



# Sibling Relationships, Disability, Chronic, and Mental Illness: Development of the Siblings' Experience Quality Scale (SEQS)

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## Abstract

The goal of this study is to propose the Siblings' Experience Quality Scale (SEQS), a measure for the assessment of cognitive, emotional and behavioral experience of adult individuals having a brother or sister with an intellectual/developmental disability, chronic physical illness or mental illness, on five dimensions: Closeness, Conflict, Jealousy, Self-Marginalization, and Worry. A sample of 213 Italian adult typically developing siblings (ages 18–69 yrs.) was used to demonstrate the psychometric validity of the scale. Results of confirmatory factor analysis, which resulted in high scores of goodness of fit, supported five identifiable factors reflecting the theoretically-based constructs of the SEQS and demonstrated convergence with the general construct of siblings' quality of experience. Correlations with the Lifespan Sibling Relationships Scale (LSRS), the Beck Depression Inventory II (BDI-II), and the Aggression Questionnaire (AQ) demonstrated the construct, convergent, and discriminant validity. In particular, Jealousy, Conflict, Worry, and Self-Marginalization were negatively correlated with LSRS, while Closeness was positively correlated with LSRS; Worry and Self-Marginalization were positively correlated with BDI-II; and the majority of the SEQS subscales were not correlated with the AQ. Furthermore, siblings of individuals with intellectual/developmental disability showed higher scores on Closeness and Worry, while siblings of individuals with chronic physical illness showed higher scores on Jealousy, and siblings of individuals with mental illness showed higher scores on Conflict. Finally, siblings with higher Self-Marginalization and Worry scores showed higher levels of internalizing problems, as well as anger and hostility. Implications for research and policy are discussed.

**Keywords** Sibling relationships · Intellectual and developmental disability · Chronic physical illness · Mental illness · Adjustment

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## Introduction and Literature Review

The sibling bond represents the longest-lasting relationship to develop throughout the lifespan (e.g., Cicirelli 1995; Donsi et al. 2010), and ever more attention is being paid to the significant role siblings play in their brothers' and sisters' lives, particularly in their psychological and social development (e.g., Sommantico et al. 2019b; Conger and Little 2010; Waite et al. 2011). Focusing on a lifespan perspective, literature reviews (e.g., Sommantico 2018; Whiteman et al. 2011) document that siblings serve as companions, confidants, and role models in childhood and adolescence, as well as sources of support throughout adulthood and aging. In particular, it has been found that adult sibling relationships are characterized by decreased rivalry and conflict, as well as increased giving/receiving of help, as well as levels of reciprocal worry. However, the impact of siblings on individuals' lives takes on specific characteristics in the cases of disability, chronic physical illness, or mental illness.

Literature reviews and meta-analyses on the siblings of individuals with intellectual or developmental disability (IDD-Sibs), as well as on the siblings of individuals with chronic physical illness (CPI-Sibs) or mental illness (MI-Sibs), have shown a lack of consensus in their findings, ranging along a continuum from positive to negative effects (e.g., Dew et al. 2008; Knecht et al. 2015; Lee and Burke 2018; Mandleco and Mason Webb 2015; McKenzie Smith et al. 2018; Meadan et al. 2010). These varying results can be at least partly attributed to the methodological limitations of the studies, especially regarding the different samples (e.g., clinical, community, general population), the different control-contrast groups (e.g., normative data, typically developing siblings, sibling with different disabilities), and/or the measures and methods (e.g., self-report instruments, interviews, observational techniques). Furthermore, research on IDD-Sibs, CPI-Sibs, and MI-Sibs has mainly focused on childhood (e.g., Mandleco and Mason Webb 2015; Meadan et al. 2010), adolescence, or young adulthood (e.g., Laghi et al. 2018; Shivers and McGregor 2019). Only recently, research has started to focus on adult sibling relationships (e.g., Burbidge and Minnes 2014; Doody et al. 2010; Heller and Arnold 2010; Rossetti and Hall 2015; Tomeny et al. 2017a, b).

IDD-Sibs, as well as CPI-Sibs or MI-Sibs, are generally considered a population at risk, especially in terms of anxiety, depression, and internalizing psychological disorders (e.g., Alderfer et al. 2010; Sommantico et al. *in press*; Goudie et al. 2013; Hastings 2003; Howe 1993; O'Neill and Murray 2016; Orsmond and Seltzer 2007; Sharpe and Rossiter 2002; Shivers et al. 2019; Vermaes et al. 2012; Verté et al. 2003). Indeed, several studies have suggested that having a sibling with IDD, CPI, or MI has negative developmental impacts and is associated with low self-concept, behavior problems, and depression (e.g., Emerson and Giallo 2014; Fisman et al. 2000; Fullerton et al. 2016; Ross and Cuskelly 2006; Taylor et al. 2008; Wolfe et al. 2014). In addition, the role of family dynamics has been highlighted (e.g., Atkin and Tozer 2014; Di Biasi et al. 2015; Graff et al. 2012; Hayden et al. 2019; Tomeny et al. 2017a, b), indicating that the perception of parental favoritism toward a disabled or ill sibling is generally associated with an individual's negative outcomes (e.g., Fisman et al. 2000; Naylor and Prescott 2004).

Regarding gender, generally speaking, more females than males are involved in caring for their disabled or ill sibling (e.g., Dyson 2010; Hallberg 2013; Prino et al. 2019). This seems to have a long-term positive impact on having a sibling with IDD,

CPI, or MI, and it provides more instrumental support to the sibling with disability or chronic or mental illness (e.g., Greenberg et al. 1999; Hodapp et al. 2010; Orsmond and Seltzer 2000).

More contrasting results emerge regarding age. Indeed, the literature has shown how, for the youngest siblings who have a disabled or physically or mentally ill brother or sister, the relationship may be related to negative outcomes because of the siblings' lack of comprehension regarding the causes and consequences of the disability, as well as typical externalizing behaviors, such as aggression, disruption, and stereotyping (e.g., Angell et al. 2012; Ferraioli and Harris 2009; Moyson and Roeyers 2011). On the contrary, other studies indicate that younger siblings' incomprehension or 'naïve' concepts regarding IDD, CPI, or MI may be a protective factor (e.g., Vermaes et al. 2012). Research findings also indicate that adjustment problems for siblings tend to increase during adolescence or in adulthood, especially in terms of developing a psychopathology (e.g., Fisman et al. 2000; Seltzer et al. 2005).

But if, as stated by Hodapp and Kasari (2004), "disability family research is more accurately characterized as "less negative" in orientation rather than focusing on positive aspects" (p. 337), the literature also shows that there are some positive effects of growing up with a disabled or physically/mentally ill sibling, such as an increase in compassion, openness, tolerance of differences, focus on life's larger meanings, social competence, and personal and social growth (e.g., Faux 1993; Dyke et al. 2008; Dykens 2005; Findler and Vardi 2009; Graff et al. 2012; Hodapp and Kasari 2004; Sharpe and Rossiter 2002). In particular, as stated by Vermaes et al. (2012), "the experience of having resisted and recovered from major life events and daily stressors can reinforce siblings' positive self-attributes, such as self-concept, self-esteem, and sense of competence" (p. 167). Additionally, while negative effects and outcomes are immediate, positive ones appear later on, i.e., in adolescence or even in the transition to adulthood (e.g., Hallberg 2013; Rossiter and Sharpe 2001).

Research findings also showed the multifaceted situation of siblings with disabled or physically/mentally ill brother or sister, which varies according to the type and severity of disability or illness (e.g., Burke et al. 2016; Doody et al. 2010; Knecht et al. 2015; Mandlco and Mason Webb 2015; Seltzer et al. 2005; Tomeny et al. 2017a, b). Indeed, several studies (e.g., Hodapp and Urbano 2007; Kaminsky and Dewey 2002; Orsmond and Seltzer 2007) reported that individuals with a brother or sister affected by an Autistic Spectrum Disorder (ASD) showed less intimacy, nurturing, and prosocial behavior toward their siblings than siblings of children with Down Syndrome (DS). In addition, other researchers reported that siblings of an individual with DS or other IDD showed higher levels of adjustment, contact, and positive relationships, with respect to siblings of individuals with ASD (e.g., Orsmond and Seltzer 2007; Tomeny et al. 2017a, b). In research on CPI-Sibs, several authors reported that these individuals are often characterized by a withdrawal attitude and by strong feelings of guilt, shame, and regret (e.g., Alderfer et al. 2010; Bellin and Kovacs 2006; Burke 2010; Hallberg 2013). The literature suggests that the affective lives of these individuals are strongly occupied by an attempt to comprehend and master feelings experienced toward their siblings' and family's troubles in facing the children's illness. In particular, Vermaes et al. (2012) suggested that these siblings "may also have learned that

going to their parents is not particularly effective” (p. 172) because parents’ emotional resources and time are taken up by their involvement with their sick child’s condition and needs, and this could lead siblings to feel neglected and put aside by their parents (e.g., Abell and Gecas 1997; Hallberg 2013; Knecht et al. 2015).

In sum, the multifaceted and sometimes contrasting research results indicate the need for further investigation in the field. Furthermore, as we have seen, even if, like all other siblings, IDD-Sibs, CPI-Sibs, or MI-Sibs also vary on variables like warmth/closeness, affection, admiration, conflict/rivalry, or social support, other feelings and experiences are unique to some of them: shame, guilt, pride, overprotectiveness, etc. (e.g., Hodapp et al. 2005; Stoneman 2005). But, to our knowledge, there is no existing instrument specifically developed to assess the emotional, behavioral, and cognitive experience of IDD-Sibs, CPI-Sibs, or MI-Sibs. The only existing instrument regarding disability is the *Sibling Attitudes toward Disability Questionnaire* (SADQ; De Caroli and Sagone 2013), specifically developed to assess only social attitudes toward siblings with disability. The SADQ is a 37 item self-report instrument made up of 5 subscales: 1) Future of the sibling with disability (7 items); 2) Characteristics attributed to the sibling with disability (8 items); 3) Popular prejudices about disabled people (8 items); 4) Feelings toward the sibling with disability (7 items); 5) Ideas about inclusion at school for a sibling with disability (7 items). Participants are asked to respond according to a 7-point Likert-type scale ranging from “*Totally disagree*” to “*Totally agree*.” Subscales scores are obtained by averaging the items that make up each subscale. To our knowledge, no data regarding validity have been reported, and its Cronbach’s  $\alpha$  values are marginal (ranging between .61 and .70).

## Aim of this Study

The present study is chiefly aimed at developing and validating a new instrument to specifically assess the quality of the emotional, behavioral, and cognitive experience of adult IDD-Sibs, CPI-Sibs, and MI-Sibs. Based on the literature findings (e.g., Angell et al. 2012; Hallberg 2013), a secondary aim is to address the relative influence of age, gender, and other structural variables (such as birth order, number of siblings, siblings’ pair composition, and nature of the sibling’s disability or illness) on siblings’ experience. Also based on research findings (e.g., O’Neill and Murray 2016; Shivers et al. 2019), a third aim is to investigate the correlations between SEQs, depression (Beck et al. 1996), and aggression (Buss and Perry 1992), as measures of internalizing/externalizing behavior problems. The study expected to find the following results: higher levels of warmth, as well as higher levels of anxiety toward disabled or ill siblings’ health in older participants; and a significant relationship between anxiety toward disabled or ill siblings, depression, and aggression.

The study of siblings’ experience of having a IDD, CPI, or MI sister or brother is important because: (a) it is a key construct in the area of development, prevention, and psychological well-being of siblings; (b) it can be a significant cause of psychological distress in siblings; and (c) the reduction of psychological distress is a key task when counseling siblings, and it can be considered an outcome measure in clinical interventions.

## Method

### Preliminary Steps and Construct Definition

According to the work of Spector (1992), we constructed our measure, the Siblings' Experience Quality Scale (SEQS), following these steps: (a) defining the construct; (b) designing the questionnaire; (c) pilot-testing the questionnaire; (d) administering the questionnaire and purifying the measure; and (e) verifying the construct validity.

The literature review regarding adult sibling relationships in the presence of IDD, CPI, or MI suggests that siblings' experience may include several dimensions other than those usually identified in studying sibling relationships (i.e., closeness, conflict, or rivalry). Firstly, regardless of the negative or positive impact of IDD, CPI, or MI, sibling relationships in these families are qualitatively different (e.g., Orsmond and Seltzer 2007). Secondly, siblings having IDD, CPI, or MI brother or sister are more at risk for internalizing, rather than externalizing, problems (e.g., Howe 1993; Ross and Cuskelly 2006; Rossiter and Sharpe 2001; Sharpe and Rossiter 2002). A difficulty in expressing emotions and feelings can be explained as a reluctance to asking for attention from their already-overburdened parents (e.g., Houtzager et al. 2005; Vermaes et al. 2012; Wood et al. 2008), as well as a response to increased caregiving demands (e.g., Atkin and Tozer 2014; Sharpe and Rossiter 2002), all of which lead these siblings to put themselves aside.

These emerging dimensions can be regrouped in the main areas usually individuated by studies of sibling relationships (Warmth/Closeness, Conflict, and Rivalry/Jealousy), to which we add a fourth specific dimension: Self-Marginalization.

To refine the definition of the construct before actually developing the items for the questionnaire, we used qualitative methods to better understand the most relevant dimension of siblings' experience. We carried out in-depth clinical interviews with adult IDD-Sibs, CPI-Sibs, and MI-Sibs ( $N=25$ ), recruited in private and public counseling centers, as well as a focus group with psychologists and psychotherapists acting in the target field ( $N=15$ ), and a focus group with nonacademic adult IDD-Sibs, CPI-Sibs, and MI-Sibs engaged in Non-Governmental Organizations (NGO) acting in the target field ( $N=15$ ). Interviews and focus groups were audiotaped, transcribed, and subjected to textual analysis – both thematic and narrative – in order to identify themes and patterns, and to identify core dimensions. These analyses suggested to us the need to insert a fifth dimension to our construct: Worry. Indeed, from the thematic and narrative analysis of interviews and focus groups, it clearly emerged that siblings' experience is characterized by a massive preoccupation with IDD, CPI, and MI brothers' and sisters' health and future.

Starting from this preliminary work and a study of the existing literature, we therefore defined the siblings' experience of having a IDD, CPI, or MI brother or sister as a multifactor construct composed of five fundamental dimensions: 1) Closeness dimension, which corresponds to sibling relationship qualities such as intimacy, companionship, affection, and knowledge; 2) Conflict dimension, which corresponds to sibling relationship qualities such as quarreling and antagonism; 3) Jealousy dimension, which corresponds to sibling relationship qualities such as jealousy and rivalry, as expressed toward parental love and partiality in the treatment of siblings; 4) Self-Marginalization, which corresponds to the impossibility of expressing needs and

difficulties, and to the feeling that one must not overextend their already-overburdened parents; 5) Worry dimension, which corresponds to siblings' preoccupation with IDD, CPI, or MI brothers' and sisters' health and future. These five dimensions were used to guide the creation and selection of SEQS items.

### Scale Design, Administration, and Item Purification

Once a definition had been outlined, the content validity judgment criteria for the items was consistent with the conceptual definition of siblings' experience. We began with an initial pool of 47 items (8–11 items for each dimension). We used a 7-point Likert scale, ranging from 1 (“*Strongly disagree*”) to 7 (“*Strongly agree*”), as response options. All items underwent the judgment of experts who were given the definition of the proposed construct and were asked to identify a) any ambiguity in the wording of the items and b) any incompatibility between the item and the dimension to be measured. Considering the comments and preferences received from the experts, 35 items were selected that could be reliably categorized into one of the five dimensions. The experts judged these remaining items from 1 (“*Least wrong*”) to 5 (“*Most wrong*”). The Kuder-Richardson reliability of the experts' judgments was .86, thus indicating stable judgments.

We administered this 35-item scale to a group of 18–53 years old Italian IDD-Sibs, CPI-Sibs, and MI-Sibs ( $N = 175$ ; 36% males, 64% females), in order to further select the items, deleting those with redundancy and comprehension problems. They were recruited (via the Internet) from private and public counseling and rehabilitation centers, and from NGO acting in the target field. We identified the factor structure of the questionnaire through Exploratory Factor Analysis (EFA, with Principal Axis Factoring and Promax Rotation). Inspection of the scree plot and the eigenvalues suggested a five-factor solution. Items that did not have loadings of at least .55 on any scale, and those with a loading higher than .35 on a second factor, were dropped from the data set (Kline 1995).

The final SEQS ultimately used in this research comprised 23 items (KMO was .820; total percentage of variance explained by the five factors was 66.3%) and included: 5 items for the Closeness subscale; 5 items for the Conflict subscale; 5 items for the Jealousy subscale; 3 items for the Self-Marginalization subscale; and 5 items for the Worry subscale (see Table 1).

### Participants and Recruitment Procedure

The sample used for the validation of the SEQS consisted of 213 Italian adult IDD-Sibs, CPI-Sibs, and MI-Sibs (153 women, 60 men; ages 18–69 yrs.,  $M = 35.9$ ,  $SD = 13.9$ ). The majority of siblings (52.1%) reported a brother or sister affected by IDD (16% Down Syndrome, 9.9% Autism Spectrum Disorders, and 26.8% other IDDs), while 30% reported to a brother or sister affected by CPI, and 17.8% reported to a brother or sister affected by MI (the diagnosis was through an official medical certificate uploaded to the survey). The majority of participants (52.1%) were first-born (40.4% had one sibling, 32.9% had two siblings, and 26.8% had three or more siblings). The sample had a high level of education, with

**Table 1** SEQS' items and factor loadings

Item	1	2	3	4	5
3. I feel close to my brother/sister	.78				
22. I consider the relationship with my brother/sister an important value in my life	.63				
12. I tell my brother/sister that he/she is important to me	.67				
7. I know really well my brother/sister	.61				
17. I laugh and joke with my brother/sister on so many things	.59				
1. I often get angry with my brother/sister		.79			
20. Me and my brother/sister often fight		.79			
10. My brother/sister and I often discuss animatedly		.78			
15. I often criticize my brother/sister		.77			
5. My brother's/ sister's behaviors often annoys me		.73			
18. I believe my parents always loved my brother/sister more than me			.90		
13. I believe my parents have always admired more my brother/sister than me			.82		
8. My parents have often treated me unfairly compared to my brother/sister			.72		
4. I was often jealous of the way my parents treated my brother/sister			.69		
23. I believe that my parents didn't take care of my problems as much as those of my brother/sister			.68		
19. I often feel that I cannot be wrong				.84	
14. I often feel that I don't have to worry my parents				.72	
9. I often feel that I cannot disappoint my parents				.55	
11. I think my brother/sister will have trouble getting into society					.87
21. I think my brother/sister will often be discriminated against					.83
6. I think that my brother/sister will never be truly autonomous					.82
16. I think that the affective life of my brother/sister outside the family will not be easy					.72
2. I think my brother/sister can never be accepted					.62

(*N* = 213)

more than half of the participants (55.5%) having a university degree or a postgraduate degree.

Participants were recruited via the Internet (by posting a link to the survey on the websites of universities, private and public counseling and rehabilitation centers, and NGO acting in the target field, and by asking to send the link to families, friends, and colleagues) from September 2018 to March 2019, according to the following criteria: be over the age of 18 years and have a brother or a sister with disability, chronic physical, or mental illness.

All data were collected through self-report questionnaires using an Internet-based survey (Hewson et al. 2016). Participants gave consent to participate in the study on the first page of the survey, which took approximately 20 min to complete.

Survey data were then entered into the SPSS 18.0 (Coakes and Ong 2011) and Mplus 7.2 (Muthen and Muthen 1998/2014) databases and checked/verified by project staff for accuracy.

## Measures

A *basic demographic questionnaire* collecting information regarding: participant's age and gender; birth order; disabled or physically/mentally ill sibling's age and gender; nature of sibling's disability or chronic physical/mental illness; number of siblings; and socio-economic status.

The *Siblings' Experience Quality Scale* (SEQS) is a self-report instrument assessing the emotional, behavioral, and cognitive experience of IDD-Sibs, CPI-Sibs, and MI-Sibs, and consisting of 23 items distributed on five subscales: (a) Closeness (5 items; e.g., "I feel close to my brother/sister"); (b) Conflict (5 items; e.g., "I often get angry with my brother/sister"); (c) Jealousy (5 items; e.g., "My parents have often treated me unfairly compared to my brother/sister"); (d) Self-Marginalization (3 items; e.g., "I often feel that I don't have to worry my parents"); (e) Worry (5 items; e.g., "I think that my brother/sister will never be truly autonomous"). Participants are asked to respond according to a Likert-type scale ranging from 1 ("Strongly disagree") to 7 ("Strongly agree"). Subscales scores are obtained by averaging the items that make up each subscale. Higher scores to subscales indicate higher levels of Closeness, Conflict, Jealousy, Self-Marginalization, and Worry.

The *Lifespan Sibling Relationship Scale* (LSRS) is a 48-item self-report instrument (Riggio 2000; Italian adaptation and validation: Sommantico et al. 2019a) assessing feelings, behaviors, and thoughts related to sibling relationships in childhood and adulthood on six subscales: (a) Adult Affect (8 items; e.g., "My sibling's feelings are very important to me"); (b) Adult Behavior (8 items; e.g., "My sibling and I 'hang out' together"); (c) Adult Cognition (8 items; e.g., "My sibling and I have a lot in common"); (d) Child Affect (8 items; e.g., "I was proud of my sibling when I was a child"); (e) Child Behavior (8 items; e.g., "My sibling and I shared secrets as children"); (f) Child Cognition 8 items; e.g., "My sibling and I were very close when we were children"). Participants are asked to respond according to a Likert-type scale ranging from 1 ("Strongly disagree") to 5 ("Strongly agree"). Participants are also asked to answer as truthfully as possible when referring to the disabled or chronically ill sibling. Subscales scores are obtained by averaging the items that make up each subscale. The total score is obtained averaging the six subscales scores. The highest mean scores on subscales and overall scale indicate the highest levels of Adult Affect, Adult Behavior, Adult Cognition, Child Affect, Child Behavior, Child Cognition, and overall attitudes toward sibling relationship. Authors of the Italian version of the LSRS (Sommantico et al. 2019a) reported good internal consistency for each subscale and for the total score. In the present study, Cronbach's  $\alpha$  ranged from .82 to .91 for each subscale and was .96 for the total score.

The *Beck Depression Inventory II* (BDI-II). The BDI-II is a 21-item self-report instrument (Beck et al. 1996; Italian adaptation and validation: Ghisi et al. 2006) assessing symptoms of depression. Each item (e.g., "Sadness"; "Loss of Pleasure"; "Self-incrimination"; "Irritability"; "Fatigue") is rated from 0 to 3 according to the severity of the experienced difficulties. Total score ranges from 0 to 63 and is categorized into four levels: absence of depressive contents (total score, 0–13); mild depression (total score, 14–19); moderate depression (total score, 20–28); severe depression (total score,  $\geq 29$ ). Authors of the Italian version of the BDI-II (Ghisi



et al. 2006) reported good internal consistency. In the present study, Cronbach's  $\alpha$  was .86.

The *Aggression Questionnaire* (AQ). The AQ is a 29-item self-report instrument (Buss and Perry 1992; Italian adaptation and validation, Sommantico et al. 2008) assessing aggression on four subscales: (a) Physical Aggression (9 items; e.g., "Given enough provocation, I may hit another person"); (b) Verbal Aggression (5 items; e.g., "When people annoy me, I may tell them what I think of them"); (c) Anger (7 items; e.g., "I flare up quickly but get over it quickly"); (d) Hostility (8 items; e.g., "I am sometimes eaten up with jealousy"). Participants are asked to respond according to a Likert-type scale ranging from 1 ("Extremely uncharacteristic of me") to 5 ("Extremely characteristic of me"). Subscales scores are obtained by averaging the items that make up each subscale. The total score is obtained by averaging the four subscales scores. The highest mean scores on subscales and overall scale indicate the highest levels of Physical Aggression, Anger, Hostility, and overall Aggression. The authors of the Italian version of the AQ reported good internal consistency and age invariance of the factor structure (Sommantico et al. 2015). In the present study, Cronbach's  $\alpha$  ranged from .79 to .84 for each subscale and was .82 for the total score.

## Ethical Considerations

The study complied with the American Psychological Association (APA) ethical standards in the treatment of human research participants and conformed to the provisions of the 1964 Helsinki declaration and its later amendments. Furthermore, the study was approved by the Ethical Committee of Psychological Research of the Department of Humanities of the University of Naples Federico II (prot. 3/2018).

## Results

### Confirmatory Factor Analysis of the SEQs

CFA was performed to determine the appropriateness of the proposed five-factor model. The verification of the factorial structure was effected through Confirmatory Factor Analysis (CFA), using the maximum likelihood estimation method. The fit indices used in this study are as follows: chi-squared distribution and the degrees of freedom ( $\chi^2/df$ ), Comparative Fit Index (CFI), Tucker and Lewis Index (TLI), Root Mean Square Error of Approximation (RMSEA), and Standardized Root Mean Square Residual (SRMR). According to the recommendations of Hu and Bentler (1999), McDonald and Ho (2002), and Tucker and Lewis (1973), the  $\chi^2/df$  must be in a range between 2 and 5, and the values of the CFI and of the TLI must be  $> .90$ . Those of the RMSEA are considered to be good if they are  $< .05$ , reasonable if they are  $< .08$ , and average if they are  $< .10$  (Kline 2005). Those of the SRMR must be  $< .09$  (Bentler 1990).

The model was tested on a sample of 213 subjects with no missing data, which resulted in high scores of goodness of fit ( $\chi^2/df = 1.98$ ;  $RMSEA = 0.047$  [.033–.061];  $CFI = 0.92$ ;  $TLI = 0.91$ ;  $SRMR = 0.063$ ). These findings support the hypothesis of a five-factor structure of the SEQs, as well as demonstrating convergence with the general construct of siblings' quality of experience.

## Descriptive Statistics and Factor Correlations

Means, Standard Deviations, and Cronbach's  $\alpha$ s for the four instruments are shown in Table 2. The internal consistency of the SEQS was relatively high: Cronbach's  $\alpha$  ranged from .74 to .88 for the subscales.

Factor correlations are shown in Table 3. The highest moderately significant correlation was between Self-Marginalization and Worry ( $r = .35$ ;  $p = .01$ ), while the other associations were small, although they indicate significant interrelationships among various aspects of the siblings' experience. Variations are apparent in the strength of scale intercorrelations, according to the nature of the subscales. The only places a significant correlation was not found was between Jealousy and Self-Marginalization ( $r = .10$ ), between Worry and Conflict ( $r = .03$ ), and between Closeness and Self-Marginalization ( $r = .04$ ).

## Correlations and Group Differences

Zero-order correlations between participants' age, chosen sibling's age, and the SEQS are shown in Table 3. Results showed small significant positive and negative correlations between participants' age, Closeness ( $r = -.21$ ,  $p < .01$ ), Jealousy ( $r = .15$ ,  $p < .05$ ), Self-Marginalization ( $r = -.19$ ,  $p < .01$ ), and Worry ( $r = .15$ ,  $p < .05$ ),

**Table 2** Descriptive statistics: Mean, SD, and Cronbach's  $\alpha$

	Females ( $N = 153$ )		Males ( $N = 60$ )		Total Sample ( $N = 213$ )		
	<i>M</i> (range)	<i>SD</i>	<i>M</i> (range)	<i>SD</i>	<i>M</i> (range)	<i>SD</i>	$\alpha$
Closeness	5.8 (1–7)	1.2	5.9 (1–7)	1.1	5.8 (1–7)	1.2	.78
Conflict	3.5 (1–7)	1.6	3.0 (1–7)	1.7	3.3 (1–7)	1.6	.88
Jealousy	2.5 (1–7)	1.6	2.1 (1–7)	1.5	2.4 (1–7)	1.6	.87
Self-marginalization	5.0 (1–7)	1.7	4.9 (1–7)	1.6	5.0 (1–7)	1.7	.74
Worry	4.5 (1–7)	1.8	4.3 (1–7)	1.9	4.5 (1–7)	1.8	.88
Adult affect	3.8 (1–5)	0.9	3.9 (1.3–5)	0.8	3.9 (1–5)	0.9	.91
Adult behavior	2.9 (1.1–5)	0.9	2.7 (1.3–4.9)	0.9	2.9 (1.1–5)	0.9	.82
Adult cognition	3.7 (1.1–5)	0.8	3.7 (1.9–5)	0.8	3.7 (1.1–5)	0.8	.86
Child affect	3.7 (1–5)	0.9	3.7 (1.1–5)	0.9	3.7 (1–5)	0.9	.91
Child behavior	3.1 (1–5)	0.8	3.0 (1.5–5)	0.9	3.1 (1–5)	0.8	.84
Child cognition	3.3 (1.1–5)	0.9	3.2 (1.3–4.8)	0.8	3.3 (1.1–5)	0.9	.88
LSRS	3.4 (1.3–4.8)	0.7	3.3 (1.8–4.9)	0.7	3.4 (1.3–4.9)	0.7	.96
BDI-II	21.1 (0–58)	14.2	21.7 (0–61)	17.4	21.2 (0–61)	15.1	.86
Physical aggression	1.9 (1–3.7)	0.7	2.2 (1–3.7)	0.6	2.0 (1–3.7)	0.7	.78
Verbal aggression	2.7 (1.6–3.8)	0.5	2.7 (1.6–3.8)	0.5	2.7 (1.6–3.8)	0.5	.84
Anger	2.9 (1.3–4.6)	0.7	2.7 (1.1–4.1)	0.7	2.8 (1.1–4.6)	0.7	.80
Hostility	2.9 (1.4–4.6)	0.7	2.7 (1.1–4.4)	0.7	2.8 (1.1–4.6)	0.7	.79
AQ	2.6 (1.4–3.7)	0.4	2.6 (1.4–3.7)	0.5	2.6 (1.4–3.7)	0.4	.82

( $N = 213$ )

**Table 3** Zero-order correlations between participants' age, chosen sibling's age, the SEQs, the LSRS, the BDI-II, and the AQ

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1. Age	–																			
2. Siblings' age	.89**	–																		
3. Closeness	-.21**	-.31**	–																	
4. Conflict	-.03	.03	.21**	–																
5. Jealousy	.15*	.21**	-.16*	.24**	–															
6. Self-marginalization	-.19**	-.20**	.04	.14*	.10	–														
7. Worry	.15*	.16*	.20**	.03	.14*	.35**	–													
8. Adult affect	-.25**	-.34**	.75**	-.38**	-.25**	-.05	-.36**	–												
9. Adult behavior	-.11	-.18**	.64**	-.05	-.03	-.04	-.29**	.66**	–											
10. Adult cognition	-.18**	-.24**	.77**	-.26**	-.12	-.01	-.26**	.81**	.74**	–										
11. Child affect	-.14*	-.22**	.55**	-.22**	-.25**	-.12	-.33**	.63**	.43**	.59**	–									
12. Child behavior	-.10	-.09	.42**	-.02	.03	-.01	-.25**	.41**	.50**	.50**	.55**	–								
13. Child cognition	-.13	-.14*	.47**	-.06	-.05	-.06	-.29**	.51**	.50**	.60**	.69**	.83**	–							
14. LSRS	-.19**	-.25**	.74**	-.20**	-.14*	-.06	-.36**	.82**	.78**	.87**	.80**	.77**	.84**	–						
15. BDI-II	-.04	-.03	-.12	.00	.11	.65**	.69**	-.29**	-.23**	-.23**	-.26**	-.13	-.22**	-.28**	–					
16. Physical aggression	-.09	-.02	-.03	.11	-.08	-.05	-.03	-.08	-.10	-.07	-.10	.03	-.02	-.07	-.04	–				
17. Verbal aggression	.02	.10	-.15*	.16*	.08	-.07	.02	-.16*	-.11	-.14*	-.12	-.05	-.13	-.15*	-.02	.15**	–			
18. Anger	-.11	-.01	-.07	.13*	.07	-.04	.01	-.07	-.03	-.01	-.04	.12	.05	.01	-.10	.53**	.11	–		
19. Hostility	-.06	-.03	.03	.01	.04	-.06	-.02	.08	-.01	.07	.12	.09	.08	.09	-.10	.25**	.03	.45**	–	
20. AQ	-.10	.02	-.06	.14*	.04	-.08	-.01	-.07	-.08	-.04	-.03	.08	.01	-.03	-.10	.74**	.38**	.82**	.69**	–

(N=213)

\*  $p < .05$ ; \*\*  $p < .01$

indicating that younger participants reported higher scores on Closeness and Self-Marginalization, while older participants reported higher scores on Jealousy and Worry. No significant correlations were found between participants' age and Conflict ( $r = -.03$ ). Results also showed small significant positive and negative correlations between chosen sibling's age, Closeness ( $r = -.31, p < .01$ ), Jealousy ( $r = .21, p < .05$ ), Self-Marginalization ( $r = -.20, p < .01$ ), and Worry ( $r = .16, p < .05$ ), indicating that participants reporting on younger siblings showed higher scores on Closeness and Self-Marginalization, while participants reporting on older siblings showed higher scores on Jealousy and Worry. No significant correlations were found between chosen sibling's age and Conflict ( $r = .03$ ).

Through two-way ANOVA, it was possible to verify both the direct effects of the participants' gender and the siblings' gender, as well as their interactions. The results only indicated a small significant effect of siblings' gender, with females reporting higher scores than males on the Conflict subscale ( $M_F = 2.8$  vs  $M_M = 3.4$ ;  $F_{1, 211} = 4.344, p < .05, \eta^2 = .02$ ).

Regarding birth order, ANOVA and Tukey tests indicate medium to large significant effects. Indeed, first-born participants showed higher scores than second-born or third-born (or more) participants on Self-Marginalization ( $M_{FB} = 5.2$ ;  $M_{SB} = 4.8$ ;  $M_{TB} = 4.4$ ;  $F_{2, 210} = 3.680, p < .05, \eta^2 = .03$ ). Furthermore, results indicated the following: participants reporting to third-born (or more) brothers or sisters showed higher scores than others on Closeness ( $M_{FB} = 5.4$ ;  $M_{SB} = 5.8$ ;  $M_{TB} = 6.2$ ;  $F_{2, 210} = 7.852, p < .01, \eta^2 = .07$ ); participants reporting to first-born brothers or sisters showed higher scores than others on Jealousy ( $M_{FB} = 2.8$ ;  $M_{SB} = 2.5$ ;  $M_{TB} = 1.9$ ;  $F_{2, 210} = 4.905, p < .01, \eta^2 = .05$ ); and participants reporting to second-born brothers or sisters showed higher scores than others on Self-Marginalization ( $M_{FB} = 4.7$ ;  $M_{SB} = 5.3$ ;  $M_{TB} = 4.6$ ;  $F_{2, 210} = 4.081, p < .05, \eta^2 = .04$ ).

Finally, ANOVA and Tukey tests indicate medium to large significant effects, depending on the brothers' or sisters' disability or chronic/mental illness. Indeed, the results indicated the following: participants reporting to a brother or sister affected by IDD showed higher scores than others on Closeness ( $M_{IDD} = 6.2$ ;  $M_{CPI} = 5.6$ ;  $M_{MI} = 5.1$ ;  $F_{2, 210} = 12.626, p < .01, \eta^2 = .11$ ) and Worry ( $M_{IDD} = 4.8$ ;  $M_{CPI} = 3.8$ ;  $M_{MI} = 4.5$ ;  $F_{2, 210} = 6.115, p < .01, \eta^2 = .06$ ); participants reporting to a brother or sister affected by CPI showed higher scores than others on Jealousy ( $M_{IDD} = 2.2$ ;  $M_{CPI} = 2.8$ ;  $M_{MI} = 2.4$ ;  $F_{2, 210} = 3.070, p < .05, \eta^2 = .03$ ); and participants reporting to a brother or sister affected by MI showed higher scores than others on Conflict ( $M_{IDD} = 3.0$ ;  $M_{CPI} = 3.5$ ;  $M_{MI} = 3.7$ ;  $F_{2, 210} = 5.038, p < .01, \eta^2 = .05$ ).

No significant differences regarding the number of siblings were found.

### Construct, Convergent, and Discriminant Validity

Zero-order correlations between the SEQs, the LSRS, the BDI-II, and the AQ are shown in Table 3.

Results indicated that: Jealousy was slightly significantly negatively correlated only with Adult Affect, Child Affect, and LSRS total score ( $r$  respectively  $-.25, -.25, \text{ and } -.14$ ;  $p = .01$ ); Conflict was only slightly or moderately significantly negatively

correlated with Adult Affect, Adult Cognition, Child Affect, and LSRS total score ( $r$  respectively  $-.38$ ,  $-.26$ ,  $-.22$ , and  $-.20$ ;  $p = .01$ ); and Closeness was moderately to highly significantly positively correlated with all LSRS subscales and the total score ( $r$  ranging from  $.42$  to  $.77$ ;  $p = .01$ ). As expected, Worry was slightly or moderately significantly negatively correlated with all LSRS subscales and the total score ( $r$  ranging from  $-.26$  to  $-.36$ ;  $p = .01$ ), and Self-Marginalization was not correlated with any LSRS subscales or the total score ( $r$  ranging from  $-.01$  to  $-.06$ ).

Results also showed that Self-Marginalization and Worry were highly significantly positively correlated with BDI-II ( $r$  respectively  $.65$  and  $.69$ ;  $p = .01$ ), thus indicating that to increases in Self-Marginalization and Worry correspond higher levels of depression. These data were confirmed by ANOVA and Tukey tests, indicating very large significant effects. Indeed, siblings showing higher levels of depression presented higher scores on Self-Marginalization ( $M_I = 3.4$ ;  $M_{II} = 4.8$ ;  $M_{III} = 5.8$ ;  $M_{IV} = 6.5$ ;  $F_{3, 209} = 72.489$ ,  $p < .01$ ,  $\eta^2 = .51$ ) and Worry ( $M_I = 2.8$ ;  $M_{II} = 4.6$ ;  $M_{III} = 5.1$ ;  $M_{IV} = 6.3$ ;  $F_{3, 209} = 81.259$ ,  $p < .01$ ,  $\eta^2 = .54$ ).

Finally, the results showed that the majority of the SEQS subscales were not correlated with AQ subscales or the total score. As expected, the only slightly significant positive correlation was between Conflict, Verbal Aggression ( $r = .16$ ;  $p = .05$ ), Anger ( $r = .13$ ;  $p = .05$ ), and AQ total score ( $r = .14$ ;  $p = .05$ ), while the only slightly significant negative correlation was between Closeness and Verbal Aggression ( $r = -.15$ ;  $p = .05$ ).

Taken together, these findings supported the SEQS construct, convergent and discriminant validity.

## Discussion

Confirmatory factor analysis has been carried out to find evidence of the construct validity of the SEQS. The model-data fit index showed good levels, indicating the hypothesized five-factor structure of the instrument. Furthermore, the internal consistencies of the five SEQS subscales showed relatively high values.

The results also supported the instrument's construct, convergent and discriminant validity. Indeed, scores on four of the five SEQS subscales correlated with almost all scores on the subscales and the total LSRS. Only the Self-Marginalization subscale was not correlated with LSRS subscales and total score, thus indicating, as expected, that it is a different construct, one which is not considered in constructing the LSRS. This means it truly is specific to the consideration of IDD-sibs, CPI-Sibs, and MI-Sibs. Furthermore, Self-Marginalization and Worry subscales were positively correlated with the BDI-II score, thus indicating, in line with the international literature (e.g., Alderfer et al. 2010; Hastings 2003; Howe 1993; Orsmond and Seltzer 2007; Vermaes et al. 2012; Verté et al. 2003), that in our sample as well, the experience of having IDD, CPI, or MI brother or sister represents a risk factor in terms of depression and internalizing psychological disorders. Finally, although in our sample scores on AQ subscales and total scale resulted under the mean, it is significant that the highest scores appeared in Anger and Hostility, which represent the affective and cognitive components of aggression. We can hypothesize that, partly in line with previous studies (e.g., Angell

et al. 2012; Ferraioli and Harris 2009; Moyson and Roeyers 2011), the experience of IDD-sibs, CPI-Sibs, and MI-Sibs is characterized by the most internalized component of the aggression and, consequently, by major difficulties in expressing it more externally.

Regarding groups' differences, our findings indicated that siblings reporting on younger, as well as on third-born (or more) brothers or sisters, showed higher scores on Closeness, as well as that first-born siblings showed higher levels of Self-Marginalization. We can interpret these data by hypothesizing that the experience of siblings of younger IDD, CPI, or MI brothers or sisters is mainly characterized by a positive affective component, but also by a sort of parentification (e.g., Hooper et al. 2011; Laghi et al. 2018; Tomeny et al. 2017a, b), leading them to put themselves aside. Furthermore, siblings reporting on older brothers or sisters showed higher levels of Worry. We can interpret this finding by hypothesizing that, in this case, due to the age of their older disabled/ill brothers and sisters, siblings' experience is mainly characterized by worry about the future (e.g., health condition, autonomy, and social inclusion) of their disabled/ill brothers or sisters. Finally, IDD-Sibs reported higher levels of Closeness and Worry, CPI-Sibs reported higher levels of Jealousy, while MI-Sibs reported higher levels of Conflict. We can interpret these data by hypothesizing, as stated by the international literature (e.g., Doody et al. 2010; Knecht et al. 2015; Mandleco and Mason Webb 2015; Seltzer et al. 2005; Tomeny et al. 2017a, b), that the siblings' experience varies according to the nature of the brother's or sister's IDD, CPI, or MI, thus calling for further investigation.

### Strengths and Limitations

This is one of the few Italian studies to examine the relationships of IDD-Sibs, CPI-Sibs, and MI-Sibs, thereby adding to the large literature in the field.

The first general limitation is related to sampling. Indeed, convenience sampling (e.g., community-based sampling, as well as snowball sampling) implies specific possible biases: e.g., volunteers' bias (related to the special characteristics of individuals who voluntarily participate in a study). Another possible bias in the study is that of mono-method, related to the fact that, having assessed all variables of the study by using self-report instruments, there can be inflation in observed associations. Because of this, future research could integrate quantitative data with qualitative ones, such as clinical interviews, in order to deepen different aspects of the sibling relationship with IDD, CPI, or MI brother or sister. Furthermore, our sample was not balanced with respect to gender. Future research could try to work with more gender-balanced samples.

The second limitation relates to the wide participants' age range. Indeed, it is possible that some construct, in particular Worry, varies across different life phases. Future follow up research could analyze this issue.

The third limitation relates to having considered, all together, different forms of IDD (e.g., ASD, DS, other IDD), due to our samples' characteristics. This did not permit us to differentiate among groups. Indeed, the literature findings, although not always unanimous, suggest that differences in sibling's experiences could be due to the specific subtype of disability/illness (e.g., Seltzer et al. 2005; Shivers et al. 2019).

A major strength of the present study is that, in constructing the instrument, siblings were seen as research participants, rather than as subjects or objects of research (Naylor and Prescott 2004). Indeed, especially in the first part of the study, siblings were seen as gatekeepers of the research, allowing researchers to enter their world, and helping them to identify specific dimensions of their experience in having a disabled or chronically ill brother or sister.

## Conclusions

As stated in the international literature, sibling relationships are the longest-lasting relationships in an individual's life, showing the importance of taking into account this relationship in developmental terms and of analyzing its evolution across the lifespan. However, the impact of brothers and sisters on individuals' lives takes on specific characteristics when they are affected by IDD, CPI, or MI (e.g., Burbidge and Minnes 2014; Fleary and Heffer 2013; Giallo et al. 2012; McHale et al. 2016; Meltzer and Kramer 2016; Saxena and Adamsons 2013; Shivers and McGregor 2019). Because of this, the SEQS is a useful self-report instrument for studying and assessing siblings' quality of experience in having a IDD, CPI, or MI brother or sister over the lifespan.

The results indicate that the SEQS has good psychometric properties, suggesting its ability to assess siblings' quality of experience in having an IDD, CPI, or MI brother or sister in the Italian cultural context. The SEQS is expected to be a useful self-report measure in future Italian studies. Among other possibilities, these could include studies examining, in broader samples, specific differences regarding etiologies, severity levels, and specific subtypes of disability/illness.

This study, together with the literature findings discussed above, indicates the necessity of improving additional support programs for siblings, such as support groups and school or community interventions (e.g., Naylor and Prescott 2004; Kryzak et al. 2015). These programs have been found to help siblings to articulate their feelings toward their IDD, CPI, or MI brothers and/or sisters, as well as in enabling self-expression and in facilitating their perception of social support. More generally, these data indicate that working with siblings and taking into account their need for support must be integrated into the planning of service delivery for families with disabled, chronically, or mentally ill children.

**Authors' Contribution** All authors contributed in the same way to conceive the study and its design, to draft the manuscript, and to interpret the data. All authors read and approved the final manuscript.

## Compliance with ethical standards

**Conflict of Interest** The authors declare that they have no conflict of interest.

**Ethical Approval** The study complied with the American Psychological Association (APA) ethical standards in the treatment of human research participants and conformed to the provisions of the 1964 Helsinki declaration and its later amendments. Furthermore, the study was approved by the Ethical Committee of Psychological Research of the Department of Humanities of the University of Naples Federico II (prot. 3/2018). This article does not contain any studies with animals performed by any of the authors.

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

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