Research Article

Representaciones sociales sobre la organización social del cuidado de personas con discapacidad. Apuntes desde San Pedro de los Milagros, Antioquia

Social Representations Around Social Organization of Care for People with Disabilities. Notes From San Pedro de los Milagros, Antioquia

Representações sociais sobre a organização social do cuidado de pessoas com deficiência. Observações de San Pedro de los Milagros, Antioquia

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INCLUSIÓN
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RESUMEN

El artículo surge de la investigación titulada "Organización social del cuidado de las personas con discapacidad en condición de dependencia en el Municipio de San Pedro de Los Milagros", realizada entre agosto de 2023 y junio 2024 en la Fundación Universitaria Católica del Norte. Esta investigación buscó comprender la configuración de la organización social del cuidado en las familias de las personas con discapacidad en condición de dependencia, definiendo la organización social del cuidado como aquella interrelación entre Estado, familia, comunidad y mercado, en la provisión, producción y distribución de servicios de cuidado. Se realizó una investigación cualitativa bajo un modelo etnográfico. Se presentan hallazgos concentrados en un objetivo específico de la investigación: comprender las representaciones sociales en torno al cuidado, presentes en los actores de cuidado de las personas con discapacidad en condición de dependencia. Se definen las representaciones sociales como aquellas estructuras de pensamiento compartidas, instituidas e instituyentes de la realidad social, por los agentes en un campo social específico (Bourdieu y Wacquant, 1995). Las representaciones sociales encontradas se asocian a tres ideas emergentes: la vinculación del cuidado a la construcción de saberes específicos, a experiencias de soledad e incertidumbre y al autocuidado como recurso estratégico.

Palabras clave: cuidado; discapacidad; dependencia; representaciones sociales.

ABSTRACT

The article arises from the research project entitled "Social organization of care for people with disabilities in a situation of dependency in the Municipality of San Pedro de Los Milagros", carried out between August 2023 and July 2024 at the Universidad Católica del Norte. The aim was to understand the configuration of the social organization of care in the families of people with disabilities in a situation of dependency, defining the social organization of care as the interrelationship between the State, family, community and market in the provision, production and distribution of care services. Qualitative research was carried out under an ethnographic model. The findings are presented, focused on a specific research objective: understanding the social representations of care present in the care actors of people with disabilities in a situation of dependency. Social representations are defined as those shared, instituted and instituting structures of thought of social reality, by the agents in a specific social field (Bourdieu and Wacquant, 1995). The social representations found are associated with three emerging ideas: the link between care and the construction of specific knowledge, experiences of loneliness and uncertainty, and self-care as a strategic resource.

Keywords: care; disability, dependency, social representations.

RESUMO

O artigo surge do projeto de pesquisa intitulado "Organização social do cuidado de pessoas com deficiência em situação de dependência no Município de San Pedro de Los Milagros", realizado entre agosto de 2023 e julho de 2024 na Universidade Católica do Norte. O objetivo era compreender a configuração da organização social do cuidado nas famílias de pessoas com deficiência em situação de dependência, definindo a organização social do cuidado como a inter-relação entre Estado, família, comunidade e mercado na provisão, produção e distribuição de serviços de cuidado. Foi realizada uma pesquisa qualitativa sob um modelo etnográfico. Os resultados são apresentados, focados em um objetivo específico da pesquisa: compreensão das representações sociais do cuidado presentes nos atores cuidadores de pessoas com deficiência em situação de dependência. As representações sociais são definidas como aquelas estruturas de pensamento compartilhadas, instituídas e instituintes da realidade social, pelos agentes em um campo social específico (Bourdieu e Wacquant, 1995). As representações sociais encontradas estão associadas a três ideias emergentes: a vinculação do cuidado à construção de saberes específicos, experiências de solidão e incerteza e o autocuidado como recurso estratégico.

Palavras-chave: cuidado; deficiência; dependência; representações sociais.

Literature Review

The notions surrounding disability as a social and health phenomenon at both the international and national levels have undergone significant transformations in the current century. One of the most significant global milestones is the United Nations Convention on the Rights of Persons with Disabilities, which has been in force since 2008. This regulatory framework led to the enactment of Law No. 1618 of 2013 in Colombia, which "establishes provisions to guarantee the full exercise of the rights of persons with disabilities," recognizing them as subjects of rights.

In the country, according to the National Administrative Department of Statistics (DANE), "as of August 2020, a total of 1,319,049 persons with disabilities had been identified and recorded in the official registry of the Ministry of Health and Social Protection. This figure represents 2.6% of the total national population" (2020, p. 4). Of this population, 50.1% are men and 48.9% are women. It is noteworthy that 70.3% of persons with disabilities are enrolled in the subsidized health system, a factor that was also evident and relevant during the research process, as it highlighted the barriers this population faces in accessing healthcare services.

Similarly, "34.62% of persons with disabilities (617,779) receive assistance from others to perform their basic daily activities" (DANE, 2020, p. 5). Those providing support in these everyday tasks are primarily women, who account for more than 55% of the caregivers recognized by DANE. Meanwhile, "of the 1,487,354 households that include at least one person with disabilities, 38.3% are classified under socioeconomic stratum one (1) and 34.7% under stratum two (2)" (DANE, 2020, p. 5). This data underscores the feminization of care work, which is largely carried out within domestic settings.

The Colombian government has formulated policies and programs to address the needs of persons with disabilities. However, most of these initiatives focus on physical, biological, and emotional aspects, overlooking a fundamental issue: the guarantee of care. Moreover, there is a lack of public programs addressing this population in rural areas, a gap that is also reflected in the scarcity of academic studies that consider the category of the social organization of care in relation to disability in rural contexts.

For this research, a theoretical review was conducted, structured along two main lines: identifying specific studies on care, its production, and its distribution; and studies focused on disability as a social and health phenomenon. Both reviews prioritized Latin American studies from the last 10 years. The category of the social organization of care has been analyzed from two central theoretical perspectives. On one hand, Latin American theories of care conceptualize it as a core component of the health-disease process in populations. On the other hand, social policy research has framed care as a fundamental factor in maintaining and ensuring well-being in Latin American societies.

The incorporation of gender perspectives into Latin American theories on health has made it possible to complement the classic health-illness-care triad with the central notion of this project: the category of care (Domínguez Mon, 2017; Batthyány, Genta, and Perrotta, 2017; Hernández, 2022). Among other aspects, care is understood as a fundamental axis in the provision of assistance for non-communicable and long-term health conditions, illnesses, or ailments. It is also recognized as a key tool for safeguarding life amid epidemiological transformations that increasingly lead to chronicity.

Latin American theories on care have also examined who assumes responsibility for care work and how its burden is distributed. Consequently, the backbone of this academic field is the category of the sexual division of labor (Batthyány, 2015; Domínguez Mon, 2017; Arango Gaviria et al., 2018, among others). This framework helps to explain how the feminization of care and its relegation to the domestic sphere align with the fundamental logic of the modern patriarchal structure, which systematically organizes care dynamics across all aspects of life (Puyana, Hernández, and Gutiérrez, 2020).

In line with this, Mendes, Domínguez, and Schwarz (2011), along with Lenguita (2020), argue that the feminization of care and its confinement to the domestic sphere reflect a patriarchal structure. This structure devalues and obscures women's labor within the home, attributing it to a supposed natural vocation, self-sacrifice, or familial love.

From the perspective of social policy, various scholars have contributed to the concept of the social organization of care, which positions care as a central element in the notion of well-being. It also prompts an inquiry into the interrelations among the state, the market, the family, and the community in the production and distribution of care work. This concept, explored by Pautassi (2016), Ceminari and Stolkiner (2018), and Pautassi, Arcidiácono, and Straschnoy (2014), among others, enables the recognition of care networks—comprising those who require care, those who provide it, institutional actors, recognized rights, and market participation. Furthermore, it advances the discussion of care distribution beyond the binary of men and women, extending it to the division between the public and domestic spheres.

This is why Pautassi (2016) proposes conceptualizing care as a set of practices that sustain and nurture individuals—practices that are as diverse as they are essential to human existence. Care tasks range from self-care to direct care for others, incorporating the creation of conditions that facilitate caregiving: purchasing food, paying for services, doing laundry; and the management of care: organizing schedules, coordinating transportation, and ensuring access to educational and healthcare institutions, among others.

Similarly, regarding disability studies, two predominant paradigms were identified: the rehabilitative paradigm and the personal autonomy paradigm. Each paradigm promotes theoretical and intervention models that approach the category from different perspectives (Aritizábal, 2021). For this research project, we adopted the social model of disability (Ávila, Nuñez, and Colchado, 2021), which aligns with paradigms that emphasize the personal autonomy of persons with disabilities while challenging the biomedical perspective that assumes the need to rehabilitate or minimize disability to conform to biomedical norms of normality (Bonilla, 2020; Victoria Maldonado, 2013). Academic literature within this theoretical framework allows for an examination of how society facilitates or obstructs the daily lives and social organization of care for persons with disabilities, with particular focus on contextual barriers—economic, environmental, social, and cultural.

Methodology

A qualitative research approach was employed, utilizing an ethnographic method. More specifically, a microethnographic study (Morse, 1994) was designed, prioritizing the selection of participants based on shared characteristics that distinguish them from other groups within a specific context. A total of eight in-depth interviews (Marradi, Archenti, and Piovani, 2007) were conducted with persons with disabilities in conditions of dependency and their caregivers, residing in both rural and urban areas of the municipality. Additionally, the Zarit Burden Interview was applied to assess caregiver burden levels, and an in-depth interview was conducted with the professional overseeing the municipality's disability program. Participant recruitment was facilitated through the municipality's disability program. Ethical considerations were guided by Colombia's professional code of ethics for Social Work, and informed consent was obtained from all participants.

Fieldwork was conducted between October and November 2023. For data analysis and processing, the constant comparative method (Glasser and Strauss, 1967) was used, employing a categorical analysis matrix that organized information into predefined and emerging categories derived from the transcription of interviews.

Analytical Results

The analysis led to the identification of three emerging ideas related to the social representations that shape the social organization of care for persons with disabilities in a condition of dependency within the territory. First, care for persons with disabilities is recognized as a skill acquired through daily practice and the development of habits and customs that ultimately result in the acquisition of specialized knowledge.

In this regard, caregiving for persons with disabilities in a condition of dependency disrupts daily life, initially presenting as a challenge. It primarily confronts women in the household with unfamiliar tasks, both in the direct provision of care and in the creation of enabling conditions for caregiving, as well as in resource management. Over time, these tasks lead to the accumulation of a form of capital and practical knowledge in those who perform them. This acquired expertise, integrated into daily routines, transforms primary caregivers into specialists in their role.

This first representation allows for three convergent analyses. First, recognizing the establishment of a continuous caregiving routine enables an understanding of intra-household care as a fundamental component of long-term healthcare processes, particularly in cases of disability involving a high degree of daily dependency. The essential nature of permanent care in these specific health situations requires not only the constant dedication of individuals to ensuring the well-being of persons with disabilities but also the formation of a caregiver who, through firsthand experience, emerges as a knowledgeable and skilled individual capable of managing the everyday challenges of caregiving. From this social representation, caregiving can be interpreted as a process that shapes a distinct type of individual: the woman who successfully navigates the challenges and obstacles associated with managing and providing care and, through the accumulation of knowledge, becomes an expert in strategies for meeting the needs of care recipients.

Secondly, this way of representing care and the caregiver makes it possible to understand the fulfillment of the needs of persons with disabilities as an invisible system of guarantees, a system that, according to testimonies, is sustained by practices rooted in specific knowledge. That is, intra-household care, particularly that provided to persons with disabilities, is not experienced as a spontaneous, simple, or accessible practice but rather as a complex system of routines and dynamics that can only be accessed through experience and the acquisition of knowledge. Although this knowledge emerges from daily practice rather than a specialized or academic process, it nonetheless constructs a distinct expertise. This expertise is acquired through the accumulation of practical capital, which in itself gains intrinsic value.

This leads to the third key analytical point: recognizing this way of representing care allows for an understanding that there is a clear distinction between those who can assume responsibility for meeting the needs of persons with disabilities and those who cannot. Thus, the notion is reinforced that some individuals are recognized as capable caregivers, while others, despite contributing sporadically or even regularly to sustaining daily life, remain in a secondary role due to their lack of the knowledge acquired through continuous caregiving practice.

This understanding justifies why adult women in the household take on the primary responsibility for care, while other household members or non-cohabiting relatives with the same degree of kinship and responsibility—typically parents, siblings, and/or grandparents—distance themselves, at least discursively, from the central management of caregiving. Even when these individuals perform certain daily caregiving tasks, their lack of specific knowledge and practical capital places them outside the primary circle of responsibility.

In this sense, care can be understood not only as a practice shaped by gender norms and the sexual division of labor (Ceminari & Stolkiner, 2018), but also as a social space that, due to its demand for complex knowledge, reinforces and perpetuates these norms. It differentiates not only between those who provide care and those who do not, but more significantly, between those who know how to provide care and those who do not.

The implementation of this social representation results in the differentiation between full responsibility for the person with a disability and the more or less sporadic assistance provided in everyday life. Even among relatives with the same degree of kinship, a construction of meaning takes place in which certain members of the household become primary caregivers out of obligation, while others contribute from a secondary position, addressing needs only occasionally. In this sense, this conceptualization of care also establishes different degrees of relevance among actors within the social organization of care.

Interestingly, this differentiation does not only operate through the division between female caregivers and male assistants but also through the distinction of which spaces are deemed valid for caregiving and which are not. The analytical process revealed that the social representation associating care with knowledge accumulated through daily experience fosters the perception, among families of persons with disabilities, that the home is the most suitable, optimal, and reliable space for providing care—often at the expense of other organizations or institutions, including healthcare facilities.

It is assumed that professional healthcare settings, despite their technical expertise, are inadequate to meet the needs of individuals requiring care because they lack familiarity with their routines, habits, ways of communicating, and methods of seeking assistance. While these institutions may possess specialized technical knowledge, they are perceived as lacking the intimate, non-professionalized, yet highly specialized knowledge that has historically positioned the domestic sphere—particularly female caregiving—as the most appropriate environment for sustaining life.

Thus, even though the social organization of care may at times extend beyond the home, as individuals may require more or less frequent interactions with healthcare institutions, the representation of care as knowledge shaped by everyday experience reinforces the idea of the home as the optimal, and in many cases, the only legitimate space for meeting caregiving needs. It also reinforces the notion that familiarity with the person being cared for is the primary criterion for distributing caregiving responsibilities. Additionally, a second social representation was identified, which frames the experience of caregiving for persons with disabilities as one of constant uncertainty, generating feelings of loneliness and fear of the future among those who assume caregiving responsibilities. Given the impossibility of distributing caregiving tasks equally among different actors, those who take on most of the daily responsibilities construct social imaginaries in which caregiving becomes an impossible task without their presence and intervention. In other words, they perceive themselves as indispensable agents for sustaining the lives of persons with a disability condition.

This does not necessarily mean that those who assume caregiving roles are the only essential actors or that others are incapable of performing these tasks. Rather, it is interpreted as an exercise in self-perception that leads to persistent feelings of anguish, fear, and anxiety about the medium- and long-term future. From this perspective, caregivers express that these tasks represent a fully obligatory responsibility—duties they cannot omit, postpone, or, even less, delegate. This social representation implies that if delegating caregiving tasks is already difficult within the family unit, the possibility of sharing responsibilities with other actors in the state, community, or market sectors seems entirely unfeasible.

It is important to highlight that positioning themselves as indispensable caregivers results in profound exhaustion in the lives of these women. In addition to the physical burden of performing a constant, unpaid, and inescapable role, there is a significant mental and emotional toll stemming from the lack of time and prioritization of other aspects of life, whether family-related, personal, or social. This situation presents a major challenge regarding the need to learn how to live with uncertainty. Some of the interviewees have been performing caregiving duties for 10 to 20 years without finding strategies for delegation, coordination, or support from other actors. As a result, they not only experience a lack of time, energy, and opportunity for other activities—especially self-care—but also live with a persistent fear of falling ill, aging, or dying, and the implications this would have for the future of persons in a disability condition. This was evident in the following testimony from one of the participants:

> "Because of the illness I have, sometimes I feel exhausted. Diabetes makes you very tired, whether you want to or not. You feel drained. The exhaustion from the daily routine, the illness, and the constant dedication to them—it all adds up, and sometimes you just feel like running away, but you don't even know where to go." (personal communication, November 10, 2023).

Thus, the caregiving of persons with a disability condition becomes the central focus of daily life, perceived as an obligation that generates anxiety and fear about the possibility of failing in a context of total dependency. This was further corroborated by the application of the Zarit Burden Interview, which revealed high levels of emotional exhaustion among caregivers and a significant risk of burnout.

Finally, especially among primary caregivers, a third social representation is consolidated, positioning self-care as an instrument for caring for others, in this case, persons with disabilities. The ability to maintain a healthy life, build supportive social relationships, and access physical and mental healthcare is transformed into a means for optimal caregiving, abandoning any possibility of being interpreted and experienced as an end in itself. It is notable that testimonies clearly reflect the notion that, in order to care for persons with disabilities, it is essential to ensure various practices that support one's own health. At least at the discursive level, activities such as attending medical check-ups, resting at appropriate times, and maintaining a healthy diet are perceived as fundamental requirements for sustaining caregiving responsibilities. For example, one of the participants stated.

> "I work a lot on that part, I really like doing things for myself, to feel good, because it is very important to give him the best of me" (personal communication, November 10, 2023).

In the background, additional needs related to maintaining social relationships, mental health care, spirituality, and leisure emerge. However, none of these activities, routines, or self-care practices are acknowledged as intrinsically valuable for personal well-being. Instead, they are framed as essential conditions for fulfilling the central role of domestic life: caregiving for persons with disabilities. Thus, self-care is conceptualized as a strategic resource for interpersonal caregiving. It is also important to note that this dynamic extends beyond the primary caregiver and involves other family members. For instance, when the person with a disability has siblings and/or nieces and nephews—whether older or younger—they also become strategic caregivers, occasionally altering their childhood experiences.

Discussion

The social representations developed in the previous section can be examined and expanded upon through engagement with various theoretical perspectives. First, we align with the constructivist theory of social representations, which posits that individuals, in this case, caregivers, produce socially shared meanings through which they construct their lived world (Araya, 2002).

Additionally, we concur with Wolfgang and Hayes (2011) that these representations are not solely confined to language, ideas conveyed through discourse, or the meanings attributed to words based on time and cultural context. Social representations serve to construct and reproduce socially shared images, such as the collective perception embedded in common sense that assigns caregiving responsibilities for family members with disabilities to the women of the household.

Another point of agreement with Wolfgang and Hayes (2011) pertains to their assertion that the analyzed representations in this study lead female caregivers to develop habits, behaviors, and perspectives on caregiving that distinguish them from other social groups. In this regard, the notion of shared representation is relevant and coherent, as it aligns with the authors' perspective that such representations function as decision-making criteria, guiding everyday actions and shaping interactions with other social actors.

This understanding supports, in accordance with Araya (2002) and Wolfgang and Hayes (2011), the multiple roles that social representations play in social reproduction. First, they provide a framework for understanding the world and its relationships, as seen in the way caregiving for persons with disabilities is symbolized as a practice rooted in complex, specialized knowledge exclusive to a specific social group—female caregivers within the home. Second, they serve a valuation function, classifying different actors as either capable or incapable of meeting the needs of persons with disabilities. Finally, they influence action, as caregiving becomes a daily practice shaped by shared representations, leading to experiences of uncertainty and distress among caregivers.

Latin American theories of care provide valuable insights that further expand this analysis. The recognition of caregiving as a permanent routine, sustained by specialized and complex knowledge that ensures the fulfillment of daily needs, aligns closely with the contributions of Domínguez Mon (2017). According to this author, intra-domestic caregiving constitutes a fundamental link in long-term healthcare processes, particularly in cases of high-dependency disabilities that affect daily life.

Additionally, the analysis of shared social representations within this specific form of social organization of care facilitates a dialogue with the contributions of Batthyány, Genta, and Perrotta (2017). The authors agree with the notion of care as a fundamental link in healthcare processes and assert that domestic care is structured "as a true invisible system of healthcare" (p. 188), a system that, as presented, is based on practices sustained by specific knowledge and capital. Intra-domestic care, particularly that provided to individuals with disabilities, is experienced as a systematic and regular occupation, one that distinguishes between trained and untrained caregivers. Although all caregivers faced this responsibility as a challenge, they successfully consolidated resources linked to expertise, challenging the notion that anyone can provide care, much like the professional healthcare field.

The emerging findings facilitate dialogue with various academic perspectives that reinforce the connection between caregiving responsibilities and health, illness, and caregivers' well-being, particularly in terms of mental health. In this regard, based on the exhaustion and persistent distress inherent in the daily caregiving duties within this population, agreement is found with Ortiz Viveros et al. (2015), Basile and López (2021), and Aguirre (2024) regarding the emotional toll this caregiving structure and distribution impose on adult women. Everyday experiences of overburden, stress, sadness, and isolation define the daily reality of caregiving.

Finally, Therborn's contributions (2010 and 2013) are brought into consideration, particularly in the recognition of self-care as a strategic resource primarily oriented toward the care of others. By assigning a secondary, subsidiary, and instrumental role to the practices that sustain the well-being of caregivers, the author's concept of existential inequalities becomes relevant: in this context, it is understood how the continued feminization and domestic confinement of the social organization of care for individuals with disabilities place caregivers in a position of inequality in terms of recognition and value.

Conclusions

The research made it possible to recognize that the social organization of care for individuals with disabilities in the region brings together various family, territorial, and community actors who consolidate more or less coordinated practices essential to sustaining life. However, the social representations constructed around the organization of care reinforce its perception—at least discursively—as a domestic responsibility, where the family is emphasized as the primary social setting and adult women as the principal guarantors of the daily care of individuals with disabilities in the municipality.

In this regard, socially shared notions are built around care that strengthen its feminization and familial association: its connection to specific knowledge acquired through practice, the formation of ideas tied to the indispensable role of female caregivers as the primary responsible figures, and the instrumentalization of any self-care practices, which relegates them to a position of existential inequality within the domestic sphere.

For these reasons, it is crucial to mobilize material, cultural, and educational efforts to actively engage other actors in the social organization of care. These include the State, as the guarantor of rights at the national, departmental, and municipal levels, the organized community, and other relevant family and/or territorial actors.

Statements

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Conflict of Interest: The authors declare that there are no conflicts of interest.

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