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Overprotection and intersectionalities regarding the sexuality of young women with disabilities: nuances between care and control

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Abstract *This article aims to discuss how the intersection of gender, disability, and social class, within the context of care relationships, can impact the sexual rights of young women with disabilities. This qualitative research was conducted in the metropolitan region of João Pessoa, Brazil, with four participants through in-depth interviews. It analyzed the lived experiences related to sexuality in the youth of cis-heterosexual women with physical disabilities during the 2000s and 2010s. The theoretical-analytical framework was grounded in intersectional approaches from the fields of care studies and disability studies. This study highlights the challenges and coping strategies adopted by the participants as forms of resistance to socially imposed norms of body normality (corponormativity), which position them as exclusively dependent and infantilized. Within care relationships, these stereotypes give rise to behaviors of discouragement or oppression in their affective and sexual lives, as well as in other dimensions of social life. Discourses and practices associated with care, when distorted into overprotection, operate as mechanisms of control over the sexuality of young women with disabilities.*

Key words *Women with disabilities, Sexuality, Youth, Care, Intersectionality*

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Introduction

Sexuality is a key aspect of the human experience, intrinsically linked to identity, well-being, and quality of life. It should be understood as a broad spectrum of human behavior, including various forms of bodily and attitudinal expression, sexual and emotional relationships, and expressions of identity and social and sexual roles, among other elements[1-5]. However, when it comes to women with disabilities, the understanding and expression of sexuality often encounter barriers imposed by social, cultural, and institutional prejudices[6-11].

The revision of concepts about disability has been moving from the traditional biomedical model to the social model, seeking to situate people with disabilities in a new perspective based on the understanding of this phenomenon as one of the constituent elements of a plural society. Social structures that reproduce ableism, sustained by exclusionary cultural narratives and based on assumptions of dissident bodies as incapable, alienated, or dysfunctional, are being challenged[12-16].

Several authors who have been studying this phenomenon corroborate that historical perceptions and stereotypes perpetuate the view that people with disabilities are asexual or incapable of expressing sexual desires and needs, contributing to the marginalization of this group in their sexual and reproductive rights[4,6-9,11,12,17,18]. This results in greater vulnerability to relationships of exploitation and exposure to violence, which are articulated and aggravated by an overlap with other social markers of difference[1,5,8,10,19].

Studies on disability have shown that the construction of a broader sociopolitical status of social exclusion often involves establishing the sexual status of this group as a socially problematic sexuality, so that this threat becomes the basis for justifying symbolic or overt forms of oppression[3,11,13,17,20,21]. The Convention on the Rights of Persons with Disabilities (CRPD)[22], ratified by Brazil in 2008, constituted a milestone in the fight to guarantee the human rights of persons with disabilities, explicitly recognizing the need to ensure their full participation in all spheres of life, including sexuality and reproduction. Despite important contributions, its provisions have not yet been effectively implemented to transform the oppressive processes experienced by people with disabilities.

Sexuality remains under-discussed in society and remains taboo, especially for people with disabilities, perpetuating the invisibility and denial of their expressions, needs, and desires[2,7,13,17,18,20,21]. Furthermore, the process of infantilization, frequently observed in women with disabilities, exacerbates vulnerabilities due to a lack of information and access to health services and sexual and reproductive rights[1,2,8,10,11,18,19,23]. Therefore, it is important to provide a deeper understanding of the challenges these women face and the coping strategies they adopt as a way of resisting imposed stereotypes.

This article aims to explore the intersection between gender, disability, and care, highlighting how these factors, linked to class issues, limit the sexual rights of women with disabilities, especially in their youth. It seeks to understand how certain forms of appropriation and distortion that permeate discourses and attitudes justified as care, when converted into overprotection, can become mechanisms for controlling sexuality, both in personal relationships and within institutions.

Methodology

This qualitative research, from which the discussion of this article derives, is part of a doctoral thesis, resulting from fieldwork conducted in the metropolitan region of João Pessoa, with 14 participants, who made up the sample for this study. The initial invitations were mediated by a key informant, a professional from an intersectoral reference institution within the regional network of the Unified Health System (SUS) and Social Assistance System (SUAS), and new participants were recruited using the "snowball" technique. The following inclusion criteria were considered: women over 18 years of age with a physical disability resulting in permanent mobility reduction and who performed direct or indirect caregiving activities for other people, whether dependent or not, given the interest in analyzing the multiplicity of positions regarding care work.

As instruments for gathering information, we used in-depth interviews, using the life story (LS) strategy, in addition to the ethnographic method of participant observation of care relationships in home and institutional settings. The interviews took place in a location chosen by the participants, preferably without the presence of other people. The LS strategy was adopted to capture biographical narratives, allowing them to reflectively evaluate their objective social contexts[24-26].

The interviews were conducted using a semi-open script, supported by the points of greatest interest to the research. The script was sensitively conducted as a conversation, allowing participants to address topics that were occasionally not covered by the script but were significant to their experience. The starting point was a free account of the experience of disability and the relationships that were established for situations of care, of caring for, and/or of being cared for by others, in various social realms.

Thus, issues related to sexuality, although not initially considered in the basic script, emerged as central to the experiences of four interlocutors in their biographical narratives, relating to disability and/or associated care relationships. Given that the definition of youth can vary depending on the cultural, social, and institutional context, international organizations adopt different age ranges to define it. In this study, the Brazilian Youth Statute was used as a reference, which considers young people to be those aged between 15 and 29 years[27]. Therefore, the experiences of four interlocutors with sexuality in their youth, experienced in this age group between 2000 and 2010, were considered.

The discussion developed in this article, focuses on thematic analysis[28] of the interviews with these four interlocutors, anchored in the articulation between the lenses of care studies and disability studies. In this context, the categories of care and disability were analyzed using the relational model, shedding light on issues of power asymmetries[29,30]. The intersectional approach outlined a panorama of inequality in relationships, including experiences related to sexuality in conjunction with relationships of care, based on the core elements that emerged from the interlocutors' narratives. In the intersectional matrix of domination, the following stood out: disability, poverty, and gender status[29-31].

This study was developed after having been approved by the Research Ethics Committee (logged under protocol number 4,672,409; CAAE: 44127221.0.0000.5188), in accordance with the prerogatives of National Health Council resolutions. Audio recordings were taken with the interlocutors' permission and signature. To ensure confidentiality, the participants' names were replaced with fictitious names, inspired by women with disabilities who are activists and campaigners fighting for their rights.

Results and discussion

The four interviewees who participated in this analysis are cis-heterosexual women with permanent physical disabilities and who are wheelchair users. Their main source of income was the Continuous Cash Benefit (*Benefício de Prestação Continuada* - BPC); they engaged in various forms of self-employment to earn additional income; and they were involved in professional development and training activities. Below, we present brief biographies of the participants, who participated in the interviews we will discuss in this article:

- Dorina: 35 years old, self-identified as White, married, with a disability, self-employed sales representative. She lived with her partner and her son from a previous relationship.
- Frida: 32 years old, self-identified as Black, with a disability, married, activist, and self-employed accessibility consultant. She lived with her husband and her stepson, a tall teenager.
- Helen: 45 years old, self-identified as Brown, with a physical disability since early childhood, married. She lived with her husband and son. In her youth, the daughter of a single mother, she lived in rural Paraíba with four siblings.
- Leandra: 21 years old, self-identified as White, with a congenital physical disability, student. She lived with her boyfriend in her parents' house, where her adult brother also lived.

The categories that emerged from the biographical accounts in the interviews and that will be analyzed below were: overprotection in youth and narratives of infantilization; the challenges of experiences related to sexuality for dissident bodies; and strategies of resistance to limiting discourses and attitudes.

Overprotection: between care and restriction of the agency of young women with disabilities

Care, or care work, consists of providing concrete responses to the needs of others, aiming to improve and maintain life and well-being[12,15]. Both gender and disability can be forged through microtechnologies of modern power that operate by distorting discourses about care. The hegemonic social perspective on the need for care constructs disability, above all, as a dependency, from a perspective in which needing care is, in some way, a deficit and one's competence as a social actor is denied or questioned, ontologically condemning one to a lack of agency[11,15,18,31-33].

Interlocutors who experienced disability from birth or early childhood frequently reported overprotection by their family members during childhood and adolescence, especially their mothers, justifying it by fear and/or concern about protecting their daughters. These attitudes ultimately hindered or even imposed additional obstacles to their feeling included in various social roles and activities considered common for young people, such as romantic relationships and sexual experiences.

Among the interviewees, there was a recurring complaint that close family members had difficulty accepting the transition they experienced in adolescence, permeated by the desires and efforts for independence inherent to this stage of life. They mentioned excessive concerns from their family and close networks regarding their romantic relationships, particularly during their first sexual and emotional experiences in adolescence and young adulthood. These aspects are reflected in Leandra's narrative:

Often when I go to my mom's appointment, everything is like, 'Hey Mom, so, she has this little flu here,' I don't know what, I don't know what, and when I go with my boyfriend, they say directly to me, 'Hi Leandra, how are you?' They already treat me differently, so it's like that, you know... Nowadays, me, my mom and I aren't on good terms because, in this regard, there comes a time when it bothers me how much she wants to involve herself in my decisions, you know? So it, like, becomes suffocating because I'm not a child anymore, I know my responsibilities, I know what I want for my life, and I know my limitations. [...] because it's one thing to listen to your mother's advice, another thing to do what she wants you to do, you know? (Leandra, woman with a congenital disability).

The intersection of biological, infantilizing, and charitable conceptions is evident, permeating and guiding discourses and behaviors that distort attitudes of care, leading to situations of overprotection and consequently generating isolation and increased exclusion[14,15,31]. They suggest a relationship between cultural narratives of disability and gender, given that, on the one hand, men with disabilities are perceived as incomplete because they cannot fully express the figure of masculinity as capable, strong, and hypersexual. The conflicts experienced by women with disabilities, by contrast, arise from assumptions about femininity, often being perceived as weak and dependent, and even more vivid in women with disabilities[15,20-23,32-35].

Beyond sexuality, according to that reported in studies conducted in different social contexts, these cultural assumptions exclude women with disabilities from work of any kind, even from traditional roles as wives, housewives, and mothers, if they in fact choose to perform them[6,8,18,20,21,23,31,34,35]. This has had varied consequences in their lives, depending on how they articulate and change these concepts through the expansion of their networks and the establishment of new experiences in the transition to adulthood.

The consequences of these approaches to care within the context of the disability experience, particularly within the family, can begin at birth or in early childhood, with consequences that can last and be reproduced throughout their lives in these relationships. These have also resulted in infantilization, asexualization, and the denial of autonomy over their own lives.

Analyzed with the necessary sensitivity, this family behavior is a possible response to the family network's struggle with the social challenges imposed by disability, without finding adequate support in social networks or policies[14,31,34]. This highlights the need for a serious debate about the ethics of care as a value, not a social devaluation, for all people, so that this allocation of responsibility is not taken for granted and exclusive to women in families. It also highlights the necessary structural changes in mechanisms to balance the allocation of responsibility for this work, primarily in the realm of public policies, such as the National Care Policy, which has been revived as a priority in Brazil[32,33].

The challenges of the sexuality of dissident bodies: intersectionalities of gender and class

In their family relationships, the interviewees reported difficulties in understanding and accepting their attempts to achieve independence as they entered adolescence. They perceived a strong tendency toward denial or difficulty in understanding this transition, and, consequently, their first sexual/affective encounters were often restricted or controlled.

The contradictions in caregiving behaviors and the ambivalences that converted care into control reveal a situation permeated by ableism and issues related to class and gender.

So, like, these things cause a lot of friction, you know? Between me and her, and she thinks I'm rebellious, but I'm not. I want to live, because my rebellious phase is over, she doesn't understand; to her, I'm still that little girl. She doesn't accept him very well, not even dating, nothing. My middle brother doesn't talk to me anymore because of my

relationship. [...] You know when you say, 'Wow, she's special,' so because I'm special, I can't date, I can't go to the movies, I can't have friends, I can't go out? Like it's something to be taken care of, that, it seems like they're supposed to put you in a glass box and leave you there, just to be admired and never touched, when that's not how it is (Leandra, woman with a congenital disability).

Evidence from various studies has revealed that cultural narratives portray people with disabilities as individuals without needs or feelings related to sexuality. This perception maintains that dissident bodies are unattractive, incapable of expressing sexual desire in others, and, ultimately, that their expressions of sexuality are inadequate or abject. These are social constructs that, for Foucault, serve to discipline and control lives and sexualities considered to be "abnormal," subjugating them as inferior or pathological[4]. This affects the personal experiences and life projects of both sexes, limiting both the freedom and self-determination of people with disabilities, although women are more vulnerable due to the intersection of disability and gender inequality[1,2,5,6,8,20,31].

The denial of adulthood and overprotective attitudes were reported as suffocating, occurring more pronounced from adolescence onward. This often resulted in isolation and confinement, the attribution of an inappropriate sexuality, and the denial of the ability to make decisions in various aspects of life[31]. Dependence on family members for excursions outside the home, due to various social barriers imposed on disability, is further exacerbated in contexts of impoverishment. This proved to be a limiting factor, accentuating the power to restrict or veto initiatives in emotional/sexual relationships in the early years of youth.

Class was an important intersectional overlap in the articulation between discourses on sexuality and discourses on disability, in light of gender and care configurations[16,31]. According to Helen's accounts, there was a strong judgment within her circle regarding the genuine interest of her partners, in a socioeconomic reality where having a stable income is rare, especially during one's youth. As a beneficiary of the BPC (Brazilian Social Contribution), her income had been incorporated into her family's budget since childhood. Thus, beyond the judgments and low expectations that hang over dissident bodies exerting affective/sexual attraction, financial interests were attributed to the partners who approached them.

[..] I was thinking about finding a husband, having a child too. Then I started doing things around the house and everything in secret. Then, when I started dating, I wanted to live alone right away, and my mother wouldn't let me, but I knew the money was mine if I became an adult. She was afraid they'd take advantage of me, but my brothers also wanted to take care of my benefits, that's what I noticed. I moved in right away, not long after I became an adult. None of my friends could do that, but I had my own room that belonged to no one, it was mine. My mother was furious; she didn't want it, she was afraid because I started flirting. But I knew how to take care of myself (Helen, woman with a disability acquired in childhood).

While they were infantilized by not being identified as adults, there was also concern about financial abuse, associated with the fear of losing a stable income for the family in question, in a context of impoverishment. This is because, in youth and adulthood, this income was generally required for personal projects, generating economic impacts on families that depended on this income for their budgets, reflecting the class position of these families.

From resistance to rebellion: sexuality as a form of assertion of independence

Among the acts of resistance and breaking with the stereotype of infantilization and circles of overprotection, the desire and/or initiative to leave their family home of origin stood out, as evidenced by Helen's experiences. This event was seen as a milestone in the recognition of her own autonomy and self-determination, as an act of demonstrating to her family circle the recognition of her capacity for self-determination to pursue life projects, including the freedom to experience her own sexuality and emotional relationships, as well as the pursuit of a married life and having children.

Another way of confronting overprotective family attitudes, as well as confronting the assumptions of infantilization, was the public expression of her position and defense of her sexual and emotional relationships. Leandra noted that she perceived a different approach in social interactions with strangers, depending on whether she was accompanied by her mother or her boyfriend, even in interactions with healthcare professionals. According to her, when accompanied by her mother, she was not even addressed by her name, using childish terms, and the questions were directed at her mother instead of her.

In her perception, the same did not happen when they identified her as being accompanied

by her boyfriend. By being considered a being endowed with sexuality, she realized she was now considered an adult. The stigmas of dependency and infantilization ultimately harmed her relationship with her mother, as the latter tended to replicate them by labeling her initiatives for autonomy and self-determination as acts of rebellion and revolt.

However, it is important to note that, as highlighted by studies on caregiving conducted among the working classes, most mothers of children with disabilities engage in exhausting caregiving routines, often alone. This strengthens a moral imperative of devotion to a vulnerable child, which ultimately creates a form of care that can become overprotective, lasting into adolescence[14,15,31]. Furthermore, there is a legitimate fear that their daughters will experience abusive relationships, which is confirmed by statistics on gender-based violence suffered by women with disabilities, perpetrated by aggressors who are often men with whom they develop romantic relationships[10,36].

In Helen's account, we observed that individual attitudes of resistance and confrontation against this socially imposed position of dependence, infantilization, and discrimination against the body, which is at odds with the standards historically disseminated by medical and media discourses, also involve asserting oneself as a subject endowed with sexuality. She recounted situations in which she attempted to demonstrate that her body endowed her with such potential, from which she derived various forms and expressions of pleasure.

I suffered but I took it in stride, because I have such a high self-esteem [...] once I went to a party, and the lady said "oh, sissy" "why am I such a sissy?" Then she said, "You little faggot, you can't even walk." Then I said, "Okay!" Well, I spent the whole night dancing with the whole group, messing around, then she said, "Woman, you're a dog," and I said, "Yeah." [...] And there was this old man once, he looked at me like that, you know... Then we started talking about dirty things, right? I have these things with my grandpa in the middle of the street, you know why? Because he'll stay quiet in his corner, he won't even see any limits, I like to provoke, you know? It's like I like to talk about dirty things, but there was this old man next to me and he kept looking at me like that, I said, "I'm not even going to do that, but just to provoke, you know?" I said, "Honey, if you did, I would do this like this and that." Then we left, laughing our heads off (Helen, woman with a disability acquired in childhood).

Helen's reflection, based on her concrete experiences, points to her "high self-esteem" as a driver of her ability to respond to people who direct discriminatory words and looks at her. This corroborates Shakespeare's arguments[18,21], when he reflects that, because they are systematically devalued and excluded by modern Western societies, people with disabilities are often not in a position to develop self-love and self-worth. He emphasizes the importance of fostering self-esteem in these individuals, as this projects self-confidence regardless of their appearance.

Adults with acquired disabilities: the dawn of a new sexuality in youth

When we examine the trajectories of women with acquired disabilities, overprotective care and the impacts of stigmas related to dependency were also present, but in different ways. This is because they could not have contested their transition to youth, as they had already experienced and lived various social roles related to this age group before being framed by essentialized and socially reproduced assumptions about disability.

They described the onset of disability as a dividing point in their experience, not only related to dependency, but also to their sexuality and relationships, especially in the initial moments after the episodes that triggered their physical impairments, when overprotective attitudes were more prevalent and frequent. These situations influenced the reconstruction of their identity, within this new configuration of their ways of living, as we observe in Dorina's statement:

Soon after my accident, my husband and I moved in with my mother-in-law, who took care of me along with him. When my husband went back to work, she would overdo it, you know? So, I'd go wash a dish and she'd say, 'No, be careful not to fall.' [...] As time went by, my husband always really liked my cooking, but while we were living in her house, she wouldn't let me, so she kept me from cooking, until the moment we left her house and went to our own, and that's when I started to take control of my life, you know? [...] I no longer felt like my husband's wife; my low self-esteem was damaging our intimacy, and we went a long time without having sex [...] It was very difficult, because I wasn't used to being in that house, living other people's routines, and my routine had changed. I've always been a very independent person; I've never needed anyone for

anything (Dorina, woman with a disability acquired in productive adulthood).

During this initial period, the most significant situations were related to issues related to self-care and her dissident body, as well as adaptations to new ways of handling daily tasks and autonomous decision-making. For Dorina, she experienced a loss of control over her own life and a shift in her roles in relationships she considered important within her intimate life, especially her relationship with her partner. These roles began to be mediated, and in some ways hindered, by her mother-in-law's overprotective attitudes. Overprotected, she no longer felt like her husband's wife, which harmed her experiences related to sexuality, affecting her self-esteem to such an extent that it hindered the couple's intimate reconnection and sexual life immediately after the disability appeared in her life.

These situations reveal the importance of reflecting on the intelligence involved in the "discreet know-how" of care work, described by Molinier[37], that is, the ability to detect a person's needs without highlighting their dependence. This demonstrates concern for the other person's psychological comfort and prevents various forms of distress related to dependency. In the case of acquired disabilities, this is particularly relevant during the transition to a new way of life, which often requires care from others. Dorina's mother-in-law's attitudes were not sensitive to this process, and her overprotectiveness ended up restricting her initiatives for autonomy to the point where she felt as if she had lost control over her own life, even though her mother-in-law was willing to help and justified her actions as attentive and caring.

In the reconfiguration and reconstruction of the self-esteem and sexuality of interlocutors with acquired disabilities, participation in social spaces and leisure activities, as well as the reintegration or maintenance of friendship networks, contributed both to the redefinition of oppressive discourses about disability and to the reinvention of some aspects related to the experience of sexuality. In the articulation of dependency, sexuality, and affective relationships in the experience of disability, being a sexual subject requires self-esteem and communication skills, because projecting self-confidence makes someone much more likely to be seen as a potential partner, regardless of their appearance. However, people with disabilities, because they are perceived as fragile and overprotected, are often not in a position to foster this task of self-love and self-worth[8,13,18,21].

Other aspects proved equally significant, such as the barriers arising from the lack of accessibility, which hinder free movement and make it difficult to adapt to new configurations and expressions of sexuality in light of the dissident bodies they have come to know. All of this gave these interlocutors a clearer understanding of society's ableist perspective, which they only began to recognize after acquiring a disability in their youth, as Frida notes:

I had the greatest support, the support of my family, my friends, and my friends were very important in this process, and then I kept trying, I was recovering my self-esteem because people were putting me in spaces so I could add my condition to that space, it was very much like that, you know? My friends found a way, they held an audition because I really liked going out, dancing, right? And for me, that had been so brutally broken, then they found a way to include me in this, I'll never forget it, there was a time when the stories of us going out to clubs started and they found a way for me to do it, for me to try to fit in with their condition in my own way, right? [...] because of the disability, right, we are seen differently, as if we were just a piece of decoration, not a woman as a whole, including this issue of sexuality and everything else, right? I said, "Now what do I do?" I remember when I went out, people would look at me like that, you know? And at first, I was really withdrawn, and then there was a moment I'll never forget. I was in Brasília, and the woman looked at me like that, and I was like, "What's wrong? What are you looking at?" Just like that, you know? Later, I realized I'd lost my balance, right? But it's because people's reactions to my condition, how I was, were so shocking, and I had the experience of both before and after (Frida, woman with a disability acquired in productive adulthood).

The attitudes reported by Frida, in her support network of family and female friends, sought to make her feel comfortable in previously habitual situations, but which now took place in new settings, facilitating her return to socializing and recreation. It is important to consider generational aspects and the bonds of proximity, affinity, and affection that influence these relationships, and are more easily articulated in youth.

Frida's friends were sensitive to the fact that care is most effective when it is erased as hard work[36]. For her, this contributed to the process of regaining her self-esteem and, consequently, new ways of experiencing and expressing her sexuality, allowing her to re-engage in activities that were previously habitual.

Final considerations

The expression of desire and sexuality by people with disabilities remains taboo, despite theoretical and social advances in the perception of the phenomenon of disability. Overprotective discourses and attitudes within social networks ended up imposing additional obstacles so that young women with disabilities feel that they are considered socially inclusive and included in areas of life that are considered to be normal, and often central, for young people, such as romantic relationships and sexual experiences.

For the interviewees, overprotection tended to disregard their autonomy and independence over their bodies, and as a result, certain areas of life were discouraged, and their initiatives were restricted. Despite being in different age groups at the time of the interviews, the participants had experiences that differed little in their youth. In other words, throughout the 2000s and 2010s, the stereotype of women with disabilities continued to be that of an asexual subject or, on the contrary, those who broke with such assumptions had their initiatives judged as forms of rebellion, deviations from the standard considered normal for sexuality, denied to their dissident bodies.

The process of infantilization, frequently observed in women with disabilities, exacerbates vulnerabilities, deprives them of information about sexual and reproductive rights, and hinders access to health services. It draws attention, above all, to the urgent need to deconstruct ableist stereotypes in society, ensuring that all women, regardless of corponormative ideals, have their sexualities respected and their legitimate rights assured.

Therefore, our study emphasizes the importance of education on gender and sexuality issues for women with disabilities, especially in their youth. This education has the potential to reduce the risk of vulnerability and sexual abuse to which they are most exposed. It also contributes to the integration of care while preserving autonomy and self-determination. Within the political debate, these reflections open avenues to consider the design of a health policy that recognizes the risks and benefits related to the provision of care, which should be adopted by the Brazilian State.

Collaborations

FD Sá: development of the research project and execution of the fieldwork; analysis of the collected data and theoretical discussion; writing and revision of the text. MR Longhi: supervision of the analysis and theoretical discussion; partial writing and revision of the text.

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Data availability statement

The data sources adopted in the research are indicated in the article's body.

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