

Parents' descriptions and experiences of young children recently diagnosed with intellectual disability

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Abstract

Aim The aim of the present study was to explore the variation of parents' descriptions and experiences of their child that was recently identified to have an intellectual disability (ID).

Methods The study applied interpretative phenomenological analysis and analysis of narrative style looking at content and form of parental narratives. Data was collected from nine fathers and eight mothers through semi-structured interviews within 6 months following diagnosis.

Results Analysis revealed three factors indicating the parents' level of processing: (1) emotional expressions regarding the child – varying between limited (distanced or idealized) and balanced/affectionate; (2) experience of the disability – varying between preoccupation and acceptance; and (3) time orientation – varying in terms of flexibility and temporal focus.

Conclusions Although parents of children with ID describe negative emotions in relation to the child and the disability, most of these parents also describe positive emotions that seemed to balance the negative experiences.

Keywords

child disability,
intellectual disability,
parent, parent
perceptions, qualitative

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Becoming a parent is, for most people, an overwhelming experience that involves a transition of identity as well as major lifestyle changes. Images and expectations of the child and parenthood are created and developed to a varying degree by the parents prior to the birth of the child (Stern 1995; Harwood *et al.* 2007). Meeting and gradually getting to know the child allows parents to adjust and develop these images of the child. When a child is diagnosed with intellectual disability (ID) an extensive revision of expectations and preconceptions may be necessary (Graungaard & Skov 2007). Previous research has established that the disability of the child affects parents in both positive and negative ways (Hastings & Taunt 2002; Beck *et al.* 2004). In the present study the aim was to look further into the variation of parents' descriptions of their child with ID.

Although children with ID differ from each other in terms of temperament, personality, diagnosis and other characteristics, an experience that many parents of children with ID have in

common is that of realizing their child has an ID. In Western society, 40–60% of these children receive a precise diagnosis (Curry *et al.* 1997). Diagnosis may take place instantly after birth, as with well-established chromosomal abnormalities, or become a gradual insight when the child's development appears to be delayed. Parents of infants with severe disability are negatively affected by uncertainty of diagnosis (Graungaard & Skov 2007). Factors that facilitate initial parental adaptation are: being able to do something for the child and equality and empathy in communication with health professionals (Graungaard & Skov 2007).

Several studies exploring parents' reactions to diagnosis (Marvin & Pianta 1996; Pianta *et al.* 1996; Button *et al.* 2001; Oppenheim *et al.* 2007) have put this experience into the theoretical context of attachment and caregiving (Bowlby 1980). Receiving a diagnosis was considered to be experienced as a loss or trauma by parents and hypothesized to affect parental

representations of the child. Parents' reactions to diagnosis were classified as resolved versus unresolved in relation to a diagnosis that was received months or years earlier (Marvin & Pianta 1996; Pianta *et al.* 1996). Approximately 50% of the mothers were classified as unresolved independent of type or severity of diagnosis, child's developmental age, or time since diagnosis. A lack of resolution was associated with insecure attachment of the child (Marvin & Pianta 1996).

Comparisons between mothers' descriptions of children with ID and typically developing (TD) children have concluded that these emotional experiences differ (Button *et al.* 2001; Beck *et al.* 2004; Hastings *et al.* 2006). Mother's descriptions of a child with ID tend to be more negative than the same mother's representations of a TD sibling (Beck *et al.* 2004), or mother's descriptions of TD children in families with no ID (Button *et al.* 2001). Furthermore, mothers' negative affective experience (worry, pain and sense of burden) was found to be associated with insensitive and unsupportive behaviour of the mother towards her child (Button *et al.* 2001).

Results from studies of reaction to diagnosis described above indicate that some parents of children with ID manage well while others find it more difficult to adapt, which in turn may affect the quality of parenting behaviour. Several authors have pointed to the tendency amongst researchers to request and focus on negative aspects such as an increase in stress-levels, depression and caregiver burden (Hastings & Taunt 2002; Green 2007). Hastings and Taunt (2002) suggested that positive and negative perceptions constitute different dimensions and that parents, although reporting greater stress, may not necessarily experience less positive emotions. Positive aspects could be sense of satisfaction and joy when caring for the child, strengthening of family cohesion, and personal or spiritual development. Positive emotions have been suggested to play an important role in relation to stressful events, serving to restore coping resources (Folkman 2008), which is relevant in the context of parenting a child with ID.

So far studies of parents' emotional experiences of their child with ID have tended to focus mainly on mothers, using methods exploring predefined emotional constructs aiming to quantify these experiences (e.g. Button *et al.* 2001; Beck *et al.* 2004; Hastings *et al.* 2006). In the present study the aim was to explore variation in parents' descriptions and experiences of their child that was recently identified to have an ID. More specifically the intention was to find out how parents' describe their child, the child's ID, and the experience of being a parent in this context. From a clinical perspective it would be of importance to further understand parents' emotions towards their child shortly after

the discovery of the ID to make appropriate support available for these parents.

Method

Sample

The sample consisted of 17 Swedish parents (eight mothers and nine fathers) of nine children aged between 5 months and 5 years (see Table 1). All parents were co-habiting or married biological parents of the child at the time of the interview. The children were diagnosed with intellectual disabilities and/or autism, or were in the process of being diagnosed. The aim in recruiting was to sample a group providing examples of the variance in the population of parents of children with ID, but with the common experience of having found out that their child has an ID within the past 6 months.

Following approval from the National Ethics Committee families were recruited through community based clinics providing services for families of children with disabilities. The sample in the present study is a subsample of a larger study of 68 parents with children diagnosed/in the process of being diagnosed with an ID. The families lived in the south-western part of Sweden and were able to communicate in Swedish. Approximately 150 families were informed about the study and 68 mailed their interest. The first 10 families who ticked a box for volunteering for a face-to-face interview were contacted by phone. One couple and another mother declined shortly before the interview due to unknown reasons.

Measures and procedure

Most interviews took place at the university premises or at local clinics for children with disabilities, a few parents were interviewed in their homes. Parents were told that the research focused on parenting the child with ID. Mothers and fathers were interviewed individually for approximately 1 h. The interview was semi-structured and the style was non-directive to elicit narratives characterized by what was most prominent for the parent in everyday life with their child at the time. The aim of the interview was to obtain an image of parents' perceptions and subjective experiences. The interview questions dealt with the following topics: positive and negative aspects of the present life situation, changes in perceptions of self and life situation related to the child, previous expectations compared to present life situation, and expectations about the future. The questions were followed by 'minimal probes' (Smith & Osborn 2003) when needed.

Table 1. Characteristics of participants

Child		Parent		
Sex, age†, birth order	Diagnosis	Mother/father	Age	Parental education
1. Boy, 5 years, third child	Initial diagnosis autism retracted. Awaiting diagnosis.	Mother	30	Upper secondary education (2 years)
2. Boy, 15 months, second child	Obstetric brachial plexus palsy	Father	34	Upper secondary education (2 years)
		Mother	32	Upper secondary education (2 years)
		Father	34	Upper secondary education (2 years)
3. Boy, 7 months, first child	Down's syndrome	Mother	33	Graduate degree
		Father	33	Graduate degree
4. Girl, 19 months, first child	Deletion on chromosome 14	Mother	27	Upper secondary education (3 years)
		Father	27	Upper secondary education (3 years)
5. Boy, 5 months, first child	Down's Syndrome	Mother	24	Upper secondary education (3 years)
		Father	25	Graduate degree
6. Girl, 4 years and 9 month, second child	Autism	Mother	41	Graduate degree
		Father	43	Upper secondary education (3 years)
7. Boy, 5 years and 3 months, second child	Awaiting diagnosis	Father (mother declined)	37	Upper secondary education (2 years)
8. Girl, 6 months, second child	Mosaic trisomy 14 syndrome	Mother	34	Graduate degree
		Father	38	Military training
9. Boy, 14 months, first child	Spinal muscular atrophy	Mother	26	Partial university studies (1 year)
		Father	31	Upper secondary education (3 years)

†Age of child is given in months or years.

Each interview was audiotaped and later transcribed verbatim. Following completion of data collection all narrative material describing the child with the disability, and parenting the child was selected and analysed.

Analysis

The aim of analyses was to explore variation of parents' descriptions and experiences of their child who had recently been identified to have an ID. Two steps of analyses were made looking at: (1) content and meaning; and (2) format and narrative style. We were not searching for previously set constructs – factors and dimensions presented as results were derived from the narratives of the parents by extracting what was most prominent in these particular interviews.

1 Analysis of content and meaning, *what* was being said: after reading and summarizing the entire interview, relevant narrative units concerning the child, the disability and parenting were extracted and organized into themes (Table 2, step 1). The method for analysing content and meaning was derived from interpretative phenomenological analysis (Smith 2003). Expansion/elaboration (Kvale 1997) of the relevant narrative units was performed by making preliminary interpretations and free commentaries of both content and format (Table 2, step 2). Condensation of content of narratives was made by re-reading the original text, checking the accuracy of

Table 2. Example of process of analysis

Steps of analysis	Interpretation of content and narrative style
1. Original narrative unit	Mother – Well, it's that she's fitting, she refuses to ... I can't get it right and it's just this ... when I'm feeding her I have to sit very comfortably and she has to have her chair ... she has a special chair to sit on. I can't sit in a café and feed her, and ... perhaps people wouldn't even mind, as it is common these days ... there are disabled people everywhere ... but it is still a stressful situation for me ...
2. Expansion/Elaboration	The child's special needs in the feeding situation are experienced as an obstacle by the mother and causes stress. Mother appears conscious of other people's perceptions of the child, which may be a reason why they cannot eat out. The child 'refuses', mother attribute intention to the child's behaviour.
3. Condensation of content	Child has special needs causing a difficult feeding situation. Experience of stress and discomfort.
4. Narrative style and format	Negative description of child: Ascribing intentionality to child's difficult behaviour. The young child with a severe disability 'refuses' to eat. Concerned with how other people perceive the child with ID. Attempt to put it into perspective.

interpretations with a focus on *what* was being told. The interpretation of content was transformed into a more condensed and abstract form aiming to capture the essence of content in each narrative unit (Table 2, step 3).

2 Analysis of format and narrative style: *how* parents spoke of the child, parenting and the disability: ideas were taken from the fields of linguistics (Grice 1975), attachment (Hesse 1999) and narrative analysis (Gergen & Gergen 1984). Aspects of format that were examined were: temporality of narratives, emotional peaks (issues that appeared to take up the parent's energy, time and thoughts), perceptions of the child (richness and depth of description, positive/negative balance, etc.), coherence and relevance of narratives, and perceptions of disability/diagnosis (Table 2, step 4).

3 When merging the steps of analysis described above, this resulted in three main factors found in all interviews that will be described in the results section.

The analysis was done by the first author in close collaboration with the second author. Overall structure and concepts as well as uncertainties about how to code individual statements were discussed until consensus was reached. Analyses were made with a focus on parents' experiences of their child inspired by the theoretical perspective of attachment and caregiving (Bowlby 1980; Mayseless 2006a) with an interest in parents as caregivers.

Results

The process of analysis resulted in the definition of three main factors that were present in all interviews. The factors were: (1) *parents' emotional expressions regarding their child*; (2) *experience of the disability*; and (3) *time orientation – past, present or future*. Similarities and differences in the parents' descriptions of each factor were summarized and described in general terms, not absolute figures, due to the limited number of participants.

Parent's emotional expressions regarding the child

Parental emotional expressions regarding the child varied greatly in intensity as well as in type of emotions expressed. The organization of positive and negative emotions towards the child was analysed. Emotional expressions ranged from *balanced*, mainly affectionate narratives, to *limited* narratives being either mainly distanced/hostile or idealized.

Most of the parents gave balanced and affectionate descriptions of their child characterized by the following elements:

- Presence of positive and affectionate/loving descriptions of the child.

- Balanced and nuanced descriptions of the child's positive and negative characteristics, usually with an emphasis on positive characteristics.
- Description of well-functioning routines and parent–child interaction.
- Description of the child as an individual or person.

A father described the characteristics of his 7-month-old son: 'I think he is a lovely person already, in a way he has his own personality, very charming. But the fact is you simply have to take care of him.'

In contrast to the balanced/affectionate narratives, a few parents described their child with a more limited range of expressions. The narratives indicated a somehow distorted or unbalanced view of the child and the story was sometimes told in an incoherent (fragmented or contradictory) or irrelevant manner (not answering the questions). Distance/hostility was characterized by the following elements:

- Predominantly negative descriptions of child.
- Use of strong negative descriptions of the child.
- Indications of ambivalence, resistance or distance towards the child.

Idealization was characterized by:

- Overly positive descriptions of the child (based on discrepancies or inconsistencies within the interview).
- A lack of descriptions of shortcomings or difficulties. Nuance in the description of the child was lacking.

A mother described her 4-year-old daughter with distance:

She began to pull her hair off, and as if that was not enough . . . the kid ate it . . . it was so disgusting that I thought I would die . . . Well, you know yourself what it's like getting hair in your mouth, you want to get rid of it at once, but she was so little at the time that the hair came out in the nappy, the natural way. In the end my husband thought, he has a trimmer, so he . . . he used the trimmer on her and she became all bald.

Experience of the disability

The diagnosis or disability appeared to affect parents to various extents. Most parents seemed more or less preoccupied with the disability and consequences of the diagnosis, while other parents spoke of the disability as an integrated part of the child and everyday life.

A few parents told narratives that indicated various degrees of *acceptance* and the disability was not a predominant part in those narratives – it was as if the figure (the disability) had merged with the background. The following themes were found in the sample:

- Acceptance of the disability as an integrated part of the child.
- Minimal focus on the disability during the interview as the disability played a minor role in everyday life.
- Reflection on emotional change since the time of diagnosis.
- Balanced descriptions of both positive and negative emotions in relation to how the disability affected the parent's life.

An example of emotional change over time told by a mother of a 6-month-old daughter:

And since I had Lina . . . I have never been so sad ever in my life . . . like a deep sadness or whatever you would like to call it, and I was completely thrown by it because they didn't know anything about Lina's impairment then or deviation and (. . .) in Lina's case they said 'we don't even know if she will survive'. And then, when things went well nobody ever took it back (. . .) and this was only six months ago and I feel great now.

Despite the short time period that had lapsed since the diagnosis, some parents had quickly arrived at a certain degree of acceptance of the disability.

Preoccupation with the disability/diagnosis and its consequences on everyday life focused on different themes, but the common characteristic was that thoughts about the disability/diagnosis played a dominant role in the parent's everyday life. The following themes were found in the present study:

- Lack of diagnosis/disagreement about diagnosis. Some parents were trying to find a diagnosis, or to understand or change the diagnosis that did not correspond with the parents' view of the child.
- The child's disability in relation to the surrounding world. A focus on existential issues such as how other people perceived the deviant/unusual child, the child's vulnerability, the rights of the child to have a place in society and how the ID affected the identity of the parent.
- One or several traumatic events. Some parents were attempting to process that their child had gone through several critical periods during pregnancy, birth or the first few months of life.
- Severe disability. A very severe disability could be described as complicating communication with and understanding the child. Some parents described their struggle to understand the child.

A father of a 19-month-old daughter described the severity of the disability and his longing to give her a positive experience:

I feel so anxious about not being able to reach her. I wish I could give her a visual experience; perhaps I could give her some, something like wow! So that she just goes wow! That is so cool! Or something like that. But I, as soon as I start to imagine what it is like for her, when she just lies there and watches and it's just like, yes it's like watching a silent movie or something. That is why I don't even think she understands what she sees and that I can't give it to her. I can't reach it as it is like a blockade [*sic*].

Time orientation – past, present or future?

When analysing the interviews in terms of temporality, it became apparent that parents differed in terms of what tense the main focus of the narrative was set in – past, present or future. They also differed in terms of flexibility or fixation.

Preoccupation with past and present

Some narratives were dominated by past experiences or the demands of the present life situation with little or no reference to the future. These parents could be preoccupied with one or several demanding factors in life making them unable to move on and see the future.

Preoccupied with the past or present, making attempts to think/speak about the future

Narratives that were mainly set in the present and past with some reference towards the future, showing some degree of flexibility. These parents were clearly affected by the disability of the child but made attempts to think about the future.

'Moving freely'

These narratives were predominantly set in the present with references to the past and future. These parents moved freely and flexibly in their storytelling between past events, present events, and towards both hopes and concerns about the future.

A mother of a 14-month-old son diagnosed with a lethal disability reluctantly spoke about the future:

Noo . . . no . . . the only thing that feels like a natural thing to worry about is whether Karl is going to become a big boy or not, but that is something I don't usually think about. (. . .) No, I couldn't bear walking around

thinking about such things. You never know. We try to keep him in as good shape as possible. One day he might not make it. One day there might be . . . stem-cell research that has resolved it so that he can get strong. It . . . we just care for him until whatever comes first. So I don't think I feel particularly sad about anything. I don't feel sad.

Discussion

The aim of the study was to explore the variation of parents' descriptions and experiences of nine children who had been identified to have ID within the past 6 months prior to the interview. In the narrative material concerning the child, three common factors were identified in all 17 interviews; *emotional expressions regarding the child, experience of the disability and time orientation*.

Considering theoretical assumptions (Zeanah & Benoit 1995; Mayseless 2006b) and empirical indications (Button *et al.* 2001) about the relation between parents' descriptions of their child and caregiving behaviour, we suggest the emotional expressions regarding the child to be a fundamental factor, offering important information about the parent's perceptions of the child, parenting experience, and possibly the climate of the parent-child relationship. Most parents in the present sample provided rich and varied descriptions of the child, and were considered to be balanced despite the relatively high prevalence of negative descriptions. Parents of TD children are mostly considered balanced, and the affective tone of these interviews contains high levels of joy, medium levels of anxiety, and moderate levels of anger, indifference and sadness (Rosenblum *et al.* 2006). In the present study we suggest that even though negative emotions had a prominent role in some of the narratives, stories of joy, love and other positive emotions could counterbalance the difficulties experienced by parents. The results of the present study agree with findings from other studies indicating that parents of children with ID may display an increase in negative perceptions of their present life situation, and simultaneously describe similar or sometimes higher levels of positive perceptions compared to parents of TD children (Hastings & Taunt 2002).

The minority of narratives that were considered limited differed from the balanced descriptions in that they were lacking in nuance and variation. The narratives that contained hostility/distance were told by parents that seemed to be greatly affected by the ID indicating a need for professional support. The implications of focusing only on positive aspects of parenting a child with ID are not easily interpreted. Mothers' minimizing strategies have been found to promote a less negative experience of

the child, but at the same time interfere with the parent's ability to sensitively interpret and respond to the child's needs (Steinberg & Pianta 2006).

Experience of the diagnosis constituted a more or less dominant factor in parents' narratives. Most parents in the present study appeared to be struggling with thoughts about the diagnosis and experience the disability as a central element in their everyday lives causing negative emotions. In some parents' narratives the disability played a less significant role and seemed to be a more or less integrated part of everyday life. Considering the short time period that had lapsed since the diagnosis, parents could be expected to be preoccupied with thoughts about the disability. It is perhaps more remarkable that some parents had already arrived at an acceptance of the disability. Even though the concept of parents' 'acceptance' of a child's ID is controversial (Larson 1998), we have chosen to use this word in the present study. Parents' level of acceptance may vary continuously over time and differs from the final stage of grieving as was described by Kübler-Ross (1969). Instead we suggest that acceptance of a child's ID includes the ability to contain opposing thoughts and emotions about the disability as proposed by Larson (1998), but without being preoccupied with or dominated by the conflict of thoughts.

Positive emotions that co-occur with negative emotions during stressful events have been suggested to restore psychosocial and physiological coping resources (Folkman 2008). We hypothesize that the strong positive emotions towards the child experienced by most parents, as well as positive thoughts and experiences by some parents in relation to the ID found in the present study could work as protective factors promoting parents' ability to cope with realizing their child has an ID. However, the relationship between positive emotions and parent well-being needs further investigation.

The time orientation factor provides an overview of each parent's narrative focus in terms of past, present or future, as well as level of flexibility. When studying the relationship between temporal orientation and ability to cope with trauma, Holman and Silver (1998) found that during normal life-events, as well as various types of traumatic events an extended temporal perspective (from the distant past to distant future) together with an orientation towards the future appeared most beneficial for over-all mental health and well-being, while an orientation towards the past was related to elevated levels of psychological distress (Holman & Silver 1998). Individuals who maintained an orientation towards the future shortly after the trauma experienced lower levels of psychological distress over time. The two dimensions temporal perspective and orientation seem to be integrated in the time orientation factor found in the

present study. We suggest that this knowledge can be applied to the present sample and that tense and flexibility of parents' interviews may be indicators of parental stress.

According to findings by Marvin and Pianta (1996), as many as about 50% of parents end up resolved and the remaining 50% stay unresolved with regard to their child's diagnosis. Parents were considered resolved if they demonstrated a recognition of emotional change since diagnosis, an assertion of moving on in life, suspension of the search for reason, an accurate representation of the child's abilities, and a balanced description of both positive and negative aspects of this experience (Pianta *et al.* 1996). Results from the present study confirm the elements used by Marvin and Pianta (1996) to classify parents. However, we suggest the concept of reaction to diagnosis could be seen as an ongoing process, and parents may vary in degree of resolution on a continuous scale. Some parents may initially go through a phase in which they are unresolved and then move quickly towards resolution. The three factors found in the present study offer a nuanced perspective of parents' reaction to diagnosis and may serve as early indicators detecting parents whom are at risk of staying unresolved.

Methodological considerations

There were several limitations in this study that need to be considered. To be able to provide the level of detail and to preserve openness during the analysing process sample size was small. Consequently, conclusions about the effects of variables such as child age, gender, diagnosis, or severity of disability, or parental characteristics could not be drawn. Due to the nature of the sampling procedure the present sample may differ from the population of parents of children with ID in aspects such as motivation and stress-level. To test transferability of the results to other groups, further studies should be performed on larger samples. Additionally, we suggest that the relationships between the factors found and parental sensitivity, as well as parent well-being need to be explored.

There were inherent challenges in the process of analysis that should to be reflected upon. During analysis we attempted to interpret and merge 'inside' (interpretative phenomenological analysis) and 'outside' psychological (analysis of narrative style) perspectives. Analyses of parents' narratives were influenced by the theory of caregiving and attachment (Mayseless 2006a), considering parents' emotions towards the child to be of significance, not just for the parent as an individual, but also to have an impact on caregiving and attachment. However, further studies are needed to establish the relationship between the factors

found in the present study and the specific needs of children with ID in terms of parental sensitivity (Oppenheim *et al.* 2007).

Clinical implications

We suggest that parents would benefit from interventions at an early stage as most parents in the present study described difficulties in adjusting to the reality of having a child with ID a few months after the diagnosis. In particular, parents with limited descriptions of their child may indicate a need for therapeutic interventions, aiming to promote parental sensitivity and parent-child interaction. Parents need to be encouraged to explore the variation of emotions in relation to their child and the disability, and allow for emotions that may be extreme or contradictory. Most parents in the present sample were experiencing uncertainty and frustration in relation to the diagnosis. Questions about how the diagnosis and medical complications will affect the future of the child and the family may be prominent, and professionals are sometimes unable to provide answers. Instead, parents should be supported in dealing with the uncertainty on a long-term basis.

Some parents experience difficulties with the disability/diagnosis in relation to the surrounding world, which in turn affects the parent's own sense of identity. These parents may benefit from meeting with other parents of children with ID to diminish the sense of estrangement and gradually accepting the special circumstances of their lives.

Key messages

- Parents' thoughts and emotions are highly affected by finding out that their child has an ID.
- For most parents there is a combination of positive and negative emotions towards the child with ID.
- The recent diagnosis of the child appears to influence parents' orientation towards past, present or future events.
- Parents may require professional support in dealing with the difficulties related to uncertainties of the child's diagnosis or prognosis.

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