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Women with disabilities and complex dependency: experiences of care relationships for surviving - living(more)[*]

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Abstract

In this study we investigated the perceptions of women with disabilities who experience complex dependence and need relationships of care to survive or "live more". The methodology involved exploratory qualitative research. This is an emancipatory feminist investigation, aligned with feminist disability studies. Based on the results we discuss the experience of complex dependence, the lack of a public policies for care, the reduction of social participation and, finally, the potential for interdependent relations between the interviewees and their caregivers.

Keywords: Women with disabilities, Complex dependence, Care, Social participation, Interdependence.

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Introduction

The World Report on Disability (World Health Organization, 2011), with data from 2010, estimated that the global population of people with disabilities exceeds one billion. That is, approximately 15% of the world's population lives with the experience of disability. This percentage is expected to grow, according to the report, since the global population is aging, and there is a relationship between aging and disability. The report also points to the increased need for care services.

There is no consensus among authors about the concept of care and its meaning. However, for most theorists, care is a practice that takes place in relations between people (Noddings, 1984; 2002; Tronto, 2007); it is "trial and error. Moreover, it is a practice with an uncertain outcome. It involves constant learning, which can be done by those who are willing" (Fietz, 2020, s/p). Care is thus understood as a practice that is established in relationships (Mol, 2008) in which someone takes care of something/someone who is cared for (Fietz, 2020). Thus, it should be thought of both in terms of how it is established and the effects it produces, with the guarantee of well-being being what matters most. The author emphasizes that well-being is invariably not something static or predetermined but depends on the situational context. This is because care practices tend to be permeated by contradictions and ambivalences, which makes it impossible to adopt universal principles or rules that are applicable to all situations and all subjects.

In terms of care for people with disabilities specifically, it is important to highlight that some of them experience complex dependence. The theorists Gesser, Zirbel and Luiz (2022) conceptualize complex dependence as

> the type of dependence experienced by people who, because they have a high degree of impairment – physical, sensory, intellectual, psychosocial or multiple – require help and/or support for most of the activities in which they need or wish to participate. Dependence is commonly thought of as something related to needs considered basic (food, hygiene, and care for the maintenance of living bodies) and confined to the private sphere (in people's homes or, at most, in the healthcare services that they need to stay alive). However, from a political-feminist perspective, we understand that complex dependence must be incorporated into the public sphere, to guarantee the social participation, in their own way, of people who need a lot of support and assistance (Gesser et al., 2022:02).

In this sense, we need to look at care more broadly. Thus, being someone with complex dependence implies the need for care relationships not just to survive, but to live more fully[1]. We use the expression live more, because we understand that, in this case, care is indispensable to the maintenance of life in all senses, and not only to aspects related to the activities that keep someone alive, biologically speaking. In terms of well-being, the care relationship needs to be conducted with certain ethics to enable the person being cared for to have their right to access guaranteed, and to be able to exercise agency over their life. For Wilkerson (2002), the term "agency" is related to the ability to recognize and act on behalf of one's own interests. Therefore, being able to count on a care network can mean the difference between surviving, being able to have agency or being vulnerable to social isolation and violence (Fietz, 2020; Masson, 2017).

In this study we are considering care for people with disabilities who experience complex dependence, for whom the presence of a caregiver is essential for the exercise of the right to maintain life - a right guaranteed in Art. 5º of the Brazilian Constitution (Brazil, 1988). This is because a caregiver is essential for people with disabilities to have an ordinary life, with the opportunity to make decisions in different realms of their trajectory. This understanding of the need to offer care involving different aspects of the lives of people with dependence dialogues with the field of Disability Justice (Mello; Fietz; Rondon, 2021), with the argument that qualified and remunerated care regulated by public policy should be understood as the guarantee of the exercise of a basic right, so that no one is left behind, corroborating the premises of this perspective (Sins Invalid, 2019).

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[1] According to the Merriam Webster dictionary, the word survive in English comes from the "Latin *supervivere, from* super- +vivere to live – more".

In an interview with Gesser and Fietz (2019:141), Eva Kittay emphasized that it is inevitable that we think about care, because “a world in which no one cared about anyone would be a world in which the needs of those who could not meet their own needs (and that is all of us at some point in our lives) would be neglected”. Thus, addressing the theme of care makes it urgent and inevitable to break with the liberal ideals of autonomy and independence, which are strongly present in the social context in general, including in theories of justice (Kittay, 2015). Breaking away from these ideals is fundamental, since they make dependence and interdependence invisible and seem to be inherent to the human condition. Liberal ideals also disqualify care, which is a basic need for some people with disabilities, even if all barriers are removed. (Kittay, 1999; Diniz, 2007; Fietz, 2017; Gesser, 2019).

Despite the various possibilities for contemporary research and problematization on dependence, ethics of care and disability, there are few studies on the intersectionality of these themes from the perception of women with disabilities who need full-time care. Therefore, there is strong potential for new research in the field which currently lacks scientific depth (Diniz, 2003; Gesser; Nuernberg; Toneli, 2012; Gesser; Nuernberg, 2014). When addressing care, we are still talking about invisible needs, which seem to be restricted to the family, the work of women, who are on the margins of the margins (Mingus, 2018; Santos, 2017). However, understanding and proposing that care is conceived from a critical and feminist perspective implies redirecting it to the center of discussions on disability, ethics, and feminism.

Kittay (1999), in the book *Love’s Labor*, emphasized that care, like any other labor activity, must be remunerated and recognized as work. When interviewed by Gesser and Fietz, Kittay also highlighted, the importance of breaking with the naturalized concept that care is a female attribution and emphasized that “as long as we fail to give care its due, both - the caregivers and those receiving the care - lose” (Gesser; Fietz, 2021:04). Tom Shakespeare (2018), in the book *Disability: the basics* highlights benefits of professional care so that people with disabilities can have agency over their lives (Shakespeare, 2018).

The fact is that although the number of people with disabilities who experience complex dependence is very significant, the numbers do not seem to reverberate politically in discussions about disability policy, since care is still something that is restricted to the family environment and performed mostly by women. In Brazil, there has never been a public policy to guarantee the right to care that is fully subsidized by the state, and that accompanies people with disabilities in meeting their most basic needs (food, hygiene, medication), much less in other life activities (travel, leisure, work, study, etc.). Despite recent advances in legislation, resulting from the incorporation of the Convention on the Rights of Persons with Disabilities (CRPD) as a constitutional amendment (Decree No. 6.949/2009), and the Brazilian Law for the Inclusion of Persons with Disabilities (LBI), No. 13.146/2015, there has been little legislative progress on this issue.

The care agenda is partially contemplated in the Convention on the Rights of Persons with Disabilities and the Brazilian Law for the Inclusion of Persons with Disabilities, which provide for care only in basic education through an auxiliary professional and in inclusionary residences. This is a throwback to the institutionalization of care for people with disabilities and seems to be insufficient, as it does not provide options that offer greater possibilities for the agency of people with disabilities in situations of complex dependence. Therefore, considering this context, this study is interested in investigating the perceptions of women with disabilities about their experience of complex dependence and full-time care.

The study was conducted from the theoretical perspective of feminist disability studies – a field that articulates feminist studies with disability studies and considers disability as a category of analysis (Garland-Thomson, 2002) that has analytical and political potential for research, activism and public policies. Among the authors who supported the study, in addition to the theorists mentioned who have been working with the issue of care, we also highlight the dialogue with the feminist perspective of situated knowledge, proposed by Donna Haraway (1995), and the emancipatory research of Mike Oliver (1992). According to Oliver (1992), emancipatory research is a critical perspective of research in the field of disability which, in articulation with the social model, proposes a demystification of oppressive structures and processes, establishing a dialogue between the scientific community and people with disabilities, to enhance their participation and emancipation. Based on this approach, the researchers put their knowledge and skills at the service of people with disabilities, jointly constructing what the movements and subjects need in terms of research. The investigative paths are determined through dialog, considering people with disabilities as protagonists and researchers throughout the study. We position the research as "feminist" because it articulates the knowledge of disability studies with feminist theories, as Haraway (1995) proposed: in a feminist logic of science, knowledge is partial and marked by power relations. The author is critical of academic writing perspectives that claim to be impartial and non-localized, considering that it is only possible to know from a particular location. In other words, "in science, every look is situated, woven from connections and mediations that make certain worlds visible and leave others in the shadows" (Moraes; Tsallis, 2016:5). Considering this idea, we can understand that all knowledge is localized and produced by subjects permeated by gender, race, class, disability/ability, and other characteristics.

Haraway's (1995) dialogue with Harding (1986) allows affirming that a multiplicity of subjects and realities exists, although we recognize that they cannot be treated relatively, since localized research does not feed stereotyped narratives of unique stories (Adichie, 2019). Therefore, it is essential to show the multiplicity of the disability experience, which encompasses dependencies, sufferings, joys, and reinventions, which can occur simultaneously.

This text was written by two women who have been working as researchers in the field of feminist disability studies. The first author is a cis, mother, white woman with a disability who experiences complex dependence and therefore needs care relationships to survive – live more. The second author is a white, cis, non-disabled woman who has been teaching, and conducting research and extension activities in the field of disability and who recognizes herself as an ally of the anti-ableism struggle.

To conclude this topic, we position this study as an exercise in feminist historical reparation. According to Diniz (2022:134), reparation happens after the violation of a right, "when a woman is affected by the suffering of another", in an attempt to crack the hegemonic power frameworks that caused injustice to this woman. Thus, listening to the participants and giving visibility to care experiences is an effort to repair injustices produced by ableism and its interconnections with other oppressive systems in the lives of the women interviewed.

Methodological paths

Research outline

This article is based on research in psychology carried out at as part of doctoral studies in a graduate program at a public university in southern Brazil. As a qualitative study, it focused on the participants' perspective on their experiences and significations, situated in specific contexts (Gialdino, 2006). Based on dialogue with feminist disability studies (Garland-Thomson, 2002; Kittay, 1999; Gesser; Fietz, 2021), emancipatory research (Oliver, 1992) and Haraway's (1995) feminist perspective of localized research, we consider the narratives obtained in the proposed research as located and connected with the many others, human and non-human, that mediate the constitution of the subjects.

Participants

Five adult women with disabilities who experience complex dependency and need care to survive or live more were invited to participate in this research. Below we present the participants who granted the interviews discussed in this article.

- Mia is from the northern region of the country. She was a 38-year-old woman with a physical disability who declared herself as heterosexual and *parda* [brown-skinned]. She is an evangelical. She lives with her mother and her partner. She has a university degree in psychology and a graduate education. She stated that her family income exceeds five minimum wages. In some moments of the conversation, Mia became emotional when talking about dependence and care.
- Aline is from the southern region of the country. She is a woman with associated physical and intellectual disabilities, was 40 years old, and declared herself to be heterosexual and white. She is

Lutheran. She lives with her mother and two brothers, attended high school and does not work. She stated that her family income is between two and three minimum wages. Aline was the only participant who requested to be interviewed by telephone, because she said that she did not know how to use other resources - such as online meeting applications.

- Carmela is from southern Brazil. She was 30-years-old woman and has a physical disability. She declared herself to be white and heterosexual. She said she is an atheist. She lives with her parents and a brother who is also physically disabled. She has a university degree in social work and additional graduate studies. She stated that her family income exceeds five minimum wages.

- Fernanda is from Brazil's southeast region. She was 36-years-old and has a physical disability. She declared herself to be heterosexual and a "light-skinned black". She is a Spiritist and lives with her parents. She has a bachelor's degree in advertising and graduate studies. She stated that her family income is between two and three minimum wages.

- Lígia is from the central-western region. She was 26-years-old and a woman with a physical disability. She declared herself to be heterosexual and white. She said she is agnostic. She lives with her parents and a sister. She has a college degree in psychology and graduate studies. She declared that her family income is above five minimum wages.

Research Instruments

To obtain information we used in-depth interviews and the life history method and a brief sociodemographic questionnaire. According to Cordero (2012), in life history interviews, the interviewer often interacts with the person being interviewed and the main function is to portray experiences lived by people. The main focus of the technique is to allow the interviewee to consider their experience retrospectively. Life histories provide an interpretative opportunity in which meanings are revealed in personal accounts, prioritizing subjectivity over methods that classify responses into predetermined conceptual categories (Cordero, 2012). Given that dependence and care permeate the entire life histories of the interviewees, we thought of some a priori foci, which guided our listening to the trajectories of the research companions, leaving them free to discuss whatever they wanted.

To this end, we conducted semi-open interviews, based on a basic script guided by the issues most pertinent to the research (Duarte, 2004). This script was composed of axes, so the interviewees would understand which themes were important, while helping them to feel free to communicate whatever they wanted, however they wanted. The axes were: 1. disability; 2. care; and 3. community participation (school, work, leisure, relationships, etc.).

The sociodemographic questionnaire was prepared in Google Forms to be answered virtually and asynchronously, with the following questions: name, age, race, type of disability, sexual orientation, religion, with whom do they live, level of education, profession, and family income. The link to the questionnaire was sent by e-mail along with the Terms of Free and Informed Consent Form and the Free and Informed Consent Form[2].

Procedures to obtain information

At first, the plan was to conduct face-to-face interviews with women from southern Brazil for geographical and logistical reasons. The interviewees are from our circles of contacts and, therefore, the criterion used to select them was that of convenience. Because of the COVID-19 pandemic[3], the interviews had to be conducted and recorded online, using programs such as Skype and WhatsApp, or in one case by phone call. Regarding the online meetings, it should be said that, while it was not possible to meet with the participants in person – and we lost a lot without physical contact – it was possible to hear from women from other regions of the country, allowing us to have contact with different contexts. Thus, geographical location ceased to be an important criterion and others gained

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[2] Since one of the research companions said that her mother was her guardian, we sent the Term of Free and Informed Consent to the mother and the Free and Informed Consent Form to the interviewee.

[3] The coronavirus pandemic directly impacted the research methodology and even appeared in the results, as we see in one of the comments.

prominence for participation, mainly, being an adult woman with a disability who experiences complex dependence, from anywhere in Brazil.

We chose to interview only women because, according to the records of the Information System of Reportable Complaints (SINAN) of the Ministry of Health (Brazil, 2019), in 2019, more than 7,000 cases of violence against people with disabilities were registered, of which 61% concerned women, in different age groups.

Regarding the duration, we let the companions feel free to speak about whatever they wished based on the issues we presented, for as long as they thought necessary to tell their stories. The interviews lasted from 40 to 90 minutes, and we conducted only one interview with each companion because we considered that we obtained sufficient material to answer the research objectives.

Analytical procedures

To analyze the interviews, we used thematic analysis, which, according to Braun and Clarke (2006), is a "method for identifying, analyzing and reporting themes in the data. It is minimally organized and describes its data set to maintain the richness of details. However, it often goes beyond that and interprets various aspects of the research topic" (Braun; Clarke, 2006:79). The authors also state that although thematic analysis is widely used, there is no consensus about its definition or how to conduct it. Nevertheless, they provide six tips for addressing the themes of analysis: 1. familiarize yourself with the information through transcripts and readings; 2. generate initial codes (by coding interesting characteristics of the data in a systematic way, in the entire data set, grouping relevant data for each code); 3. search for themes (grouping codes into potential themes); 4. review the themes (checking that the themes work in relation to the coded extracts and to the dataset as a whole, generating a thematic 'map' of the analysis); 5. define and name themes; and finally 6. produce the report (the analysis itself, drawing on examples from the data and relating them to the literature).

In summary, this was the path we followed to arrive at the themes and the analyses in this article. After transcribing, reading, and re-reading the interviews, we grouped them by codes. One of the codes found was care. Subsequently, by reading and re-reading all the statements that fit into this code, it was possible to observe specificities and subdivide it into dependence and interdependence. Finally, through various readings, we defined and named the themes as: "The experience of dependence: perceptions about the need for care", "The lack of a public care policy and the decrease in social participation" and "The potential of interdependent relationships between the interviewees and their caregivers". The analysis of these themes is presented below, in the Results and Discussions section.

Ethical issues

This research was approved by the Committee for Ethical Research with Human Beings of the Federal University of Santa Catarina (CAAE 29072920.0.0000.0121) and, therefore, all ethical principles recommended by Resolutions 466/12 and 510/2016 of the National Health Council were respected. The Term of Free and Informed Consent with information about the study was read and signed by all participants. To ensure the participation of the women interviewed, after the study was ready, the term was sent to them to ask how they would like to be identified in the text. Thus, they were given fictitious names that they chose.

Results and discussions

The excerpts from the interviews presented in this section were chosen from a political and epistemological perspective to make visible the difficulties of the experience of complex dependence - especially due to the lack of public policies for care. However, we also want to point out the potential for caring relationships in the lives of all people, including those with dependence, considering interdependence as an intrinsic characteristic of human existence.

The analyses of the statements that compose this research show that dependence and care permeate all aspects of the participants' lives. They presented their perceptions about the experience of dependence with ambivalent meanings. At times, the statements portray how difficult it is to need help for all daily activities and how the lack of support for those who are dependent reduces participation in social activities.

Ye it is also possible to observe how the statements recognize the potential for interdependent relationships between the interviewees and their care networks. These perceptions are articulated with the affirmation that care always operates relationally and often in contradictory, conflicting and ambiguous ways (Fietz, 2017). In addition, they corroborate the perspective that dependence and care are inherent to human life and not only to a specific group - in this case, people with disabilities (Kröger, 2009; Fietz, 2017).

The Experience of Dependence: perceptions about the need for care

According to the participants' statements, we can observe that dependence is perceived in different ways. At times they see their dependence to be limiting, responsible for restricting or making it impossible to participate in basic situations of survival, including those involving social life and leisure, while at times it is recognized as part of human relationships, and to involve an interdependence. Thus, it is possible to affirm that the analyses of this study indicate that perceptions about the experience of dependence vary and are ambivalent, considering precisely the relational character of care (Fietz, 2017; Gesser; Fietz, 2021; Kittay, 2011).

One important aspect mentioned by the participants is how dependence imposes a lack of privacy, since care is required in intimate situations. About bathing, for example, we highlight the reports of Carmela (personal communication, June, 2020):

> I think it's very complicated this issue of not having privacy. It's very annoying, not a minute alone. I can't take a shower alone." And Fernanda (personal communication, July 2020): "Look, care is now mediated, right? So you always have to be bathed by another person... It was difficult, it's not a very easy thing, no. I confess to you.

In this sense, the body is the mediator between ourselves and the world, composed of numerous characteristics - including bodily impediments - which compose the worldview of each society, the result of long historical construction (Ayres; Rial; Nuernberg, 2014). The contemporary view of the body involves a more individualistic perspective that breaks with collective solidarity, and that is circumscribed by the closure of the subject on/in himself. In the case of physical disability, "the body is the main marker of difference" (Brah, 2006, cited by Ayres; Rial; Nuernberg, 2014:76). Regarding this body, several representations are created focused on the incapacitating and individualized perspective, which provides us clues about the perceptions of care and intimacy. The myth of the independent subject is also articulated with this modern notion of body and permeates and constitutes our notion of the need for care, as we will see below.

In addition, some of the women interviewed demonstrated difficulties in experiencing dependence in different aspects of life due to the important psychosocial implications of dependence. In their statements, feelings such as emotional overload, anguish, pain and anxiety appear when talking about the need to be cared for. Mia (personal communication, May 2020) emphasized: "I think this is the great [cause of] pain, in relation to the experience of disability, it has to do with this, with this need, with this dependence" [She becomes emotional]. Lígia, (personal communication, July 2020), in turn, commented "And it distresses me a lot to think about [dependence], because they [her parents] are also getting older and now, with the pandemic, the anxiety I feel about my and their contamination.

It should be said that these feelings do not necessarily appear because of the disability itself, but because of the lack of support and the way people deal with dependence. This is because, in modern and liberal societies, independence is a category fundamental to the valorization of subjects and, consequently, perceptions of dependence are understood to be something bad and limiting, which attributes a value of inferiority to the person. In this context, subjects with dignity are those who (supposedly) manage to be free, independent and able to administer their lives on their own (Ferguson, 2013; Fietz, 2017). That is, "rationality and choice are thus central to the modern individual and autonomy becomes a central category in liberal modes of subjectivation" (Fietz, 2017:108). This idea is closely linked to Kittay, Jennings and Wasunna's (2005) concept of personhood: autonomy is understood as a basic and constitutive attribute of subjects and directly influences the way we conceive and value each other.

As a consequence of this conception, dependence is something that must be fought, while independence is desired. Thus, subjects who do not fit into an independent status are seen negatively, as "incapable or undeserving of rationality and self-governance" (Kittay et al., 2005:1012). Thus, in contexts where independence and autonomy are an ideal to be achieved by all people, dependence will invariably be negative and must be rejected (Fietz, 2017) - which can be seen in practices of omission and negligence of the state and the lack of a public policies for care, attributing to families the responsibility for the care of their members, for example.

However, to confer dignity to all people, and especially to those with complex dependence, dependence needs to be recognized as an inherent attribute of human life. Obviously, this perspective does not intend to deny or make invisible the "oppressive aspects that can arise from these relationships" (Fietz, 2017:111), but it means that understanding the basic notions that involve the issues of dependence, in the sense of being a human dimension, helps us to (re)position it as a possible form of existence, which lacks recognition and dignity for those who are inevitably dependent. (Kittay, 2011).

In this sense, it is essential that we recognize dependence as part of the human trajectory in the same way that we understand interdependence as possible in relationships between subjects, including those in which people who are inevitably dependent are inserted. Next, we see how the lack of support in the experience of complex dependence has implications for the participants' lives by reducing social participation or making it impossible.

The lack of a public policy for care and decreased social participation

As we mentioned, it is necessary that we recognize dependence and care as aspects of human life. From this perspective, we observe how the participants do not have their most fundamental rights guaranteed. The lack of a public policy for care decreases the participation of these women in social and community life. Some of them affirmed that they have stopped doing common, everyday things because of the lack of support for the experience of dependence, such as going out socially or traveling, for example.

About the lack of support for leisure activities, Mia (personal communication, May 2020) says: "The dependency really limits, for example, arrival time, right? Outings, how long I can stay on the street, which places I can travel to". Lígia (personal communication, July 2020) corroborated Mia's comment:

> And then my experiences end up being conditioned to this: will there be someone to help or not? Can I really count on this person or not? It seems like a life that is not private, you know, that does not depend only on my choice and so on, on what I want to do at that moment.

These two accounts give us a dimension on choices. It should be said that we are not referring to the neoliberal and Western meaning of the term "choice", but rather to how much we actively participate in what interests and engages us. For Mol (2008), we need to move away from a "logic of choice" and redirect our gaze to a perspective of a "logic of care". In doing so, we begin to conceive subjects through the various relationships in which they participate (Mol, 2008). In this sense, we realize from the statements that the interviewees, despite wanting to live certain experiences, are unable to due to a lack of security in relation to care. If public policies were based on a logic of care, as advocated by Mol (2008), these women could probably have greater social participation.

Lígia's comments (personal communication, July 2020) highlight the difficulties of accessing leisure opportunities, for example, due to dependence, pointing out another possibility of thinking about care: "'Oh, in college we went out to drink' and that's an experience that I did not have, because of this issue of care". To ensure the possibility of agency in different areas of their lives and participation on equal terms with other people, as promulgated by the Convention on the Rights of Persons with Disabilities (CRPD) (Decree No. 6.949/2009), the presence of a caregiver and/or personal care services is essential and inalienable. According to article 19 of the CRPD, for this to happen, the state must guarantee a series of support services, including the services of personal attendants. However, we still do not see this right being realized in the lives of people with disabilities. The comments presented above indicate how much the lack of support for care makes it impossible for the women interviewed to have their right to community participation guaranteed, as called for by the CRPD.

Feminist Disability Studies (Garland-Thomson, 2002) and Disability Justice Studies, which are so important to the analyses we propose, question the concepts of autonomy and independence valued by liberal societies as we mentioned earlier. Authors such as Eva Kittay, for example, state that independence is “a construct that is an abstraction of all the various dependencies that we have decided to make invisible” (Gesser; Fietz, 2021:8).

McRuer (2018:110) problematizes that, “as neoliberalism relies on private solutions to all problems, ‘the family’ assumes an increasingly important role as a provider of goods and services, such as the work of caring for the youngest or oldest”. Thus, the fact that we currently live in an economically liberal and morally conservative society prevents us from advancing in the construction of public care policies that can implement the rights already guaranteed by law, as mentioned above. This means that, as long as the right to care is not broadly met by public policies less dependent on the role of the family, people with complex dependence will continue to have their social participation diminished or made impossible. Guaranteeing this right can mean the difference between social participation or exclusion.

The potential of the relations of interdependence between the women interviewed and their care providers

The comments related to this topic indicate that even those people with complex dependence - who supposedly only receive care and cannot provide care – do somehow exercise care for other people. The information obtained in this research indicates that both dependence and care must be reframed in the sense that those who depend on others can also take care of others, recognizing that care does not occur in a restricted manner.

Next, we see how the participants, even though they are people with disabilities who experience complex dependence, also exercise care. We note that, even for people who need the care of another person to stay alive, interdependence is possible and powerful in a relationship of exchange and affection with their caregivers. This finding brings to light two important aspects: 1. the fact that care is still a mostly female activity, mistakenly linked to a supposed “female essence”, which is reinforced by the sexual division of labor and affirmed by the precariousness of female labor; and 2. the central role of families in providing care, which prevents progress in public policies, overburdening and exploiting women as caregivers - often without pay for their work (Passos, 2016; Santos, 2017). The consequences of the patriarchal family model are related to the way that the care conditions of the research participants were arranged: they were cared for by family members, especially by other women.

Regarding the relationship with her mother, who is her caregiver, Fernanda (personal communication, July, 2020) says:

> She is a woman who had to leave her job and give up her own life to take care of me. Today, I try to compensate with my work and I provide a kind of ‘allowance’. She uses the money to do a few of her own things (...) because she can’t do that. Since my father can continue to work.

This account makes us think about how gender and economic issues impact family arrangements in relation to care. The nuclear family emerged and became consolidated under capitalism, and gained an important role in the reproduction of certain values. In contemporary political discourses, independence and self-sufficiency are terms that complement each other and are seen as positive, while dependence and support are seen negatively (Zirbel, 2016).

In the neoliberal mold, the family is based on an individualistic character of the private appropriation of the means of production and the commodification of products and labor power. In this way, capitalism makes care work subordinate and invisible and uses it to sustain the mode of production (Passos, 2016). Passos points out that the constitution of the patriarchal family was fundamental for the organization of care, establishing it as a function of women and determining how it should be performed.

According to Nogueira (2004), this situation was conducive to the "feminization of the world of work" and, consequently, women began to occupy the most precarious jobs. Regarding the paradoxes of female employment, Hirata (2010) problematizes that the sexual division of knowledge is inseparable from the power relations between men and women, expressed both in society and in family relationships. For the author, this reinforces the unequal power existing within the nuclear family.

In the case of the participants in this research, all of them are cared for by family members, especially by their mothers. For most of them, as in Fernanda's case, the mother had to give up her personal projects to care for a daughter with disabilities. The interview revealed that this decision influenced the economic life of the interviewee's mother.

One of Lígia's accounts (personal communication, July 2020), expresses how she experiences an interdependent relationship with her sister:

> So it's very cool like this right? Because she [the sister] helps me, but today, because I'm older, I can also help her. (...) We had organized for her to stay during the week [in another city, to go to college] and come [home] on Friday and go back on Monday. And then many people (...) kept saying 'no, you can't go, who will help your mother? Who's going to take care of your sister?' (...) And I didn't want her to feel that pressure. So we talked about it several times. I said: 'You have to go.' (...) So, I was very worried that she would understand these things that our relatives said to her as if it were my issue, you know? But no. It relieves me a little because it really feels like a relationship of exchange, you know? A relationship of interdependence.

From the statement presented above, we can reflect on "how the relationships of dependence and care in which the subjects are inserted can resignify the notions of autonomy and dependence" (Fietz, 2017:110). It can be seen that Lígia - the person with dependence who, supposedly, can only be cared for - also began to care for someone else to some extent. Thus, disability ceases to be an isolated and individual phenomenon to become a collective experience that includes family and community networks, in such a way that the subject becomes part of the relationships in which he or she is inserted (Das, 2015).

In this sense, although dependence is something that is strongly present in the life trajectories of all the people interviewed, the information obtained showed the power of interdependence and mutual support (or care) as constituents of the relationships established between the participants and their caregivers. We emphasize that making these interdependent relationships visible is a political act that breaks with stereotyped narratives about disability, since it creates an opening for the potential of these relationships (Luiz; Silveira, 2020).

Final considerations

The objective of this text was to problematize the meaning and impacts of complex dependence on the lives of women with disabilities who need care to survive, live more. We reiterate that our analyses were based on feminist disability studies, with emphasis on the dialogues between theorists of care, the perspective of localized research and emancipatory research. Feminist disability studies offer important theoretical, methodological, and political support to the elimination of generalizing narratives, which circumscribe the experience of people with disabilities who experience complex dependence as a tragedy. This field of knowledge also provides contributions to the construction of policies that break with the family dependent perspective that is still the foundation of public care policies in Brazil.

Nevertheless, we point out the limitations of the study: only five participants were interviewed, all of whom had physical disabilities - although one had an associated intellectual disability. In addition, all participants can communicate verbally - which highlights the need to conduct research with people who use other forms of communication. Moreover, four of the five interviewees have postgraduate education, which points to the need to carry out new studies with women with disabilities who experience complex dependence from other social strata. In addition, the study was conducted in a pandemic context, making field visits impossible.

We emphasize that the findings of this research are important to the dissemination of feminist disability studies, especially about care and people with disabilities who experience complex dependence. The issue of caregivers is widely debated in the literature, but there is little discussion about care from the point of view of those who receive it. To make visible the narratives of the people being cared for is a fundamental step to showing the need to build public care policies aimed at the needs of specific groups, such as the women interviewed who depend on these policies to guarantee the right to survive, live-more. In addition, the research results point to the need to break with patriarchal practices and ableist paradigms, since they diminish or make the lives of people with disabilities unfeasible in the individual and collective dimensions. Another important contribution of the study was to show how gender and disability are articulated in the care practices received by the women interviewed, since all of them are cared for by their mothers and other family members, who are mostly women, and this care is unpaid. Thus, considering issues such as gender in care practices is fundamental to broaden and qualify the debate on the subject.

Finally, we suggest new research on care to more deeply investigate topics such as the deconstruction of the family-dependent character of public care policies and the implications of the absence of an ethic of care in the lives of women with disabilities in situations of complex dependence, considering their access to work, education, leisure, social/community participation and sexual and reproductive rights.

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