Abstract

In special pedagogy and in psychology, the term <siblings> indicates the relationship between a subject with a disability and a neurotypical one (Dondi, 2018). This connotation of the term has taken hold today in Italy thanks to the initiative of the Siblings Committee, as Federico Girelli, President of this Committee explains, in the presentation for the book “SIBLINGS: Being brothers of children with disabilities” by Alessia Farinella (2015). In English, the term <siblings> is gender-neutral and apt to simply indicate the bond between siblings, without the pathological component of which it has taken the connotation. The Committee first used this term as “brother of a person with a disability”.

Disability invades the whole family. In the first part of this article, a strong focus on the experience of the disabled person will be provided, and, then, all the possibilities of intervention and rehabilitation will also be taken into account and examined. Moreover, attention will be focused on the parents and on their reworking of the event. The comparison with the impact that the disability has in the relationship between the two siblings is increasingly rare. Growing up with a disabled brother is an experience that shapes the personality of the siblings and that can have innumerable repercussions and risk indices for the health of the normal brother. In light of the dynamics that exist between the two, it is good to notice since early childhood possible signs of stress in the latter. The fraternity in which a member has a disability is not always directly related to a discomfort, but it is still right to consider the possibility of impact in the relationship.

Among those attitudes that can highlight a discomfort in the siblings, Strohm highlights (2006): acts, or those emotional responses that are not processed by thought, in other words, we refer to the free expression of what can be felt without any filter, which is a very common process in smaller children, but it can be transformed into a signal of alarm when these acts become repeated over time; they can be recognized when reactions not in line with the emotional load of the lived experience are faced, and, consequently, children who tend to have exaggerated and apparently-out-of-place reactions can be thus obtained. Behaviour problems can be isolation, anxiety, somatization, (for example, frequent stomach ache), perfectionism, which is thus the tendency of children, especially male, who totally commit their energies to whatever they do, with the aim of redeeming their brother’s limits, trying to compensate for what the disability entails.

In pedagogia speciale e in psicologia, il termine <siblings> indica la relazione fra un soggetto con disabilità ed uno normotipico (Dondi, 2018). Questa connotazione del termine ha preso oggi piede in Italia grazie all’iniziativa del Comitato Siblings, come ci spiega Federico Girelli, presidente di tale comitato, nella presentazione per il libro “SIBLINGS: Essere fratelli di ragazzi con disabilità” di Alessia Farinella (2015). Nella lingua inglese il termine “sib-
"lings" è neutro e atto ad indicare semplicemente il legame tra fratelli, senza la componente patologica di cui ha preso la connotazione. Il Comitato ha usato per primo tale termine nell’accezione di “fratello di persona con disabilità”. La disabilità invade tutta la famiglia. Inizialmente ci si concentra sul vissuto della persona diversamente abile e si prendono al vaglio tutte le possibilità di intervento e riabilitazione. L’attenzione poi si orienta sui genitori e sulla rielaborazione dell’evento. Sempre più raro, invece, è il confronto con l’impatto che la disabilità ha nel rapporto tra i due fratelli. Crescere con un fratello disabile è un’esperienza che plasma la personalità dei siblings e che può avere innumerevoli ripercussioni e indici di rischio per la salute del fratello sano. Alla luce delle dinamiche che intercorrono tra gli stessi, è bene rilevare fin dall’infanzia possibili segnali di stress in questi ultimi. La fratria in cui un componente abbia una disabilità non è sempre direttamente correlata ad un disagio, ma è comunque giusto considerarne la possibilità di impatto nella relazione.

Tra quegli atteggiamenti che possono evidenziare un disagio nei siblings, Strohm evidenzia (2006): agiti, ovvero quelle risposte emotive che non sono processate dal pensiero, in altri termini, ci riferiamo alla libera espressione di ciò che proviamo, processo molto comune nei bambini più piccoli, ma che può trasformarsi in un segnale di allarme quando questi agiti diventano ripetuti nel tempo; li riconosciamo nel momento in cui ci troviamo di fronte a reazioni non in linea con il carico emotivo dell’esperienza vissuta, avremo quindi bambini che tendono ad avere reazioni esagerate e apparentemente fuori luogo. Comportamenti problema possono essere l’isolamento; l’ansia; la somatizzazione, (ad esempio frequenti mal di pancia); il perfezionismo, quindi la tendenza dei figli, soprattutto bambini, che impegnano totalmente le loro energie in qualunque cosa essi facciano, con l’obiettivo di riscattarsi dei limiti del fratello, cercando allora di compensare ciò che la disabilità comporta.

Keywords
Siblings, emotions, education, data analysis
Siblings, emozioni, educazione, analisi dei dati

Introduction

The aim of the proposed study is to verify the possible presence of consistent indices of psychophysical stress related to the practice of care and caregiving that the siblings implement towards their relatives and therefore to demonstrate the necessity and the need to take care of the familiar caregiver. However, the importance of the siblings’ educational style is essential in the caregiving practice. To demonstrate this, the pivotal role of the attachment figure of the ones has thus been reported: in order to develop in the individual adequate functions and abilities to overcome the adversities that arise, this one, in fact, must have first experienced a secure and stable relationship of attachment (Gherardini, 2011).

Attachment is what Bowlby, the father of this theory, defines as a behavioral control system aimed at the purpose, or rather that biological predisposition in the child that would lead him to develop a privileged relationship with those who take care of him, thing that will influence in first place his personality, and secondly his way of relating to others. Several authors (Pezzati, 2005; Bartholomew e Horowitz, 1991; Carpenter, 2001; Gillath et all, 2011; Markiewicz et all, 1997)1 have questioned themselves on this topic, drawing different conclusions: it would seem, in fact, that caregivers with secure attachment create healthy relationships in which it is possible to experience the desire to feel available and reliable; those are the kind of people that are able to take advantage of existing social supports, are welcoming in offering support, facing and integrating the emotions linked to the experience of one’s relative; thanks to the low perception they have of the burden of care; moreover, they are emotionally more available people than others with different styles of attachment, since they are able to understand the needs of the other; on the other hand, caregivers with insecure attachments will struggle to provide the right support to the family member, as well as to take advantage of external aid, avoiding situations

---

where a high level of support is required and, as they mainly perceive the burden of treatment, they often suffer from a depressive symptomatology. Caregivers with **avoidant** style will probably tend to delegate to other people, using external help, to take care of the fragile person; finally, caregivers with an anxious ambivalent style will implement avoidance and detachment responses, with mainly emotional responses.

Our childhood experiences, particularly those with primary caregivers, shape our instincts and behaviour, and give life to the many aspects of the human personality. The primary caregivers are those who, when we are still in a condition of heteronomy, determine the first state of identity. In order to survive and adapt to our environment, we need to build more or less reliable knowledge about ourselves and the reality in which we live. The term “beliefs” describes this set of implicit and explicit representations of oneself and one’s own interpersonal world (Gazzillo 2016).

Some of these beliefs are defined as pathogenic when they are linked to the achievement of a healthy and realistic goal with an internal (i.e. feelings of guilt or shame) or external (i.e. suffering of loved ones) danger. Therefore, the way we react to the different challenges of our environment depends on a series of primary affections, motivations, and propensities that have been selected during the evolution of the species, since they have allowed the survival of the individual and the group, but have made the instinctive behaviours that take shape within the primary relationships and our social and cultural context rather plastic. Beliefs play the role of mediators between our innate motivations and propensities, and our actual behaviours, regardless of whether they are conscious or not. (De Luca E., Mazza C., Gazzillo F., 2017).

It is therefore evident that a good relationship of attachment to the base of development and education of the child is strongly indicative of an emotional and relational well-being that will inevitably affect the life of the child even in adulthood.

The survey takes place at two levels:
- **At a social level** - To return an image as close as possible to the reality of current society, thanks to the construction of a socio-demographic index in which will be indicated: gender, age, area of origin, area of residence, level of education, of people that will take part in the survey.
- **On a psychological level** - *Family Strain Questionnaire* \(^2\) (Action, 2011) is a questionnaire designed to evaluate the emotional burden and stress experienced by the caregiver in their practice of caring for the relative, in order to predict the possible psychological risk related to this employment. Its extended version is composed by 44 dichotomous items (YES / NO), which can be administered in 20 minutes.

The target audience is composed of subjects (children m/f, boys/girls, adults) at more than 6 years of age, having a brother or sister with a disability. The survey was disseminated via the web in a digital version, through the appropriate compilation of the same items reported in an online survey, thanks to the creation of a specific website designed to facilitate accessibility to the test.

1. **Focus of Research**

The aim of this paper is, therefore, to record the burden of discomfort that the siblings emotionally, psychologically, and physically live in their caregiving practice, in such a way as to

\(^2\) Professor Giulio Vidotto and collaborators (2012), from the University of Padua, in the study for the Journal of Clinical Nursing, presented the *Family Strain Questionnaire* in its short form (30 dichotomous items, yes / no), designed to be administered by experienced staff and not.
understand which the most appropriate strategies are to provide them for a better management of the relationship between them. Certainly, at the basis of a pedagogical strategy, there is the need to direct the siblings towards healthy relational styles, providing them with those tools suitable for the sustainability of the relationship with their own relative. Siblings with balanced relational styles will be able to live serenely the fraternal relationship: on the one hand, the frail brother will feel welcomed within the fraternity, and, on the other hand, the brother with typical development will feel less the burden given by the practice of care. It will also be advisable to direct the siblings towards a more correct knowledge and management of their own emotional experiences, such as anger, stress, anxiety, and fear, which, as emerged from the results of the FSQ, negatively affect their relationship and well-being, both within the family context and in the long term in the life situations that they will face.

2. Development of emotive competences between Psychology, Neuroscience and Education

The neuroscientific studies of Jaak Panksepp et al. (Panksepp, Biven, 2012) explain how, starting from a series of emotions and innate behaviours, various aspects of the human personality and certain behaviours are formed (Panksepp, 2006).

The author investigated on the effects of the activation of a number of subcortical areas, in particular the periacquedottal gyrus, the hypothalamus, and the medial thalamus. These regions of the brain, if stimulated, generate very intense affections of a positive or negative nature. Panksepp traces back to the activation of these areas the basic emotions that, with development, constitute the different motivational systems. The positive or negative value of emotions fosters adaptive behaviours. Moreover, in his study it is argued that there are at least seven basic emotional/motivational systems: research, anger, sexual desire, care, panic/suffering (or attachment), fear, and play. Furthermore, these studies indicate that every primary emotional/motivational structure is supported by an emotion, pleasant or unpleasant, which originates at the level of specific subcortical areas and which is regulated by hormones and neurotransmitters. Each system is structured with levels of greater complexity thanks to the connections that are created at the level of the limbic system and the neocortex, and in a way closely related to the experiences that the subject lives in his familiar, social, and cultural environment (Panksepp, 2014).

This research work aimed to detect the main emotional states experienced by a sample of heterogeneous siblings, especially by age. The analysis of emotions will be addressed trying to take into account an intermediate age group, which is that of adolescence. This period is particularly delicate not only for the psychophysical development of the caregiver and its relationship with the disabled relative, but, considering the understanding of emotional states, it is possible to understand the moods and behaviours acted by the adult sample.

During the adolescence, the increase in self-awareness stimulates insistent and intense evaluations that can give rise to negative emotions, such as fear related to a sense of inadequacy, or sadness resulting from the loss of competition between peers, or even disgust related, for example, to physical appearance (Abe, Izard, 1999). Shame can trigger anger in order to defend and protect one’s image (Tagney, Wagner, Flatcher, Gramzow, 1992). D’Urso (2001b) also highlights that expressions of anger are more assiduous and uninhibited in adolescents than in adults.

Fear, sadness, and shame are typical feelings of the adolescence, in which the evolution of the tasks of individuation and autonomy implies the exposure of the self, the discovery of one’s own existence, and the awareness of death. (Pietrolli Charmet, 2000). Barone and Zaccagnino (2004) correlate life events and emotional semantics, observing that fear in adolescence is “linked to an acceptance of danger focused on oneself and one’s own physical and mental safety”.

Sadness is connected to the development functions linked to the protection of affections and to the efficient achievement of one’s purposes (Barone, Zaccagnino, 2004). Shame, however, in this phase of life, is linked to feeling exposed to the judgment of others. An in-depth analysis of the experience of shame shows that the perception of uncertainty and precariousness with
respect to the future is a particularly significant condition (Barone, Zaccagnino 2004).

In the study of the same authors, jealousy that relates to the fear of being postponed to others in emotional relationships (Ibid.) is also taken into account. In particular, in the adolescent period, it is required to solve important tasks of development, including the construction of one’s own identity, in opposition to a period characterized by “identity confusion”. From the formal cognitive point of view, the acquisition of operative-formal thinking, metacognitive skills, and access to the category of the possible characterizes this developmental phase. Thus, identity takes shape within the life cycle (Grazzani, Albanese, 2013).

The research carried out by Confalonieri and Grazzani Gavazzi (2005) on a group of adolescents shows that the psychological vocabulary related to pleasant emotions is quite varied, and contemplates labels related to emotions which are complex and sophisticated. The idea of conflict linked to this age group, mitigated by the socio-cultural conditions of belonging, is therefore moderated. The same research shows how positive emotions are felt more in public places and outdoors, and only in a second place at home and at school. The scholastic environment occupies a great part of the day, and, therefore, the positive emotion is linked to school success, sports performance (especially males), and friendship. Positive moments experienced alone are also highlighted, and those are depicted as emotional experiences that Zammuner (2001) describes as prior to aesthetic emotion. The theses of Spangler and Zammuner (1999) underline that positive experience, especially at a relational level, strengthens psychological resources to cognitively and emotionally explore different growth scenarios.

3. Data Analysis

114 people participated in the survey.

As reported by the following graphs, with reference to the socio-demographic survey, it appears that of this sample: 70.2% are female while only 29.8% are male; moreover, 46.5% of the people who underwent the study would be over 40, compared to 24.6% and 14.9% respectively of an age between 21-30 and 31-40 years of age, only the 8.8% would be under 17, the remaining 17 to 20 years.

With regard to the results achieved with the FSQ-SF, an average of 13.4 YES responses was recorded for the 30 items (M = 13.4) present in the test. According to this figure, the entire sample of siblings taken into consideration would enter the SR area (12-20 answers YES). It is interesting to notice, in fact, from the percentages shown below, that the majority of YES responses are recorded in the following items:

---

3 Individuals who place themselves in the SR area (Strongly Recommended) according to the scoring methods foreseen for the FSQ-SF, would be included in that group of subjects that it is strongly advisable to consult and support a specialist.
3. Queries

- I am worried about my relative’s illness - 61.4%;
- I feel powerless in the face of illness - 60.5%;
- I feel the need to have advice on how to assist my relative - 62.3%;
- Sometimes I think about the death of my relative - 58.8%;
- I always think about how things will end - 63.2%;
- I have too many things to think about - 60.5%;
- I would like to know more precisely what care they are giving to my relative - 51.8%;
- I would like to check my emotions more - 60.5%;
- In this period, I feel anxious about the future - 60.5%;
- At this time, I feel very stressed - 51.8%;
- I would need to talk about things that don’t go with an expert - 55.3%;
- I wish I had more time to dedicate to myself - 62.3%;
- I have the impression that I cannot cope with all my problems - 51.8%;
- Sometimes it is difficult to contain my anger - 51.8%.

It is possible to observe peaks of YES responses in subjects between 17 and 20 years of age (A = 15.1) and subjects with an age greater than 40 years (A = 15.1), thus showing how these subjects particularly affected by the disability of the relative; the average would then be slightly lower, although a strongly recommended consultation with a specialist persisted, in subjects of 21-30 years (A = 12.7) and less than 17 years (A = 12.3); on the other hand, subjects between 31 and 40 years of age would appear to be within the R area (recommended), having obtained an average of 9.3 YES responses, an indication of how probably people in this range are less affected by impact with disability.
4. Score

It would then seem that the sample coming from the North of the peninsula, with an average of 15.9 YES replies, would be particularly affected by the influence of the disability of its relative, returning to the SR Area of the FSQ-SF. Middle and southern Italy would be placed in the R area of the same, with an average of 11.8 and 11.9 YES replies respectively.

5. Distribution

An interesting piece of data could be the one shown in the graph below, according to which, referring to the sample of more than 30 years of age and crossing the data referring to them with the result from the FSQ-SF, it would seem, with regards to the degree of education, that disability has a greater emotional impact in non-graduated than in those who have graduated:
4. Health and Psychophysical Well-being

It was decided to subdivide the items of the SFQ according to the three dimensions constituting the global well-being of the person: on the basis of the results that emerged, a predominance of difficulties can be seen with regard to the sphere linked to emotion.

Regarding the construct “I would like to control my emotions more”: we observe more sensitiveness to this aspect in the feminine subjects, with more than 40 years of age and coming from North and Middle Italy; this requirement seems to be less felt by male subjects and in general by subjects under the age of 17, from 17 to 20 years, and from subjects aged between 31 and 40 years of age.
8. Correlations scores

By gathering the sample’s need to manage their emotions and, wanting to maintain attention on this aspect, it has been analyzed in the same way those that were considered the most representative items of this category, concerning:

Anger management: “Sometimes it is difficult to contain my anger” (51.8% YES). Higher values in this area are found in female persons, over 40 years of age and resident in the North and Middle of the Peninsula; in female and male persons between 21 and 30 years of age and coming from Middle Italy. On the other hand, the younger ones would not be affected by this need.
Sense of powerlessness: “*I feel powerless in the face of illness*” (60.5% YES). Higher values in this area are found in female persons, over 40 years of age, and resident in the North and Middle of the Peninsula; and also in female and male people aged 21-30 years of age, and coming from Middle Italy. On the other hand, the younger ones would not be affected by this need.

10. Correlation scores of Stress

- Perceived stress: “*In this period I feel very stressed*” (51.8% YES). Higher values in this area are found in female persons, over 40 years of age, and resident in the North and Middle of the Peninsula; particularly, in female persons between the age of 21 and 30, and from Middle Italy. On the other hand, the younger and more generally male subjects would not be affected by this need.

11. Correlation scores
It has been decided to pay considerable attention to the sphere linked to the person’s emotionalism because in recent decades the contribution that this, together with other subdued dimensions, gave to the term “health”, which has undergone a radical change, is important. In particular, it has been witnessed an evolution of the aforementioned term, to be understood as an overcoming of that archaic conception of health as a mere absence of disease, and, instead, it should be attributed to it a connotation that took into consideration the globality of the person. This term comes into line with the concept of psychological well-being, according to which the person will no longer be judged healthy if they do not present an actual pathological symptomatology: the healthier will be the one who enjoys psychological well-being.

This psychological well-being will be the result of six specific dimensions (Ryff, 1995) intersected between them:

- autonomy;
- self-acceptance;
- positive relationships with others;
- personal growth;
- environmental mastery;
- purpose in life.

The World Health Organization (WHO, 1868) in the Ottawa Charter for Health Promotion⁴, declares psychological well-being as the state in which the individual, in dealing with those requests and needs to which daily life subjects him, is able to exploit in the best possible way his abilities, to be understood as cognitive and emotional capacities. In addition to this, lights will be shed on the importance of the role that the relational dimension plays in terms of welfare and well-being: building healthy and satisfying relationships and adapting constructively to society and one’s own group will allow the individual to satisfy his own needs, and to change the environment in which it is inserted, thus adapting to it. This is the case in which health becomes a positive concept that focuses on the resources of the individual as well as those strictly related to physical appearance.

By focusing on the purely relational aspect, several authors have confirmed the importance of sociality in the construction of subjective well-being (Mela, 2016; De Piccoli, 2014): according to their testimonies the health condition of the individual can only be achieved in the moment in which personal needs, relational needs, and collective needs will coexist in balance between them; social well-being is nothing other than the evaluation of one’s own conditions of existence and the functioning within a broader context.

Based on the above considerations, and after an in-depth study of the reality of the siblings, following the identification of those areas which are the most compromised in relation to their own caregiving practice, and following an accurate analysis of the data received thanks to the administration of the FSQ-SF, accompanied by a socio-demographic index, it has been obtained data that can verify the starting hypotheses, and the importance of paying attention to the individuality of all those who take care of their relative with disabilities within the community, since this practice itself affects the life and well-being of the sibling, affecting and developing consistent indices of psychophysical stress that will fall into the different areas of life of the caregiver.

---

Conclusions

Emotions also have an impact on reasoning processes. The so-called affect-as-information is the psychological mechanism that determines the relationship between emotional experience and cognitive processes. It demands the emotional state to be used as information collected to express evaluations and judgments (Arntz, Rauner, Van Den Hout, 1995; Butler, Mathews, 1987). The affective state is thus used as fundamental information to express judgments and evaluations (Clore, 1992). Therefore, it can be argued that the informative value provided by emotion becomes authoritative in subjects who live that emotional experience with chronicity (Mancini F., Gangemi A., 2013) such as anxious people.

The results of certain experiments (Mancini, Gangemi, Van Den Hout, 2005) show that the induction of a negative emotion such as guilt, involves several factors: mainly a greater probability and gravity is attributed to a possible negative event. Moreover, the evaluation standards that subjects acquire to evaluate their own abilities increase. Lastly, some choices are always preferred. It has also been shown that the sense of guilt sometimes influences and increases the emotional reasoning put in place by the analyzed subjects (Gasper, Clore, 1998; Muris Merckelbach, Van Spawen, 2003).

In adolescence, guilt is used as important information to create estimates and judgments, in accordance with affect-as-information. The “guilty” subjects show a high level of dissatisfaction with their future performance at the expense of self-esteem (Mancini F., Gangemi A., 2013). This mechanism is important to understand the relationship between conscious experience, emotion, and cognition, and in particular to comprehend the awareness behind the modalities through which an emotion can influence cognitive functioning and, consequently, the processes of reasoning.

It is, therefore, of fundamental importance, in the light of the results of the questionnaire presented in this research, to intervene with effective educational methods in the family of the siblings to build stable and healthy relationships. This should help the siblings to create their own strong identity, but at the same time proactive in the growth of the family nucleus.

References


