

elSSN 1807-5762

Articles

Social representations of primary care physicians about health care for people with disabilities

Representações sociais de médicos da Atenção Primária sobre a atenção à saúde para pessoas com deficiência (resumo: p. 16)

Representaciones sociales de médicos de la atención primaria sobre la atención de la salud para personas con discapacidad (resumen: p. 16)

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The objective was to analyze the Social Representations of physicians working in the Family Health Strategy on health care for people with disabilities (PwD). The Theory of Social Representations was used, with a structural approach of the Central Nucleus Theory based on the technique of evoking words analyzed by the EVOC® and IRAMUTEC® software. 109 physicians participated, predominantly younger individuals and women. Care to PwD is guided by an incomplete, unsafe practice, permeated by the fear of doctors who mention gaps in the professional training process, in addition to communication difficulties with patients identified as PwD. Few physicians have more inclusive reports on PwD care. The predominant perceptions are restricted to the body, standardized by the biomedical model and ignoring social structures.

Keywords: Primary Health Care. Disabled persons. Quality assurance, health care. Qualitative research.

Fernandes VBL, Sant'Anna PA, Rocha JFD, Aguiar BS, Maia PR, Caldeira AP. Social representations of primary care physicians about health care for people with disabilities. Interface (Botucatu). 2023; 27: e230309 https://doi.org/10.1590/interface.230309

Introduction

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Primary health care (PHC) is the first level of a health service system and the preferential way for people to make first contact with health care¹. In principle, a strong PHC, guided by its main defining attributes (Accessibility, Longitudinality, Comprehensiveness, and Coordination) is qualified to provide quality care that is more cost-effective and with emphasis on health promotion for all population groups², including the health of minorities and people with disabilities (PwD).

In the Brazilian context, according to the National Policy for the Health of People with Disabilities³, there are already important actions aimed at this public, with the leading role of the PHC teams, operationalized by the Family Health Strategy (FHS). However, there are still few studies that address the development of these actions or health care for PwD, and it is relevant those that highlight difficulties of access and low quality of health care, with worse clinical outcomes^{4,5}.

In order to gain a deeper understanding of the situation, studies are needed to evaluate, among other aspects, the perception of professionals responsible for health care in PHC about health care for PwD. Despite great advances, especially in access to services and provision of doctors, the Brazilian PHC still faces great challenges in service organization, incompleteness in the supply of actions, poor architectural structure, and difficulties in the provision of personnel⁶. Especially for PwD, the physical, structural and organizational adequacies of the units are important barriers to the inclusion and welcoming of these users⁷.

The quality of PHC care in Brazil is precarious, and improvements are sorely needed⁸. Health professionals in PHC are unaware of the Brazilian legislation for PwD⁹, not being prepared for welcoming and communicating, as a peculiar instrument for some PwD which contributes to excluding services¹⁰⁻¹². Although many professionals advocate the comprehensive care to PwD, not reduced to gnoseological processes, they credit specialized and philanthropic institutions with the best care for these individuals¹³.

It is relevant to highlight that the health care for PwD denotes eloquently the principles of the Unified Health System. This relationship goes from universality, as a requirement that does not exclude or discriminate, through the equity of care, which brings in itself a close relationship with the concepts of equality and justice, with the proposition of serving individuals according to their needs, to the integrality of care, which advocates the recognition of each individual as a whole, in health promotion, disease prevention, treatment, and rehabilitation.

For a better understanding of the actions and results that PHC services project to users, it is necessary to know and reflect on the perceptions developed by professionals working in this context^{10,14}. In recent years the Theory of Social Representations (TSR), originally proposed by Serge Moscovici¹⁵, has become recurrent in studies that seek to evaluate the values, notions and practices of certain social groups, considering that such representations are considered a form of socially developed and shared knowledge, with a practical orientation and contributing to the construction of a common reality for a social group¹⁶. Thus, knowledge of the social representations (SR) of a group allows to characterize the collectively constructed phenomena, not disregarding the individuality of the subjects, mediated by language¹⁷.

The literature records some studies that clarify the SRs of health professionals about educational practices in the service¹⁶, about professional autonomy involving HIV/Aids from the gender perspective¹⁸, and about the approach to neglected diseases¹⁹. However, no studies were identified that address the SRs of health professionals about health care for PwD. This aspect highlights the invisibility of PwD in society and in the academic and scientific environment. The present study aimed to analyze the Social Representations of physicians who work in primary care teams about health care for PWD.

Methods

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This is a qualitative study, based on the TSR and with a structural approach of the Theory of the Central Nucleus (TCN), proposed by Jean-Claude Abric¹⁷. The structural approach presents itself in the form of two complementary systems, the central nucleus and the peripheral nucleus. The central core is what gives meaning to the representation, with constituent elements that are more resistant to modification. The peripheral nucleus, on the other hand, constitutes most of the elements of evocation, and is changeable and adaptable to the prevailing social reality. TCN systematizes the social representations around nuclei that establish, at the same time, their significance and internal organization¹⁷.

The research was carried out in Montes Claros, in northern Minas Gerais. This is the region's pole city, a reference in the provision of services, with an estimated population of 410 thousand inhabitants. In the context of PHC, the city has 142 FHS teams, 132 urban and 10 rural, allowing for a coverage rate above 100%.

For the purposes of this study, 109 physicians were randomly selected among those allocated to FHS teams in the urban area of the city, who expressed interest in participating in the study. This sample corresponds to what is recommended in the literature for prototypical analysis²⁰, since, although there is no exact indication of the minimum number of participants required, the higher the number, the more stable will be the results. Starting at 100 elements in the sample is considered ideal for more robust conclusions^{21,22}. Data collection was conducted between the period June 2019 to August 2020. Initially, 56 physicians were interviewed face-to-face in the basic health units, and a date was previously scheduled with the participants, according to availability, thus avoiding the interruption of professional activities. As data collection included part of the pandemic period caused by the new coronavirus (Covid-19), we chose digital contact for the remaining interviews. The questionnaire was transcribed into Google forms platform and made available to doctors through personal e-mails, provided by the FHS coordination of the Municipal Health Secretariat. In this stage, 53 professionals were interviewed virtually, for a total of 109 professionals.

Data were collected from an instrument developed by the researchers, addressing the sociodemographic profile and professional training, as well as characteristics of medical care for PwD and its frequency. Additionally, specific questions were presented for the test of evocation of words, to analyze the SR: (1) "Name five words or expressions that come to mind when thinking about the care to the disabled person"; (2) "Choose a word or expression that you consider the most important among the five mentioned above"; and (3) "Justify the importance of the choice of the word you considered the most important". Based on the evocations in the four boxes and the justifications presented by the professionals, we carried out a lexical analysis of these excerpts, aiming at understanding the meaning of these terms for the physicians.

The data referring to the sociodemographic and professional profile were analyzed by simple descriptive statistical analysis. Data from the technique of free association of words or evocation of words were examined by structural analysis and presented in a table of four boxes, built with the help of the software Ensemble de Programmes Permettant l'Analyse des Evocations (EVOC®) version 2005²⁰.

The transcribed interviews composed a single corpus submitted to IRAMUTEQ, (Interface de R pour analyses Multidimensionnelles de Textes et de Questionnaires) which originated the Descending Hierarchical Classification (DHC). This is an analysis built through classes, from text segments of a corpus, which classifies and categorizes the words according to their frequency and semantic content^{23,24}.

All ethical aspects were considered in this research. The study had the consent of the Municipal Health Secretariat of the city where the study was carried out. The participants agreed to participate and signed an informed consent form. The project was approved by the Research Ethics Committee with opinion number 3.332.823.

Results

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The group of physicians participating in the study was predominantly female (n=78; 71.6%), most of them younger than 30 years old (n=41; 37.6%), and reporting single as their marital status (n=56; 51.4%). About half of these professionals are generalists or undergoing residency in family and community medicine, and 70% of them have worked in the FHS for less than five years. All of them reported having contact with disabled patients during their care activities. On the topic of previous training, about 10% of the respondents reported some kind of training for PwD care, but without characterizing the procedure.

Regarding evocations, the participants together produced 522 words or expressions, of which 171 were different words or expressions. The minimum frequency of evocation for insertion into the four-box frame was equal to nine (representing 50% of the cumulative frequencies of quotations/evocations). The average Mean Evocation Order (MEO), i.e., the "rang" was equal to 2.93 and the cutoff point of the MEO was 2.70.

The free evocation of words technique made it possible to identify the main elements associated with PwD health care by PHC physicians, generating, from the EVOC® software, the Four-House Chart (Figure 1), which demonstrates the relation of evoked words and their frequency and the mean evocation order (MEO). In the TCN structural approach, the elements that are located in the upper left quadrant stand out as the probable central core of the SRs. Based on the assumptions of TCN, the semantic elements situated in the upper left quadrant represent the most frequently and most readily evoked evocations. The core consists of stable elements that do not vary depending on the immediate context^{25,26}.

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Central Nucleus Elements			First periphery elements		
Frequency \geq 17/ Rang < 2,70			Frequency ≥ 17 / Rang $\ge 2,70$		
	Freq.	Rang		Freq.	Rang
Communication Difficulty	51	2,569	Empathy	17	2,824
Difficulty	37	2,216			
Care	35	2,400			
Accessibility	25	1,680			
Limitation	17	2,353			
Contrast Elements			Second periphery elements		
Frequency ≥ 9 e < 16 / Rang < 2,70			Frequency $\ge 9 e < 16/ Rang \ge 2,70$		
	Freq.	Rang		Freq.	Rang
Access	13	2,538	Equity	14	3,286
Inclusion	13	2,385	Unpreparedness	13	2,846
			Patience	11	2,909
			Respect	9	3,889

Figure 1. Four-box grid - frequency distribution and average order of position generated by Rangfrq of EVOC® software of the free evocation of words of PHC physicians from the induction with the terms "care to the person with disabilities" - Montes Claros (MG), 2019/2020.

The component elements of the probable central nucleus of the SR were: "Communication difficulty", "Difficulty", "Care", "Accessibility" and "Limitation". Among these the most evoked was "Difficulty in communication" and the most readily evoked (lowest "rang") was "Accessibility".

The first and second peripheries contain five evocations, distributed as follows: "empathy" present in the first periphery and the elements "equity", "unpreparedness", "patience" and "respect" which constitute the second periphery. The evocations "access" and "inclusion" are in the lower left quadrant and represent the contrasting elements of the SRs of the FSH physicians regarding PwD healthcare.

The Descending Hierarchical Classification Dendrogram (DHC) represented in Figure 2 demonstrates the most frequent words and those with greater association in and among the classes. In this figure, the corpus was divided into two subgroups: class 4 and classes 1, 3 and 2.

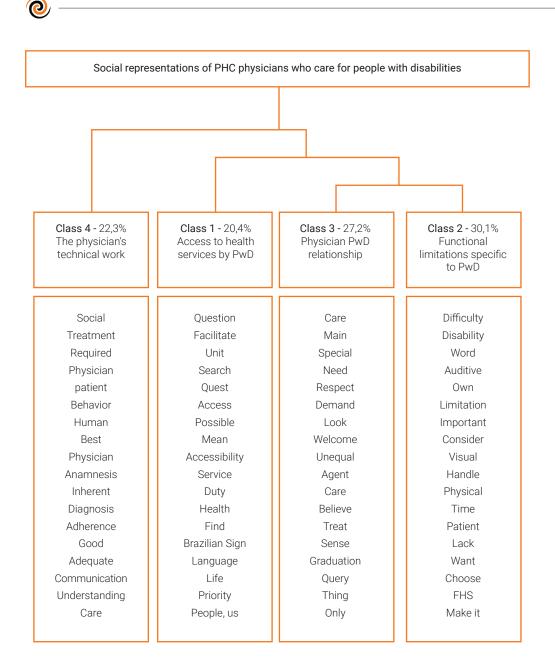


Figure 2. Dendrogram of the descending hierarchical classification of the corpus on social representations of PHC physicians about PwD care, Montes Claros (MG), 2019/2020 Source: corpus analysis processed by the Iramuteq software

It may be noted that the most incident words in the DHC, class 4 refer to words associated with the physician's work, within aspects of diagnosis, semiology and treatment. In class 1, the words show the difficulties that PwD go through when in need of health services, specifically in the items 'access' and 'accessibility'. Class 3 brings words which denote inter-relational and behavioral aspects between doctors and PwD, introducing the word 'graduation' in this group possibly alluding to the academic medical training. Finally, class 2 refers to the characteristics and difficulties of people with their respective disabilities.

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Regarding the analysis of the terms and expressions and their justifications, we note that in the first quadrant, which characterizes the SR of the group investigated, the representation of the 'difficulty' of assistance is remarkable, while highlighting the technical limitations of doctors in dealing with this demand. This demand refers, especially, to the failures during the professional's graduation. This limitation also denotes aspects related to anatomical and/or functional restrictions, peculiar to people with disabilities.

[...] in face of the difficulty we have in caring for these patients, exactly because of the lack of preparation during and after graduation, it makes it difficult to follow up, to better adhere this patient to the treatment that is proposed [...]. (E53)

[...] limitation' because I think it is a word that suggests my difficulty in relation to some types of disabilities, for example, the hearing and verbal disabilities, as I do not know how to deal with the Brazilian Sign Language, my difficulty in communicating with the patient; and the limitation when I see it on the part of the patient as well, in maybe getting some things, some rights and benefits in society due to his/her limitation. (E77)

In the first periphery quadrant, the analysis refers to the physician's perception in experiencing, in a subjective way, the feelings that PwD experience, in an attempt to better understand this universe.

[...], but from the moment that you start to put yourself the shoes of the patient, to look at him/her with different eyes, [...] and I believe that this way it is easier to treat that patient, [...] then when you look at the patient with empathy you begin to forget all the problems and difficulties during the consultation, [...]. (I49)

In the quadrant of the second periphery, the elements direct towards the idea of lack of professional preparation in PwD care, which, in turn, is supported by attitudes of "patience", "respect" or "equity" in an attempt to remedy the technical inability of the physician.

[...] if we receive training, during graduation, in assisting people who have some type of disability, we do not receive it, and then we graduate and are exposed to situations in which we do not know how to act [...]. (E27)

[...] I think that especially with the person with disability it is necessary that professionals be human when assisting them because they are people that require special care than others, so this aspect is very necessary when assisting them. (E91)

Finally, the quadrant referring to the contrast zone shows the movement of ideas toward more inclusive attitudes of physicians, both in recognizing the barriers of access and the need for the insertion of PwD in the context of society and the professional's work.

I chose the phrase 'social inclusion' because of the importance of this in the conduct of patients, both professionally, in professional ethical-medical conduct and in the inclusion of their social environment. (E50)

Discussion

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The analyses performed, allow us to infer that caring for PwD in primary care is guided by an incomplete and insecure practice, permeated by the fear and difficulties of doctors and patients. The difficulty expressed by professionals sometimes highlights gaps in the training process, sometimes refers to communication difficulties (information) and approach to the patient, sometimes addresses characteristics inherent to the patient (difficulty to understand or to access health care). In the expressions pointed out by the professionals, it is registered that the social representations build an assistance that is mediated by the physician from the patient's demand, without considerations about the knowledge of specific public policies on which this practice could also be based.

Santos et al.²⁷, in a study that evaluated the results of the National Census of Primary Health Care Units regarding architectural and communication barriers in PHC, state that poor architectural conditions compromise access to the service and, consequently, the resolutivity of care. They also point out that the issues of communication and information directed to PwD in PHC are key. In specific, for sensory disabilities, the units do not have Braille characters or figures in relief, or interpreters for the hearing impaired, demonstrating the inadequacy of health services.

Regarding health professionals, the assistance for sensory PwD is more complex when compared to people with reduced mobility or cognitive impairment. They consider that there is a need for permanent training to reduce barriers in communication with users, as well as policies aimed at the development of health services with more quality²⁸.

In regards to the perception of the deaf persons, the absence of an interpreter, either by a companion or by the unpreparedness of the professional, greatly compromises the service, to the point to induce the individual to avoid seeking assistance²⁹. Hearingimpaired individuals complain specifically of problems with communication during the medical history and physical examination, understanding about prescriptions, and difficulties in scheduling appointments²⁸. Visually impaired people also report major obstacles in accessing health services. They refer to barriers related to communication, to the scarcity of materials written in Braille, and attitudinal barriers from doctors who consider blind people incapable of taking care of their own health²⁸. Health professionals wish and consider important the training to enable them to better care for PwD. This training should occur from the time of graduation, and not be limited to a few hours or a specific moment in a discipline, after their academic training¹⁰.

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Referring to the SRs of physicians, it is notorious the reaffirmation of limited assistance due to the difficulty: of access to knowledge, of communication, and even of defining behaviors, in relation to how to guide and how much to guide. The assistance practice is, in this sense, essentially based on a biomedical model of punctual care, which is reflected in an incomplete assistance in which, apparently, the physician does not understand and cannot make himself understood. In this context, the other element of social representation arises, that is, the search for a more humanized and empathetic care as an attempt to compensate for a perceived failure. However, it is is not enough to ensure the comprehensiveness of care in PHC. Comprehensive care presupposes articulated health care networks at different levels of complexity. But beyond the articulation of levels of care, primary care teams, based on their attributes of family and community orientation and cultural competence, must seek possibilities of connections with other networks of social inclusion.

In the structural approach of TRS, the central nucleus is constituted by normative and functional elements. Thus, when analyzing the evocations of the central nucleus elaborated from the evocations of health professionals, it is observed that the terms "difficulty", "communication difficulty" and "limitation" are configured as the most pronounced aspects of PwD care expressed by doctors. Among these, the expression "communication difficulty" stands out as the representation most valued by the physicians for not having the fundamental and basic communication skills for a desired fruitful doctor-patient interaction.

The SR peripheral system, from the evocations presented by the professionals, registered in the first periphery the term "empathy". In this quadrant, the word expresses a positive connotation related to PwD health care, but it may be also inferred attitudes of insecurity and compensation that coexist with a very fragmented medical practice in PwD care.

Referring to the perspective of equity of care, the expression "equity", evoked more frequently in the second periphery, infers assistance centered on the person, in their diverse and unequal needs, especially of PwD. This register already denotes a more proactive reflection on the aspect of social inclusion. Wanting to be able to attend is inclusive. Together with the other words that appear in this quadrant, unpreparedness, patience, and respect, they are also attempts at compensation or justification for a practice permeated by the physician's insecurity, without a theoretical-practical foundation. The literature has little reference to this theme.

In the quadrant called the contrast zone, there are the terms or expressions that had low frequency, but with prompt evocation, that is, with higher MEO. These terms are considered very important for the few who evoked them. In the context of the theme addressed, they denote the anguish of the medical professional in recognizing the difficulties of access and/or accessibility of the PwD to the PHC service, triggering losses in the assistance. Moreover, they perceive the need for greater social inclusion, associating to this concept positive and healthy aspects of human relationships such as empathy and respect. In a complementary way, doctors can attribute their technical inability in PwD care to the situations of social exclusion that PwD face, as well as the difficulties in moving through the health services when faced with their needs. In this way we see again an anchoring in the relational dimensions of PwD care, configuring the vocational aspect of the profession rather than the technical one.

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Physicians convey orderly feelings or attitudes when faced with their insecurities in dealing with PwD. The polarizations of "vocational" versus "professional" characterize a stress running through the reports, characterizing the central idea that originates the social representation of this group in relation to PwD. This tendency toward a natural relationship with PwD, based on 'vocation', goes back to the historical-social trajectory of exclusion/elimination, from ancient times until the Middle Ages, with the advent of Christianity. From then on, PwD are considered 'God's creatures', no longer being allowed to exterminate them. At this point, a pious movement to care for these people, still considered unfortunate, was created. Moving into the Renaissance, scientific thought and social relations went through profound changes³⁰.

In a historical analysis of the model of assistance to PwD, the religious interpretation of bodies marked by aesthetic difference, considered as cursed, was replaced by biomedical or anatomical concepts, which interpreted these bodies as "sick". The Medical Model of Disability was born, a concept marked by the disadvantages of the deformed body of the disabled. However, from the 1960s on, in opposition to this model, the Disability Rights Movement began, based on reflections in the academic field from Disability Studies. These studies approached the social oppression of the disabled person, based on capitalist ideas that praised independence through productive and functional bodies, besides a cultural and ideological construction of atypical bodies³¹. By deepening the debate on the social limitations experienced by these people, the authors also discussed the political articulation of people with disabilities and questioned the ideology of normalization. From then on, a new paradigm was recognized, the Social Model. This model was based on the assumptions of historical materialism and defended the idea that the medical model meant a reality of oppression and intense inequalities to the participation of people with disabilities in research and in the political decisions that involved them^{32,33}.

This way of being anchored in the vocational model, that is, in the philanthropic vision represented by empathy and welcoming, in the care of PwD, however, does not represent an effective care. It is possible to infer that insecurity coexists and the

work is not effective in itself. The words "empathy", "patience" and "respect" evoke a feeling of "wanting to help". In this sense, empathy is complementary to the core social representation. In the analysis of the four-house picture it is possible to see that in the first periphery and in the contrast zone the elements that compensate for the "difficulties" registered in the central nucleus appear.

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The dendrogram presented earlier corroborates the duality of the social representation exposed in the semantic field of the four boxes. Class 4 of the DHC explains aspects of medical semiology intermingled with the referred "difficulties" in "care" and "understanding" of PwD, similarly to the associations recorded in the first quadrant. In class 3, words that translate empathic attitudes are evidenced, in counterpoint to the difficulty of handling these patients, considered here as a gap in 'graduation'. The table of four boxes reaffirms this representation, to the extent that it isolates the various difficulties faced by PwD patients in its main quadrant and moves to the periphery behavioral attitudes of compensation for the feeling of impotence of the physician.

Another aspect worth mentioning concerns the fact that most of the medical professionals in this research are female. The feminization of the health job market is already a recognized phenomenon³⁴. Gender-related aspects can influence these discourses. Historically, it is attributed to women to 'care' in its most varied connotations³⁵. More studies are needed to corroborate the health care aspect of physicians facing PwD.

In the recorded associations, there are recurrent explanations from physicians for not having been properly trained in how to care for PwD, resulting in technical difficulties in the approach to these individuals. Medical schools tend to emphasize in the curriculum the acquisition of knowledge compared to the acquisition of skills and attitudes of the doctor-patient encounter, but there is not a systematized proposition of assistance to minorities. These aspects are almost always approached as minor or elective subjects. It is essential that students live with PwD during graduation in the most varied scenarios, including having teachers who present some kind of disability³⁶.

Upon entering the course, the students feel fascinated and attracted to the profession, to the physician, considered a humanized professional. As the undergraduate course progresses, the students start to identify the difficulties in the job market and even the reduction in professional prestige, conflicting with the illusion they had previously developed. Even so, they consider medicine a great achievement in their accomplishments and show concern about the medical-social responsibilities of their practices³⁷. It is worth reflecting on a possible representation that is associated with an incomplete and insecure practice, disconnected from the responsibility of continuous self-directed professional education, which is necessary. More studies are needed on this topic.

The analysis of the results allows us to infer, in a global way, that the PHC doctors consider themselves unqualified to assist PwD, present significant limitation in communication with this group, especially the hearing impaired, in addition to demonstrating, in a veiled way, reactions of evasion when they reveal their inability to deal with PwD. On the other hand, it must be emphasized that some professionals glimpse a more inclusive attitude, in the sense that they register that the assistance to PwD must be regulated in a heterogeneous way. The health needs of PwD, due to the fact of being peculiar, characterize a possible celebration of the diversity of human beings in the reports of physicians.

Final considerations

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The results point out to the need to broaden the discussion on health care for PwD. Although the PHC teams have special conditions for a care centered on a social model, which enforces, especially, the principles of equity and comprehensiveness, they still lack grounds for reviewing the practice. It is necessary that this discussion reaches health training centers, with emphasis on medical schools, which must restructure their educational proposals based on the contemporary paradigms of PwD care, integrating this theme to the ordinary practices of the curriculum. Otherwise, health care for PwD will continue to perpetuate punctual and incomplete practices, which refer to behaviors as normatized by the biomedical model, focused on body functionality, which ignore social structures and reaffirm exclusion.

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Authors' contribution

All authors actively participated in all stages of preparing the manuscript.

Acknowledgments

Municipal Health Secretariat of Montes Claros.

Conflict of interest

The authors have no conflict of interest to declare.

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Submitted on 07/05/22 **Approved on** 05/28/23

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O presente artigo objetivou analisar as representações sociais de médicos atuantes na Estratégia Saúde da Família sobre atendimento à saúde para pessoas com deficiência (PcD). Utilizou-se a Teoria das Representações Sociais, com abordagem estrutural da Teoria do Núcleo Central, a partir da técnica de evocação de palavras analisadas pelos *softwares* Evoc® e Iramutec®. Participaram da pesquisa 109 médicos, predominantemente jovens e mulheres. A atenção às PcD se orienta por uma prática incompleta, insegura e permeada pelo receio de médicos que referem lacunas no processo de formação profissional, além de haver dificuldades de comunicação com pacientes identificados como PcD. Poucos médicos apresentam relatos mais inclusivos na assistência de PcD. Predominam as percepções restritas ao corpo, normatizadas pelo modelo biomédico e que ignoram as estruturas sociais.

Palavras-chave: Atenção Primária à Saúde. Pessoas com deficiência. Avaliação da qualidade dos cuidados de saúde. Pesquisa qualitativa.

El objetivo fue el análisis de las Representaciones Sociales de médicos actuantes en la Estrategia Salud de la Familia sobre atención de la salud para personas con discapacidad (PcD). Se utilizó la Teoría de las Representaciones Sociales, con abordaje estructural de la Teoría del Núcleo Central a partir de la técnica de evocación de palabras analizadas por los softwares EVOC® e IRAMUTEC®. Participaron 109 médicos, predominantemente jóvenes y mujeres. La atención a las PcD se orienta por una práctica incompleta, insegura, atravesada por el recelo de médicos que refieren lagunas en el proceso de formación profesional, además de dificultades de comunicación con pacientes identificados como PcD. Pocos médicos presentan relatos más inclusivos en la asistencia de PcD. Predominan las percepciones restringidas al cuerpo, normalizadas por el modelo biomédico y que ignoran las estructuras sociales.

Palabras clave: Atención Primaria de la Salud. Personas con discapacidad. Evaluación de la calidad de los cuidados de salud. Investigación cualitativa.