

'The overall quality of my life as a sibling is all right, but of course, it could always be better'. Quality of life of siblings of children with intellectual disability: the siblings' perspectives

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Abstract

Background The concept of family quality of life is becoming increasingly important in family support programmes. This concept describes the quality of life of all family members and the family system as a whole, but only the opinion of the parents has been included. The opinion of the siblings has been incorporated in the opinions of the parents, although research has shown that there is discordance between parents' and siblings' reports. The principal goal of this study is to investigate how young siblings of children with intellectual disability define their quality of life as a sibling.

Method As we were more concerned with understanding the experience of being a sibling from the siblings' own frame of reference, we opted for a qualitative research design and more specifically used in-depth, phenomenology-based interviews. Data were sorted by means of a process of continuously comparing the codes according to the principles of grounded theory.

Results Siblings described the following nine domains as domains of sibling quality of life: joint activities, mutual understanding, private time, acceptance, forbearance, trust in well-being, exchanging experiences, social support and dealing with the outside world.

Conclusions This study shows not only that siblings can define their quality of life, but also that this definition of sibling quality of life differs from the family quality of life concept. Therefore, it may be not only a valuable addition to the family quality of life concept but also an appropriate concept to describe siblings' experience.

Keywords disability, family, quality of life, siblings, support

Introduction

During the last decade, the concept of quality of life has become increasingly important in the area of special education. Quality of life is about having a life that is good and meaningful for every individual. In fact, the main reason for focusing on a

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quality of life approach is to encourage improvement in people's lives (Schalock 2004; Jokinen & Brown 2005). Although quality of life addresses similar aspects and processes of life for everyone, it is a personal and unique concept that is best viewed from the individual's own perspective. As most people can judge aspects of their own lives, they are in the best position to describe their quality of life and to indicate how it can be improved or deteriorated. The concept was originally developed to describe the individual quality of life of a person with a disability, and the further concept of family quality of life has recently been developed (Brown *et al.* 2003; Poston *et al.* 2003; Turnbull 2004). Because a child with a disability has an influence not only on the other family members but also on the family system as a whole, the concept of family quality of life is intended to describe the quality of life of all family members and the quality of life of the family system and their influence on each other (Brown & Brown 2003; Turnbull *et al.* 2004).

In the development of this concept, however, only parents or the main caregivers have been asked to describe their family quality of life. The opinion of the siblings on their quality of life has been incorporated in the opinion of the parents. Recent research on sibling quality of life has, however, found a discrepancy between parents' and siblings' reports (Houtzager *et al.* 2004, 2005). Similar discordances between parental and sibling reports were found in studies on the influence of a child with a disability (Bat-Chava & Martin 2002; Guite *et al.* 2004; Lobato *et al.* 2005). Most research on sibling adjustment is based on parental report. Recent research has, however, shown that parents' perspectives may be strongly coloured by their own adjustment (Taylor *et al.* 2001; Bat-Chava & Martin 2002; Guite *et al.* 2004; Lobato & Kao 2005; Cuskelly & Gunn 2006; Verté *et al.* 2006). In summary, these studies on sibling adjustment present mixed results about the detrimental versus beneficial effects of having a brother or sister with a disability (Stoneman 2001; Cuskelly & Gunn 2006; Verté *et al.* 2006). On the one hand, these mixed results suggest that these effects are modified by several factors, such as the individual characteristics of the sibling and the child with a disability and the characteristics of the family (Hastings 2007). On the other hand, these results also show that most

sibling research is only focused on the detrimental effects of a child with a disability on the siblings, which is the maladjustment view (Fisman *et al.* 2000; Pit-Ten Cate & Loots 2000; Fanos *et al.* 2005; Giallo & Gavidia-Payne 2006). Therefore, Hastings (2007) stresses the importance of asking more positively framed questions about the impact of a child with a disability on the siblings.

Thus, to obtain the most comprehensive picture of the sibling's experience, it is also necessary to use self-report. Nevertheless, only a little research has been based on sibling report, and in most cases, data were collected from adult siblings. Hardly any study has investigated how young siblings, aged between 6 and 14 years old, describe their experience of being siblings of a child with a disability, even though a good insight into this experience is becoming more and more important in our inclusive society where siblings of individuals with a disability are increasingly taking care of their brother or sister (Taylor *et al.* 2001; Dew *et al.* 2004; Dodd 2004; Naylor & Prescott 2004).

Hence, we need a more general concept which can fully describe the dynamic relationship between siblings and their brother or sister with a disability. This concept will be useful not only in describing the relation between siblings and their brother or sister with a disability, but also in developing and evaluating sibling support programmes (Pit-Ten Cate & Loots 2000; Kaminsky & Dewey 2001; Lobato & Kao 2002; Skotko & Levine 2006; Orsmond & Seltzer 2007). As mentioned above, the concept of quality of life, and more specifically the concept of family quality of life (i.e. FQOL), has become important in the area of special education and family support. We can assume that parents' definition of family quality of life will differ from the siblings' definition of this concept. Therefore, the principal goal of this study is to explore how siblings define their quality of life as a sibling.

Method

Participants

Siblings were recruited to obtain a maximum variation sample which looked for variability across age, birth order, family size, gender and geographical region. Recruitment was conducted through

Table 1 Socio-demographic characteristics of siblings

Variable	Siblings (n = 50)
Age of siblings, mean (SD)	9.16 (2.04)
Age range (years)	6–14
6–8, n (%)	22 (44)
9–11, n (%)	20 (40)
12–14, n (%)	8 (16)
Gender, n (%)	
Female	27 (54)
Male	23 (46)
Position in family, n (%)	
First	18 (36)
Second	19 (38)
Third	12 (24)
Fourth	1 (2)
Position in relation to child with disability, n (%)	
Older	30 (60)
Younger	18 (36)
Twin	2 (4)

parents' associations, family support services, rehabilitation centres, special schools and (semi-) residential care services, equally spread in Flanders (Dutch-speaking Belgium). Inclusion criteria were the age of the sibling (between 6 and 14 years old), the age of the brother or sister with intellectual disability (ID; between 3 and 18 years old) as well as the type of disability (ID or profound intellectual and multiple disabilities).

Finally, 50 siblings, belonging to 37 families, volunteered to participate in this study. Socio-demographic characteristics for siblings, parents and children with a disability are presented in Tables 1–3, respectively.

Procedure

Qualitative research design

Recent childhood studies (Lewis & Lindsay 2000; Christensen & James 2008) have shown that children are the best resource for understanding their experience. Therefore, we started with the narratives of the young siblings, because we were interested in how they themselves would describe their quality of life. This involved choosing a qualitative research design, as we were more concerned with understanding the experience of being a sibling from the

Table 2 Socio-demographic characteristics of parents

Variable	Parents (n = 37)
Respondent's age, mean (SD)	39.70 (4.12)
Respondent's relationship to sibling, n (%)	
Biological mother	33 (89.2)
Biological father	4 (10.8)
Marital status, n (%)	
Married or cohabitation	35 (94.6)
Divorced	2 (5.4)
Respondent's educational level, n (%)	
Lower secondary education	1 (2.7)
Higher secondary education	5 (13.5)
Bachelor degree	27 (73.0)
Master degree	4 (10.8)
Respondent's employment, n (%)	
Full-time	11 (29.7)
Part-time	20 (54.1)
Not working	6 (16.2)
Partner's age, mean (SD)	41.54 (4.25)*
Partner's relationship to sibling, n (%)	
Biological mother	4 (10.8)
Biological father	29 (78.4)
Stepfather	2 (5.4)
Partner's educational level, n (%)	
Lower secondary education	0
Higher secondary education	15 (40.5)
Bachelor degree	14 (37.8)
Master degree	6 (16.2)
Partner's employment, n (%)	
Full-time	29 (78.4)
Part-time	4 (10.8)
Not working	2 (5.4)
Number of children in family, mean (SD)	3.02 (0.98)

* n = 35.

siblings' own frame of reference rather than with testing specific hypotheses (Bogdan & Biklen 1998; Corbin & Strauss 2008). More specifically, we chose to use in-depth, phenomenology-based interviews, as described by Seidman (2006).

This method combines life history and in-depth interviewing where the interviewer needs to build upon and explore the participants' responses to open-ended questions. This model of in-depth, phenomenological interviewing involves conducting a series of three separate interviews with each participant, allowing the interviewer and the participant to place the experience in context. In the first interview, the interviewer asked the participants to say as

Table 3 Characteristics of the children with a disability

Variable	Children (n = 38)*
Age of child, mean (SD)	10.0 (3.91)
Gender, n (%)	
Female	15 (39.5)
Male	23 (60.5)
Type of disability, n (%)	
Down syndrome	11 (28.9)
Intellectual disability	13 (34.2)
Profound and multiple intellectual disorder	14 (36.8)

* One sibling has two sisters (a twin couple) with a disability.

much as possible about him or herself up to the present time. The purpose of the second interview was to concentrate on the experience of being a sibling and on quality of life. In the third and final interview, the participants were asked to reflect on the meaning of being a sibling (Seidman 2006).

Based upon the foregoing principles, three lists of interview topics have been developed (see Table 4). As it was important to maintain enough openness for the siblings to tell their stories, the interview schedules were handled as flexibly as possible to give the siblings the opportunities to come up with unanticipated topics.

Research with young children

Actually, there was a second and even more important reason to handle this interview schedule flexibly. Because the participants in this study were rather young children, it was important to consider carefully the basic principles and landmarks of qualitative research and to adapt them if necessary. Openness is fundamental to qualitative research. Not the researcher but the participants have to decide which topics within the research theme are important. This meant that the siblings were given the opportunity not to talk about topics they disliked discussing. After all, talking about the experience of having a brother or sister who is different is an emotionally charged topic for siblings and could be threatening not only to them but also to the other family members. For this reason, in developing the research design and carrying out the study, we paid particular attention to the theme of trust

Table 4 Interview topic lists: examples of questions

Interview 1: focus on the life history of the sibling
Until today, what are the most important events in your life? (drawing time line)
Which things, that are happening now in your life, would you like to stay the same for ever?
Which things, that are happening now in your life, would you like to be changed immediately or a little bit later?
Can you tell me when you first realised, felt, saw that your brother or sister is different?
Interview 2: focus on the experience of being a sibling and on quality of life of the sibling
Can you tell me on which moments you really feel that you're experiencing things, because you are a sibling?
Drawing a thermometer measuring how you feel as a sibling. If I had a magic wand, what would you want me to change you, your brother or sister, your parents and other people (relatives, friends . . .) into, so you would rise on the thermometer? How would I have to change you, your brother or sister, your parents and other people (relatives, friends . . .), so you would fall on it?
What would be different here in your family, in your life, in your parent's life if your brother or sister wouldn't have a disability? Would some things be better or worse?
Interview 3: focus on reflection on the meaning of being a sibling
If other people ask you how it feels to be a sibling, what do you answer?
If our minister, responsible for the care for families with a child with a disability, decides to organise 'something' for siblings, which advice would you give to him?
Now we have almost finished our three interviews, are there some things left which we didn't talk about and which you would like to talk about?
Sometimes things can change after having talked about it. Do you feel that you or some things here at home have been changed by the things we talked about?

and the development of a relationship between the interviewer and the siblings.

The overall quality of this study was profoundly influenced by the degree to which the siblings felt at ease during the research in general and during the interviews in particular. Therefore, to attain this trust, different measures were taken. First, all the interviews took place at the siblings' home. For children it is often easier to feel comfortable in familiar surroundings and most of the time the interviewer and the sibling could sit and talk in a private room (in the sibling's bedroom, in the kitchen or in the office of one of the parents). If this was not possible, the researcher was very

sensitive to signals that the sibling did not feel at ease in the presence of other family members. If so, the researcher tried to find a solution (by closing the door or window or by moving outside or to another room).

Second, the background of the study and the methods used were clearly explained to the siblings and confidentiality was assured. The siblings chose their own pseudonym. Third, the importance of the sibling's participation in the success of our research was strongly underlined. The siblings were duly acknowledged and they were designated as co-researchers. Finally, during each visit, enough time was left for the researcher to play with the siblings after the interview was finished. This 'extra' time proved to be important for several reasons. As mentioned above, talking about the experience of having a brother or sister who is different is an emotionally charged topic for many siblings and can put a lot of stress on them. By playing after the interview, the sibling can relax and 'get rid of' his/her story. If the researcher had immediately left the siblings after the interview, they might have felt let down, in a low mood and perhaps with no one to comfort them.

This 'extra' time also proved to be important and interesting, because it gave the researcher the opportunity to observe the siblings' behaviour in their own 'natural' environment.

Because many siblings invited their brother or sister or their parents to participate in the game or the handicraft, the interactions between the siblings and their family members could be observed. These observations proved to be a useful addition to the narratives of the siblings.

A third benefit of this 'extra' time was that the siblings received exclusive attention for 1 h or sometimes even longer. Many siblings enjoyed this extra time, mainly because of this exclusivity. Finally, children like to play or to tinker with things, and by spending extra time with them and doing something they enjoyed, the researcher could give them something back in return for their story.

Talking about quality of life

Because the principal goal of this study is to define how young siblings define their quality of life, it was

a challenge to find a way to discuss this with the siblings.

The notion of quality is hard to understand for or difficult to explain to young siblings. So, based upon the research on the concept of family quality of life (Brown *et al.* 2003; Poston *et al.* 2003; Turnbull 2004; Summers *et al.* 2005), the following open-ended questions were asked: tell us about times when you like to be a sibling; what helps things to go well? tell us about times that have been especially tough for you as a sibling; what are the things that usually create tough times?

In addition to those questions, the metaphor of a thermometer was used. A thermometer was drawn on a sheet of paper and the siblings were told that this thermometer was measuring how much they liked to be a sibling: 0 meant the sibling really disliked it and 10 meant that the sibling really liked it. First, the siblings were asked to put themselves on this thermometer and to explain this. Next, the following question was asked: if I had a magic wand, what would you want me to change you into, so you would rise on the thermometer? how would I have to change you so you would fall on it? The same question was repeated, with any necessary changes, for the brother or sister with ID, the parents and other people such as relatives, friends and neighbours.

Data collection and data analysis

Following the principles of grounded theory (Miles & Huberman 1994; Bogdan & Biklen 1998; Mortelmans 2007; Corbin & Strauss 2008), there was an interplay between data collection and analysis (see Fig. 1).

Each sibling was interviewed three times. Each interview lasted between 40 and 70 min and was digitally recorded. The records of the interviews were transcribed verbatim by the researcher. Field notes were recorded that provided details and descriptions of the interview, the participant and his or her family members. The second and third interviews started with reading and discussing with the sibling the transcript of the previous interview. This member checking was important to guarantee and improve the validity of the research. The siblings were asked to check the text and to mark any

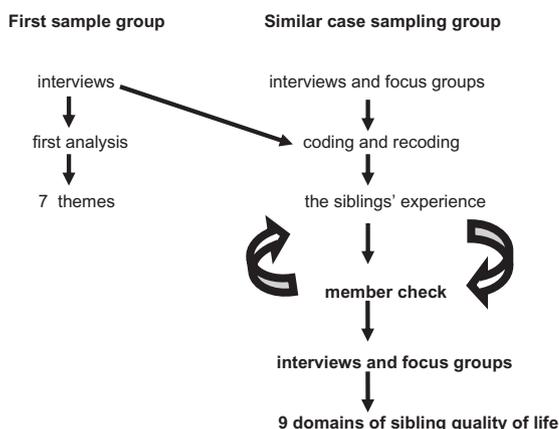


Figure 1 The process of data collection and data analysis.

material they wished to be deleted before it was used in the research.

In the second phase, the focus group method (Barbour 2007) was used in addition to the interviews. By giving the siblings the opportunity to talk with other siblings about their experience of being siblings and their quality of life, we found that the results of the interviews could be refined and completed. Two members of the research team facilitated two sessions (four and three participants) using a question route. Each focus group lasted approximately 80 min. Data were videotaped and transcribed verbatim afterwards. Additionally, one of the moderators recorded notes during the focus group to capture any observations that would not be apparent from the transcriptions.

Finally, additional family data, like education and occupation of the parents, marital status, composition of the family and the type of disability, were collected by asking the parents of the siblings to complete a family data questionnaire.

Based upon the principles of convenience sampling, the total group of 50 siblings was divided into two groups, a first sample group (32 siblings) and a similar case sampling group (18 siblings).

In the first phase, the siblings of the first sample group were interviewed three times. The transcripts were read twice line by line, and comments noted in the margins. Based upon this reading, a first list of seven themes emerged.

Then the second phase started with interviewing the similar case sampling group, following the same

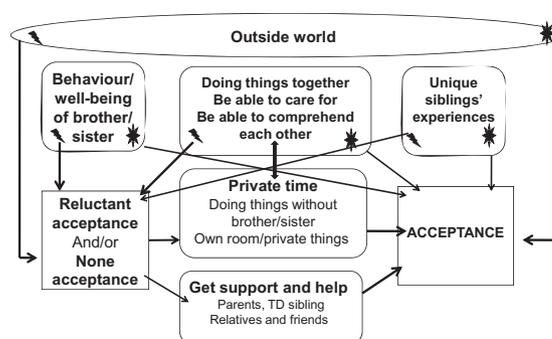


Figure 2 The sibling's experience. TD, typically developing.

procedure as in the first phase. A series of intensive individual (by the researcher) and team approaches (by the research assistants) to data analysis were conducted with NVIVO 8, a computer-based qualitative data management program, to facilitate the analysis. In addition, the interviews of the first sample group were coded and recoded again. During this continuous process of open and axial coding and constantly comparison of the codes, the codes were clustered into themes and patterns related to the central phenomenon, that is, sibling's experience (see Fig. 2; Miles & Huberman 1994; Corbin & Strauss 2008).

Finally, the third phase consisted of two focus groups and eight member check interviews. The purpose of this phase was twofold. At first, we wanted to test the themes and the patterns identified in phase 2. The second purpose of this phase was to explore if and how siblings can define their quality of life. To reach this, we first explained to the siblings the general concept of quality of life. Secondly, we showed them the 10 quality of life domains, generally accepted as important quality of life domains for children (i.e. physical well-being, psychological well-being, moods and emotions, self-perception, parent relation and home life, etc.). The siblings were asked to reflect on these domains and to tell us if those domains are also important for them as a sibling of a child with ID or not. Further, we asked the siblings if they could think of other important domains of quality of life. Nine domains of sibling quality of life emerged from these discussions (see Table 5). These nine domains represent aspects of the sibling experience that are considered to be important for a good quality of life as a sibling of a child with ID.

Table 5 Domains of sibling quality of life**Nine domains of sibling quality of life**

1. Joint activities
2. Mutual understanding
3. Private time
4. Acceptance
5. Forbearance
6. Trust in well-being
7. Exchanging experiences
8. Social support
9. Dealing with the outside world

Results**First domain of sibling quality of life:****Joint Activities**

Siblings appreciate the opportunity to do things together with their brother or sister with ID. It is their intention to do 'normal' things together as much as possible, and 'normal' refers to the things they would also do if their brother/sister did not have a disability. In other words, this means that it is important for siblings that the disability does not hinder a lot of activities.

It's good that I can play with him. We play football together, or we play billiards. We can do those things. (Stephan, 9 years old)

Yet, some activities will indeed be obstructed and so for siblings it is crucial to have the opportunity to do things together with their brother/sister with ID, albeit somehow differently, with the sibling adapting to the brother/sister with ID.

I can play with my brother, but only on his level – you understand? Without his disability, I really could play with him, like games I also like to play. Because, last week, I played with the dominoes with him, but then I have to say to him which card he needs to lay down, so we play without winning and losing. (Diewke, 12 years old)

It is, however, impossible to adapt everything and so siblings realise that some things cannot (yet) be done together with their brother/sister with ID. This also means that siblings with a brother or sister

'who really can't do anything' feel very bad about it.

My sister – of course I love her, but she can't do anything – can you imagine? Nothing is nothing – so I really wish I had a normal brother or sister to do all the things together. Only then, I will be really happy. (Standard, 9 years old)

Special kinds of activities are those in which siblings assume care tasks. Siblings consider these a bonus of being a sibling provided that the tasks are not imposed too much and that they do not hamper the siblings' own activities.

My mother always asks me to get my brother's glasses or to help my brother with other things. On some days, I'm the oldest one here! But I don't mind, I also take advantage of this! (Chris, 10 years old)

In fact, I'm a helpful person, but only for my sister! I really like taking care of her! (Rosie, 12 years old)

When my brother has made a mess, just guess who is asked to clean it up? Right, me! Even when I'm busy or doing my homework! (Anitha, 8 years old)

Second domain of sibling quality of life:**Mutual Understanding**

Really comprehending each other is assumed to be as a *conditio sine qua non* of successful interactions. For siblings it is vital to understand their brother/sister with ID: what does (s)he say, what does (s)he want, what does (s)he feel?

I can understand my brother – a lot of other people don't – even my dad doesn't always understand him – then he's asking me: what does he mean? And I always know what my brother means. (Diewke, 12 years old)

This also implies that siblings are anxious to have the opportunity to look inside the mind of, or be, their brother/sister with ID just for one day to be able to comprehend him/her even better.

Sometimes, I want to be just like him, because I want to know what he wants, how he feels, what

he thinks. So, I will be more considerate with him. (Nell, 9 years old)

Moreover, siblings also want to be comprehended themselves by their brother/sister with ID, although they realise that the extent of the comprehension will be quite limited.

Sometimes I ask her: 'Please give me the zapper' and then I point: 'Look, there is the zapper, give it to me'. And then she will bring me for example a cushion – I say: 'no, not the cushion, the zapper is just a little bit next to that cushion' and then she will start to look far away from that cushion . . . ; so then I give up, and take the zapper myself. (Martin, 8 years old)

It would be better if he could understand me better, for example, if I could tell him about my love life and so on. But I can't talk with him about such things. He only understands the simple things of life. (Laura, 13 years old)

Third domain of sibling quality of life: Private Time

Although siblings emphasise the importance of 'doing things together with their brother or sister with ID', they also express the need 'not to be a sibling for a while'. They want to have the opportunity to do things without their brother or sister with ID, to have private activities with their parents, to have a place of their own at home. In short, they want to have a life besides their life as a sibling.

Every school day, I come home at four o'clock and my brother is only at home at six o'clock. So, every day, there are two hours I can do the things I want and I don't have to show consideration for him. That's really good! It's also important that siblings have their own bedroom or a place where your brother can't come in; siblings really need a place where they can be alone. (Nell, 9 years old)

Sometimes, at night-time, we go to bed and when my brother is sleeping, I may go downstairs and then my mum and I play a game or watch television together. My brother doesn't know this! (Richard, 8 years old)

These moments of 'not to have to be a sibling for a while' prove to be helpful in more difficult situations.

For me, it is important that I have my own bedroom – because when my brother is teasing me or just bothering me, then I just go to my room, because my brother isn't allowed to come in there and he respects this! (Nell, 9 years old)

Fourth domain of sibling quality of life: Acceptance

Learning to accept that their brother or sister is different and always will be different appeared as a connecting thread in the stories of the siblings. For siblings, this acceptance process is a *conditio sine qua non* for their well-being as a sibling or for their quality of life. Therefore, it is not surprising that the siblings defined this acceptance process as an important domain of sibling quality of life.

You know, you really have to write down in your research report the following thing: if you are a sibling, then you have to accept that your brother or sister has a disability. Otherwise you will always have problems. (Laura, 13 years old)

Being able to accept the disability helps siblings not only to deal with situations which are different because of the disability of their brother or sister, but also to take advantage of it.

One day, I said to myself: come on Marie, it is sad to have a sister with a disability, but that's the way she is and always will be. She is different, she has other capacities and that's so nice! I really learned to appreciate the things she can do! (Marie, 11 years old)

Last summer, we visited an amusement park in France. My sister got a special disability card and therefore we didn't have to shuffle along. (Rebecca, 11 years old)

But of course, this does not alter the fact that sometimes it is still difficult to be a sibling.

When my friends are talking about all the things they did together with their brother or sister, then I can't take part in this conversation. I can't do such things with my sister and then I feel sad. (Marie, 11 years old)

Fifth domain of sibling quality of life: Forbearance

The behaviour of the brother or sister with ID will define the siblings' welfare to a large extent. On

'normal days' being a sibling is fine as the brother's or sister's divergent behaviour is not inconvenient.

You know, I got used to his special behaviour – that's just the way he is and most of the time, specially here at home, I don't mind. (Diewke, 12 years old)

Good news about the brother's or sister's behaviour can make siblings feel good, too.

Once, I was away during one week on a school camp and my mother sent me a letter, saying that my brother was well-behaved. I remember I felt happy and proud! (David, 12 years old)

On the other hand, however, there are days on which the irritating, peculiar conduct of the brother or sister with ID can give the sibling a hard time, even when he or she is not involved in it.

I know he can be good and he can be nice, but on some days he just refuses to it. Then it's really hard for me! (Tieme, 8 years old)

When I'm in my bedroom, doing my homework, and I can hear my brother screaming and yelling and throwing things away, then it's hard to be a sibling. (David, 12 years old)

Siblings develop different coping strategies to handle this behaviour, such as ignoring the behaviour, trying to understand it or adapting to it. Isolating themselves, doing something single-handedly (see also domain 3) and/or looking for support (see domain 8) will also help siblings.

Sixth domain of sibling quality of life: Trust in Well-being

Siblings feel fine about having a brother or sister with ID provided that the latter is also well. Siblings are strongly concerned about the physical and mental welfare of their brother or sister with ID.

When my brother is feeling sad, I'm sad too. (Laura, 13 years old)

When she was younger, she had to go to the hospital very often. I remember me sitting in the classroom and thinking of her and worrying . . . (Rosie, 12 years old)

Siblings also like the fact that their brother or sister with ID can have a worthwhile, pleasant time and that their future can be arranged properly.

I really hope that he will have a good life as an adult. We must find a good place for him to live, so he can be happy. Then, I will be happy too. (Laura, 13 years old)

The well-being of their brother or sister with ID is so important for siblings that they say they will do everything to improve it. This also implies that siblings really feel sorry about the disability of their brother or sister, not only for themselves as a sibling, but also for their brother or sister.

There are a lot of things I can do, but my brother can't. Sometimes we play a game and he asks if he can play with us. But then we have to say: no you can't, because it's too difficult. I think it is hard for him to see us doing things he can't. (Chris, 9 years old)

Seventh domain of sibling quality of life: Exchanging Experiences

By getting to know other siblings and exchanging experiences, but also by having fun with them, siblings do feel better. The story of like-minded persons helps them to understand their own story, to accept and at the same time to put things into perspective. Some siblings even describe those meetings as an opportunity to be a brother or a sister.

When I'm at school, I am just Diewke, I don't think about Emiel. When I go out shopping with Emiel and people are staring at him because of his behaviour, then I feel I am a sibling and I feel a lot of stress. But when I go to the activities of the parent group, I can be his sister, because I know that all people there are experiencing the same things. So, then I can relax and even enjoy Emiel's behaviour. (Diewke, 12 years old)

Although siblings recognise that meeting other siblings supports their well-being as a sibling, they also stress that 'solving the problems of siblings' is not the objective of such meetings.

I like the sibling camp, because there one will never ask us to talk about our 'sibling-problems'.

I never feel I have problems because of being a sibling, although it can be hard to be a sibling – you understand? (Delphine, 11 years old)

For siblings, activities specially organised for them as a sibling, are a benefit of being a sibling. Siblings experience a lot of unique events because of the disability. Some of those events, such as special sibling activities, can support the acceptance process, while others will harm it.

Thanks to my sister with a disability, I can go to the sibling day, organised by her school. We can eat pancakes there, or go on a boat trip . . . I like these sibling days, and I think her school organises it to thank us for all the things we do for our sisters and brothers! (Christine, 8 years old)

Eighth domain of sibling quality of life: Social Support

Siblings indicate that sooner or later they need support and help. In the first place they expect to get this support and help from their parents, so siblings will initially approach their parents, although they are aware that they already have a lot of worries. Consequently, siblings will not readily 'bother' their parents with their own worries.

It's hard for my parents too to handle my brother, day after day. So, in the evening, when my brother is in bed, they're just happy that they can sit down and relax. I don't want to disturb them then with my worries or problems! (Diewke, 12 years old)

Although siblings acknowledge that their brother or sister with ID needs more attention or care, they expect their parents to treat all their children equally. Siblings are aware of the benefits their brother or sister enjoys because of the disability. Hence, it is important that parents also spend time only with the siblings (see also domain 3).

For siblings, having a 'normal' brother or sister is also an additional resource. With this normal brother/sister, they can do the activities that (usually) cannot be done with the brother/sister with ID; moreover, the additional responsibilities can also be shared.

It's good that I also have Peter as a brother, otherwise I could never play games in a 'normal' way. (Laura, 13 years old)

Oh yes, it's much better that I also have one other sister and two other brothers: now we all help and support our special brother. Otherwise I would be the only one! (Delphine, 11 years old)

Some siblings who only have their brother or sister with ID are missing a typically developing brother or sister badly and they idealise this relationship.

I wish I had also another brother or sister, a younger one and a healthy one, so we always could play together. (Anitha, 8 years old)

Other relatives can also be a support for siblings, particularly because they are willing to take care of a brother/sister with ID, so the siblings can 'stop being a sibling for a while' or because siblings can call on them without the brother/sister being present (see domain 3).

Recently, my parents arranged that my brother could stay for a weekend with our grandparents. During that weekend we all could relax and we did things we can't do with my brother, like going to a musical and going out for dinner. (Diewke, 12 years old)

Finally, friends are important for siblings, not to talk with them about the disability, because siblings are realising that friends can never really understand them, but friends are just important because they can help you forget sometimes you're a sibling.

Ninth domain of sibling quality of life: Dealing with the Outside World

The outside world consists of all the people from the wider circle around the siblings who are aware that the siblings have an extraordinary brother or sister. For siblings this outside world can be a real support and help, provided that it appreciates the brother or sister with ID and at the same time accepts the sometimes difficult situations that siblings go through.

For siblings, an outside world that does not appreciate the disability of the brother or sister or

that laughs at siblings and/or their brother or sister with ID is a major source of stress.

Do you know what can make me feel very uncomfortable? If we go out for a walk with her, then people really are staring at her and at us! Perhaps this isn't meant badly, but still . . .
(Marie, 11 years old)

When we go out for a walk with her, I just want to show everybody, ehm, I don't know how to say it, ehm, I just want to say to everybody that we really love her! (Rosie, 12 years old)

Discussion

The principal goal of this study was to examine how young siblings of children with ID define their quality of life as a sibling. Because the individual's perception of their quality of life is unique, it is necessary to elicit information from the individual himself, even when this individual is still a young sibling. Although it was assumed for a long time that young children, precisely because of their age, are unable to report or to report accurately on their experiences, there is now growing evidence they can do so, if they are given the opportunity and appropriate questions are asked (Eiser *et al.* 2000a).

Moreover, the new sociology of childhood as described by James & Prout (1997 in Christensen & James 2008) emphasises that children, as active and independent subjects, interpret the practices that make up their everyday lives. Therefore, researchers have to treat children's accounts of their own experiences as valid in their own right.

Notwithstanding the casualness with which we handed the floor over to the siblings, we needed not only to be conscious of their rather young age but also to ensure that the information obtained was valid in that it genuinely represented the perspective of the siblings. As described earlier, by choosing and developing our methods in a particular way, we were able to take the age of the siblings into consideration. The validity of the results was guaranteed by the member check strategies.

The results of this study show that young siblings can describe their experience of being siblings. Looking more closely at their descriptions, we noticed that siblings often referred to a discrepancy

between what they could do as a sibling with their brother or sister with ID and what they would like to be able to do. This theme of discrepancies or differences between the hopes of a person and their present experience is often used in definitions of quality of life. People will adjust their expectations to what they perceive to be possible and that is the reason why, living under difficult circumstances, they can maintain a reasonable quality of life (Eiser *et al.* 2000b). It should be noted that those discrepancies denote the individual's perceptions and therefore refer to a subjective quality of life. The siblings in our study indeed expressed that they try to reduce the gap between experiences and expectations by adjusting to the disability, coping with the particular experiences and/or learning to accept the disability of their brother/sister. Therefore, in the light of the discussion on siblings' experience and quality of life, we can derive a first definition of sibling quality of life (see Table 5). It was remarkable that the broader domains that have been identified in quality of life literature, such as physical and psychological well-being, moods and emotions, self-perception, autonomy and parental relationships, are not fully supported and in general they are only partially addressed. This suggests that children's perspective is narrower than what adults may imagine, but it also confirms the finding of other studies that siblings' perspective is quite different from that of parents (Eiser & Morse 2001; Bat-Chava & Martin 2002; Guite *et al.* 2004; Houtzager *et al.* 2004, 2005). Because most of the research on sibling quality of life is based on proxy ratings, the results of this study constitute a surplus value for the study of quality of life, and more specifically for the study of family quality of life.

Despite their apparent narrowness and despite that one might consider these domains rather as indicators than domains itself, we decided to retain those domains as domains of sibling quality of life for two reasons.

A first and important reason is that the siblings themselves stated that the broad domains as formulated in general definitions of children's quality of life are important for them as children, but that those domains are not necessarily important for them as siblings of a child with ID. During the interviews as well as during the focus groups, siblings observed that being the sibling of a child with

ID is a very important part of their lives but that they are also 'normal' children, just like any other children without a brother or sister with ID. This means that siblings can distinguish between the factors influencing their quality of life as a child and factors influencing their quality of life as a sibling of a child with ID. As the siblings clearly explained the importance of the narrow and rather concrete description of these nine domains and as we stressed in this study the importance of not only starting from the perspectives of the siblings but also of accepting the self-reports as reliable, it was obvious to retain their descriptions.

A second important reason to retain those nine domains is that their narrow and rather concrete character serves to support siblings. Similar to the development of the family quality of life concept, we think it is important that the concept of sibling quality of life can be used to extend, to improve and/or to evaluate sibling support programmes.

Several studies have already highlighted the importance of support groups and workshops for siblings of children with ID (Evans *et al.* 2001; Houtzager *et al.* 2001; Lobato & Kao 2002; Williams *et al.* 2003; Dodd 2004; Naylor & Prescott 2004; Smith & Perry 2004; Fanos *et al.* 2005). Such support programmes provide an informal opportunity for siblings to get to know each other, to share the experiences and problems which they cannot talk about at home. It is also important that these meetings allow siblings to enjoy themselves in activities that are not compromised by their brother or sister with ID. Research has shown not only that those programmes are evaluated positively by siblings and parents, but also that they seem to increase siblings' adjustment. It is, however, almost impossible to determine if these effects can be attributed to the intervention. To do this, one needs measures which are reliable, valid and sensitive to change. Up to now such measures have been unavailable. We consider that the sibling quality of life concept is an appropriate concept to measure the effectiveness of sibling support programmes. Further work on this concept is needed to develop an instrument which can measure the quality of life of siblings.

The results of this study gave us an insight not only into the quality of life of siblings, but also into the siblings' experience. By giving siblings the

opportunity to talk about their life as a child and as a sibling, we received a 'total' story about the siblings' experience, the good and the bad. Hastings (2007) has already stressed the importance of studying siblings' own perceptions of positive contributions and the investigation of the functional significance of these perceptions for adjustment.

This research indeed shows that the good side of being a sibling can be helpful for siblings to learn to accept that their brother or sister is different. Most research on siblings' adjustment studies this adjustment in relation to static variables like age, birth order, family size. Apart from the fact that the results of those studies are frequently conflicting, their disadvantage is that one cannot change the static variables and so they are not helpful in supporting siblings' adjustment. Therefore, more dynamic variables, like family functioning, parental attention, parental relationships, family and sibling interactions, relationship between the siblings, are more relevant mediators of sibling adjustment, and it is useful to examine the effects of these variables on sibling outcomes. Although studies on dynamic variables also show some conflicting results, they nevertheless prove that interventions aimed at those dynamic variables successfully enhance siblings' adjustment (Cuskelly 1999; Schuntermann 2007).

In line with Stalker & Connors (2004), we also found that 'barriers to doing' and even 'barriers of being', as described in the social relational model of disability [Thomas (1999) cited in Stalker & Connors (2004)], could affect siblings. Siblings in our study told us about things they cannot do or are not allowed to do because of the disability of their brother or sister (barriers to doing) and about the reactions of the outside world, laughing at or bullying the siblings because of their brother or sister (barriers to being).

The results of our study show that siblings' adjustment can be enhanced by training in skills they can use to interact with the brother or sister with ID, to comprehend them, to handle their behaviour and to handle the reactions of the outside world. By learning those skills, siblings can control their own adjustment process and take control of the situation, which enhances their quality of life.

Limitations of the study

Because the participants in this study are young siblings, we could only approach and contact them through their parents. For several reasons, some parents refused to allow their child to participate. Consequently, we are aware of the pre-selection of our participants and the consequences of this on the results.

Moreover, although we tried to obtain a maximum variation sample, most participants belong to middle or high socio-economic families. Other studies have already shown the relationship between socio-economic status of the family and siblings' adjustment (Powell & Ogle 1985; Lobato 1990; Giallo & Gavidia-Payne 2006). We are aware of the influence of this fact on the results of our study and it remains a challenge to involve more siblings living in lower socio-economic families.

In this study, we only talked to siblings of children with ID or profound intellectual and multiple disabilities. Although there was enough diversity within this group, we are aware that siblings of children with another disability could define their quality of life differently.

Finally, it is also important to note that this study was carried out in Flanders (Dutch-speaking Belgium). We are aware of the potential differences of sibling responses in other cultures. Therefore, future research on sibling quality of life in other countries is recommended.

Future research

This study resulted in a preliminary definition of sibling quality of life. Further research is needed to refine this concept, to define sub-domains and to describe indicators which are domain-specific perceptions, behaviours and conditions which can give us an indication of sibling well-being.

It would be useful to repeat this study with siblings of children with another disability, like autism spectrum disorder or a physical disability. Because of the specific characteristics of those disabilities, we can assume that siblings will define their quality of life differently. For this reason, it is also recommended to extend this study to older siblings, because at different ages different aspects can be important in terms of a good quality of life.

Finally, it could be of interest to study the quality of life of siblings without a brother or sister with ID. By comparing this 'typical' sibling quality of life concept with the results of this study, we can distinguish between domains which are important for all siblings and domains which are only important for siblings of children with ID.

Conclusion

The family quality of life concept is intended to describe the quality of life of all family members. Therefore, we needed to study the quality of life of siblings. The results of this study show not only that siblings can define their sibling quality of life, but also that this definition differs from the parental definition of quality of life. This sibling quality of life concept, although further research is needed to refine it, can be used to support siblings, and to extend and evaluate sibling support programmes and family support programmes. In addition, this concept also gives us more insight into experience of being siblings and is therefore a good concept for a full description of the influence of a child with ID on his/her siblings.

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