DOI: 10.15343/0104-7809.202448e16572024I

User embracement and care for people with disabilities in the Family Health Strategy: perception of the health team

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Graphical Abstract

User embracement and care for people with disabilities in the Family Health Strategy: perception of the health team.

In Brazil, more than 12 million people with disabilities have acess to primary health care, wich essencial to guarantee adequate embracement and care.

The lack of acessibility, communication and knowledge creates barriers to healthcare.

Continuous team qualification and continuing education are essencial to overcome these challanges and improve care pratices.

DOI: 10.15343/0104-7809.202448e16572024I

Abstract

In Brazil, there are more than 12 million people with disabilities who are covered by primary health care, which plays an important role in promoting access, reception, and care for this population. The study aims to analyze the perceptions of a family health team regarding the embracement and care of people with disabilities. A cross-sectional mixed methods study was carried out, with an online questionnaire and interviews with 16 professionals from a family health unit. We observed a strong understanding among the professionals regarding the importance of the subject, and one of the potentialities lies in the user embracement that sustains the relationship with the health team in an integral, longitudinal and humanized way. Difficulties in carrying out health promotion actions and the lack of infrastructure meeting minimum accessibility requirements were the biggest barriers mentioned, which, together with communication barriers and lack of knowledge about the subject, create an unfavorable environment for health care. It is possible to indicate qualification of the professional team, which suggests that health managers allow continuing education, and that the professionals take continuing education as an opportunity to reflect on the work process and to transform their practices.

Keywords: User Embracement. People with Disability. Unified Health System. Primary Health Care. Continuing Education.

INTRODUCTION

The Unified Health System (SUS), guaranteed by Law No. 8,080/1990, is an achievement of the Brazilian people[1]. This system includes the first level of health care, Primary Health Care (PHC), which is characterized by a set of health actions, at the individual and collective levels, and is the main gateway and communication center within the entire SUS Care Network[2]. The Family Health Strategy is recognized as a strategy for expanding, qualifying and classifying PHC, as it favors a reorientation of the work process with greater potential for increasing resolution and impact on the health situation of individuals and communities[3].

Brazilian society has more than 12 million people with disabilities, which corresponds to 6.7% of the population, and these disabilities may be visual, hearing, intellectual/mental and/or motor in nature[4]. This specific population requires professional and continuous attention regarding health. For this reason, in 2002, the National Health Policy for People with Disabilities was established, which promotes inclusion and responds to complex issues related to health care for this population[5]. In 2012, the Care Network for People with Disabilities was established, representing a movement to create, expand and integrate health care points within the scope of the SUS[6].

According to the Brazilian Law for the Inclusion of People with Disabilities[5], a person with a disability is characterized by long-term impediments of a physical, mental, intellectual, or sensory nature, which, in interaction with the most various barriers, can obstruct their full and effective integration into society on an equal basis with other people. The health-disease-care process goes beyond the specific conditions of this population, as they can also present common health problems throughout their life[7]. In this sense, the PHC, as coordinator of care and organizer of the network, plays an important role in promoting access, reception and care for this population. Regarding the embracement and longitudinal care of this population, such processes depend on adequate communication tools and an ethical posture. And despite the commitment of the teams in the health units, this difficult context can serve as an imminent field for ethical conflicts in routine actions. Therefore, the objective of this study is to analyze the perceptions of a Family Health Strategy team regarding the embracement and care of people with disabilities[8-11].

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METHOD

This is a cross-sectional qualitative study. The study was carried out in a Family Health Unit in the Western Health District of Ribeirão Preto - SP, Brazil. The municipality has a population of 720,116, according to an estimate from the Brazilian Institute of Geography and Statistics in 2021[12], and for the West District, the population estimate was 180,847 inhabitants in 2017[13].

Seventeen professionals from the family health team were invited to participate in the study, with as inclusion criteria being a team professional, working in the unit for at least the last 6 months, including residents of the Multiprofessional Comprehensive Health Care Program and Medical Residency in Family Medicine Program, and having had contact with patients with disabilities in recent months in 2022. The participants invited were workers from the areas of nursing, medicine, occupational therapy, psychology, speech therapy, pharmacy, dentistry, administrative assistants, access controllers, and community health agents, of any ethnicity, gender, or age.

Data collection was carried out through a questionnaire applied remotely, without limitations or harm to the progress of the study, aimed at characterizing the professional profile and, in a second moment, through a semi-structured in-person interview conducted in privacy with the support of an open question script, which provided the opportunity to engage in dialogue with the participants.

The professionals from the family health team were contacted in advance, by phone or in person, to present the project and formalize the invitation to participate. At this point, the research project and the Free and Informed Consent Form were presented, and any doubts were resolvedse. After acceptance, they received the link to the questionnaire and the interview was scheduled for the day and time that best suited them.

We used the thematic content analysis technique proposed by Minayo[14], to process the data. This technique is carried out in the following stages: Pre-analysis; Exploration of the Material, and Treatment of Results/Interference/Interpretation. In the first stage, a full reading of the selected contents was carried out, seeking to gain a broad view of the subject, understand the particularities of the material, and select hypotheses for analysis and interpretation, while also identifying relevant classifications and theoretical concepts[14].

After the description and characterization of the study population, we proceeded to the qualitative analysis stage with the schematization of the selected content organized into a table and grouped by themes. This table served as a tool for classification, allowing a dialogical reading of each highlighted fragment, the identification of the nuclei of meaning (i.e. the central point of each answer elaborated by the interviewed professionals) in the schematized content, and an interaction between the nuclei of meaning and the hypotheses supported by the theoretical framework. The last stage consisted of processing the results/inference/interpretation, which was defined as a form of complementation. An interpretative synthesis of the groups of nuclei of meaning was structured, relating the themes to the objectives, questions and hypotheses of the research[14].

The project was submitted to and approved by the Research Ethics Committee of the Ribeirão Preto School of Dentistry, University of São Paulo. All ethical aspects were duly respected.

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RESULTS

The invitation was sent to the 17 professionals working in the health unit in 2021 and 2022, of whom 16 (94.1%) were willing to participate in the interview. Of the participants, 81.3% were women, and 18.7% were men. Additionally, 43.8% had a postgraduate degree in progress, 37.5% completed secondary education, 12% had incomplete higher education, and 6.3% had completed higher education.

Regarding their work in PHC, six of them (37.5%) had been working for more than a year to two years, four (25%) for six to ten years, three (18.8%) had been working for more than ten years, and three (18.8%) for more than two years but less than five years.

In the distribution of participants regarding their current occupation or their role in the health unit, there were three (18.8%) community health agents, two (12.5%) nursing assistants, three (18.8%) doctors and all other occupations were represented by one professional each (nurse, speech therapist, dentist, occupational therapist, pharmacist, administrative assistant, and access control officer), each corresponding to 6.3%.

With regard to the interviews, during the analysis, four classificatory axes emerged based on the most relevant selected excerpts, with their respective categories: 1. Knowledge of health policies/rights; 2. Limits and potential in embracement and/or care; 3. Care Network for people with disabilities; and 4. Health actions aimed at the population with disabilities.

Knowledge of health policies/rights

With regard to knowledge of health policies and the rights of people with disabilities, the responses focused mainly on the theme 'accessibility', as we can see in the excerpt:

P1: 'That we need to adapt establishments for accessibility[...] Not only physics, but interpreter, visual...'

P2: 'I know that there are several policies, but among them I know that there is the guarantee of accessibility in all structures within the municipality, from physical structures to service provider that has to facilitate accessibility for this population, in addition, vacancies in jobs, universities are also guaranteed, so the policies are more in this sense, to facilitate access and accessibility and also to protect the physical integrity of this population.'

P3: 'Look, I don't know how to tell you exactly about this, but... what I see: a space for disabled people, a seat, I think that's it, in my opinion.'

However, some professionals claimed to have little or no knowledge about the topic:

P4: 'I've heard of something, but very little.'

P5: 'I've heard of it, but I don't know much about it in depth.'

P6: 'No, I know they exist, but I can't tell you now...if they have the right...'

Another large group of responses brings up the relationship between the health rights of this population and the National Humanization Policy (PNH), as we can see in this excerpt:

P7: 'I've heard, there's even the National Humanization Policy like the one you talk about, I've also heard it talks a lot about access, embracement, expanded clinic, this also involves people who have special needs.'

P8: '(in the Unit) I can see the National Humanization Policy, but in other services I think there is a lack of commitment from people, because they know the policy, but they don't put it in practice.'

Limits and potential in reception and/or care

When asked about the limits and potentialities in the embracement and/or health care of this population, the answers related to the presence of the multiprofessional team in the unit and to personal engagement, as we can see in the excerpts:

P4: 'I think our potential is the 'multi-team', which is not something we see a lot, *and their good will.' P7: 'I think so, I think the advantage of the health unit is for being a teaching environment, specifically this one, for having residents, each one from a different profession here... each one is able to contribute in their own specific way to the patient.'*

P8: 'But in human resources, yes, because thank God, we have a 'multi team', both multi and medical residency and this greatly enriches the service.'

P9: 'We have to look at it as a whole and the involvement with the team, I felt the need, it's good that I had these other professionals.'

The limits mainly involved the physical structure of the unit and the self-reported lack of preparation of the professionals, which is presented below:

P11: 'we have a lot of difficulty because of the rooms, so you call the person and they say:

P12: 'I can't climb stairs'... So, you go back and wait until you get a room down here, it's very annoying.'

P13: 'So we don't have adequate ramps, many offices are on the second floor, we don't have an elevator, many places are difficult to get to with a wheelchair.'

P14: 'The impossibilities end up coming more from us than from the people themselves [...]'

P15: 'I can't understand what the patient is saying. The patient goes to the service, on the scheduled date, with the exams, everything.... but it was not resolutive...'

P16: 'We even feel a little helpless'.

Care network for people with disabilities

When asking about the health care network with regard to health services for people with disabilities, opinions turn to the feeling of failure in the network's articulation, as well as limitations in the provision of services and also the lack of counter-referral. However, they mentioned good structure at other levels of health care, as we can see in the excerpts:

P3: 'There is a network, it has good services, but it doesn't meet the demand and this issue of communication, which I think is also not good.'

P6: 'Now, thinking about the child who has multiple disabilities: sensory, motor, speech, I won't be able to do it, but then they send them to the network and stay there forever.'

P9: 'Because I think that regarding the structure, the secondary (level) it's better than us. In terms of adaptation, there are wider corridors, there are chairs, I'm thinking more about the physical thing, right? Now, if you think about the deaf person, I think things are morecomplicated.'

P10: 'It has a lot of barriers, of displacement, of counter-referral... I think there are a lot of limitations.'

Furthermore, the professionals said the patients complain a lot about the distance of the locations:

P15: 'The referral of my patient is to that location, there is no way I can take the person, wheelchair user, probe...'

P16: 'The only problem I've ever heard from patients complaining about is when the appointment is in another city, in this case it's (a near Municipality). There are things that we don't have here in Ribeirão.'

Health Actions Aimed At The Population With Disabilities

With regard to health actions aimed at the population with disabilities, professionals perceived actions in the most diverse ways, mainly individual actions, despite the limitations imposed by the Covid-19 pandemic:

P1: ' [...] and education in health with the caregiver, or health promotion in aspects other than just disability, monitoring, because we often focus only on this issue, but in fact they are patients like any other.'

P4: 'I've seen it! In these two years, regardless of not being able to make the visit, there was a moment when there was a meeting, conversations with the staff, with the group, to help, guide. Mainly due to the pandemic, many families were left unstructured, especially psychologically.'

P7: 'So, with the team there is a lot of this

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issue of ongoing education, of discussing and thinking together, so everyone contributes, so it helps a lot with care. Now we try, but sometimes it's not possible.'

P8: 'Yes, we've had a lot of conversations about caring for caregivers.'

P9: 'The question of where to get a wheelchair, a bath chair, a walker, we have these Non Governmental Organizations (NGO) that help us. We even have strengthened relations with one of the NGOs here.'

P14: 'Preventing injuries is what we do the most, since promotion wasn't enough to do it.'

DISCUSSION

Throughout the interviews, the potential, as well as the limits and the search to overcome them, contributed to the Expanded Clinic, PNH guideline, which allows a vision beyond the biological model of people with disabilities, considering the individual's uniqueness and complexity of the health/disease process. This approach allows to face the fragmentation of knowledge and health actions and their respective damages and ineffectiveness[15,16]. It is also clear that is the team makes an effort in carrying out their actions in alignment with that guideline.

Regarding the participants' profile, it was observed the predominance of female workers, with recent working experience and different education levels, notably in postgraduate courses, some of them during multiprofessional residence programs. This study confirms the trend of feminization in the health workforce[17]. In addition, the multidisciplinary residency has an important representation and contribution to the qualification of actions in the PHC as a device for changing the health care models, noticed by the proposals of the Permanent Health Education Policy[16].

For Starfield[14], PHC must be the gateway, that is, easily accessible to the health service system for all users, and also needs to have some tools, such as: longitudinality, or care throughout the individual's life; integrality, that is, attention to the person as a whole; coordination of the health care network; family approach; and community focus, being everyone's right. However, for these tools to be efficient for each user, there must be inclusion, that is, putting equity into practice. These attitudes are observed in the team, with statements that faithfully maintain the obligations and possible functions of PHC towards the enrolled population and, specifically, the population with disabilities within their area of care. There is clearly a search for compliance with actions in an ethical and appropriate manner.

Among the topics raised, when it comes to policies specifically aimed at people with disabilities, one of the most discussed topics is accessibility, which can be defined as: *'the adjustment between the characteristics of health resources and those of the population, in the process of seeking and obtaining health care, and makes it possible to identify the factors that facilitate or hinder the seeking and obtaining this care'*[18]. Therefore, it is the result of a combination of factors, such as geographic, organizational, sociocultural and economic aspects. When asked about knowledge about health policies and rights for this population, a significant proportion of the professionals mentioned ensuring accessibility, although they highlighted flaws in the unit where they work, particularly the absence of minimum structural requirements and the presence of architectural barriers[19]. In addition to these architectural barriers, communication and information barriers were identified. These refer to any obstacle, attitude or behavior that hinders or prevents the expression or receive messages and information through communication systems and information technology. However, the reports do not contain any elements that refer to attitudinal barriers[18], which are attitudes or behaviors that prevent or hinder the social participation of people with disabilities on an equal footing and with equal opportunities. Based on the evaluation of the interviews, there is a clear commitment by the team to fulfill the duty to provide this right, as observed in the Brazilian Law for the Inclusion of People with Disabilities[19]. The team actively usestools in an attempt to overcome communication and information barriers, including intersectoral efforts.

Also, professionals found an important relationship between the rights of people with disabilities and the National Humanization Policy, which brings the concept of 'humanization' as *"inclusion of differences in management and care processes"*, which must be done in a collective and shared way.

As highlighted by professionals, one of the PNH[20] guidelines is the embracement. As a value in health practices and collectively constructed, the term embracement is recognized as the primary responsibility of the PHC professional, that is, this professional recognizes what the other brings as a legitimate and unique health need. This way, when putting it into practice, it fosters an adequate relationship between teams/services and users/populations[15]. And in several responses, we can see the team's great adherence to this responsibility and how active listening helps in the reception process, in ensuring these users have timely access to health technologies and increasing the effectiveness of health practices. Given its importance, this topic must be explored through health education, an extremely important aspect of PHC, especially with regard to health promotion[21].

The literature brings an important recognition of comprehensiveness, in which the care taken as a whole; therefore, longitudinality in PHC should not rely on illness for professionals to work[15]. Among the various topics addressed by the professionals in the interviews, there were no comments on the impacts of the suspension of 2020 funding for Family Health Support Centers (NASF), a policy responsible for creating and organizing the practices of various professionals supporting family health teams within the scope of primary care. It is worth noting that Ordinance GM/MS No. 635, of May 22, 2023, established multidisciplinary teams to replace the NASF format, expanding health areas and specialties. This could suggest that, since a health unit counts with a multidisciplinary team operating daily, it did not suffer considerable losses[22].

As for the team's potentialities, interprofessionality and multidisciplinarity play an essential role in the implementation of health care[15]. Both terms are associated with the mutual participation relationship of professional/patient, which is favored by the proximity to the context in which the patient is inserted, something possible in PHC, as well as the observation of priorities such as vulnerability, severity and risk, factors that favor care in a receptive and integral way[15,16,23-25].

Finally, despite the dedication to health care of people with disabilities, which is evident in the embracement and involvement of each professional, it is observed that little is still known about health policies for the population in question, thus raising a need: the emphasis on continuing education, as proposed by the National Health Policy for People with Disabilities[6,19]. There is great potential for improvement and the search for solutions through continuing education, characterized as *"An intense educational aspect with potential linked to mechanisms and themes that make it possible to generate reflection on the work process, self-management, institutional change and transformation of practices in service, through the proposal of learning to learn, working as a team, building daily lives and constituting themselves as objects of individual, collective and institutional learning"*[19].

As a limitation of the study, we can mention the small number of people with disabilities treated at the health unit, which directly influences the contact with the subject on a daily basis and the experience of the professionals. Therefore, it is essential to better train professionals in the search for equity in the embracement and care of this population.

CONCLUSION

In the context studied, we can conclude that professionals have a strong understanding of the importance of the topic and are involved in trying to meet the demands that are within the team's reach. One of the potentialities is to observe the embracement that sustains the team/user relationship in an integral, longitudinal and humanized way, seeing the other person as unique, without unnecessary focus on the disability, and acting through strategies such as qualified listening. However, there are difficulties regarding the promotion and prevention actions carried out by the team specifically aimed at this population. Therefore, it is possible to point out a need for greater preparation of the team, which suggests that local health managers develop continuing education, that is, training and improvements on the topic, and that the team emphasizes continuing education as necessary to have reflective actions on the work process and transformation of health practices.

FUNDING: This work was supported by the Brazilian Ministry of Health by means of a residence scholarship.

CRediT author statement

Conceptualization: Junior, WM; Lago, LPM; Gonçalves, LSS. Methodology: Junior, WM; Lago, LPM; Gonçalves, LSS. Validation: Junior, WM; Lago, LPM; Gonçalves, LSS. Statistical analysis: Junior, WM; Lago, LPM; Fumagalli, IHT; Gonçalves, LSS. Formal analysis: Junior, WM; Lago, LPM; Fumagalli, IHT; Gonçalves, LSS. Investigation: Junior, WM; Lago, LPM; Fumagalli, IHT; Gonçalves, LSS. Resources: Junior, WM; Lago, LPM; Fumagalli, IHT; Gonçalves, LSS. Original draft preparation: Junior, WM; Lago, LPM; Fumagalli, IHT; Gonçalves, LSS. Writing-review and editing: Junior, WM; Lago, LPM; Fumagalli, IHT; Gonçalves, LSS. Visualization: Junior, WM; Lago, LPM; Fumagalli, IHT; Gonçalves, LSS. Supervision: Junior, WM; Lago, LPM; Fumagalli, IHT. Project administration: Junior, WM; Lago, LPM; Fumagalli, IHT; Gonçalves, LSS.

All authors have read and agreed to the published version of the manuscript.

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DOI: 10.15343/0104-7809.202448e16572024I

Received: 29 august 2024.
Accepted: 27 november 2024.
Published: 18 december 2024.