research. Data collection took place in 2018 through interviews recorded with a semi-structured script. The analysis took place through content analysis resulting in three empirical categories. **Results:** The dependent recognizes the activities performed as well as understands the role of the family member as a reference for their care. In this relationship, positive and negative feelings about the act of caring appeared. Regarding the health team, the study confirmed the bond with community health agents. **Conclusion:** This study offers subsidies so that family caregivers as well as professionals of the Family Health Strategy understand the proper modes of care of a user dependent on mild care and the expectations of that user in a care relationship at home.

Keywords: Nursing. Family Nursing. Chronic Disease. Primary Health Care. Caregivers. Home nursing.

INTRODUCTION

In Brazil, Chronic Non communicable Diseases (CNCD) are responsible for 72% of deaths frequently caused by cardiovascular diseases, cancer, chronic respiratory diseases and diabetes, representing the largest cause of mortality today⁽¹⁾.

CNCDs are characterized by multi-causality, have a gradual development, with an uncertain prognosis and with periods of worsening, generating disabilities⁽²⁾. These injuries result in an increase in the percentage of people who have debilitating and disabling chronic processes, such as blindness, amputations and paresis or plegia, which when grouped in the same subject configure users called pluripathological⁽³⁾.

Considering the high rates of morbidity and mortality, as well as changes in the lifestyle and

well-being of the individual caused by a CNCD, care for people affected by these diseases has become an important challenge for professionals, family members and health services as they result in devastating consequences⁽¹⁾.

The large number of people who have limitations resulting from being affected by a CNCD has resulted in an epidemic of people with chronic care-dependent processes, requiring continuous home care, restricted to the home and without autonomy to carry out their daily activities⁽⁴⁾.

In Brazil, the home care of users who live with chronic care-dependent processes has in Primary Health Care (PHC) services, through a multiprofessional family health team that operates it, the opportunity for the organization of health care. health and care coordination in

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conjunction with the other services in the care network.

The National Primary Care Policy, which understands the family as a relevant and often conditioning element in people's lives, designed an intervention model in which the Family Health Strategy (FHS) teams must carry out home visits and home visits to families⁽⁵⁾. However, studies show that Home Care (HC) has been affected by structural factors such as the lack of medication; the non-systematic monitoring of users and families, often caused by the disorganization of the team; lack of interest from some professionals, devaluation of AD by the FHS; the great demand for work in health units; and the lack of frequent transport⁽⁶⁾.

In some Brazilian municipalities, there are also support programs for home care that benefit many families living with entities affected by CNCDS and who have disabilities. Despite the benefits of the programs, they still present extremely strict criteria, focusing on elderly patients, without measuring the degree of dependence and the indicators of family vulnerability, with low case evaluation by nurses from the FHS or Hospital teams, being programs individual, of little scope, that still do not compose an articulated support network⁽⁷⁾.

In this sense, the family has been configured as an essential element for the sustainability of the public health system, especially in the current situation of early onset of CNCDS, as well as resource constraints.

One of the approaches that recognizes the importance of the family as a partner in improving practices and the care system, thus ensuring their participation in the planning of actions and decision making within the family is the Family Centered Care (FCC). This term considers the family as influencing the health of its family members, and also discusses the support and encouragement about the participation of family members and patients in the care, choosing how they will act⁽⁸⁾.

The family caregiver has assumed the responsibility of providing, organizing the resources requested by the care dependent and exercising continuous assistance. In most cases, the family member does not have specific training to perform care activities and exercises it intuitively without financial and social

support.

In this context, the family as a caregiver needs to reorganize and adapt so that the roles and functions of each member of the caregiver are divided and rethought according to the needs of the individual, since confused and painful feelings arising from the loss of autonomy, the impossibility of performing self-care alone and impaired functional capacity may be present⁽⁹⁾.

The user, family and professionals can be considered complex units that, when articulated and organized, form a system to be understood in the relationship they maintain with the environment and time. In this way, the team acts as support to families, providing them with the tools to take care⁽⁶⁾.

In order to seek improvements for comprehensive care and family care relationships for individuals dependent on care who live with a chronic health process, we sought to know how the user is dependent on care and who has a chronic health process affected by a CNCDS has been taken care of by the family and by the professionals of the Family Health Strategy.

METHODOLOGY

This is a descriptive study with a qualitative approach, supported by the theoretical framework of family-centered care (FCC), as there is an understanding that the family is a crucial factor in the care of its individuals⁽⁸⁾. This theory converges to the consolidation of comprehensive, participatory and shared care between professionals and family members, in addition to revealing that listening, user and family choices, knowledge, values, beliefs and culture are paramount in this relationship⁽⁸⁾.

The study was carried out in a Family Health Team of a Basic Health Unit (BHU) in the city of Belo Horizonte (MG). BHU has an enrolled population of approximately 15,000 users. It has four Family Health Teams (FHT), and was chosen as a scenario because it has 100% coverage by the FHS and enjoys a population comprised of different levels of vulnerability. The team chosen to approach the users dependent on care was team three because it was the only team that had an organized list of users bedridden and restricted to the home.

For the selection of care dependents, three steps were necessary:

1st stage - meeting with the Community Health Agents (CHA) at BHU study scenario for the survey of dependent users. At this stage, 25 users were found to be dependent on care. A higher number than the material presented by the team;

2nd stage - after the survey, the research team was conducted with the CHA responsible, to the home of the family who had a situation of care dependency. At home, the level of dependency was assessed using the Barthel Index (BI). The BI is an instrument validated in Brazil that is most used in the world to assess the Activities of Daily Living (ADL) performed by the individual⁽¹¹⁾.

3rd stage - after identifying the level of dependency of the family member affected by a CNCD, it was identified that there were a total of 25 dependents, four of whom were severe, five of moderate degree and 16 of light degree, according to the Barthel index⁽¹¹⁾.

Those who met the following inclusion criteria were selected: users aged 18 years or older, dependent on care due to a mild CNCD, according to the Barthel index, who was conscious and communicative and who received care from the family, except for professional caregivers. Exclusion criteria were users who were dependent on care in a moderate and high degree, as well as those whose caregivers received any amount of money as payment for care.

For the purpose of knowing how the user who is dependent on care and who has a chronic disease has been taken care of by FHS professionals and family members, the choice for only those identified with a degree of mild dependence according to the Barthel Index¹¹ is justified in virtue of the user being able to answer the survey and being an active participant in the care process.

Data collection took place from June to September 2018, through two stages. First, a survey was made of users dependent on care and who had a chronic disease following the inclusion criteria mentioned above, ending with a total of 16 participants. Of these, eight participants were no longer part of the research, as they did not fit the inclusion criteria, with two

deaths in the course of the research, one refusal, two participants who were no longer part of the coverage area, and three were no longer light dependents. during the development of the research, totaling a sample of eight users.

In the second stage of the collection, home visits mediated by the CHA were carried out to the eight families that had members dependent on care in a mild degree, in which it was feasible to conduct an audio recorded interview through a semi-structured script that addressed questions such as: "When (a) do you need it, who is the caregiver?", "How do you feel about being cared for?", "When do you need professional assistance, how do you do it? And in this service, what are you looking for? And do you have a reference professional?"

The interviews were conducted with the purpose of obtaining relevant information about the understanding of the interviewee's perspectives and experiences. The interviews lasted, on average, 20 minutes in length and were transcribed covering a total of 25 pages with Times New Roman and simple spacing for the continuity of data analysis.

The data analysis process was built following the content analysis phases proposed by Bardin⁽¹²⁾, with the following units of meaning being built: Feelings in the care relationship between the family caregiver and the care dependent member; Main activities developed by the family caregiver from the perspective of the member dependent on care and care provided by professionals of the Family Health Strategy.

In this study, it was decided to discuss the categories mentioned above, revealing excerpts from the speeches of care dependents, which were identified with the letter E of the interviewee, followed by the number corresponding to the sequential order of the interviews in order to guarantee the anonymity of the participants. The results were compared and discussed based on the literature.

The research was approved by the Research Ethics Committee of the *Universidade Federal de Minas Gerais* (UFMG, Federal University of Minas Gerais) under registration CAAE nº 54550412.0.0000.5149 and authorized by the Belo Horizonte Municipal Health Department. The study participants signed the Free and Informed Consent Term (ICF), voluntarily, after

clarification of the study proposal in all stages. Absolute confidentiality of the information was guaranteed as well as the privacy and anonymity of the participants.

RESULTS

Profile of family groups with mildly dependent care members

The predominant age group of the participants in this study was between 60 and 90 years old (87.5%). It is noteworthy that 75% were female, widowed (62.5%) and 50% were not literate. Of the interviewees, 50% were retired and pensioners with a salary range of up to 3 minimum wages (75%). The most common underlying diseases were senility and ophthalmic diseases (37.5%), with 50% of dependent users having 2 or more Non communicable Diseases and Ailments (NCDA). All used medication and the majority used orthosis or prosthesis (87.5%). Most of the disease developed gradually (87.5%), with 37.5% between 4 and 6 years of dependence. The majority used exclusively the public health system (75%) and did not need hospitalization in the last 12 months (87.50%). With regard to the caregivers of these dependent users, it is noteworthy that the majority were female (87.50%), with care being mostly exercised by daughters (62.5%), and in the age group between 40 59 and 60 to 79 years (50%).

Feelings in the care relationship between the family caregiver and the care dependent member

From the analysis of the collected data, it was noticed that most of the care provided to dependents who live with a chronic health process is performed by the family, mostly women and daughters aged between 50 and 69 years. According to family members dependent on care, the care provided by the family gives rise to trust.

I trust everyone. I settle things with everyone, I like everyone. Everyone, thank God, takes good care of me, my grandchildren, my granddaughters, my daughters. (E2)

It is my daughter that I trust to take care of me, she already knows all the struggles, everything,

everything. (E7)

The feeling of trust in the relationship with the family caregiver is perceived by the care dependent member when the family member is available and willing to help with their needs.

I like the care they are taking with me. I'm satisfied. They don't stop paying attention right? Just like that, do what you can, right? Goes shopping when I ask. (E8)

We combine a lot, so she does it willingly, so there is no difficulty whatsoever. (E4).

According to members dependent on care, despite recognizing that the family caregiver is willing to help with their needs, there are some attitudes such as calling attention, lack of affection and not believing in their needs that make the relationship difficult and makes the dependent have a negative view of the care provided by the family.

When they get my attention, I get angry at them. They don't believe me when I'm sick, I'm going to be sick, I'm not going to talk to them. (E1)

I feel good, being cared for by them. But there are days when they fight with me, do what, right? You have to accept it. (E6)

You know everything is difficult, my children are weird, they give me a hug just for Christmas, New Year. These days I even scared him, he was traveling and when he arrived he gave me a hug. (E5)

Another factor pointed out by dependents of care that makes the relationship difficult is the shame felt when some act of intimate care is necessary, such as taking a shower to be performed by someone from the male family. Although most of the caregivers in this study are women, the preference for care to be performed by women appears in the statements.

Yeah, to take a shower. I'll take it, I'm ashamed right? Look at you see, it's wrong, right? It leaves me [...]. The way of caring ... women have more ways with us. He's a man, it's very difficult. (E5)

The feeling of fear in relation to the worsening of their chronic health process with the increase in care dependence also appears in the speech of one of the care dependent members interviewed, especially when their wishes are not respected.

Our relationship is good, you know? She takes care of me. She doesn't like me doing things, but I do, do you know why? Because I'm afraid to atrophy. And if I atrophy there, I'll give you all trouble. (E7)

I was never like that, I stopped taking care of myself and stayed like that. I was limping, but I was. I didn't need that chair. I don't know where I'm going to stop! (E5)

It is worth noting that, in view of the activities carried out by the family caregiver, the dependent care members express feelings of frustration for feeling a burden for the caregiver.

Ah, I think I'm having trouble, right? Sometimes you have to leave, I can't leave alone. (E6)

Colic that hurts, these girls suffer a lot from me [...] (E1)

Main activities developed by the family caregiver from the perspective of the care dependent member

After analyzing the data, it is clarified that the family member has actively participated in the Instrumental Activities of Daily Living (IADL) of the dependent member of care, especially those related to the routine of the home and personal care, such as: the preparation of food, cleaning, house organization, assistance with personal hygiene and clothing.

My son makes food, cleans the kitchen. When I clean while sitting on the chair, it is very difficult [...] (E5)

She helps me bathe, helps me, helps me put on my clothes. I'm having a lot of difficulty so she's helping me (E4).

Other activities mentioned by care-dependent members involve finding supplies for the health of the care-dependent, and purchasing food and clothing.

He receives and buys medicine for me, buys clothes when I need them, when I need shoes he buys [...] (E1)

He goes to the bar nearby, then he goes and brings me a cookie. Ah, I want a juice, he goes there and brings the juice to me too. (E5)

Care-dependent members also recognize that family caregivers carry out activities related to professional care, either by making

appointments, going to the Health Center or taking exams.

When it comes to the clinic, my granddaughters take me there. (E2)

My daughter makes an appointment, takes me to appointments whenever I need [...] (E6)

Care provided by professionals of the Family Health Strategy

The health care model in Brazil favors contact between professionals and users of the public health system. In this perspective, care-dependent members recognize Community Health Agents as a reference for solving health-related problems, such as scheduling medical appointments and home visits.

My daughter asks our CHA when I need some professional assistance (E6).

I haven't been to the clinic for a long time, but even today, if I need anything, I go to the CHA [...] (E7).

It was also observed that the member dependent on care recognizes the relationship of joint action between doctors and community health agents of the Family Health Strategy. They express the need to have the doctor as a central figure in providing care and the relevance of the Community Agent for access to health.

Anette (CHA) she comes accompanied, she comes with the doctor, she makes appointments, she comes along. I even have her phone. (E5)

My daughter asks our CHA and she tells Dr. Antônio our clinic here at the clinic. (E6)

Analice (CHA) always messes with papers and everything, and manages to make an appointment with Dr. Antônio, sends it to other doctors who need to send it, right? (E8)

The central figure of the doctor is assumed by the dependent users as the source for solving problems, given the technical capacity to make referrals to specialized services and recommend tests.

Dr. Luana, she makes these referrals to the Holy House, to the clinic, everything is her, referral for more sophisticated exams and she makes these referrals, everything is Dr. Luana. (E1)

Doctor Antônio, He is a thousand and one

utilities, checks pressure and brings the prescription (E6).

DISCUSSION

When chronic illness becomes present in the family environment and the sick individual is no longer able to perform their routine activities, requiring care, the role of the caregiver appears practically naturally within the family⁽⁹⁾. Care is inherent to human beings and causes a feeling of social responsibility. It appears when someone's existence is important to someone else, and they feel involved and affectionately connected, and then they dedicate themselves, willing to help and participate in their searches, dreams, sufferings and successes⁽¹³⁾. Article 229 of the Brazilian Constitution⁽¹⁴⁾ states that it is the duty of parents to support minor children and that older children are responsible for providing assistance to parents in old age, shortage or illness, ensuring the care of dependents even in cases where the family don't want to assume that role.

Even with all the social changes, in family formation, especially because many women are currently family breadwinners, the interviewed users highlight the presence of women in care in general, even if they have a job outside the home. Due to this socio-cultural background, the chronic dependent references women as the protagonist of the care offered to them, a role that she did not always choose to assume, but due to circumstantial imposition she ends up assuming⁽¹⁵⁾.

CNCDs can lead the individual to have difficulty performing daily activities, causing partial or total loss of autonomy, leaving the dependent user vulnerable and in the care of family members⁽⁴⁾. In this care relationship, the users participating in the study claim to feel confident, but they often perceive that the family caregiver starts to make decisions feeling entitled and empowered to do so, nullifying the possibility for the patient to express their wishes. The feeling of limitation in view of the interviewees' own wishes tends to stimulate a mechanical care relationship which can lead the dependent user to feel like a burden on the other's life, mainly due to the continuous care needs, fear of the advancement of dependence

and for monopolizing family attention as indicated by the interviewees in the results.

In addition to the care under the aspects of care, the dependent users present the need for assistance in matters involving the Instrumental Activities of Daily Living and access to health. It is in this sense, that the participation of the health team of the Family Health Strategy, together with the help of the family caregiver, plays an essential role: that of guiding and encouraging the dependent of care to actively participate in their self-care with the objective to give opportunity to the process of independence of care. As a result of this participation, the care dependent may feel more valued, responsible for himself and for the care process itself, rescuing his autonomy, which was eventually present, but which was canceled⁽¹⁰⁾. In this context, the FCC has as one of its functions to promote the well-being of families and their members and, although it is centered on the family, care does not cancel participation in decision-making by users dependent on care about their own health⁽⁸⁾.

Bearing in mind that in Brazil the current healthcare model has health surveillance as an opportunity for health professionals to be closer to people's homes, it is believed that families who live with members dependent on care due to a chronic condition should be known to this team. Access to a reference professional helps the caregiver to perform roles related to the care of the dependent family member. In this study, users recognize the Community Health Agent as the main reference for health needs. The daily contact of people with the CHA allows these professionals to experience the specific health problems in the area in which they work, to know the way of life of the population and to contribute to a process of decentralization of information⁽¹⁶⁾. The visibility of the CHA in the speech of the participants in this study reveals coherence between the perception of their professional role and the attributions defined by the national primary care policy. However, it is clear that the image of the CHA is associated with a biomedical understanding of health⁽¹⁷⁾. The trust placed in the work of the CHA is often perceived as a possibility to access the medical professional. The CHA's social insertion potential added to the physician's scientific and

technical knowledge seems to be an important symbiosis for the process of monitoring families that have users dependent on primary care.

It is noteworthy that the nursing team was not mentioned during the interviews. It is perceived that the role of the nursing team is limited only to technical procedures, such as, for example, measuring pressure, applying injections and performing dressings, not knowing how to identify other activities of nursing responsibility in primary care⁽¹⁸⁾. In this sense, it is essential that the nursing team is more available to these families who have care dependent homes in their homes, supporting family caregivers and helping families with the restructuring that will take place, since, after the onset of a disease chronic, both family caregivers and care dependents will need to learn to live with, manage the situation of illness and seek a balance between the feelings that will come, be they good or bad. More than that, the nursing team has the function of continuously monitoring the evolution of the chronicity of the care dependent, in order to keep the disease under control and prevent new disabilities, in addition to being essential that they have the necessary knowledge and sensitivity to meet the needs and individuality of each family nucleus, contributing to its help by sharing it with other FHS professionals in carrying out actions that make the best progression of the chronic disease possible^(4,7). These actions may contribute, eventually, so that the feeling of fear resulting from the worsening of the chronic health process with a consequent increase in the dependence on care does not become present for this dependent user, minimizing the feelings of guilt and weight that they bring with them when centralizing family caregivers' attention to themselves.

Finally, although the practices of the Family Health Strategy Teams are directed towards the exercise of a multiprofessional team, in the view of users dependent on care, it was not yet possible to break with the medical-centered dynamics. The fragility of the Family Health Strategy as a conception of a family-centered care model is still limited and this view is the result of the precariousness of health that, with low investment in infrastructure, discourages the breadth of access to the Unified Health System, endorsing primary care as a service of low

technological density and with no effective response from diagnostic support systems, directly impacting family-centered care⁽¹⁹⁾.

FINAL CONSIDERATIONS

From the results of this study, it was reaffirmed that the care provided by the family caregiver represents feelings of trust, efforts, decision-making that allow the dependent member to recognize the activities performed in this care as well as to understand the role of the family member as a reference for their care.

It was found that there are different feelings in the care relationship between the family caregiver and the care dependent in which the care provided designates feelings of trust, satisfaction and zeal. In contrast, negative feelings about the act of caring appear in this relationship, arising from attitudes that family caregivers have when in the care routine they make decisions for the dependent family member. Failure to respect their wishes and draw attention express control over the health status of the care dependent and nullify the expression of their own wishes. In addition, the worsening of the clinical course of chronic diseases are concerns of these dependents because they can become a burden for the family due to increased dependence on care.

The study made it possible to verify that the care provided by the Family Health Strategy is centered on the interventions performed by the CHA. Although they are presented as a reference for access to health, the actions of the CHA are linked to a medical-centered dynamic. The technical capacity of the medical professional is valued by the study participants as they offer opportunities to access referrals, exams and prescriptions. The invisibility of nursing professionals in the home context draws attention.

The present study, although limited in the possibility of generalization, focused on peculiar aspects of the care relationship between the family caregiver, the lightly dependent member of care and the professionals of the Family Health Strategy. Other limitations of the study were: the CHA's unavailability to follow the interviews and understand the value of the family approach and the caregiver's interference

in the responses issued by users dependent on care. As much as the interview was planned individually, the family caregiver looked for ways to be present.

Thus, it is hoped that this study can offer

subsidies so that family caregivers as well as professionals of the Family Health Strategy understand the own modes of care of users dependent on care in a light degree and the expectations of this user in a care relationship.

O CUIDADO FAMILIAR E DA ESTRATÉGIA SAÚDE DA FAMÍLIA NA PERSPECTIVA DO USUÁRIO COM PROCESSO CRÔNICO DE SAÚDE

RESUMO

Objetivo: Conhecer como o usuário dependente de cuidados e que possui um processo crônico de saúde acometido por uma doença crônica não transmissível vem sendo cuidado pela família e pelos profissionais da Estratégia Saúde Família. **Métodos:** Estudo descritivo, qualitativo, realizado em uma Unidade Básica de Saúde e no domicílio dos usuários que possuem um processo crônico de saúde, na cidade de Belo Horizonte. Foram participantes da pesquisa oito usuários com 18 anos ou mais, que possuíam alguma doença crônica, dependentes de cuidados em grau leve. A coleta de dados ocorreu em 2018 por meio de entrevistas gravadas com roteiro semi-estruturado. A análise se deu por meio da análise de conteúdo resultando em três categorias empíricas. **Resultados:** O dependente reconhece as atividades realizadas bem como compreende o papel do familiar como referência para seu cuidado. Apareceram nessa relação sentimentos positivos e negativos sobre o ato de cuidar. Com relação à equipe de saúde o estudo confirmou o vínculo com os agentes comunitários de saúde. **Conclusão:** Esse estudo oferece subsídios para que os cuidadores familiares bem como os profissionais da Estratégia Saúde da Família compreendam os modos próprios de cuidado de um usuário dependente de cuidados em grau leve e as expectativas desse usuário em uma relação de cuidado no domicílio.

Palavras-chave: Enfermagem. Enfermagem Familiar. Doença Crônica. Atenção Primária à Saúde. Cuidadores. Assistência domiciliar.

EL CUIDADO FAMILIAR Y DE LA ESTRATEGIA SALUD DE LA FAMILIA EN LA PERSPECTIVA DEL USUARIO CON CASO CRÓNICO DE SALUD

RESUMEN

Objetivo: conocer cómo el usuario dependiente de cuidados y que posee un caso crónico de salud afectado por una enfermedad crónica no transmisible ha sido cuidado por la familia y por los profesionales de la Estrategia Salud de la Familia. **Métodos:** estudio descriptivo, cualitativo, realizado en una Unidad Básica de Salud y en el domicilio de los usuarios que poseen un caso crónico de salud, en la ciudad de Belo Horizonte. Fueron participantes de la investigación ocho usuarios con 18 años o más, que poseían alguna enfermedad crónica, dependientes de cuidados en grado leve. La recolección de los datos ocurrió en 2018 por medio de entrevistas grabadas con guion semiestructurado. El estudio se llevó al cabo por medio del análisis de contenido resultando en tres categorías empíricas. **Resultados:** el dependiente reconoce las actividades realizadas, así como comprende el papel del familiar como referencia para ese cuidado. En esta relación surgieron sentimientos positivos y negativos sobre el acto de cuidar. Respecto al equipo de salud, el estudio confirmó el vínculo con los agentes comunitarios de salud. **Conclusión:** este estudio ofrece informaciones para que tanto los cuidadores familiares como los profesionales de la Estrategia Salud de la Familia comprendan los modos propios de cuidado de un usuario dependiente de cuidados en grado leve y las expectativas de este usuario en una relación de cuidado en el domicilio.

Palabras clave: Enfermería. Enfermería de la Familia. Enfermedad Crónica. Atención Primaria de Salud. Cuidadores. Atención Domiciliaria.

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