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TELLING TO RESIST: CONTRIBUTIONS OF MOTHERS' NARRATIVES AND CARE NETWORKS IN DISABILITY

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ABSTRACT

Objective: To discuss the contributions of narrative as a methodological and ethical approach in qualitative health research, based on the analysis of meanings and care strategies constructed by mothers and support networks of People with Disabilities.
Method: This is a qualitative, reflective study with a narrative approach, conducted in Chapecó, Brazil, with four mothers, one grandmother, one sister of a person with disability, and two healthcare professionals. Data were produced in April 2025, during a conversation circle, using trigger words to evoke memories and develop narratives about caregiving, the challenges of ableism, and subjective reconstruction. The speeches were recorded, transcribed, and analyzed from the perspective of hermeneutics, narrative bioethics, and critical discourse analysis.
Results: Four core themes were revealed: (1) solitude: the mothering territory, (2) the network as resistance to ableism, (3) care as faith and reinvention, and (4) the elaboration of meaning in the face of the unexpected. The narratives allowed access to deep layers of human experience, highlighting resilience, symbolic reconstruction, and the production of ethical and existential meanings.
Conclusion: The narrative approach proved to be an ethical, political, and aesthetic gesture. Narrating can serve to care for, resist, and produce situated knowledge that emerges from life stories, committed to people's dignity and existence. The research reaffirmed narrative as an instrument of transformation and sharing, capable of repositioning subjects and reconstructing ways of existing.

DESCRIPTORS: Qualitative research. Family. Bioethics. People with disabilities. Caregivers.

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CONTAR PARA RESISTIR: CONTRIBUIÇÕES DAS NARRATIVAS DE MÃES E REDES DE CUIDADO NA DEFICIÊNCIA

RESUMO

Objetivo: discutir as contribuições da narrativa como abordagem metodológica e ética na pesquisa qualitativa em saúde, a partir da análise de sentidos e estratégias de cuidado construídos por mães e redes de apoio de Pessoas com Deficiência.
Método: estudo qualitativo, de natureza reflexiva, com abordagem narrativa, realizado em Chapecó, Brasil, com quatro mães, uma avó, uma irmã de pessoa com deficiência e duas profissionais de saúde. Os dados foram produzidos em abril de 2025, durante uma roda de conversa, utilizando palavras-disparadoras para evocar memórias e elaborar narrativas sobre cuidado, desafios do capacitismo e reconstrução subjetiva. As falas foram gravadas, transcritas e analisadas sob a perspectiva da hermenêutica, da bioética narrativa e da análise crítica do discurso.
Resultados: foram revelados quatro núcleos de sentido: (1) solidão: território do maternar, (2) a rede como resistência ao capacitismo, (3) o cuidado como fé e reinvenção, e (4) a elaboração de sentido diante do inesperado. As narrativas permitiram acessar camadas profundas da experiência humana, evidenciando resiliência, reconstrução simbólica e produção de sentidos éticos e existenciais.
Conclusão: a abordagem narrativa revelou-se um gesto ético, político e estético. Narrar pode servir ao cuidar, resistir e produzir conhecimentos situados, emergentes das histórias de vida, comprometidos com a dignidade e a existência das pessoas. A pesquisa reafirmou a narrativa como instrumento de transformação e partilha, capaz de reposicionar sujeitos e reconstruir modos de existir.

DESCRITORES: Pesquisa qualitativa. Família. Bioética. Pessoas com deficiência. Cuidadores.

CONTAR PARA RESISTIR: CONTRIBUICIONES DE LAS NARRATIVAS DE LAS MADRES Y LAS REDES DE CUIDADO EN EL ÁMBITO DE LA DISCAPACIDADE

RESUMEN

Objetivo: Analizar las contribuciones de la narrativa como enfoque metodológico y ético en la investigación cualitativa en salud, basándose en el análisis de los significados y las estrategias de cuidado construidas por madres y redes de apoyo de personas con discapacidad.
Método: Se trata de un estudio cualitativo y reflexivo con un enfoque narrativo, realizado en Chapecó, Brasil, con cuatro madres, una abuela, una hermana de una persona con discapacidad y dos profesionales de la salud. Los datos se obtuvieron en abril de 2025, durante una mesa redonda, utilizando palabras desencadenantes para evocar recuerdos y desarrollar narrativas sobre el cuidado, los desafíos del capacitismo y la reconstrucción subjetiva. Los discursos fueron grabados, transcritos y analizados desde la perspectiva de la hermenéutica, la bioética narrativa y el análisis crítico del discurso.
Resultados: Se revelaron cuatro temas centrales: (1) la soledad: el territorio de la maternidad, (2) la red como resistencia al capacitismo, (3) el cuidado como fe y reinvención, y (4) la elaboración de significado frente a lo inesperado. Los relatos permitieron acceder a capas profundas de la experiencia humana, poniendo de relieve la resiliencia, la reconstrucción simbólica y la producción de significados éticos y existenciales.
Conclusión: El enfoque narrativo demostró ser un gesto ético, político y estético. La narración de historias puede servir para cuidar, resistir y producir conocimiento situado que surge de las historias de vida, comprometido con la dignidad y la existencia de las personas. La investigación reafirmó la narrativa como un instrumento de transformación y compartición, capaz de reposicionar a los sujetos y reconstruir formas de existencia.

DESCRIPTORES: Investigación cualitativa. Familia. Bioética. Personas con discapacidad. Cuidadores.

INTRODUCTION

Narratives constitute an epistemological and methodological resource that is increasingly valued in qualitative health research, especially in research focused on understanding subjective and collective experiences of illness, care, and social exclusion. Since pioneering studies in the Social Sciences in Health, its potential as a technique for generating empirical materialities and as an object of knowledge capable of translating human experiences into communicable, sensitive, and critical forms has been recognized[1-2]. Narrating is a way of intervening symbolically[2] on reality by problematizing hegemonic discourses and opening space for implicated epistemologies. Ethical deliberation then emerges as a formative and applied pathway, in which sensitive listening and the recognition of singularities become central aspects in the analysis and confrontation of ethical issues[3].

The research involving mothers and networks of People with Disabilities (PwD) is presented in this context because it exemplifies the power of narrative as a methodological strategy in qualitative health research. These women live through experiences marked by intense subjective, social, and political demands, often rendered invisible by traditional research models. In narrating their experiences, amidst silences, pain, support networks, and subjective reinventions, mothers produce meanings that could not be captured by standardized or detached approaches. The use of narrative, in this case, allows access to deep layers of human experience, revealing ethical, affective, and existential aspects of care in the context of disability[1].

In light of these contributions, the aim is not to reiterate already established concepts about narrative, but to shift them towards a situated practice of listening and care, such as the one developed in this study. The word narrate comes from *narrare*, which means “to drag forward”, and also derives from *gnarus*, “the one who knows” and “the one who saw”. The narrator, therefore, is the one who carries forward the trace of lived experience, externalizing it in memory and language. As Larrosa Bondía[4] points out, narrating is not just about reporting past events, but about mobilizing experience to educate the gaze, transmit meanings, and create possibilities for shared understanding. In this context, the narrative becomes a pedagogical gesture: by telling, the subject rewrites their own memory and opens space for others to learn how to see, feel, and think in a situated way[4].

In the field of Public Health, the use of narratives represents an important shift away from traditional biomedical models. Narrating life experiences and caregiving breaks with the impersonality of official discourses and takes the form of a political and subjective act, capable of transforming both the subjects and the ways of caring. Narrative, therefore, appears as a “germinating force” of new forms of care and symbolic resistance[5-6].

Research based on hermeneutics and dialectics[6] emphasizes the relational and ethical nature of this type of approach, which proposes the construction of shared meanings between researcher and participants, often through the re-creation of life stories, validation workshops, and the integration of different voices into a collective narrative. Understanding the suffering, struggle, and love that permeate the daily lives of mothers of PwD requires methods that account for the complexity and uniqueness of these journeys[6].

This study starts from this premise and proposes to discuss the use of narratives as a method of data collection and analysis in qualitative research focused on women, family members of support networks of PwD. This excerpt focuses on the role of these women in confronting structural ableism[7-8], in the care networks that support them and, above all, in the ways they process their experiences through words, silences, and memories. By transforming listening into sensitive accounts and analyses committed to the dignity of the stories told, this study’s experience allowed seeing the narrative as a way of caring and resisting in scientific practice, beyond the method itself[9].

The selection of narratives, in this context, is also anchored in a theoretical and political field that recognizes women as protagonists in a continuous process of reinvention of themselves, of motherhood, and of caregiving. Previous studies indicate that disability, as a socially constructed condition, reorganizes family lifestyles and imposes disproportionately distributed responsibilities on mothers[7-8]. Atypical motherhood, therefore, demands listening, visibility, and methodological tools that respect and reveal these layers of meanings, life events, and experiences.

In this sense, it is not a matter of reiterating concepts already established in the fields of narrative, bioethics, or disability studies, but of shifting them towards a situated practice of listening and care, built in encounters with PwD mothers and support networks. The objective of this study is to discuss the contributions of narrative as a methodological and ethical approach in qualitative health research, based on the analysis of meanings and care strategies constructed by mothers and support networks of People with Disabilities. The term “mothering” is used deliberately and intentionally in this study to shift the focus of motherhood from the merely biological or institutional aspect to the effective care practices that are manifested in everyday life. Mothering involves ethical and emotional engagement, a continuous task that demands dedication, availability of time, subjective involvement and affection, and the constant confrontation with social norms and regulations that govern maternal processes—elements that become particularly present in the context of disability. Thus, mothering is not simply about giving birth or having children, but involves a complex network of interactions, affection, and responsibility that shape care in its multiple aspects, especially when it involves PwDs[10].

Thus, this article emerges from experiences with women/PwDs, whose narratives revealed concrete challenges of care, but mainly, provoked storytelling as a gesture of subjective elaboration and epistemic resistance, capable of confronting established truths and affirming other ways of existing, caring, and knowing[11]. It therefore represents an advance over other studies in discussing the issue of neurodiversity[12-14] regardless of the level of commitment of the people involved. This approach promotes the active participation of mothers in the construction of knowledge that directly concerns them. Furthermore, the text stands out for adopting the neurodiversity paradigm as a theoretical possibility, giving visibility to other epistemic perspectives in this field.

Neurodiversity is the biological fact expressed by the variation in human minds and neurocognitive functioning, while the neurodiversity paradigm argues that such differences need to be respected and accommodated rather than pathologized, promoting movements of social justice, equity, and inclusion, based on mutual learning that transcends cultural boundaries and welcomes and values each individual[13]. Furthermore, such thinking can lead to changes in local clinical policies and practices[14]. By replacing the notion of disorder or dysfunction with that of brain atypicality (divergence in thought and action), the focus shifts to understanding the environments that define the experiences of neurodivergent people; these individuals participate in the undertaking of a new translational science of neurodevelopment, whose objective ceases to be targeting the dysfunctional brain or correcting deficits and starts promoting positive environments and affirmative experiences[12, 14-15]. Given its potential, it is important to warn that neurodiversity paradigm(s), originating primarily from autism research in North America and Europe, should not simply be translated and transposed to diverse contexts without due regard for sociocultural scenarios, histories, and local perspectives, thus reproducing colonizing research practices[15].

METHOD

A qualitative study, with a methodological and reflective character, was carried out based on the empirical experience of participatory research, conducted with four mothers, a grandmother, a sister of a PwD, and two health professionals, through a conversation circle. The research focused

on understanding the challenges, meanings, and care strategies employed by these women in the context of disability.

The participants were selected using a chain sampling technique, also known as "snowball sampling"[16], recommended when prior identification of the entire target population is not feasible. The process begins with the selection of key informants, or "seeds," who meet the research criteria and, through their networks, identify new participants. With each new contact, the chain of referrals expands until sufficient data is obtained. In this case, information overload was assessed by code stability and the absence of new relevant meanings in the latest statements. It is important to highlight that multiple seeds were defined to reduce network circumscription.

The inclusion criteria were**:** women aged 18 or older who were mothers of PwDs or had direct involvement in daily care; in addition to a grandmother (direct family link), a sister (family support network), and two healthcare professionals with experience in providing care to PwD in the study area. The exclusion criteria were individuals without family/affective ties or without direct caregiving involvement with PwD, disagreement with audio recording and use of confidential speech, unavailability for full participation in the discussion.

The narratives were produced in April 2025, using trigger words that served as facilitators for evoking memories, feelings, and meanings. Each participant was asked to choose a card containing a meaningful word. The trigger words ("Silence", "Faith", "Destiny", "Rebirth", "Struggle", "Affection", "Meaning") were selected by the researchers based on a previous literature review and in findings from a previous stage of the project (macro research), which pointed to the recurrence of these affections and meanings in atypical motherhood. The set was defined by consensus among the researchers and pre-evaluated for clarity and semantic relevance to the local context. The use of trigger words aimed to evoke memories and senses[5-6] without directing the narrative, favoring free association[5] and the collective production of meanings in a circle, in line with the proposal of situated listening and with the ethics of narrative bioethics[2].

The conversation circle took place in a single in-person meeting, lasting approximately three hours, a time considered sufficient to encourage the emergence of rich narratives and the construction of shared meanings. The group's composition, although numerically small, proved adequate for the study's objective, as it prioritized the depth of listening, the diversity of positions within the care network, and the interpretative saturation of the meanings produced, observed through thematic recurrence and the stability of codes in the final narratives.

The analysis was conducted using an interpretative approach, in harmony with perspectives that understand narrative as a method of situated understanding and hermeneutics[6], to access the meanings, silences, and resistances present in the narratives. The researcher was considered an involved subject and author of the analytical process, in dialogue with narrative bioethics, ensuring rigor with meaning and ethical-political commitment.

The narratives were produced in a collective environment, favoring individual expression and the construction of shared meanings, permeated by sensitive listening, identification, and acceptance among the participants. The speeches were recorded, transcribed in full, and organized into thematic groups, taking into account the meanings attributed, the discursive recurrences, and the symbolic density of the accounts.

Inspired by Foucault[11,17], the analyses sought to identify the content of the speeches as well as the regimes of truth that permeate them, the structuring silences, and the forms of subjection and resistance emerging in the narratives, engaging with the assumptions of narrative bioethics[1-2]. Narratives, understood as discursive productions marked by social, historical, and subjective influences, take on a different meaning from the simple retelling of experiences[1,18]. The analysis went beyond

the explicit content of the speeches, delving into the contexts of discourse production, the unspoken, power relations, and the processes of subjectivation involved[11].

This reflection is permeated by a critique of methodolatry, understood as the tendency to empty the method of its critical and political intentionality, converting it into a mere technique or protocol detached from its context[19]. In response to this reduction, we propose a repositioning of the method as an ethical and situated practice, which assumes listening as an act of care and shared creation of meanings. In this context, Freire inspires us[20], as he believed that methodological practice is inseparable from educational praxis: it is alive, dialogical, and rooted in the subjects' concrete conditions. Thus, rigor and meaning are not opposing categories, but inseparable in an ethics of situated listening.

Ethical procedures were strictly observed, in accordance with Resolution No. 466/2012 of the National Health Council. The project was approved by the Research Ethics Committee of the *Universidade Federal de Santa Catarina*.

Consent was understood as an ongoing process, not as a one-off act. Before the conversation circle, participants were informed about the objectives of the study, the possible uses of the narratives, the methods of recording, and the voluntary nature of participation. Furthermore, the confidentiality of all shared information was guaranteed, ensuring the anonymity of participants through the suppression of identifying data and the use of codes or pseudonyms in the transcriptions, analyses, and dissemination of results.

Throughout the meeting, the right to interrupt speeches, request the removal of excerpts, revise one's own narratives, or withdraw from the activity at any time, without any prejudice, was reaffirmed. Considering the emotional weight evoked by the narratives, the meeting prioritized sensitive listening, mutual acceptance, and respect for silences, without inducing the sharing of painful experiences.

In the results, the excerpts that emerge from the women's speeches are followed by the initials of their English equivalents: Mommy - M, Sister - S, Nurse - N, and Grandmother - G, followed by an order number, respecting anonymity.

During the stages of this research and in the production of this article, no Artificial Intelligence tools were used; therefore, the authors assume full responsibility for the content of the publication.

RESULTS

Weaving voices: care, pain, and meaning in mothers' narratives

The analysis of the narratives revealed the methodological power of trigger words in evoking memories and deep meanings associated with the experience of care in the context of disability. The participants' statements, organized by thematic affinities and symbolic density, allowed for the emergence of four major core meanings: 1) solitude: the mothering territory; 2) the network as resistance to ableism; 3) care as faith, rebirth, and subjective reconstruction; and 4) destiny and meaning as existential elaborations of the unexpected.

The construction of the core meanings resulted from an analytical process that articulated discursive recurrence, symbolic density, and the context of the speech production. For example, passages that evoked silence, invisibility, and a lack of emotional sharing, such as "I kept this to myself" or "my grief exists in solitude," were initially coded as isolation and non-recognition, and were later grouped under the heading "solitude: mothering territory". A similar process occurred with narratives that highlighted family support, belonging, and reciprocity, gathered under the theme "the network as resistance to ableism."

Loneliness: the mothering territory

Some narratives comprised the collection of stories about mothering a PwD child, where loneliness appears not only as an absence of companionship, but as a way of being in the world marked by incomprehension, invisibility, and social and institutional isolation. In this regard, meetings of mothers, in waiting rooms of doctor's offices, in schools, or even in groups with such characteristics, constitute a moment of listening and sharing. *I've tried therapy a few times, but therapy for an atypical mother? Who can experience this? It's very specific. Our meetings, for me, are much more therapeutic* (M1).

The following excerpt, from the same mother, articulates silence and solitude as subjective markers of a journey of intensive and unshared care, where even grief takes on new forms: *I've been trying to cope with loneliness and understand, because my grief never existed in the past. Today it exists in solitude. In whose solitude? My son's mainly* (M1).

Another mother points to the loneliness at the beginning of the journey, marked by forced silence, fear of burdening others, and the absence of emotional sharing, from the moment the child was diagnosed: *I was afraid to tell them* [her parents]*, that they might freak out. I kept it to myself, I hid my entire pregnancy.* [...] *I see that he* [son] *is alone, and when my husband and I pass away...* [pause/crying] *That's another difficult issue* (M2).

Mommy 3, in turn, expresses a type of symbolic isolation: the break with the ideal of control in motherhood, which separates her from more predictable experiences. *Before I had* [daughter with Down Syndrome], *I was very neurotic, very worried... we think we control everything, but we don't* (M3).

For Mommy 4, loneliness takes on identity-related dimensions, marked by the process of denying her daughter's disability and her own condition as a mother. This initial refusal reveals a sense of not belonging that permeates her experience, intensifying their isolation and delaying the possibility of recognition and acceptance. *I spent many years denying my status as a mother of children with disabilities, denying my daughter's status as a person with a disability* [...] *If I hadn't had* [daughter with neurological sequelae], if *I hadn't gone through all that, I would be one of the people who would look at things differently, who would be curious, who would say something ableist* (M4).

The network as resistance to ableism

Support networks emerge as a counterpoint to exclusion and provide sustenance in daily care, distributing the emotional burden and shifting the focus from the individual to collective responsibility. They function as a technology for recognizing and legitimizing differences, especially during times of crisis.

If we were prepared in our families and schools to be a support network, perhaps prejudice wouldn't happen. [...] *He* [deaf brother] *was never listened to. Now he suffers with this.* (...) (S1).

We had therapeutic support from the beginning that clarified her condition [daughter], *and since we had that support, we always try to provide that support to the people close to us.* [...] *We* [mothers of PwD] *called each other, offered support, it makes a huge difference* (M3).

I remember being by my daughter's side when she received the diagnosis over the phone: a brain tumor. It was always difficult for me, I suffered doubly, for my daughter and granddaughter, but it was my family that held me together (G1).

Thus, the network produces behavioral accessibility, reciprocity, and belonging, converting bonds into an ethical mechanism of resistance to ableism.

Care as faith, rebirth, and subjective reconstruction

The narratives reveal that intensive care in the context of disability operates as a subjective journey. Far from being merely a practical task or a naturalized affection, care emerges as a

transformative experience, marked by pain, surrender, and reinvention. In many speeches, faith, rebirth, and self-reconstruction intertwine as ways of sustaining the continuity of life when it deviates from the promises of normality. *I chose the word faith because at that moment, I turned completely to God; He was the one who held me up and helped me move forward* (M2).

Even in the face of fear and uncertainty, faith becomes an ethical practice, a way of preparing for what cannot be controlled. *I'm clinging to God, preparing myself... I have to prepare myself more than he does, because in fact, he doesn't really understand what's going on* (M2).

Nurse 1 was not the mother of a PwD, but she was also a mother. She approaches rebirth as a spiraling process that runs through her experience as a mother, professional, and woman. A difficult and unplanned pregnancy marks the beginning of a journey of subjective reconstruction: *She* [daughter] *rekindled in me the desire to be a mother again... even though it was a difficult pregnancy.* [...] *Motherhood is a learning opportunity. We are born and reborn together with our children* (N1).

By acknowledging the challenges of the unique motherhood experiences of those she cares for, Nurse 2 also points to the power of this experience as a catalyst for strength and empowerment: *When we think about atypical motherhood, the challenges are more intense... but a positive side is this capacity for overcoming and empowerment in women* (N2).

These testimonies indicate that care, when experienced in the context of disability, is not only an action towards others, but also a practice of self-care. It destabilizes certainties, calls for surrender, but also paves the way for the emergence of new subjectivities, more conscious, more powerful, more ethical ones.

Destiny and meaning: existential elaborations of the unexpected

Faced with the unexpected challenges imposed by disability, the mothers interviewed reveal a continuous process of existential elaboration, an attempt to create meaning where before there was expectation, control, and defined plans. Mommy 4 translates this journey with the notion of *amor fati* inspired by Nietzsche, as an attempt to love one's own destiny, not as resignation, but as a form of affirmative resistance. *You have to find out why it came to me, what I had to learn from it, and that becomes the meaning of your life.* [...] *I tattooed 'amor fati' on my skin... trying to love your destiny, to love what came to you* (M4).

Mommy 3 also gives meaning to the arrival of her daughter, shifting the disability from the realm of accident or lack to the field of learning and belonging: *She was meant for me, not for anyone else... she came to teach us a lot of things* (M3).

Mommy 2 recalls the moment of discovery as an abrupt rupture of the ideal of predictability, evoking the collapse of biomedical guarantees: *My tests were all normal* [...] *and then a cyst appeared on the baby's head. And now?* [...] *It was a desperate situation* [...] *but I'm clinging to God, preparing myself for what's to come* (M2).

Mommy 1, in turn, poetically expresses the feeling of isolation and constant effort when talking about the path of atypical motherhood: *For other mothers, there is a paved road, we have at most a trail in the middle of the forest... or we are with a scythe in our hand opening our own path* (M1).

Sister elaborates on her brother's suffering as an ethical warning. Listening to others transforms into engagement. *This sadness he's showing, I can see that he has some emotional disorders because of it.* [...] *The fact that we are not part of a network somehow makes many people with disabilities feel displaced, or unseen. That, to me, is prejudice* (S1).

These voices reveal that, in the face of the unexpected, care is not limited to technical or emotional adaptation. Mothers construct narratives that reorganize the meaning of life, shifting the focus from what has been lost to what can still be experienced. These are elaborations that do not eliminate pain, but transform it into ethical and existential matter. These narratives point to profound processes

of symbolic reconstruction, in which destiny ceases to be a burden and becomes incorporated as a path, as a possibility for reinvention.

The meanings in conjunction

Based on the participants' testimonies, four major core themes emerge in the narratives, as previously described: (1) solitude: the mothering territory; (2) the network as resistance to ableism; (3) care as faith, rebirth, and subjective reconstruction; and (4) destiny and meaning as existential elaborations of the unexpected. The conjunction of these core meanings allows us to understand the manifestation of meanings and care strategies constructed by mothers and support networks of People with Disabilities, as shown in Figure 1.

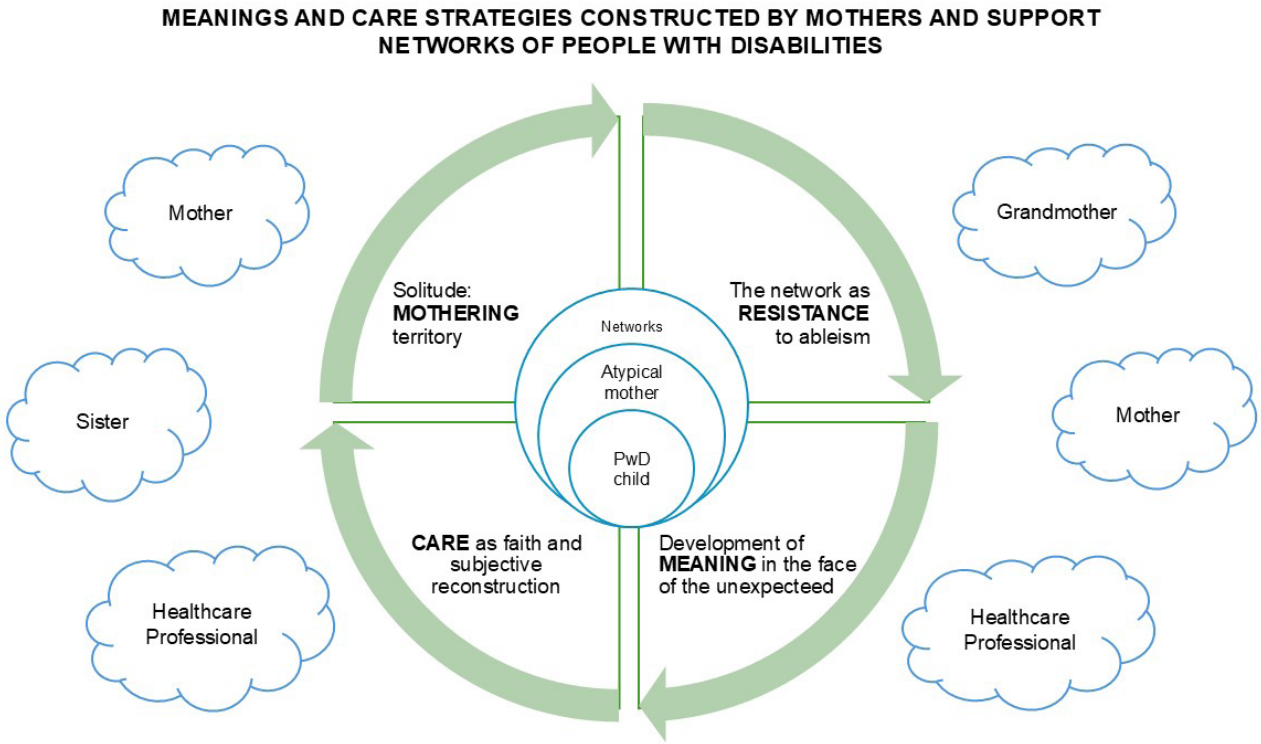

Figure 1 – Meanings and care strategies constructed by mothers and support networks of people with disabilities.

The diagram depicts the child with a disability as the center of all attention, immediately protected and nurtured by the atypical mother, who is also supported and assisted by the support network. All of this unfolds amidst meanings and strategies that involve motherhood as a solitary condition, resistance to ableism sustained by a support network, the unexpected, and the search for meaning in this experience, with faith and reinvention as strategies for care. The diagram depicts a continuous, circular movement, highlighting the interrelationship and complementarity between the actors involved and the understanding of meaning as significance, feeling, and direction for the construction of care. Around these elements are the people who provide care for the PwD child and their perceptions expressed in the core meanings.

DISCUSSION

Non-ableist care

Ableism is the manifestation of prejudiced attitudes that hierarchize individuals based on how well their bodies conform to an ideal of beauty and functional capacity. Based on structural ableism[7], people with disabilities are systematically discriminated against and made invisible, being viewed through the lens of incapacity. Ableism constitutes a power regime that regulates affections, expectations, and social relations, determining how people with disabilities are generally treated as incapable of producing, learning, loving, caring, feeling pleasure, or exercising motherhood or fatherhood. This perspective goes beyond a simple analytical category. In this sense, authors[21] emphasize that ableism cannot be separated from gender inequalities and patriarchy, since women with disabilities and caring mothers suffer double oppression, both from the condition they face and from the socially imposed burden on women. Thus, thinking about ableism from a feminist perspective implies recognizing how exclusion is also traversed by relations of gender, sexuality, and motherhood, demanding more complex ethical and political responses.

Boff relies on Heidegger to assert that "Care is found at the very root of human existence, before anyone does anything. And if something is done, it always comes with care and is imbued with care." He adds that "From an existential point of view, care is, a priori, before every attitude and situation of the human being, what always means that it is present in every attitude and situation in fact"[22,34].

Care is essential for survival[23] and to the maintenance of life forms, and given human fragility and vulnerability, it is not possible to survive the first years of life without daily and constant care, just as it is necessary to maintain it for more than a decade for an individual to reach adulthood. Human fragility and vulnerability make care indispensable throughout life, but some conditions intensify its need, such as illness, old age, or disability. The fact that such activities are predominantly performed by women and are undervalued or even unnoticed by society draws the attention of care scholars. This statement confirms findings that women are predominantly the caregivers of their children with disabilities[24].

Narrating is caring: towards an epistemology of listening and creation

Instead of narrative approaches focused predominantly on reconstructing individual trajectories or retrospectively analyzing experiences of illness, the proposal presented here shifts the focus to narrative as a collective, situated, and implicated practice[6]. By integrating listening, analysis, and aesthetic feedback into a single movement, this approach critically engages with more descriptive or interpretive narrative models, affirming narrative as a technology of care and resistance, and not merely as a technique for accessing experience. Therefore, the study revisits narrative bioethics, using established interpretive methodologies, but proposes an ethical-political shift by repositioning the participants as co-authors of meaning and not merely as sources of data.

This experience and the construction described here demonstrate that narrative, as a methodological and ethical gesture, allows access to layers of meaning that remain invisible under positivist lenses. This is a path of knowledge that goes beyond factual description, inscribing itself in the territory of lived experience, where care is also language, body, memory, and resistance. The mothers, grandmother, sister, and professionals who participated in the conversation circle offered discourses marked by affection, grief, hope, and coping that would hardly emerge in approaches centered on protocols or rigid categories[25].

Considering these contributions, narrative is not revisited here as an abstract theoretical category, but rather as a concrete practice of listening, creation, and care, which takes place in the encounter between researcher and participants. In this context, narratives function as practices of subjectivation and resistance to structural ableism[7], which permeates these women's experiences, and also the dominant epistemology that naturalizes the silencing of subjugated voices[11,26]. In this direction, they evoke what Parker[27] calls the value of disagreement: by diverging from hegemonic versions of reality, narratives create spaces for contestation and moral plurality, affirming that the conflict of perspectives can be fertile ground for care and ethics. They thus construct a situated, embodied, and insurgent knowledge that challenges both the normative biomedical logic and the romanticized ideals of motherhood. They therefore align with the proposal of narrative bioethics, which values sensitive listening and the dignity of stories as the ethical foundation of care[1-3].

From the risk of methodolatry to the situated invention of method

The methodology itself, listening prompted by trigger words in a collective setting, challenges the centrality of the researcher as the holder of knowledge and shifts the focus from scientific validation to the co-construction of meaning. Active listening thus becomes a technology of care and knowledge production[1-3].

By rejecting illusory neutrality and embracing the complexity of the voices heard, this research repositions PwD mothers as authors of their own stories, beyond mere objects of study. However, it is recognized, in accordance with Max Weber's notion of axiological neutrality[28], that scientific analysis requires distinguishing between judgments of fact and value, even though it is acknowledged that every choice of object and approach is influenced by values. Starting from this understanding, we opt here for an engaged stance, which considers listening as an ethical and situated act. Shared listening, when transformed into literary narrative and analytical reflection, broadens the ethical, epistemological, and political horizons of health research. The narrative then ceases to be a mere technical instrument and becomes also a gesture of care and symbolic repair[25].

Overcoming methodological obsession, therefore, does not mean abandoning rigor, but rather placing the method at the service of listening, interpretation, and ethical-political commitment to the research subjects[19]. It is necessary to propose viable alternatives that are consistent with the principles of public health, nursing, and studies related to social justice.

Recognizing narrative as a hybrid methodological technology[1,25], which navigates between data production, analysis, and aesthetic feedback, is a step in that direction. Based on the experience gained from this research, this paper proposes an original systematization of the narrative approach, recognizing it as such a technology, inspired by narrative bioethics and the interpretative description[25], which is structured from the concrete practice of transforming sensitive listening into literary stories, interludes, and feedback. This paper proposes a possible systematization of the narrative approach, organized into five interconnected movements: (1) Provoked (and not directed) listening: use of trigger words that evoke symbolic and profound meanings; (2) Collective and situated production: Conversation circles as a way to confront the individualizing logic of the traditional interview; (3) Narrative transcription: Writing as an act of listening and aesthetic feedback, which transforms speech into narratives, respecting voices and silences; (4) Analytical-poetic interludes: insertion of short texts that articulate literature, philosophy and analysis, producing meaning beyond description; (5) Reversibility of analysis: openness for participants to challenge, validate or complete the narratives, giving voice and expression to the actors.

This approach also opens up the possibility for the narrative to be transformed into aesthetic-analytical feedback, such as short stories, literary texts, or shareable products, broadening the ethical and political scope of the research.

By recognizing that disagreement is inherent in human relationships, narratives also constitute an act of ethical care, as they promote listening to difference and including marginalized voices, in line with the horizon of an insurgent narrative bioethics[26]. Within this framework, research becomes a territory for encounter, creation, and reconstruction of possible worlds, where rigor is achieved through the ethical, theoretical, and aesthetic consistency of the analysis[29].

Adopting narrative as an interview technique lends a more sensitive and welcoming character to data collection. This approach allows participants to expand their vocabulary, reframe difficult experiences, and envision positive possibilities for the future. The narratives also revealed traces of resilient processes, reaffirming the potential of narratives as a powerful methodological strategy, capable of accessing deep subjective dimensions and promoting transformative elaborations[30].

Recommendations and implications

It is recommended to incorporate conversation circles with trigger words as a narrative listening tool in care services and/or Primary Health Care, including ongoing education for situated listening and anti-ableist protocols (support network, behavioral accessibility). For future research, we suggest conducting multicenter/longitudinal studies, including people with disabilities as participants and co-authors, testing triangulation of methods (field diary, observation, individual interviews), and evaluating the impact on indicators of support and caregiver burden. For this purpose, one can use the bioethical framework of Moral Deliberation[2].

Study limitations

This was a contextual qualitative study with chain sampling, subject to network circumscription. The use of trigger words may have privileged certain meanings, which was mitigated by non-directive and feedback-based mediation. Without methodological triangulation in this analysis, the depth of the chosen method was prioritized. The results aim at transferability, supported by dense description and reflexivity.

FINAL CONSIDERATIONS

The research argues that narrative, operated as a hybrid methodological technology (data collection–analysis–feedback), is powerful for embracing silenced voices and producing situated meanings in the care of mothers of people with disabilities. The use of trigger words in conversation circles enabled the emergence of four core themes (loneliness, networks, care, destiny) and highlighted narrative as an ethical-political gesture of recognition and resistance. Methodological ritualism is abandoned in favor of a situated, rigorous, and engaged listening approach. As implications, it is recommended to incorporate narrative listening devices into Primary Care and health education, to guide anti-ableist practices centered on support networks, and to adopt aesthetic-analytical feedback as part of care.

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NOTES

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DATA AVAILABILITY
The datasets generated and/or analyzed during the current study are available from the corresponding author upon reasonable request. The data are not publicly available because they contain qualitative narratives and sensitive information that could compromise participant privacy and confidentiality, even after anonymization.

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