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Disability by association for siblings of adolescents and adults with cognitive disabilities

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ABSTRACT

This paper analyses the impact of disability on the social identities of siblings of young people and adults with cognitive disabilities. The main aim is to empirically support the concept of 'disability by association', which refers to the attribution of an associative identity due to the presence of a disabled member in the family. Evidence is drawn from a qualitative study, made up of 32 in-depth interviews and two focus groups with siblings without disabilities. The results confirmed the impact of interactive effects on the lives and behaviours of the interviewees. The internalisation of the oppression experienced by siblings, even in the absence of actual negative incidents, limits their social life experience and identity construction. Although the siblings develop non-medical representations of disability and impairment, this conceptual repertoire is not strong enough to challenge devalued images of cognitive disability.

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KEYWORDS

Cognitive disability; siblings; disability by association; disability studies; courtesy stigma

Points of interest

- Siblings' points of view are underdeveloped, while most studies focused on parents' perspectives.
- The research found that siblings have different views on disability and impairment than parents.
- Siblings may experience stigma and exclusion due to their brothers and sisters' disability.
- The research recommended that siblings' difficulties and needs be taken into account when talking about the experience of disability within families.

Introduction

Literature focusing on the brothers and sisters of individuals with disabilities is relatively new. Siblings' experiences have been the object of scientific inquiry since the late 1950s. The first studies, mostly inconsistent and inconclusive, were based on the perspectives of parents and professionals and represented a highly negative picture of families with a disabled member

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(Baldwin and Carlisle 1994). They focused on the psychological impact of disability on the brother or sister without disabilities in terms of stress, trauma, isolation and stigma (Meltzer and Kramer 2016). One exception is represented by Joan Ablon's research (1990), which highlighted the ambiguous experiences of families with dwarf children. Since the 1990s, research has shown that the relationship between brothers and sisters does not necessarily have negative consequences when one of them is disabled (Stainton and Besser 1998). It has highlighted not only the difficulties but also the opportunities intrinsic to the siblings' experiences. The lacuna in this initial group of studies resides in the role of the social context in producing the positive and negative consequences of disability for siblings. In other terms, this strand of research concentrates on the individual outcomes of disability on siblings without disabilities' quality of life and largely ignores the social conditions that influence their experiences (Meltzer and Kramer 2016). Moreover, it marginalises the experiences of siblings with disabilities (*ibidem*).

Through the social model of disability, Disability Studies aim at challenging individual and medicalised perspectives on disability and advancing a more complex understanding of the phenomenon. They specifically shed light on the importance of social mechanisms and reactions for turning an impairment into a disability (see, for instance, Thomas 1999; Goodley 2016). Second-generation scholars (Thomas 1999; Shakespeare and Watson 2001) put forward the analysis of the subjective experiences of disabled people. A specific range of theoretical and empirical contributions, influenced by feminist theory, focused their attention not only on 'barriers to doing', namely on socio-structural dimensions of discrimination and exclusion (structural disablism), but also on 'barriers to being', that is, social practices and processes that undermine the psycho-emotional well-being of disabled people (psycho-emotional disablism), related to negative societal attitudes to impairment and disability (Thomas 1999; Reeve 2013; Genova et al. 2023). This useful repertoire for the analysis of the social elements of disability was mainly directed at parents (Thomas 1999) and only rarely at siblings, particularly in the childhood phase (Stalker and Connors 2004). Limited knowledge exists regarding the impact of disablism (either the psycho-emotional or the structural kind) on the brother or sister with and without disabilities throughout their lifetime, particularly during adolescence and adulthood. In the same vein, the concept of courtesy stigma (Goffman 1963; Scavarda 2020a) – namely the discredit that spreads from a person to others with whom the bearer of the negative traits associates – is underdeveloped in relation to siblings' experiences.

This article aims to fill the gap on siblings by providing a qualitative insight into the psycho-emotional effects of disablism on the siblings of adolescents and adults with cognitive disabilities, drawing on the concept

of disability by association as it was recently rephrased by Peter Burke (2010). The paper begins by outlining its theoretical framework, discussing both the literature on siblings' experiences when a disability is present in the family and the concept of disability by association. I will next describe the study design and, finally, illustrate some of the key findings that have emerged from the siblings' accounts.

Literature review

Siblings and disability

Siblings' experiences offer a privileged observatory on the development and the interconnections of difference, impairment and disability, all core concepts within Disability Studies (Shakespeare and Watson 2001). Moreover, they allow us to highlight the psycho-emotional consequences of disablism not only for the individual with disabilities but also for people who are connected to them through the social structure (Reeve 2013). Studying the relationship between siblings is relevant because this is one of the more lasting relationships within a family, to the point that some scholars (Seligman and Darling 2007) conceive siblings' experiences as 'life span issues' that cover the entire life course of the individual with disabilities.

Nonetheless, sibling–disability research is not widespread and adopts a predominantly psychological point of view, aimed at assessing the impact of disability on the brother or sister without disabilities. Most research studies in this field are related to a single condition: autism (see, for instance, Pilowsky et al. 2004), Down Syndrome (Skotko and Levine 2006) or dwarfism (Guse and Harvey 2010). Overall, these studies indicate the contextual presence of risk and protective factors, and the positive and negative effects of disability on the brother or sister without disabilities. According to a recent review, this strand of research shows that siblings may experience stress, sadness and anxiety related to their brother's or sister's disability during childhood and stigma during adolescence. At the same time it reports that the siblings benefit from their experiences in terms of empathy, maturity and acceptance (Meltzer and Kramer 2016). Some studies emphasise the factors that affect siblings' experiences: for example, family factors (i.e. the socio-economic status and parents' attitudes) and how these influence the siblings' adjustment to the situation (Giallo and Gavida-Payne 2006). Other studies analyse the long-term caregiving duties of siblings (Arnold, Heller, and Kramer 2012; Kramer and Coyle 2013), particularly in adulthood, when the parents age or pass away (Coyle, Kramer, and Mutchler 2014; Dew, Llewellyn, and Balandin 2004; Griffiths and Unger 1994) and when their brother or sister has a cognitive disability (Azeez 2002). The social forces that impinge on siblings' experiences, in terms of negative attitudes and

discrimination, or courtesy stigma (Goffman 1963) beyond the effects of the disability itself (Stoneman 2005), are consistently underdeveloped.

Disability by association: siblings and disability studies

Some scholars (Meltzer and Kramer 2016) consider the use of feminist concepts by Disability Studies theorists a promising development in sibling–disability research. One of the most influential texts in Disability Studies that draws on feminist theory is Carol Thomas' *Female Forms* (1999). The author defines disability as the combination of the unequal access to social opportunities, the personal experiences of oppression and the effects of the impairments. Thomas contends that disability involves the 'social imposition of restrictions of activity on people with impairments and the social engendered undermining of their psychoemotional wellbeing' (Thomas 1999: 60). The scholar acknowledges that disability is both an individual and a structural phenomenon by reframing disablism as something that can have an impact on the individual psyche and well-being of disabled people (Hernandez-Saca and Cannon 2016). As Donna Reeve suggests, 'these *psycho-emotional dimensions of disability*, which affect what disabled people can *be*, rather than what they can *do*, include being hurt by the reactions of other people, being made to feel worthless and unattractive, and have their roots in the negative attitudes and prejudices about disabled people within society' (Reeve 2002, 495). Psycho-emotional disablism is a form of oppression that operates at an inner level but is caused by stigmatising social relationships and therefore demands cultural and social change to be avoided (Reeve 2014). This concept can be equated with the notion of 'felt stigma', the internalised sense of shame and the anticipation of the enacted stigma that sometimes precedes actual instances of rejection and discrimination (Scambler and Hopkins 1986). Moreover, recent advancements in stigma theorisation can be successfully included within this body of literature when stigma is seen as a process developed at the intersection of culture, power and difference (Parker and Aggleton 2007; Scambler 2018).

Stalker and Connors (2004) used Carol Thomas's social relational model to analyse the representation of disability expressed by siblings without disabilities. In their study, disability is not conceived as a form of deviance from normality. Although young people interviewed by Stalker and Connors are aware of the impairment of the brother or sister with disabilities and often portray it in medicalised terms, they state that this does not make them different from the other peers. Siblings are in an intermediate position between their family and the social context that considers disability a form of abnormality, and they strive to find a balance between them. They often push the boundaries of normalcy to include their brother's or sister's

characteristics – of which disability is only one – in it. Using Thomas's repertoire, Stalker and Connors were able to link siblings' individual experiences to the societal perspective of disability by outlining the psycho-emotional disablism they suffer from. Siblings often reported being bullied and discriminated against, and they highlighted the consequences of 'disability by association', as Peter Burke (2010) put it. Their brother's or sister's difference is determined by the unfair and hostile attitude of their peers, teachers and strangers. 'Disability by association' entails the social experiences that siblings encounter in the wider social context because of the presence of disability within the family (Burke 2010). This concept has its roots in Goffman's 'courtesy stigma' (1963), later used by many scholars who study the experiences of families with a disabled member (see, for instance, Birenbaum 1970; Gray 2006; Scambler and Hopkins 1986), but it avoids the contradictory nature of the term 'courtesy' (which means 'by virtue of' but also refers to 'being kind') by changing it to 'association'. The latter term sheds light on the effects of disability in giving an 'associative' identity to family members, which impacts on their social activities. It is also mirrored in an amount of uncertainty during interactions with other families that is similar to the existential insecurity postulated by Donna Reeve (2014), with positive as well as negative consequences (Burke 2010). Burke's original contribution, compared to Thomas and Reeve's conceptualisations, is related to the possibility that interactions with other people can have positive consequences for families with a disabled member. Conversely, Thomas and Reeve assume that the effects of social interactions are inevitably stigmatising and oppression is a taken-for-granted result of them. The associative negative identity, therefore, is a sort of destiny for siblings. For Burke, the impact of the interaction on individuals may be stigmatising to the point that they internalise the oppression (Reeve 2014), or empowering when they resist their situation and challenge the negative images ascribed to them. As the scholar maintains: 'Disability by association is a conceptual aid to our understanding of a social construction of disability by way of a disabled sibling's experience. This is not a label to be worn by all siblings; it is a concept that is used to help explain situations that arise when living with a disability, as a consequence of interactive effects that impinge on the lives and behaviour of the young people involved' (Burke 2010: 1684). Nonetheless, Burke's studies (2010) are quantitative and mainly involve parents, only marginally looking at siblings without disabilities.

This paper contributes to deepening the issue from a qualitative standpoint to unpack the concept of 'disability by association' and its relationship with psycho-emotional disablism by analysing the construction of difference, impairment and disability within the narratives of adolescent and adult siblings without disabilities.

Research process

Although most siblings-related research is focused on a single age group (Stalker and Connors 2004), the study presented here compares two different age groups, each marked by specific difficulties: adolescents and adults. Two groups composed of 16 families each were involved in the study: the first group with siblings aged 14–20 years, the second with siblings aged 40–60 years. These two phases of the life course are relevant because, during adolescence, siblings often wish to distance themselves from their family (Seligman and Darling 2007). In adulthood, siblings again become involved with their family of origin and are expected to take care of their brother or sister when their parents age or pass away (Hodapp, Glidden, and Kaiser 2005).

In line with a theoretical sampling approach, participants were selected in such a way as to balance the sample according to theoretically relevant properties: age, gender and type of disability (cognitive). The decision to include only people with a cognitive disability derives, firstly, from the fact that it is highly stigmatised (Cardano et al., 2020; Scavarda 2020a) because it is often inconspicuous and perceived as static and pervasive, challenging the model of the Cartesian ego, which is provided with rationality and self-consciousness. Secondly, in a previous study (Scavarda, 2020b), I have shown that the siblings of individuals with cognitive disabilities are constantly burdened with care responsibilities because their parents are persuaded that the dependency of the brother or sister with cognitive disabilities – unlike individuals with physical disabilities – is unchangeable, even with specific support. The interviewees included siblings of individuals with Prader-Willi Syndrome, Down Syndrome, Cerebral Palsy, Ohdo Syndrome or a cognitive disability caused by traumas during childbirth, meningitis in early childhood or other, unknown incidents.

I pursued two main research questions. First, how do siblings define their brother or sister and their relationship? Second, what are the main challenges they face during social encounters?

Participants were recruited through local advocacy associations and a daily centre that offered therapeutic and recreational activities to children, young people and adults with cognitive disabilities.

I conducted 32 interviews with adolescents and adults without disabilities in the north-west of Italy and two focus group interviews with a subsample of siblings without disabilities. The interview guide combined standard questions with visual prompts. I used a selection of images, to help interviewees define the brother or the sister. They had to choose between a tree, a person – a toddler, a young man/woman or an elder – or an object. Moreover, a vignette - interviewees had to complete the scene of the interaction between two brothers or sisters by adding text in the balloon - solicited the siblings'

emotions in line with a sort of projection mechanism, as emerged in a previous study (Scavarda 2020b). Interviews were digitally recorded and transcribed verbatim, and they lasted between an hour and an hour and a half. Transcripts of the interviews underwent a thematic analysis according to the template analysis approach (King and Brooks 2016), based on a combination of theory-driven and data-driven codes. This enabled me to produce both codes based on actual data and emerging hypotheses. The main topics of the interview guides provided guidance for the initial coding categories, whereas new codes suggested by the data were added throughout the analysis. The original template included the following set of themes: the concept of a brother's/sister's impairment; the concept of a brother's/sister's disability; disability by association; enacted stigma; changes in everyday life; the impact on the marital relationship (adults); the effects on job decisions; future expectations; planned solutions when parents will pass away. This paper focuses on the first four theoretically driven macro codes, which were specified during the analysis by the following, empirically driven codes: the process of gaining awareness of a brother's/sister's difference; the impact of the information provided to siblings in the family (related to the concept of the brother's/sister's impairment and their disability); the positive effects of the interactions; the negative effects of the interactions; the pitiful attitude; the fear of bullying (related to disability by association and enacted stigma).

Documents were imported into Atlas.ti (version 7) and electronically linked to each other. The focus group guide was based on the topics that emerged from the interviews' analysis. The first focus group involved a subgroup of adolescent siblings (7 participants, 3 females and 4 males, aged 15–23 years) and the second one a subgroup of adult siblings without disabilities (4 participants, aged 42–60 years). The focus group interviews, too, were digitally recorded and analysed in Atlas.ti.

Ethics

Ethical approval was not required as it is not compulsory for sociological research in Italy. Nevertheless, the daily centre and the advocacy associations validated the research project despite not giving formal ethical approval. The researcher discussed potential ethical risks inherent in the siblings' participation in the study with psychologists and members of the associations. It was agreed that their participation did not pose a particular risk to the interviewees. Each participant was anonymised as all identifying information was removed: a pseudonym was given to individual interviewees and focus group participants were named with a number. Moreover, during the first meeting, interviewees received the informed consent form,

which explained the goals of the study and the use of the data (only for research purposes).

Results

The awareness of the brother's or sister's difference

In line with Stalker and Connor's study (2004) on siblings without disabilities, their brother's or sister's condition is part of their own 'normality': an everyday experience, rather than a trauma or an unexpected event. The majority of the interviewees became aware of the brother's or sister's difference progressively, without being able to recall a specific moment of awareness or distinguish between two different phases (before and after becoming aware of the disability). One of the interviewees, 53-year-old Vincenzo, talked about his experience with his brother with Down Syndrome comparing it to his parents' account:

Maybe it was a trauma for my parents. I experienced it differently. I experienced it next to him, we grew up together. For me, it was not a trauma. I considered him ... my brother, I considered him 'a normal' guy.

For siblings, a cognitive disability, even when it is combined with physical traits, as in the case of Down Syndrome, does not represent a labelling trait for their brothers or sisters. The specific ways of communicating, perceiving and behaving of the brother or sister are considered expressions of their personality, rather than signs of a certain condition. They are part of the siblings' everyday life, presenting both strengths and weaknesses, depending on the point of view. Roberto, a 38-year-old interviewee described his experience as follows:

You do not know other situations; when you are a child you only know your life context, and for me, my brother's way of walking was one of his traits, it was normal. I'll give you an example: if your mum had set the table with two forks for a lifetime, then it would have represented your normality. As shocking as it may be, it is also comfortable if you have to eat dumplings, [but] it is uncomfortable if you have to eat a steak.

Moreover, the specific characteristics of people with disabilities do not affect the relationship between siblings: in most cases, they can understand and support each other throughout their life course, even if their needs and objectives differ. In the following extract, 17-year-old Emilio described how he managed to have an emotional connection with his little sister with Ohdo Syndrome, even without using words:

We are bound to each other, even if we always argue, because I am a bit more mature than she is, [and] we have different hobbies and objectives. She can be so stubborn when she wants something! However, in some way, even if she does not speak very well, we understand each other, sometimes only with a look. She knows how to comfort me when I am sad, better than anyone.

The process of consciousness raising of disability occurs when friends and schoolmates ask questions and make remarks. These comments thus highlighted the perceived 'irregular' behaviour of the brother or the sister with a cognitive disability. For 16-year-old Monica, being mocked by her schoolmates ever since middle school had made her wonder about the characteristics of her younger brother with Cerebral Palsy, namely his speech difficulties, which she had never detected since she could understand his way of communicating with gestures.

In middle school, my schoolmates teased me because my brother was different. They told me that my family was weird because I had a brother they did not understand. I understood his language because I had grown up with him, but I see that a stranger may not understand him when he speaks and does not understand anything about him. When my friends came to my house, they asked me: 'Aren't you ashamed of him?' or stuff like that, [so] then I started wondering why they said that, because I considered him normal, right?

The information provided to siblings in the family

In general, interviewees began wondering about their brother's or sister's condition during puberty and tried to satisfy their curiosity mainly by turning to their parents (Powell, Gallagher, and Rhodes 2006). The subsamples vary consistently according to the parents' willingness to meet the siblings' information requests: in the adolescents' subgroups (14–20years), parents were often ready to answer their children's questions, while in the subgroups made up of adults (40–60years), numerous parents considered disability a sort of taboo, even refusing to name it. Adolescent siblings, who received comprehensive and reassuring information about their brother's or sister's characteristics, perceived the latter as something they could deal with and were more confident in explaining them to friends or people outside the family. As Daniele (15years old) put it:

My mother always answers my questions; sometimes she makes fun of them. Therefore, I calmly speak about my sister's disability with my friends, too.

On the contrary, adult siblings, who rarely communicated with their parents about their brother's or sister's disability, complained about the lack of information, which created widespread anxiety within the family because of the unspoken topic and made them feel embarrassed in front of their friends. Donatella, the 38-year-old sister of an adult with cognitive disabilities (unknown reason), outlined the consequences of what she called her parents' 'code of silence' in the following terms:

I do not recall having asked many questions because of my parents' code of silence. It was a major problem, with many consequences for the relationship with my brother within my family and also my relationships with my friends (...) When they asked about his condition, I did not know what to tell them.

Felt or enacted stigma?

In the narratives of siblings without disabilities, the consequences of a 'disability by association' did not directly emerge.

First, their brother's and sister's supposedly 'irregular' behaviour, often represented as a form of immature or annoying behaviour, did not make the interviewees feel uncomfortable, as Giuliana, the 19-year-old sister of an adolescent with Prader-Willi Syndrome, puts it:

In the beginning, he is a bit reserved; sometimes he is annoying, because maybe the other person comes up to play a complicated game and he is a bit immature, [so] it takes him more time to understand the rules of it. But generally speaking, he has never bothered me.

During the focus group interviews, the subsample of adolescent siblings confirmed that the difference between their brothers or sisters and their peers is hardly detectable, decreasing over time and rarely representing a problem for them:

Gianni: I do not see my sister's difference when we are with other people, it is not a problem for me.

Carlo: While growing up, he is more relaxed when he is in a group, he feels more comfortable with peers than in the past.

Fabrizio: He has this know-it-all attitude, [so] you need to be patient with him, but I get used to it and my friends, too.

Second, only a few interviewees reported cases of enacted stigma, namely discriminatory acts by schoolmates and friends, specifically in preadolescence, while most of them did not indicate stigmatising episodes at all. In some cases, though, what changed from adolescence onwards was not the presence of other people's negative attitudes, but the interviewees' reactions to these. In the following extract, 16-year-old Felicina told us that she refused to go out with her little brother when she was at middle school, not because she was ashamed of him but to avoid being bullied. However, this situation ended with the transition to secondary school because by then, she no longer cared about it:

In sixth grade, I no longer went out or played with him. I did not help him so much not because I was ashamed of him, but because I was fed up with being bullied by my schoolmates. Luckily, it ended at middle school. Now, at secondary school, someone sometimes throws in a jab but I do not care about it. I couldn't give a damn!

At the same time, the unnerving stare of strangers can be perceived as irritating and oppressive, but this discomfort rarely continues after adolescence; in adulthood, it turns into a sort of indifference to the reactions of peers and strangers in the immediate environment. Cristina, the 20-year-old

sister of an adolescent with Prader-Willi Syndrome, explained her attitude when *being stared at* by others (Reeve 2014) in these terms:

I am not the kind of person who usually shouts 'Look, she is not an alien, she is only a disabled child' because these people often go away and I simply let them think what they want.

Nevertheless, a more in-depth analysis of the interviews shows that the stigmatising episodes are more common for adult siblings than for adolescent ones, probably due to the shift in mentality towards a more sensitive approach to disability.

I remember this episode [of] a friend of mine who shouted, in the middle of the garden: 'Ew! She has a disabled brother'. Yes, yes, very bad situations (Donatella, 38 years old).

I speak about the curiosity that everyone has, gazes above all, but I cannot mention negative situations with strangers or friends (Emilio, 17 years old).

As Orlando, the 60-year-old sibling of a Down Syndrome adult, puts it, in the 1970s and 1980s, disability in Italy was a less familiar phenomenon for the general public than it is today, and this widespread ignorance has produced a negative attitude towards it:

At that time, there was, unfortunately, widespread ignorance. Most people did not know what disability was and disabled people were teased, more than today.

When recalling their experiences in adolescence, adult interviewees reported instances of felt stigma or, better still, the fear of being discriminated against even in the absence of actual negative episodes, which prevented them from interacting with their peers, for instance inviting friends at home. They were afraid that other people would not understand their brother's or sister's characteristics and feel sorry for them, in line with the remarks outlined in the previous section, which reflect a perception of disability as something out of the ordinary, murky and troublesome:

I did not invite many friends to my house when I was an adolescent. (...) Sometimes, you prefer not to talk to friends because many people do not understand the situation; they conceive of disability only in terms of the difficulties it creates (Stefano, 48 years old).

Disability by association: the effects of psycho-emotional disablism

The pitiful attitude that portrays disability as a family tragedy is what most adult interviewees wanted to avoid during adolescence. Some of them reported the past desire to keep the two domains (family and peer group) separated and the experience of being caught 'between two fires': the family members, on the one side, and the outside world, on the other. They

perceived disability as something that makes you 'different' and impacts on your social interactions by changing other people's attitudes and making them feel uneasy:

My high school was far away from home and so I had to take the train to get there. I used to say: 'My brother has had some problems, therefore we went there ...' but I did not explain very much. I kept the two domains separated because if you said too much, then they began to look at you differently or they felt uneasy. And you are caught between two fires, between people you want to hang out with outside the family and people you love (Graziella, 47 years old).

Conversely, adolescent interviewees mentioned the beneficial effects of honest communication with friends and schoolmates, which reduced the interviewees' fears of discrimination, on the one side, and fostered other people's understanding of the brother's or sister's specific characteristics, on the other. However, they often spoke about a sort of selection of friends based on the reactions to the brother's or sister's difference:

My closest friends know my sister fairly well. They always greet her, they love her, [and] it was useful to explain her condition to them; they understand her. But I do not like to speak about it publicly. I talk about it with my friends, yes, but not to all of them; it depends on how they react (Rosella, 20 years old).

Over time, I have begun to choose my friends with great difficulty, because they have to understand the problem. Therefore, I moved from being expansive and friendly and withdrew into myself (Margherita, 14 years old).

Nonetheless, the consequences of 'disability by association' emerged indirectly in the siblings' accounts because they were concerned about their brother's or sister's social image. Siblings without disabilities often claimed being worried that their brothers or sisters would be bullied, and so they acted preventively to protect them.

Sometimes, he told me about a schoolmate who was the tough guy... Not such a big deal ... I have never used violence, also because it is not in my nature; all I had to do was to go and get him at the school, stay there and show them that I was there, with two pretty muscular friends (laughing) (Fabrizio, 20 years old).

Therefore, the adolescent or adult with cognitive disabilities is represented as a vulnerable and naïve person; the most common image used to depict them is that of the toddler, because it is associated with the need to nurture and protect a person. The possibility that other people take advantage of them is one of the main concerns expressed by the interviewed siblings.

Discussion

The narratives of siblings without disabilities shed light on the effects of the phenomenon of 'disability by association' (Burke 2010) in different age groups:

adolescence and adulthood. The analysis of the interviews and focus groups shows that what is most challenging for siblings of cognitively disabled people is not the impairment effects, but the labelling and social interpretation of impairment itself. In contrast with previous studies (Seligman and Darling 2007), none of the interviewees mentioned stress and limitations as a result of the management of the brothers' or sisters' healthcare needs in their everyday lives. This is partly because the conditions taken into consideration are not associated with specific health problems, except for heart defects and blood disorders for some adolescents with Down Syndrome. However, in a previous study (Scavarda 2020a), I conducted interviews with parents of cognitively disabled people that revealed how the siblings' were involved in their brothers' or sisters' therapeutic activities on a daily basis. A possible explanation for the results of the current study is that medical examinations and visits as well as home interventions were not mentioned during interviews because they have been experienced by siblings since birth or childhood. As one interviewee highlighted, there is a striking difference between the parents' and the siblings' impairment and disability accounts. While for parents, cognitive impairments may represent a violation of their expectations of their children (Scavarda and Cascio 2022), to the point that a sort of biographical disruption takes place, for siblings, they are something they grew up with. In line with Stalker and Connor's study (2014), cognitive impairments are part of siblings' normality and they do not prevent siblings from building a relationship and an emotional bond. For the interviewees, the ways of communicating and behaving of the disabled brothers or sisters are part of their personality, more than they are signs and symptoms of a developmental disorder. They do not express a medicalised version of their brother's or sister's disability, unlike siblings interviewed by the two British scholars (Stalker and Connors 2014); rather, their representation of disability is more consistent with the social model of disability. Interviewees developed a broad concept of normality, which may also include cognitive impairments, as an expression of human behaviour and difference (Scavarda 2021). The brothers and sisters with disabilities are simultaneously 'different from' their peers and 'the same as' other people. This proposal can be traced back to Catherine Runswick-Cole and Dan Goodley's 'dishuman' perspective (2016) regarding the possibility that disability can trouble and reshape the human being while at the same time maintaining disabled people's humanity. Moreover, the interviewees have found a way to understand their brothers and sisters and, in the majority of the cases, they do not perceive their situation as irregular. The brother's or sister's cognitive impairment turns into a form of disability when it clashes with a social environment unable to accept this form of human expression without labelling it (Oliver 1996; Scavarda 2020b). As Stalker and Connor (2014) and Peter Burke (2010) suggested, the disparaging remarks of peers as well as the hostile staring of

strangers trigger the siblings' attempt to raise awareness of their brothers' or sisters' impairment and disability. Both these phenomena can be conceived as empirical manifestations of 'disability by association' (Burke 2010) because they depict impairment as something inherently out of the ordinary, and they also affect the interviewees' self-construction and social interactions. Many adolescent interviewees expressed concerns about the reactions of peers towards their brother's or sister's perceived immature and annoying behaviour, and they confessed to making a sort of selection of friendships on this basis. The majority of adult interviewees recalled the fear of being pitied or discriminated against during adolescence and the restrictions on their social life that they imposed on themselves as a consequence. Both these situations can be related to felt stigma (Scambler and Hopkins 1986) conceived as a form of interiorised oppression (Reeve 2014), because siblings are made to change their social identities as a result of their relationship with the brother or sister with disabilities. Cognitive disability is therefore an associative condition that is due to the barriers created by other people to dissociate from it and make disabled people and their siblings feel different and undesirable (see also Genova *et al.* 2023).

At first glance, the interviewees did not systematically experience the consequences of direct psycho-emotional disablism, namely the acts of invalidation that are enclosed in staring, words and actions put into practice by friends, strangers or family members (Reeve 2014) as outlined by other studies (Stalker and Connors 2004; McGraw and Walker 2007). Only a few of them described episodes of bullying or stigmatisation, particularly in the adolescent subgroup. However, while closely analysing the siblings' narratives, I noticed that the effects of 'disability by association' go beyond actual manifestations of psycho-emotional disablism, rather being a definition of the situation that is assumed by the interviewees and affects their social interactions beforehand (see also Scavarda 2020a). The representation of disability as a family tragedy and a troublesome condition is internalised by the interviewed siblings and, even in the absence of negative episodes, impacts on their social status. This happens because of the persistence of stigma, in terms of stereotypes and negative images about cognitive disability that are still widespread in Italy (Medeghini *et al.* 2013; 2018). Stigma – and particularly felt stigma, in Scambler's (2018) terms – has become a weapon to keep people with disabilities and their family members on the edge of society by perpetuating their otherness. The structural and cultural underpinnings of stigma are powerful and hard to tackle because they are embedded in social representations of normalcy. Being pitied for their condition, the interviewed siblings are separated from their peers and forced to limit their social inclusion through a technology of the self (Foucault 1979) that represents a subtle form of governmentality.

According to some interviewees, however, the situation has significantly improved in the last thirty years. The comparison between two different age groups allows me to consider the effects of the changing cultural environment and background on siblings' experiences of stigmatisation. As a matter of fact, the adolescent subgroup experienced fewer negative episodes than the adult one, probably thanks to a wider public consciousness of disability and a more sensitive attitude towards the phenomenon due to deinstitutionalisation. The latter began in Italy with the Basaglia Law of 1978, which entailed the progressive closure of psychiatric institutions and the parallel emergence of integrated education in mainstream schools (Scavarda and Cascio 2022). The disability management of families has also changed: the majority of the parents of the interviewed adolescents are described as being able to discuss the topic with their children. Conversely, most of the adult interviewees have never openly talked with their parents about their brother's or sister's specific strengths and difficulties, and they are not even able to ask questions. In line with Guse and Harvey's study (2010), the parents' style of communication affects the siblings' conception of disability and the management of their social encounters, when their brother's or sister's difference is at stake. Adolescent siblings are more able to answer to other people's invasive questions and also to advance information requests, while adult siblings are often unable to describe their brother's or sister's characteristics and feel ashamed.

However, both adolescent and adult siblings were worried about the possibility of their brothers and sisters becoming victims of bullying or circumvention; in some cases, they took preventive actions. This is another technology of the self (Foucault 1979) that affects siblings' social identities and interactions, because they assume the specific role of advocates for their brothers and sisters. This role endangers their social inclusion because it fosters the separation between their family and the outside world, perceived as stigmatising and hostile. This may also explain the reported feeling of being 'caught between two fires' and the desire to keep the two domains (peers and family) apart. Moreover, in this way, the interviewees strengthened the image of cognitive disability as a form of frailty and dependence by implying their brothers' and sisters' inability to independently manage their social relationships and possibly face stigmatising episodes. For this reason, the visual prompt that most interviewees chose to portray the brother or the sister with cognitive disabilities was that of the toddler. The interviewees, therefore, seemed unable to oppose the infantilisation of people with cognitive disabilities that, according to some scholars (Medeghini and Valtellina 2006; Battaglia et al. 2002), is expressed in Italy through the representation of cognitively disabled people as 'eternal children'. Although siblings of people with cognitive disabilities strive to resist the negative consequences of psycho-emotional disablism as well as

the dominant imaginary related to cognitive disability (Titchkovsky, Goodley et al. 2018), they do not seem to successfully rebuff stigmatisation. 'Disability by association' (Burke 2010) is mainly expressed through the internalisation of the oppression (Reeve 2014) they experience in their interactions with peers and strangers. The results of these interactions are far from empowering because the interviewees rarely challenge the negative images given to them; they just ignore hostile staring and rude comments over time. Moreover, they preventively limit social life experiences to avoid social devaluation. Even though they express non-medical representations of disability and impairment akin to certain theoretical approaches within Disability Studies, this conceptual repertoire is not strong enough to assist siblings without disabilities in countering the labelling process they undergo. The latter is expressed by two powerful technologies of the self (Foucault 1979) that portray the siblings' condition as either troublesome, up to the point of arousing compassion, or a constant struggle to protect vulnerable brothers and sisters. In both cases, disability is portrayed as a negative trait and the discredit attached to it spreads from the disabled person to their siblings.

It must be noted that the current study presents a limitation, namely the failure to include individuals with disabilities in the research process, which is due primarily to funding reasons and time constraints. There is a need for further research into the experiences of siblings with disabilities and the intersection between disability and other social elements, such as gender and ethnicity.

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References

- Scavarda 2020a. "Come pinguini nel deserto'. Strategie di resistenza allo stigma di famiglie con figli autistici e con Trisomia 21", *Rassegna Italiana di Sociologia* 61 (3): 537–561.
- Cardano, M., Cioffi, M. Scavarda, A. 2020. *Sofferenza psichica, follia, disabilità*, in Cardano, M., Giarelli, G., Vicarelli, G. (eds) *Sociologia della Salute e della Medicina*, Bologna: Il Mulino 129–153.
- Scavarda 2020b. *Pinguini nel deserto. Strategie di resistenza allo stigma da Autismo e Trisomia 21*, Bologna: Il Mulino.
- Scavarda 2021. "Quale sociologia della disabilità? Per una proposta teorica post-convenzionale allo studio della disabilità". *Quaderni di Teoria Sociale* 2: 183-205.
- Scavarda, A., Cascio, M. A. 2022. "Embracing and rejecting the medicalization of autism in Italy". *Social Science and Medicine*, 294:114728.
- Genova, A., Scavarda, A., Swiatkiewicz-Mosny, M. (eds, 2023). *Disability Welfare Policy in Europe: Cognitive Disability and the Impact of the Covid-19 Pandemic*, Bingley: Emerald
- Ablon, J. 1990. "Ambiguity and Difference: Families with Dwarf Children." *Social Science & Medicine* 30 (8): 879–887. doi:10.1016/0277-9536(90)90215-e.
- Arnold, C. K., T. Heller, and J. Kramer. 2012. "Support Needs of Siblings of People with Developmental Disabilities." *Intellectual and Developmental Disabilities* 50 (5): 373–382. doi:10.1352/1934-9556-50.5.373.
- Azeez, C. C. 2002. "Siblings of People with Disabilities: A Developmental Analysis of the Effects, Impacts, and Patterns of Adaptation." PhD, University of Massachusetts, Amherst.
- Baldwin, S., and J. Carlisle. 1994. *Social Support for Disabled Children and Their Families: A Review of the Literature*. Edinburgh: HMSO.
- Battaglia, A., A. Canevaro, M. Chiurchiu, A. Leone, M. M. Pierro, and A. M. Sorrentino. 2002. *Figli per Sempre. La Cura Continua Del Disabile Mentale*, Roma: Carocci Faber.
- Birenbaum, A. 1970. "On Managing a Courtesy Stigma." *Journal of Health and Social Behavior* 11 (3): 196–206. doi:10.2307/2948301.
- Burke, P. 2010. "Brothers and Sisters of Disabled Children: The Experience of Disability by Association." *British Journal of Social Work* 40 (6): 1681–1699. doi:10.1093/bjsw/bcp088.
- Coyle, C. E., J. Kramer, and J. E. Mutchler. 2014. "Aging Together: Sibling Carers of Adults with Intellectual and Developmental Disabilities." *Journal of Policy and Practice in Intellectual Disabilities* 11 (4): 302–312. doi:10.1111/jppi.12094.
- Dew, A., G. Llewellyn, and S. Balandin. 2004. "Post-Parental Care: A New Generation of Sibling-Carers." *Journal of Intellectual & Developmental Disability* 29 (2): 176–179. doi:10.1080/13668250410001709520.
- Foucault, M. 1979. "On Governmentality." *Ideology and Consciousness* 6: 5–22.
- Giallo, R., and S. Gavidia-Payne. 2006. "Child, Parent and Family Factors as Predictors of Adjustment for Siblings of Children with a Disability." *Journal of Intellectual Disability Research : JIDR* 50 (Pt 12): 937–948. doi:10.1111/j.1365-2788.2006.00928.x.
- Goffman, E. 1963. *Stigma, Notes on the Management of the Spoiled Identity*, Englewood Cliffs, NJ: Prentice Hall.
- Goodley, D. 2016. *Disability Studies: An Interdisciplinary Introduction*. London: Sage.
- Goodley, D., and K. Runswick-Cole. 2016. "Becoming Dishuman: Thinking about the Human through Dis/Ability." *Discourse: Studies in the Cultural Politics of Education* 37 (1): 1–15. doi:10.1080/01596306.2014.930021.
- Griffiths, D. L., and D. G. Unger. 1994. "Views about Planning for the Future among Parents and Siblings of Adults with Mental Retardation." *Family Relations* 43 (2): 221–227. doi:10.2307/585326.

- Guse, T., and C. Harvey. 2010. "Growing up with a Sibling with Dwarfism: Perceptions of Adult Non-Dwarf Siblings." *Disability & Society* 25 (3): 387–401. doi:10.1080/09687591003701322.
- Hernandez-Saca, D. I., and M. A. Cannon. 2016. "Disability as Psycho-Emotional Disablism: A Theoretical and Philosophical Review of Education Theory and Practice." In *Encyclopedia of Educational Philosophy and Theory*, edited by Peters, M. A. Singapore, Springer Science and Business Media.
- Hodapp, R. M., L. M. Glidden, and A. P. Kaiser. 2005. "Siblings of Persons with Disabilities: Towards a Research Agenda." *Mental Retardation* 43: 334–338.
- King, N., and J. M. Brooks. 2016. *Template Analysis for Business and Management Students*. London: Sage.
- Kramer, J., and C. Coyle. 2013. "Changing Profiles in Family Caregiving: Sibling Caregivers of Adults Aging with Intellectual or Developmental Disabilities." Paper presented at the 2013 Roundtable on Aging and Intellectual Disability, 19 September, Simmons College, Boston MA.
- McGraw, L. A., and A. J. Walker. 2007. "Meanings of Sisterhood and Developmental Disability: Narratives from White Nondisabled Sisters." *Journal of Family Issues* 28 (4): 474–500. doi:10.1177/0192513X06297312.
- Medeghini, R., and E. Valtellina. 2006. *Quale Disabilità?: Culture, Modelli e Processi di Inclusione*, Milano: Franco Angeli.
- Medeghini, R., S. D'Alessio, A. Marra, G. Vadalà, and E. Valtellina. 2013. *Disability Studies. Emancipazione, Inclusione Scolastica e Sociale, Cittadinanza*. Trento: Erickson.
- Goodley, D., S. D'Alessio, B. Ferri, F. Monceri, T. Titchkosky, G. Vadalà, ... R. Medeghini. 2018. "Disability Studies e Inclusione." *Per Una Lettura Critica Delle Politiche e Pratiche Educative*. Erickson, Trento.
- Meltzer, A., and J. Kramer. 2016. "Siblinghood through Disability Studies Perspectives: Diversifying Discourse and Knowledge about Siblings with and without Disabilities." *Disability & Society* 31 (1): 17–32. doi:10.1080/09687599.2015.1127212.
- Parker, R., and P. Aggleton. 2007. "HIV-and AIDS-Related Stigma and Discrimination: A Conceptual Framework and Implications for Action." In *Culture, Society and Sexuality*, edited by Parker, R., & Aggleton, P., 459–474. London, Routledge.
- Pilowsky, P., N. Yirmiya, O. Doppelt, V. Gross-Tsur, and R. S. Shalev. 2004. "Social and Emotional Adjustment of Siblings of Children with Autism." *Journal of Child Psychology and Psychiatry, and Allied Disciplines* 45 (4): 855–865. doi:10.1111/j.1469-7610.2004.00277.x.
- Powell, T. H., P. A. Gallagher, and C. A. Rhodes. 2006. *Brothers and Sisters – a Special Part of Exceptional Families*. Baltimore, MD: Paul H. Brookes.
- Reeve, D. 2013. "Psycho-Emotional Disablism: The Missing Link?." In *Routledge Handbook of Disability Studies*, edited by Watson, N., Roulstone, A., and Thomas, C., First Edition, 92–106. London: Routledge.
- Reeve, D. 2014. "Psycho-Emotional Disablism.", In *Disability Studies. A Student's Guide*, edited by Cameron C. London: Sage.
- Scambler, G., and A. Hopkins. 1986. "Being Epileptic: Coming to Terms with Stigma." *Sociology of Health and Illness* 8 (1): 26–43. doi:10.1111/1467-9566.ep11346455.
- Scambler, G. 2018. "Heaping Blame upon Shame: 'Weaponising Stigma' for Neoliberal Times." *The Sociological Review* 66 (4): 766–782. doi:10.1177/0038026118778177.
- Schneider, J. W., and P. Conrad. 1980. "In the Closet with Illness: Epilepsy, Stigma Potential and Information Control." *Social Problems* 28 (1): 32–44. doi:10.2307/800379.
- Seligman, M., and R. B. Darling. 2007. *Ordinary Families, Special Children*. New York: Guilford.
- Shakespeare, T., and N. Watson. 2001. "The Social Model of Disability: An Outdated Ideology." *Research in Social Science and Disability* 2 (1): 9–28.

- Skotko, B. G., and S. P. Levine. 2006. "What the Other Children Are Thinking: Brothers and Sisters of Persons with down Syndrome." *American Journal of Medical Genetics Part C: Seminars in Medical Genetics* 142C (3): 180–186. doi:10.1002/ajmg.c.30101.
- Stainton, T., and H. Besser. 1998. « "The Positive Impact of Children with an Intellectual Disability on the Family." *Journal of Intellectual & Developmental Disability* 23 (1): 57–70. doi:10.1080/13668259800033581.
- Stalker, K., and C. Connors. 2004. "Children's Perceptions of Their Disabled Siblings: 'She's Different but It's Normal for us.'" *Children & Society* 18 (3): 218–230. doi:10.1002/chi.794.
- Stoneman, Z. 2005. "Siblings of Children with Disabilities: Research Themes." *Mental Retardation* 43 (5): 339–350. doi:10.1352/0047-6765(2005)43[339:SOCWDR.[PMC]2.0.CO;2]
- Thomas, C. 1999. *Female Forms: Experiencing and Understanding Disability*. London: McGraw-Hill Education.
- Titchkosky, T., and D. Goodley. 2018. "La Necessità Dell'immaginazione. Le Politiche in Materia di Disabilità ai Tempi Del TrumpBrexit." in (A.A.V.V.) *Disability Studies e Inclusione. Per Una Lettura Critica Delle Politiche e Pratiche Educative*, Trento: Erickson.