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Quality of Life of siblings and parents of people with intellectual disabilities: A pilot study

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Abstract
This study explores the Quality of Life (Schalock, Verdugo Alonso, 2002; Giaconi, 2015; Cottini et al., 2016) of family caregivers of people with intellectual disabilities with particular attention to the perspectives of parents and siblings (brothers and sisters). Specifically, using a qualitative approach, the research aims to understand their perceptions about the levels of Quality of Life they experience (Arnold, Heller, 2018; Múries-Cantán et al., 2023). In line with the literature on the subject (Del Bianco, 2019; Taylor, Cobigo, Ouellette-Kunzt, 2019; Caldin, Giaconi, 2021; Lepri, 2023), the study highlights the importance of rethinking policies and practices to provide more effective support to families, both during the 'During Us' phase and in the long-term planning of 'After Us'. The results underline the importance of considering the quality of life of the entire household in the design of interventions and services to the person, promoting empowerment and partnership between families and local services.

Key words: Quality of Life; caregivers: parents; siblings; self-determination

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1. Quality of Life of caregivers of people with disabilities

Reference literature, proper to pedagogical-special reflection (Montobbio, Lepri, 2000; d'Alonzo, 2008; 2020; Pavone, 2009a,b; Cottini et al., 2016; 2021; Mura, 2018; Caldin, Giaconi, 2021), has long paid particular attention to the centrality of the person with disabilities in the construction of a Life Project that takes a dynamic, open and flexible perspective. The complexity inherent in the implementation of this trajectory encourages consideration of how to design

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coherent pathways oriented to the Quality of Life (QOL) construct from birth, in order to avoid the risk of sudden or even emergency solutions in adulthood (Pavone, 2009).

Part of larger studies and research (Felce, Perry, 1996; Schalock, Verdugo Alonso, 2002; Schalock et al., 2000; Schalock, Gardner, Bradley, 2007; Layte, Sexton, Savva, 2013; Giaconi, 2015; Cottini, Zorzi, Fedeli, 2016; Zappella, 2019; Amor et al., 2023; Verdugo Alonso, Schalock, 2024) the conceptual frame of Quality of Life is now central to orienting the design of the existential paths of people with disabilities, representing the perspective towards which any educational intervention can tend. Raising the perceived quality of life on a personal level means, in fact, increasing opportunities for participation, integration, equity, choice and self-determination (Schalock, Verdugo Alonso, 2002; 2006). On the other hand, the QOL is the key criterion for planning effective interventions and for organising quality services (Schalock, Verdugo Alonso, 2002; 2012; Schalock, Verdugo Alonso, 2006; Townsend-White, Pham, Vassos, 2012; Gomez et al., 2013; van Loon et al., 2013; Giaconi, 2015; Giaconi, Rodrigues, 2018; Del Bianco, 2019; D'Angelo, 2020; Amor et al., 2023).

The importance of the construct for multidimensional handling (Schalock, Verdugo Alonso, 2002; 2006; Cottini, 2016; Giaconi, 2015) prompts us to ask ourselves about its articulations and its operationalization in reference to the complex dimensions of taking care of families with children with disabilities (Pavone, 2009; Caldin, 2006; Zanobi et al., 2002). The importance of proceeding in this direction is highlighted by various lines of research carried out by the scientific community of Special Pedagogy, which make it possible to enter into the main pedagogical issues relating to the care of persons with disabilities by their caregivers, especially at the delicate moment of 'After Us'.

In the first place, it seems appropriate to underline the mutual and direct relationship that exists between the Quality of Life of those who care for the person with disabilities and that of the person with disabilities (Blacher, 2001; Seltzer et al., 2001; Schalock, Verdugo Alonso, 2002; Giaconi, 2015; Arnold, Heller, 2018; Luijkx et al., 2019). In the same direction, there is a need to proceed with the 'family interpretation of the Quality of Life' (Schalock, Verdugo Alonso, 2012, p. 201). Special Pedagogy has long recognized the centrality of this reflection, supporting the active involvement of both the person with disabilities and caregivers in the construction of Life Projects, able to align expectations, needs, and desires (Giaconi, 2015). However, there are several studies (Lujik et al., 2016; Maes et al., 2021; Scavarda, 2022; 2023; Wolff et al., 2022; Kruithof et al., 2024) which highlight the need to conduct more in-depth studies with regard to the dimensions perceived as having an impact on the quality of life of the person with disabilities and of the caregiver himself.

Secondly, to highlight the need for further research on the quality of life of caregivers of persons with disabilities, critical issues arise regarding the increase in life expectancy and the ageing of the family support network (ISTAT, 2019). In other words, the planning of the future of persons with disabilities must go beyond the logic of the emergency to leave room for sustainable and timely planning, developed in synergy, both with the person with disabilities and with their caregivers and with the relevant territorial services (Giaconi, 2015; Del Bianco, 2019; D'Angelo, 2020). In the latter direction, the studies highlight how crucial it is to support a design that unfolds in the 'During Us' for the planning of the 'After Us' (Brennan et al., 2018; ISTAT, 2019; Giaconi et al., 2020).

To raise reflections to guide policies and services, so that they can move towards qualitative terms, supporting forms of empowerment and partnerships with the entire family (Pavone, 2009a,b; Schalock, Verdugo Alonso, 2012; Caldin, Cinotti, Serra, 2017), in this study we will reconstruct the perceptions of the Quality of Life of family caregivers, focusing our specific attention on the dynamics experienced by siblings, i.e. the brothers and sisters of people with disabilities.

1.1 Quality of Life: from parents to siblings

The premises outlined above allow us to briefly examine some of the complex dimensions of family care when people with disabilities are present (Pavone, 2009b; Caldin, 2006; Giaconi et al., 2020; Caldin, Giaconi, 2021; Quatrosi et al., 2023; Múries-Cantán, 2024).

Studies conducted on the subject (Farinella, 2015; Trenceri, 2016) have long recognised the importance of deepening and learning about the experiences of siblings, using qualitative approaches in order to detect factors that can influence their well-being and resilience strategies (Meltzer, Kramer, 2016; Scavarda, 2023). As they grow up, the brothers and sisters of people with disabilities face numerous challenges and complex moments of 'reorganisation'. In childhood, for example, siblings may experience both moments of stress and increased sensitivity to the needs of others (Scavarda, 2023). This dual experience can persist into the adolescent period, adding to other conflicting emotions. During the search for affirmation of their individuality and independence (Macedo Costa, Pereira, 2019), siblings can, in fact, harbor feelings of shame or embarrassment related to the presence of a brother / sister with disabilities in the family, but also a strong sense of pride for their progress and their achievements (Macedo Costa, Pereira, 2019). In adulthood, expectations about taking on a more substantial caregiving role than a sister or brother with a disability have an impact on the siblings' life plan.

This demand increases in relation to parental ageing or the loss of one or both parents (Hodapp, Glidden, Kaiser, 2005; Pavone, 2009a, b; Burke et al., 2012; Caldin, Giaconi, 2021; Niedbalski, 2023).

In addition, research conducted on the theme of care roles assumed by siblings of people with disabilities highlights significant gender differences in care modalities and future life choices. In particular, studies by Burke and collaborators (2012) and Scavarda (2022) have highlighted a differentiated trend between siblings in the approach to caring for family members with disabilities. Specifically, it was found that male siblings tend to be more inclined to consider the option of institutionalisation as a long-term solution for family members with disabilities. While the sisters have shown a greater propensity towards more intimate and participatory care, often opting for solutions that involve direct and continuous involvement in the care of the disabled brother or sister.

As involvement in caring for and supporting the person with disabilities affects the future expectations of siblings, influencing their professional and relational choices (Scavarda, 2022; Karni-Vizer et al., 2023), the Family Life Project must maximise the potential of the person with disabilities, guaranteeing their autonomy and supporting the Quality of Life of each member (Caldin, Giaconi, 2021; Scavarda, 2022; 2023).

In light of the findings that have been reconstructed, the study we will present below aims to rebuild perceptions about the QOL of siblings of young adults with intellectual disabilities, drawing on the perceptions of both themselves and their parents.

In detail, the methodology includes a qualitative research design (Bogdan, Biklen, 1998; Corbin, Strauss, 2008) with interviews and focus groups analyzed according to the procedures of Grounded Theory (Glaser, Strauss, 2017). Indeed, it was not possible to address the survey with standardised and validated tools in Italy (Del Bianco, 2024) since most of these are addressed to the QOL survey of brothers and sisters with disabilities who are still in the developmental stage, mainly children with fragile health conditions. Although these tools are particularly relevant from a scientific and methodological point of view, they do not appear to be in line with our research questions, which are directed instead towards the analysis of the perceptions of the quality of life levels of siblings of adults with intellectual disabilities.

2. The research: the methodological system

To reconstruct the perceptions we are interested in, the survey sample comprises 30 parents (proxy reports) and 15 siblings (self-reports). Among the interviewees, involved thanks to the collaboration of associations of people with intellectual disabilities, there are: parents, siblings, sisters of adults with Down syndrome, childhood cerebral palsy, early childhood meningitis, Williams syndrome, intellectual disabilities caused by trauma during childbirth or other unknown causes.

In accordance with the scientific literature outlined above, this research is based on the multidimensional model of the QOL developed by Schalock and Verdugo Alonso (2002; 2006; 2012).

The methodological framework provides for a qualitative research project, as our interest is limited to the recognition of what it means to experience Quality of Life when one is a sibling of people with intellectual disabilities (Bogdan, Biklen, 1998; Corbin, Strauss, 2008).

For these reasons, the investigation process involves semi-structured individual interviews with both the siblings and the parents. Then it proceeds with the analysis of the interviews through the creation of focus groups.

The interviews were calibrated to some specific focus, allowing the interviewer and the participant to contextualise their personal experience. Based on the principles mentioned above, three lists of topics for interviews have been developed (Focus 1: tell their own life story; Focus 2: the experience of being a brother/sister and considerations about one's own quality of life; Focus 3: Think about what it means to be a brother/sister. In order to maintain flexibility for siblings to tell their stories, the questions asked during the interviews were managed in such a way as to give an opportunity to propose unforeseen topics. Each interview lasted between 40 and 70 minutes and was recorded digitally, then each researcher faithfully transcribed the content by annotating field notes to add details and descriptions. Following the principles of Grounded Theory (Miles, Huberman, 1994; Bogdan, Biklen, 1998; Mortelmans, 2007; Corbin, Strauss, 2008), data collection and analysis were iterative: Brothers and sisters were asked to check the text and report any materials they wished to supplement or modify.

Finally, in order to proceed with the return of the perceptions obtained and in the comparison with the interviewees about the results obtained from the analysis of the interviews, focus groups were created that involved separately both the siblings group and that of the parents (Barbour, 2007).

3. Presentation and analysis of data

In this section, we will discuss the results of interviews conducted with siblings and parents of adults with intellectual disabilities.

Through the Grounded Theory approach (Glaser, Strauss, 2017), it was possible to identify the main patterns emerging from the narratives of siblings and parents, in order to better understand their experience and the relational dynamics within the family structure. The choice of Grounded Theory responds to the objective of constructing a theoretical framework that reflects the specific experiences and perceptions of the quality of life of siblings, starting from the raw data to arrive at conceptual categories and an emerging theory.

The data analysis followed the steps of the Grounded Theory (Corbin, Strauss, 2015):

- Open coding: at this early stage, data from interview transcripts were broken down into significant units to identify early conceptual labels;
- Axial coding: The concepts that emerged were organised and linked together to create broader and more structured categories. At this stage, conceptual labels were grouped into categories (Table 1 and Table 2);
- Selective coding: In the final phase, an emerging theory was identified that connects categories and macro-categories in a coherent framework, capable of explaining the experiences of siblings in their complexity (Table 1).

Table 1 - Perceptions of siblings with reference to their Quality of Life

Conceptual labels	**Categories**
Experience isolation and limited social integration in group contexts.	Participate in social contexts
Internalize negative emotions and manifest symptoms of anxiety, stress, sleep disorders and a growing demand for attention.	Demonstrate your state of well-being
Demonstrate affection and protection with emotional closeness, but possess limited skills in relational dynamics.	Building a Fraternal Relationship
Affirming preferences and autonomy with difficulties in emotional elaboration in certain contexts and a tendency towards self-determination that is mainly achieved through dialogue.	Express your preferences
Require educational, psychological and social support to strengthen support.	Receive support and resources
Adapt with resilience and compensatory strategies in social challenges, highlighting the development of personal compensatory strategies to address challenges.	Develop adaptive skills

The results presented in Tables 1 and 2 reveal a convergence between the perceptions of siblings and parents with regard to Quality of Life, especially with regard to emotional management, building family ties, the importance of supports and resources, personal growth, and social participation.

Table 2 - Perceptions of parents about the quality of life of siblings

Conceptual labels	**Categories**
Internalize and process emotions with vulnerability and resilience.	Processing emotions
Cultivate protective fraternal bonds and relational dynamics in the family and social context.	Building Family Relationships
Create environments of comfort and opportunities for personal development.	Experience Supports and Resources
Develop adaptability and autonomy through the recognition of own resources.	Growing and adapting
Affirming the self through self-determination and awareness in choices.	Affirming the self
Building belonging and participation through social networks and inclusion.	Participate in social life
Affirming rights and dignity through self-awareness and self-defense.	Recognize your rights

In the third phase of the Grounded Theory process, the categories emerged from the interviews of siblings and parents were grouped into macro-categories and organized into broader and abstract concepts that could return a more descriptive knowledge of the phenomenon (Strauss & Corbin, 1990).

The macro-categories identified are the following: “Processing emotions”; “Building meaningful relationships”; “Finding your place”; and “Self-determination”. Based on the results obtained, it can be said that the theory emerging from the research suggests that a continuous interaction between personal needs and the demands of the family support network defines the experience of being a sibling of a person with a disability. This theory highlights the balance between adaptive resources (such as resilience and adaptive skills) and aspects of vulnerability (including anxiety and social isolation), offering new perspectives on sibling support.

4. Discussion and practical implications

The data collected reveal a generally positive trend regarding the perception of the Quality of Life of the siblings belonging to the sample.

Concerning the macro-category 'Processing emotions', the evidence gathered shows that the management of emotions is a particularly critical element for siblings. Interviews reveal that brothers and sisters often experience multiple emotional experiences, characterized primarily by anxiety and a heightened sense of responsibility, factors that can lead to somatization and stress. Many siblings feel overwhelmed by the care needs of the sibling with a disability, a perception in line with the reference literature that indicates that the disability of a sibling greatly influences the emotional well-being of the sibling, contributing to a high state of stress (Macks, Reeve, 2007; Hannon, 2012; Scavarda, 2022; Kruithof et al., 2024). In addition, part of the emotional well-being of siblings is linked to access to supports and resources, revealing a significant pattern related to the need to have personal spaces and objects. The literature supports this perspective, highlighting how access to adequate material resources can positively influence the quality of life (Schalock, Verdugo Alonso, 2002). In the context of our survey, a seemingly positive picture emerges of the material well-being of siblings and their families. Brothers and sisters of people with disabilities report a satisfactory level of material resources at their disposal, while parents express a favorable perception of their children's environments and life contexts. This optimistic view, however, stands in stark contrast to what is widely documented in the scientific literature. The most recent studies highlight a series of critical issues related to the emotional and economic pressures that weigh on these families, deriving from specific care needs (Emerson & Giallo, 2014; Wolff et al., 2022). In particular, it was found that siblings are significantly more likely to reside in disadvantaged neighborhoods and face chronic financial difficulties. These conditions have a considerable negative impact on their overall material well-being, potentially influencing multiple aspects of their daily lives and development (Emerson & Giallo, 2014; Wolff et al., 2022).

Turning to the macro-category 'Building meaningful relationships', we highlight the importance of building fraternal, family, and social relationships for the siblings of people with disabilities. An analysis of the interviews reveals that the topic of fratria is a constant point of comparison within the family. In detail, most siblings report having a strong and deep relationship with the brother or sister with disabilities, characterized by protective attitudes, affection, and mutual esteem. Parents also confirm the quality of the relationship between their children. This type of relational dynamics confirms what is reported in the literature on the subject (Rossetti, Hall, 2015; Macedo Costa, Pereira, 2019), which highlights that the disability of a family member can foster attitudes of warmth and proximity in siblings, creating a bond based on esteem and mutual understanding. In addition to the fraternal relationship, our study highlights the importance of family support as a pillar for the psychological well-being of siblings. Parents, aware of the relevance of this relationship, seem committed to facilitating opportunities for dialogue and comparison, enhancing the lives of all children and encouraging a climate of openness that allows us to face daily challenges together. The analysis shows that siblings attach significant value to this sense of family unity, seeing mutual support as a source of stability and strength to cope with the complexity of disability-related situations (Farinella, 2015). Finally, from a social point of view, siblings are generally perceived to be included in their social context, managing to maintain ties outside the family environment and to cultivate meaningful relationships with the peer group. In this direction, complex patterns of adaptive skills and resilience in siblings emerge from our study, showing a remarkable ability to adapt to everyday challenges. The perception of parents is equally positive and suggests that siblings can balance the commitments related to the care of the brother or sister with an active participation in social life, finding spaces to express themselves and strengthen their identity beyond family dynamics (Farinella, 2015).

These considerations can be read in continuity with the macro-category ‘Finding your place’, whose data show that in relation to social participation, most siblings feel an integral part of their social context, investing time in interpersonal relationships and rarely experiencing feelings of marginalisation linked to the presence of a person with disabilities in the family. Parents also perceive their children as being included in social contexts. However, sector literature (Koukouriki et al., 2022; Wolff et al., 2022) points out that siblings can frequently experience feelings of loneliness and dissatisfaction in relationships with peers, undergoing isolation and stigmatisation (Hannon, 2012; Marquis et al., 2019; Caliendo et al., 2020). What emerged from the interviews conducted is in continuity with the numerous studies on the subject (Dew et al., 2008; Mulroy et al., 2008; Hannon, 2012), according to which the presence of a brother/sister and/or son/daughter with disabilities can affect both positively and negatively their personal development (Mulroy et al., 2008). In this regard, Hannon (2012) states that the presence of a brother/sister in the family can increase, for example, personal levels of empathy. It is therefore essential to support and enhance these emerging skills so that siblings can fully develop their adaptive and individual growth potential.

The analysis of interviews conducted directly with siblings reveals a complex dynamic within the macro-category “self-determination”. The majority of participants report that they perceive substantial freedom in the expression of their desires, opinions and preferences within the family context. However, this perception is counterbalanced by difficulties reported in the emotional processing of certain situations and in the practical exercise of autonomy.

It is noteworthy that while siblings demonstrate a significant awareness of their rights, in line with the perception of parents, considerable criticalities emerge in relation to contextual barriers. Most of the participants perceive the surrounding environment as an obstacle to the free expression of ideas, expectations, and needs. This phenomenon is reflected in the scientific literature, in particular in the study of Guralnick (2006), which suggests that the presence of hindering factors in life contexts can negatively affect the social and communicative skills of siblings, with significant consequences on personal empowerment, self-advocacy, and, more generally, on the entire construct of Quality of Life.

The results outline a process of developing decision-making autonomy and personal agency characterized by an intrinsic tension between the desire for independence and the need for support in choices. In parallel, the majority of parents believe that the emotions, preferences, opinions, needs, and inclinations of siblings are respected, and that they manifest their self-determination mainly through "dialogue and confrontation with the other".

The observed discrepancy between the perceptions of siblings and those of parents is reflected in the reference literature (Farinella, 2015; Scavarda, 2022; Rochefort et al., 2023). Studies indicate that parents tend to expect levels of excellence from siblings in various areas of life, and that the latter often impose high standards on themselves, but conceal a deep sense of loneliness and fatigue (Farinella, 2015). In summary, the analysis of the interviews suggests that siblings tend to give up some of their life plans to meet the care expectations placed on them by their parents (Scavarda, 2022).

This complexity of dynamics underscores the need for a multidimensional approach in understanding and supporting sibling self-determination, considering both individual perceptions and environmental and family influences.

5. Conclusions

The analysis of the results emerged from this research corroborates the conceptualization of “sibling” as an experience characterized by a constant dynamic interaction between the individual needs of the brothers and sisters and the requests coming from the family support network. This interpretation aligns with the existing literature on the subject while offering new perspectives for the analysis of the Quality of Life of siblings.

In particular, the need to achieve an optimal balance between adaptive resources, such as resilience and adaptive skills, and aspects of vulnerability, such as anxiety and social isolation, is particularly relevant. This balance is a crucial element for the promotion of the overall well-being of siblings, opening new horizons of research and intervention within the QOL.

The main concerns expressed by the siblings, with particular emphasis on future planning, growing care needs and health issues associated with the aging of the person with disabilities (Mansell & Wilson, 2010; Taggart et al., 2012; Davys, Mitchell, & Haigh, 2016; Casale et al., 2021; Kruithof et al., 2021, 2024), highlight the urgent need to develop a longitudinal approach to the life cycle design of persons with disabilities. This approach should include the implementation of targeted media and specific services (Gilbert et al., 2008; Arnold et al., 2012).

In this direction, a significant element that emerged from the research concerns the need for a substantial ‘rethinking’ of family support policies and practices (Del Bianco, 2019; Taylor, Cobigo, Ouellette-Kunzt, 2019; Caldin, Giaconi, 2021; Lepri, 2023). This rethinking must be geared towards planning that goes beyond the logic of the emergency, instead developing sustainable and planned strategies ‘on time’ (Pavone, 2009; Giaconi, 2015; Giaconi et al., 2024). This approach requires effective synergy between people with disabilities, caregivers, and local services, with particular attention to planning for both ‘During Us’ and ‘After Us’ (Pavone, 2009; Giaconi, 2015). In this regard, the literature highlights the need for a longitudinal approach that considers the evolution of the fraternal relationship throughout life (Farinella, 2015; Giorgini, Murolo, Salvitti, 2021), with a focus on moments of transition and changes in family dynamics (Chiusaroli, 2022). This is crucial to understanding how relationships change over time and to identifying the most appropriate interventions at different stages of development.

This longitudinal perspective not only responds to the immediate needs of siblings but also serves as a preventive strategy to address future challenges related to the ageing of both siblings and persons with disabilities. The adoption of such an approach could significantly contribute to the improvement of the QOL of the entire household, promoting greater resilience and adaptability in the face of the evolutionary challenges of the life cycle.

In the same direction, another critical element that emerges from our analysis is the need for siblings to receive more substantial support, including from social and health services. This need is manifested not only in the desire for greater family inclusion, but also in the aspiration to be able to freely and consciously choose one's future care role, in anticipation of the time when parents will no longer be able to provide primary care (Mansell & Wilson, 2010; Arnold et al., 2012; Taggart et al., 2012; Davys, Mitchell, & Haigh, 2016; Kruithof et al., 2024). This significantly affects the well-being and caregiving experiences of siblings (Farinella, 2015; Giorgini, Murolo, & Salvitti, 2021), highlighting the crucial importance of preventive interventions and ongoing support.

The scientific literature has specifically identified the support needs of siblings (Farinella, 2015; Giorgini, Murolo & Salvitti, 2021), underlining the importance of dedicated services that can accompany them on their life path (Giaconi, 2015). In particular, emphasis is placed on the need to adequately support the next generation of caregivers (Farinella, 2015; Del Bianco, 2019; Giorgini, Murolo, & Salvitti, 2021), recognising the crucial role that siblings will play in the future care of people with disabilities.

This perspective underlines the importance of a holistic and longitudinal approach in the design of support services, which takes into account not only the immediate needs but also the future challenges that siblings could face in their role as caregivers. The implementation of such services could significantly contribute to the improvement of the quality of life of siblings, promoting their decision-making autonomy and their long-term psychosocial well-being.

Continuity of educational interventions is, therefore, the essential condition to be met together with the criteria of synergistic integration between the different contexts experienced by the person during the various phases of life (Schalock, Gardner, Bradley, 2007; Palmer, 2010; Giaconi, 2015). Ignoring the alignment between the different expectations of the reference "systems" involved can compromise the implementation of integrated interventions, negatively affecting the general perception of the Quality of Life of the person with disabilities and those providing support and care actions (Giaconi, 2015). On the other hand, planning 'in time' and 'in time' makes it possible to overcome purely welfare and rigid logics (d'Alonzo, 2008), thus promoting a complex and articulated educational process (Canevaro, 2011) aimed at the well-being of the person with disabilities and the figures who support them.

In conclusion, the overall analysis suggests the need for a holistic and integrated approach to the quality of family life. For these reasons, future lines of research and implementation of services may concern the facilitation of networking between siblings, to be supported by professionals able to support training and education specific to the role of caregiver, in order not only to offer emotional support, but also the promotion of self-determination in the choice of the level of involvement in caregiving (Del Bianco, 2024).

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