

Relazione fraterna e disabilità: dal caregiver familiare ai siblings

Brotherhood and disability: from the family caregiver to siblings

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Abstract

Il presente lavoro intende porre in evidenza come la disabilità, fisica o/e intellettuale possa influire nella relazione tra due fratelli, i siblings. “Siblings” è un termine con il quale indichiamo “fratello/sorella di ragazzo con disabilità” in campo psicologico. È importante considerare la centralità del ruolo dei siblings, in quanto saranno questi ultimi ad occuparsi del fratello vulnerabile, assumendo il ruolo di caregivers, quando i genitori saranno impossibilitati o quando essi non ci saranno più.

The aim of the research is to highlight how physical and mental disability could influence the relationship between two brothers, siblings. In psychological field, “siblings” means “brother or sister of a boy with a disability”. Siblings play a central role because they will be the ones who will take care of brothers and sisters with a disability, becoming their caregivers when parents are no longer able to fill that role.

Keywords

Siblings, disability, caregiver, care, burden.

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Introduction

Since the 1980s, *caregivers* have been recognised as having a very important role in the caring process; they consider themselves a specific group, on both a political and social level, able to realise relevant consequences from professional, ethical, theoretical perspectives (Barnes, 2010). According to research conducted by Censis, more than 80% of caregivers are women, as it appears to be the nature of female sex to take care of others (Censis, 1999). Despite this, in general, different caregivers, each with a different background, will have different motivations for taking care of others. While some decide to become caregivers, others have no choice.

The birth of a child with a *disability* is an event that generates different reactions from each member of the family, even though it surely involves critical dynamics for all of them. These criticalities remain at central to the debate for many authors who have tried to identify, understand and describe them (Valtolina, 2004). These dynamics can become even more delicate when there is another child in the family. There are multiple reasons: first of all, *brotherhood* is important to the development of the personality of the children; secondly, the disability might have a strong impact on siblings' *personalities* and at the same time it might compromise it; last but not least, disability could be experienced in a different way by different people and could lead to a series of difficulties in siblings, which might then become real emotional and psychological problems.

1. Family caregiver and caregiver burden

“*Caregiver*” literally means “the one who takes care of”, generally a parent, an expert, a friend, a collaborator who takes care of a specific person (Taccani, 2010). A caregiver could become an attachment figure if he responds to the user's physical and emotional needs and if the relationship is characterised by an adequate constant and continuous emotional investment (Maiano, 2018).

There are two types of caregiver: an *informal caregiver* (Fondazione Onda, 2018) takes care of people without being paid and, most of the time, these are parents, family members, friends or volunteers; a *formal caregiver* takes care of people in exchange for a salary and these include nurses, doctors, private supporters etc. *Family caregivers* are therefore normal caregivers: taking care of a person who is not self-sufficient, as demonstrated by laws made in recent years, can have a big impact in many areas of family caregivers' lives (mother, father, brother etc.), exposing them to very high levels of stress. The psychological and physical illness can lead to a repercussion called burden. This term literally means “load” or “weight” and it *indicates the psychological distress* that affects the caregiver, following a pathological condition linked to his practice of caregiving (Rezzonico, 2016). So, *burden* is the weight felt by caregivers linked to their practice of caregiving. It can have an objective or subjective vision. The last one is related to negative emotion and psychological illness, and the first one regards the cure, for example time spent on caring (Gritti, 2011).

According to the statistics, in 2005 the *Center on Aging Society* (Washington) conducted research in which 13% of family caregivers feel frustrated because of the absence of an improvement in the health condition of their relative; 16% and 22% of caregivers feel “exhausted” and as if they don't live up to the demands of their role. The remaining 26% feel a big emotional weight originating from the caring activity (Ghisi, HumanTrainer.com).

Caregiver crisis arises from the belief of being unable to meet the expectations they set when they begin their practice of caregiving. Isolation reduced social availability and sense of guilt, non-exhaustive knowledge about the condition of relatives, poor coping skills, tension, fatigue and socio-environmental conditions are surely all factors that affect family caregivers' psycho-physical wellbeing (Tognetti, 2004).

2. From family caregiver to siblings

In psychology, “siblings” means “brother or sister of a boy with a disability” (Dondi, 2018). Relationships between brothers and sisters is very important to their development and it must be free from parental interference. In fact, children feel the presence of many protective attitudes in the relationship between parents and a vulnerable brother or sister; consequently, they will develop patterns of action such as inhibition of aggression, surrender, parental attitudes which will tend to exclude the vulnerable brother from the phratry. Among the variables that influence the relationship between siblings, we recognise the dynamics that Farinella (2015) would summarise as follows:

Embarrassment. It can happen that the vulnerable child assumes particular behaviours such as causing embarrassment to a brother or sister, embarrassment which requires the family to intervene. That can be eased by accepting that children can go through phases in which they feel the need to distance themselves from the family nucleus, and in giving them the appropriate space, the family will also have to be careful to demonstrate to the child that experiencing discomfort in certain situations also happens in adults.

Identification in the other. With non-obvious disabilities, such as autism and other mental disabilities, it could happen that the siblings feel that they share the same disability as their brother or sister.

Sense of guilt. It is a feeling often experienced by siblings, especially on those occasions in which they believe they have no right to discuss or be angry with the disabled relation.

Shame. There are some occasions in which other people claim the sibling’s family are “different” because of the child with a disability. Combined with guilt and embarrassment, this process causes a sense of shame in the siblings.

Isolation, loneliness, feelings of loss. These are all sensations brought about by a multitude of aspects: siblings could feel excluded by their peer group, because they live a particular situation which is not understood by everyone; siblings can also feel abandoned by their own parents. The family, in fact, focus their attention on the vulnerable child, most of the time, so siblings can experience a feeling of resentment because of this energy and attention by their parents on their vulnerable brother or sister. Siblings may even feel excluded too, from the brotherhood itself, as if they have lost the opportunity to establish a positive fraternal relationship, especially in the case of there are only two children. Finally, there are sometimes in which parents don’t speak about the condition of disability and they do not ask questions about the future in terms of caring for the member of the family with the disability, assuming that siblings will take their place as a caregiver. This will inevitably lead to excessive responsibility and an excessive demand for services to siblings.

2.1 Siblings’ roles

According to these dynamics, siblings take on different roles. We can distinguish them as (Mazzoncini, 2012):

- Parents’ role: sibling assumes an adult behaviour, taking the parents’ burdens and responsibilities. This role would arise from the perception that siblings share their parents’ concerns, and so siblings start to feel discouraged and anger towards their relative with a disability;
- Only child’s role: siblings often feel a sense of shame and embarrassment because of their situation. So, they became diffident with their parents, especially during their adolescence and become distant from their disabled relative, focusing outside family;
- Role of sibling who doesn’t want to grow up: siblings assume typical attitudes of those who want attention, even seeing disability as an opportunity to get what they want. Assuming this role, siblings feel emotions like loneliness and abandonment. Monica

Spagnolo says that the reaction to the sensation of abandonment, when there is a brother or sister with a disability, could be linked to two other dynamics: believing that to be an adult, means siblings not making clear their condition to their parents; believing that siblings do not have their own place in the family. It could happen that children with disabilities feel the same as their siblings.

In Pavone's work (2009)¹ we can find a table, elaborated by Anna Oliverio Ferris, in which the author explains that those situations which determine more difficulties in sibling adaptation are those in which family is small in size (two children), or when the sibling is the younger brother, in which there is a serious and very serious level of disability, indefinite and ambiguous and, finally, when family has a low socio-economic status, because of limited resources, or a high socio-economic status, because of the consequent expectations. On the other hand, a good probability of sibling adaptation may arise when there is a larger family in which the sibling is older than the child with a disability, possibly male and where the disability itself is slight, defined and visible.

3. Relation between attachment styles and siblings' relationship

There are a multitude of authors (Pezzati, 2005; Bartholomew e Horowitz, 1991; Carpenter, 2001; Gillath et al, 2011; Markiewicz et al, 1997), who question and reflect on this topic (Etters, 2008). It seems that: caregivers with *secure attachment style* have relationships in which they feel available and reliable. Siblings with this type of attachment take advantage of external social support mechanisms, they are hospitable and they offer emotional support, listening to their disabled family member; thanks to the low perception of the *burden* of care, they are more available, emotionally speaking, compared to those with a different style of attachment, because they totally understand the needs of the other. On the other hand, caregivers with *insecure attachment style* will have problems providing the right support and, at the same time, struggle to take advantage of external social support because they strongly feel the *burden of care*. For this reason they often live a depressive symptomatology. Caregivers with an avoidant attachment style probably will delegate others, using external support to take care of their brothers or sisters with a disability. Lastly, caregivers with *anxious ambivalent attachment style* will be detached from their relatives, with a prevalence of negative emotive answers.

3.1 How family manage siblings' emotional experiences

According to professor Dondi (2018), psychologist and psychotherapist, family members have to become aware of siblings needs and peculiarities to activated an adequate management of their emotional experiences: nowadays, that of siblings is a topic that is expanding in the world panorama, despite the studies are still lacking. It would be appropriate for siblings to be actively listened, that means listen in a careful, concentrated, reasoned manner, in a way to create the condition for them to ask important questions. Parents have to give the right importance to siblings' needs, so they can feel themselves supported and listened, just before advising them. Looking for an help and support as a parent, could be a good way to help siblings: in fact, parents have to live a well-being situation for themselves first of all and only after they can take care of their own children.

Parents who spend some time for themselves will found balance and they will be more present in family, with a good energy. Offering a "human" parenting model, in which parents them-

¹ Table "I livelli di adattamento dei fratelli all'interno di famiglie con disabilità" di Oliverio e Ferraris (1994), In PAVONE, M., Famiglia e progetto di vita. Crescere un figlio disabile dalla nascita alla vita adulta, Erickson, 2009.

selves show their children their concern about the disability, means that siblings will not feel they have to be their parents support because they will still be able to find the best strategy for is own well- being. Spending special time alone with siblings could be an appropriate strategy: also the sibling, as the vulnerable relative, needs his parent's attentions. This aspect is strongly correlated to the enhancement of the contribution of siblings in family management: to each responsibility is encouraged the right recognition, to valorize sibling's work. Siblings' contribution to the family should not be taken for granted: it is necessary found a balance between responsibility and autonomy to management of disability. When parents give to the siblings a lot of responsibilities, at the same time they have to give them also moments to take break and to satisfy their own needs. Siblings feel often a sense of guilt, especially when they leave alone their vulnerable brother, it is very important, for this reason, to encourage their initiative and independence and parents have a central role in this.

4. Supporting siblings

Remaining in accordance with the psychotherapist Dondi (2018), it is important to offer sibling information about disability. This information has to be correct and pertinent with their level of comprehension: it means that parents have to calibrate information to make it age appropriate but still useful even to younger siblings. This is so important because in this way siblings could grow up with a greater awareness. The psychologist considers necessary that parents learn to observe and communicate with siblings, even if it is difficult and sometimes impossible: being careful parents, observing all those behaviours and reactions to quotidianity allows parents to recognise warning signs of discomfort and ultimately avoid the onset of future abnormal behaviour. This includes the free expression of all emotions such as anger, worry and suffering, often anticipating inappropriate attitudes and which if reversed towards the disabled child, can be seen by the parents as wrong or unjust. It is important that the parent leaves the children free to experience the fratria in all its meaning.

Where the management of discord by the parent proves excessively difficult, parents could contact an expert. Dondi also speaks about fair educational method, a method which considers disability but also the experiences and lives of siblings: according to this, education has to be as similar as possible between children, considering when it is right to reprimand the disabled child. Another important aspect is to include siblings in decisions and keep them informed about their disabled family member's life, so they can feel themselves as an integral part of the family unit. It is advisable to discuss the future with adult siblings. Finally, it is important to offer support and some strategies to manage different situations which could be offensive or embarrassing: there are many cases in which siblings are mocked for the disability of their relatives. First of all, parents could console their children and, together with them, find the right strategy to resolve these situations. Dondi invites parents to encourage contacts with other siblings: about this, many initiatives are born with this aim. A lot of siblings don't have many opportunities to meet others like them. Finding a group where siblings could feel accepted and understood is a big resource for their development.

Conclusions

Growing up with a brother with disability is an experience which models siblings' personality and it could have a multiple repercussion and risks their health. Strohm (2006) underlines a series of factors that are indices of illnesses in siblings like: emotional responses not processed by thought. It means the free expression of what we feel without any filters. This is a very common process in younger children, and it could develop in a risk index when they grow up. We can recognise these signals when children have emotional reactions not in line with the

emotional load of the situations they are experiencing, so children will have exaggerated, apparently inappropriate reactions. Other indices of risk could be: anxiety, somatization frequently as stomachache; perfectionism, as a tendency to invest all their energy in everything they do, especially if they are young children. Siblings have the aim of redeeming the limits of their disabled relatives. They try to compensate for the disability. Because of these dynamics, it is good to note possible signs of stress from childhood: in fact, although it is not fair to take for granted the discomfort caused by a fraternity in which a member has a disability, it is nevertheless right to consider the presence of its impact in brotherhood.

References

- Barnes, M. (2010). *Storie di caregiver. Il senso della cura*. Trento: Edizioni Erickson, 13.
- Censis. (1999). *La mente rubata*. Milano: Franco Angeli Editore.
- Dondi, A. (2018). *Siblings. Crescere fratelli e sorelle di bambini con disabilità*, Roma: Edizioni San Paolo, 32.
- Etters, L., Goodalli, D., Harrison, B.E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *J Am Acad Nurse Pract*, 20(8):423-428.
- Farinella, A. (2015). *SIBLINGS. Essere fratelli di ragazzi con disabilità*. Erickson, 38.
- Fondazione Onda. (2018). *La salute della donna. Caregiving, salute e qualità della vita*. Milano: Franco Angeli Editore, 65-68.
- Gherardini, R. (2011). *Psicoterapia e disabilità acquisite. Dopo il trauma: le risorse possibili e il ruolo del caregiver*. In Goussot, A. (a cura di), *Le disabilità complesse. Sofferenza psichica, presa in carico e relazione di cura*, Rimini: Maggioli Editore, 154.
- Ghisi, A.M. *Caregiving Familiare: il peso del supporto e dell'accudimento quotidiano. Effetti somato psichici del prendersi cura dei propri cari*. In: HumanTrainer.com
- Gritti, P., Buralli B. (2011). *Il caregiver informale nel rapporto con il volontario: definizione di burden*. In Buralli, B., Amoroso, D. (a cura di), *Camici invisibili. Manuale pratico per volontari in oncologia*. Milano: Franco Angeli, 250.
- Maiano, P., Tramonte, L. (2018). *Caregiver multipli e legami a rischio: generazioni a confronto*. In Merenda, A., Milano, P. (a cura di), *Caregiving e attaccamento. Una lettura dinamica dei contesti di accudimento*. New Digital Frontiers S.r.l., 3.
- Mazzoncini, L., Musatti, L. (2012). *I disturbi dello sviluppo. Bambini, genitori e insegnanti*, Milano: Raffaello Cortina Editore, 129-131.
- Rezzonico, G., Belloni, S., L. (2016). *Diagnosi e malattia: decostruzione e ricostruzione del significato*. In
- Rezzonico, G., Florit, G. (a cura di). *Epilessia e resilienza familiare. Una guida per genitori e operatori*. Milano: Franco Angeli, 130.
- Spagnolo, M. (2015). *Siblings. Essere Fratelli di persone con disabilità: limite o risorsa?* La Zisa.
- Taccani, P. (2010). *Anziani non autosufficienti e cure familiari*. In Taccani, P., Giorgetti, M. (a cura di). *Lavoro di cura e automutuo aiuto. Gruppi di caregiver di anziani non autosufficienti*. Milano: Franco Angeli, 180.
- Tognetti, A. (2004). *Le problematiche del caregiver*. *Giornale di Gerontologia*, 52: 505-510.
- Valtolina, G.,G. (2004). *L'altro fratello. Relazione fraterna e disabilità*. Milano: Franco Angeli, 37.