

Special Issue

The experiences of Dutch fathers on fathering children with disabilities: ‘Hey, that is a father and his daughter, that is it’

A. Schippers,^{1,4,*}  M. Berkelaar,^{2,*} M. Bakker¹ & G. Van Hove³

¹ Department of Medical Humanities, Amsterdam University Medical Centres, Amsterdam, The Netherlands

² Athena Institute, VU University Amsterdam, Amsterdam, The Netherlands

³ Department of Orthopedagogics, Ghent University, Ghent, Belgium

⁴ Disability Studies in Nederland, Amersfoort, The Netherlands

Abstract

Background Due to a predominant focus on mothers, fathers of children with disabilities are greatly overlooked in research. One could argue that there is a lack of research on the multifaceted nature of fatherhood altogether. Therefore, this study aims to gain insight into the perceived experiences of fathers of children with disabilities.

Methods These perceptions were studied by analysing data generated through semi-structured interviews, which were conducted with 12 Dutch fathers of children or young adults with disabilities.

Results Categories found during our data analysis were similar to those illustrated in the ‘conceptual framework on responsible fathering’ by including *role identification, commitment, employment characteristics, cultural expectations* and *social support*.

Conclusions Overall, the fathers in this study reported similar experiences, but this study identified *new life perspective* as an additional category, which might be specific for fathers of children with disabilities. This *new life perspective* included a *positive*

attitude, living in the moment, appreciation of the little things and *transformation of expectations*. Some fathers expressed that their child(ren) has enriched their lives, which positively influenced their fathering experience.

Keywords children with disabilities, father, new life perspective, responsible fathering

Introduction

People with disabilities are more likely to depend on their families. In Western society, political developments are trending towards informal networks providing more care, resulting in families that increasingly fulfil a central role in the support and care of their children with disabilities, including into adulthood (Boelsma *et al.* 2018; Brown *et al.* 2003). This is related to the belief that children with disabilities are served best within their families (Samuel *et al.* 2012; Summers *et al.* 2005). Overall, families with children with disabilities experience more difficulties compared with families with typically developing children (Pelchat *et al.* 2003; Shave and Lashewicz 2016). However, the impact of having a child with a disability varies between families, as some families ‘flourish in the presence of disability, while others do not’ (Faragher and Van Ommen 2017, p. 42).

Correspondence: Dr. Alice Schippers, Department of Medical Humanities, Disability Studies, Amsterdam University Medical Centres, PO Box 7057, Amsterdam 1007 MB, The Netherlands. (e-mail: alice.schippers@tiscali.nl).

*The first and second author share the first authorship.

Over time, the role and contribution of fathers in family life has evolved (Williams 2008). For a long time, fathers were viewed as all-powerful rule givers and exclusive breadwinners (Brannen and Nilsen 2006; Johansson and Andreasson 2017; Lamb 2010). However, over the last 50 years, father involvement has changed because of a changed view in society on fatherhood. Since the 1970s, fathers have become more engaged in family life (Boström and Broberg 2014); besides breadwinning (Tseng and Verklan 2008), fathers now also engage in caregiving activities (Dermott and Miller 2016; Schmidt 2018) and household work (Bonsall 2014). Furthermore, they spend more time with their children (Shandra *et al.* 2008; Simmerman *et al.* 2001).

Research has thus shown a change in the role of the father. This change has, however, not been reflected in scientific literature. Models of fathering are scarce in scientific literature. This lack can be partially explained by a predominant focus on mothers in research on parenting (Goetze-Morey & Cummings 2007; Hornby 1995; Simmerman *et al.* 2001). Generally, it is still assumed that mothers are the primary caregivers (Simmerman *et al.* 2001), resulting in the construction of fathers as 'secondary' parents (West and Honey 2016).

However, one example of a father-specific model is the conceptual framework on 'responsible fathering' (Doherty *et al.* 1998). This model stresses that fathering takes place in the context of a multilateral relationship influenced by father, child, mother, contextual factors and the co-parental relationship. Above all, this model highlights how fathering is 'uniquely sensitive to contextual influences' (Doherty *et al.* 1998, p. 289). Several other studies confirm this substantial influence of contextual factors such as societal support, cultural expectations and institutional practices on fatherhood (Braun *et al.* 2011; Cabrera *et al.* 2000; Daly 1993; Marsiglio *et al.* 2000; Williams 2008).

Correspondingly, fathers of children with disabilities are also greatly overlooked in research (Bogossian *et al.* 2017; Macdonald and Hastings 2010; Marsiglio *et al.* 2000). However, the transformed societal perception of fatherhood towards more involved fathering indicates that fathers are worth studying. Moreover, several studies report that father involvement results in benefits for children with and without disabilities (Dyer *et al.* 2009;

McBride *et al.* 2017), such as improved behavioural and cognitive functioning (Coley 1998; Lamb and Lewis 2010; McBride *et al.* 2017; Paquette 2004).

Over the last decades, research on the experiences of fathers of children with disabilities has increased. Many of these studies were directed at the burdens and negative aspects related to the diagnosis of a child's disability (Bonsall 2014; Hornby 1995; Horsley and Oliver 2015), such as parental stress (Darling *et al.* 2012; Saloviita *et al.* 2003), and on fathers' coping strategies (Dardas and Ahmad 2015). Currently, a trend towards studying positive aspects is starting to emerge, including looking at how fathers of children with disabilities value their parenting role and father-child relationship (Boyraz and Sayger 2011; Ferguson 2002; Potter 2016). Several of these studies show that fathers of children with disabilities experience both challenging and positive perceptions simultaneously (Boström *et al.* 2009, 2010; Boyraz and Sayger 2011; Cheuk and Lashewicz 2016; Hastings *et al.* 2005; Horsley and Oliver 2015; Potter 2016). Still, in many studies that examine experiences of parenting a child with disabilities, the views and perceptions of fathers are rarely represented (Willingham-Storr 2014). Therefore, this study aims to gain insight into fathers' perspectives on their daily life experiences regarding fathering children with disabilities, in order to understand how these intersect with their view on fatherhood.

Methodology

Study design

By investigating their perceptions of and experiences with fathering one or more children with disabilities, this study aims to gain insight into the views of these Dutch fathers on fatherhood. To this end, in-depth data on individual perceptions of a varied group of fathers were required. A qualitative study design was chosen for this purpose (Lincoln and Guba 1985), which means that the fathers' perceptions were studied by analysing data generated through semi-structured interviews.

Participants

Because the goal was to interview a group of Dutch fathers of children with various disabilities, selection criteria included the age of the child (under 23 years),

the diagnosis of the child, the father's marital status and the father's employment status. The demographics of the participants are depicted in Table 1. The first participants were purposively sampled, meaning that 'information-rich cases for in-depth study' were included (Patton 1990, p. 169). These participants were recruited through the networks of first authors, and snowball sampling has enriched the sample.

Data collection

One-on-one semi-structured interviews took place at the participants' home or workplace, depending on their personal preference. Prior to the interview, participants were informed about its procedure and asked to sign a consent form. After obtaining the

participant's permission, the interview was audio recorded.

In preparation for the interview, participants were asked to choose either a video fragment with a maximum duration of 15 min or some pictures of themselves and their child(ren) with disabilities. These were used as a conversation starter. An interview guide composed of several open questions was flexibly used to allow the participants to discuss themes that are meaningful to them. All interviews lasted approximately 60 min and were transcribed verbatim.

Data analysis

Interview transcripts were sent to the participants to enhance the trustworthiness of the data (Robson 2011). Data collection and analysis were not sequential but iterative, as interviews were analysed immediately after transcription. This iterative process allowed exploration and validation of the categories found in the subsequent interviews. After 12 interviews, no additional codes were found during analysis. NVIVO 11 was used to support the process of data analysis (Hutchison *et al.* 2010).

First, a thematic content analysis was executed in order to stay close to the data, decrease bias and produce a rich code tree. Two members of our research team were involved in the analysis process. The individual analyses were deliberately compared and discussed to achieve consensus on the meaning of themes and to increase the credibility of findings (Lincoln and Guba 1985). The analysis included the following steps: (1) *familiarising oneself with the data*, (2) *identifying themes*, (3) *coding the data* and (4) *organising codes and themes* (Green and Thorogood 2013). In Step 2, identifying themes, concepts of the 'responsible fathering framework' (Doherty *et al.* 1998) were used as sensitising concepts, providing a general frame of reference for approaching our data (Blumer 1954; Charmaz 2000). During Step 4 of the analysis, we chose to organise the themes in accordance with the 'responsible fathering framework' (Doherty *et al.* 1998). Two groups of factors depicted in the conceptual framework were found in the data, including *father factors* and *contextual factors*. In addition, a new category was found, which we titled *new life perspective*. Rich verbatim quotes were selected and included in

Table 1 Demographic information of participants

	Dutch fathers' study
Total	
Fathers	12
Children with disabilities	14
Age of father	
35–39	2
40–44	1
45–49	5
50+	4
Employment status	
Employed	11
Unemployed	1
Economic status	
Lower class	2
Middle class	6
Upper class	4
Marital status	
Married	10
Not married	2
Region	
Rural	3
Minor urban	5
Major urban	4
Partly non-Dutch background	3
Age of child (mean)	6–21 (11.9)
Gender of child	
Son	10
Daughter	4
Disability category of child	
Intellectual disability	4
Physical disability	1
Physical and intellectual disability	3
Severe multiple disabilities	6

Section 3 to support our findings (Noble and Smith 2015).

Ethical considerations

This study followed the ethical standards of the Medical Ethics Committee of the VU Medical Centre and Academic Medical Centre. Participation was voluntary, and all participants signed a consent form prior to the interview. Confidentiality was maintained through restricted access to the data, destruction of audio recordings after transcription and anonymisation of transcribed data.

Results

Categories and subcategories revealed via data analysis included the following *father factors*: *role identification*, *commitment* and *employment characteristics*. The *contextual factors* included *cultural expectations* and *social support*. These correspond to the framework of Doherty *et al.* (1998). A new category that falls under father factors, *new life perspective*, was also found (see Fig. 1).

Father factors

Fathers of children with disabilities perceive family life in a variety of ways. The fathers acknowledged that their family image had changed dramatically since their child with a disability was born. All fathers participating in this study agreed that family life is sometimes more difficult because of the child's

disability or bad health. The fathers in this study recalled 'being in survival mode' during periods of sickness affecting their children with disabilities. One father expressed great difficulties coping with his fathering role. He explained that this experience was caused by the many responsibilities associated with being a father of a child with a disability, including providing income, sharing in the care for their children with his wife and 'keeping the family going'. Feeling responsible for their family was also acknowledged by other fathers: 'You are an employer in a way, you have to keep a company running. I really feel that way. As a father, you have to run a small business, but if you have a child with severe multiple disabilities, you are running a large company'.

Role identification

Fathers described their role in the lives of their children with disabilities as caregiver, educator and/or supervisor. Some fathers emphasised that they took on multiple roles. Fathers frequently notice differences between their roles in the lives of their children with and without disabilities: 'I have a completely different role as a father towards my two other children'.

Caregiver

Eight fathers identified themselves as a caregiver. They explained that parenting mainly consisted of caregiving activities, as their children needed demanding care for an extended period of time.

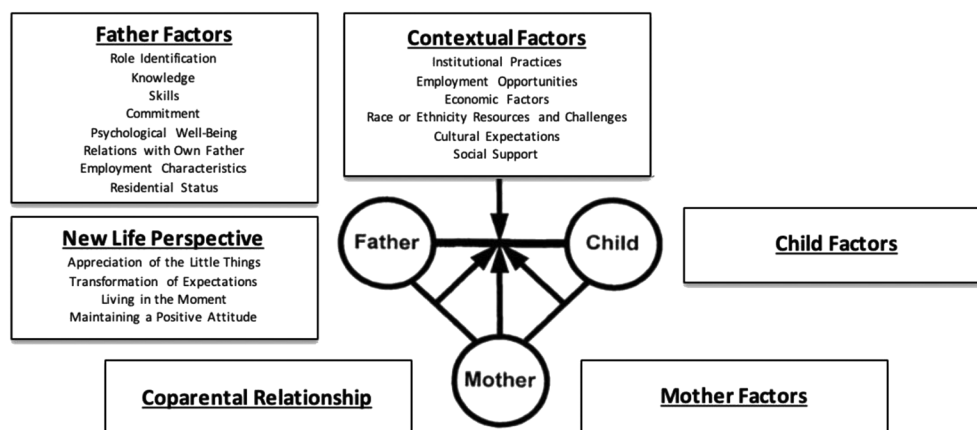


Figure 1. The conceptual framework on 'responsible fathering' (Doherty *et al.* 1998) as adapted for the purpose of this study.

Nonetheless, there were striking differences in how men perceived this caregiving role, and these depended on characteristics of the child and father. One father said that he felt ‘not like a father, but like a caregiver’ and expressed wanting to include father–son-like activities in his caring routine. Another father described how disability-related characteristics of his son had an impact on how he experienced his caregiving role: ‘And that was very hard for me at the time, as my son was very limited in making contact and making an emotional connection. [...] You could never comfort him, he did not allow it, he pushed you away. [...] So many times, I could not do anything for him, he would not let you. [...] I can take care of him, but I get nothing in return’.

In contrast to this father, the majority of fathers explained that they did feel connected with and appreciated by their children during extended caregiving activities.

Fathers in this study differentiated between ‘caregiving’ and ‘caregiving with love’. One father highlighted that, although he is mainly the caregiver of his son with a disability, ‘what I do feel very much is the loving way I engage with him’, which can be seen as a part of his fathering role.

Supervisor

Apart from the role of caregiver, five fathers described themselves as supervisors. They discussed supervising play activities and outings and assisting in doing homework: ‘I call myself a PAS: personal activity supervisor. [...] I enjoy doing things with my children, playing soccer or games, but also being involved in their lives. To guide them towards growing up, you have to know what they are doing’.

This supervisory role can be perceived as a guiding role in life, for instance, guiding their children with disabilities in the process of growing up. It can also be noted that the kind of guidance required changes over time: ‘I try to transform my role as supervisor slowly towards a strict father. [...] The period of fun outings is slowly getting behind us, because he is turning 17. At some point, I think my role has to shift towards the serious stuff’.

This quote indicates that this father’s role depended on his son’s age, regardless of his disability.

Educator

Three fathers in this study thought of the educator role as the traditional fathering role: imparting family values and teaching their children the rules of life. The majority of fathers of children with intellectual disabilities in this study explained that they were not able to perform this role as a result of their children’s disability. A father of two sons with disabilities indicated that he ‘sometimes tries to compensate for this [fathering role] with his nephews and nieces.’ He explained the difference in the fathering role for his children with disabilities as follows: ‘It is a different role than you would have with [children without disabilities] like raising and teaching your children certain norms and values; for us, that is totally different. I can teach my sons very little. [...] You have to be realistic. I can tell them nice stories, but I will not receive any response’.

Commitment

All fathers in this study demonstrated great commitment and emphasised their focus on the well-being of their children. In fact, a few fathers became advocates for their children and decided to set up associations and innovative daytime activities. One father explained that through his efforts, his daughter was the youngest person in the Netherlands to receive a personalised budget for support. He described the personalised budget system as being very unfair and, therefore, decided to help other parents to apply for this fund.

The fathers in this study also showed their commitment through their presence and by spending time together. All fathers claimed that being there was most important for them as a father. They took days off to be at hospital appointments or rescheduled work to be present at home after school or day care. Moreover, fathers found that taking care of their children by themselves, without the presence of their wife, was of vital importance: ‘As a father, it is important that you are there and share things. That you do not just have to be informed by your wife’.

Spending time together was considered to be a major constituent of fathering by all fathers participating in this study. Activities were undertaken one-on-one or together as a family. In the interview, the majority of fathers verbally expressed the great joy they feel when being together with their children and

indicated that they value their time together highly. Furthermore, fathers enjoy sharing hobbies with their children with disabilities. For example, a father expressed the positive influence on the father–child bond of sharing his interests as follows: ‘I have two great passions: music and soccer. Even though his ability to speak is now diminished and he also underwent severe brain surgery due to persistent epilepsy, you can still make contact through a shared passion [music]. And he also likes soccer. What else do you need?’

The fathers in this study found creative ways to combine activities that they enjoyed with spending time with their children with disabilities. However, one father reported he felt as if he was missing out on doing ‘father–son-like activities’ and on sharing his hobbies with his son. He further explained that this inability to share his passions with his son was related to his son’s disability.

Employment characteristics

The majority of fathers explained that employment is an important part of fatherhood as a comment by one father underlines the following: ‘You know, as a father, you also have to work, you also have a job in addition [to fatherhood]’. The fathers experienced the combination of work and having a child with a disability as being significantly difficult: ‘We have spent ... more than half of his whole lifetime in the hospital. That is pretty tough if, next to this, you want to have a job or a kind of life. Well, that’s the difficult side of it. But I do not blame Down syndrome or whatever; that’s just bad luck, mostly for him’.

In line with this father’s experience, having a child with a disability influenced the employment status and career of some other fathers in this study.

Career choice

Nine fathers underlined the influence that having a child with a disability has had on their career. For some fathers, ‘the priority of pursuing a career’ had changed because of this experience. Some fathers felt insecure about how to manage their working life after their child was diagnosed with a disability. ‘After she was born, I immediately felt like “what will this mean for my job, can I continue doing this?” I was able to continue, but I think looking back, I did make different decisions’.

Four fathers decided to turn down promotional opportunities or consciously chose not to pursue the career they previously/initially had in mind. Fathers explained that these career paths were no longer possible, for reasons such as ‘my wife wants to have her own life and continue to work’ and ‘I want to put him on the bus in the morning’. Thus, these decisions were influenced by the father’s wish to be involved in the life of his child. By contrast, one father described an ‘involuntary’ effect on his career: ‘I was not able to get a promotion because my boss said: “Well, your situation at home is not stable, so I do not think you should be promoted”’.

Flexibility was an important principle for all employed fathers, which included the flexible organisation of time and the ability to work from home. All fathers expressed the necessity of a flexible work schedule when having a child with a disability. This was the reason for one father to work in a hospital, as ‘it is a 24-hour organisation, so whether I work in the evening or morning, my employer does not care’. Another father expressed that in his work, ‘if one day something happens, you are not prevented from just being with your family’. The majority of fathers in jobs requiring higher education decided to reduce their working hours, with most working about 32 h a week. Three fathers decided to start working independently, mainly to have more flexibility: ‘which also has to do with my daughter, because now I can coordinate my working hours myself’.

One of the fathers in this study gave up his full-time job to take on the majority of care for his disabled child. He and his wife made this decision based on ‘who earns the most and who wants a career the most’. He also admitted that ‘sometimes it sucks to be home, although it is also work, [...] but I get a lot in return’.

Not all fathers in this study sample felt the need to change their job or working hours. One father explained that he would only do this if it proved necessary to relieve his wife’s burden. These findings show that the influence of having a child with a disability on the career or employment of fathers varies.

Motivation to work

The fathers who participated in this study expressed different motivations for being employed.

Their general incentive to work was to generate income for their family. Almost all fathers reported that they felt responsible for providing financial support for their family. One father explained that he experiences an enhanced feeling of responsibility because of having a child with a disability: 'I always thought that money could guarantee the future of my son [with a disability]. Because you never know where healthcare in the Netherlands is headed to, [the financial aid] keeps getting less and less...'

However, most fathers stated that they prioritise family or quality time over a higher income or employment in general: 'Maybe I am less career-focused than before, while I still have, I feel, a tough job. [...] For me, the balance between work and private life is very important; that is absolutely preferred to a higher income, but that used to be different'.

In addition to generating an income, fathers explained that working is 'your own interpretation of your life, something you like to do'. One father stated that when he decided to reduce his working hours, he felt that 'for me it was just too little. I noticed that at work I missed the connection with my colleagues. I felt like the field was passing me by. At that point, I should have searched for a different job, but I did not want to. I thought: "no, this makes me happy" '. The employed fathers in this study said that working was, in fact, a necessity for them in life because they had career ambitions.

Three fathers said they needed to work in order to distract themselves. A few fathers explained that 'only being with the kids' is not something they would aspire to in life. Other fathers admitted that they needed an escape from pressures at home: 'I was running away from a very difficult situation, I think. I felt very responsible, but I mainly expressed this by working and providing income'.

Additionally, some fathers explained that there were almost always care providers at home. Because of the amount of support available, one father said that 'if I do not have to be at work, I am usually at home; but sometimes I was not, because I wanted to get away from [home]'. Because most fathers were not solely responsible for care, they could make these choices.

Contextual factors

Cultural expectations

Fathers were also asked to reflect on how they are viewed by society. One father, who is the primary caregiver of his child with a disability, described his experiences with activities for caregivers of children with disabilities, as he found that they are generally aimed at women. A divorced father explained that it must not be common for a father to participate in household chores to the extent that he does, as people are often pleasantly surprised when they hear about this. A few other fathers expressed appreciation for the positive regard they receive from family, friends and acquaintances for being involved in family life.

At the same time, the majority of fathers reported that they felt pitied by other members of society for being a father of a child with a disability. Moreover, all fathers were bothered by the usual 'staring and gazing' at their children's physical characteristics: 'I find it important that she is a part of society, so that people do not think 'oh well, that is weird,' but that they just think "hey, that is a father and his daughter" and that's it'.

All fathers described that, when their child was younger, this 'staring and gazing' was very hard for them. They had to learn to deal with it and decided to ignore it. Remarkably, fathers stated that this 'staring and gazing' only bothered them if it could hurt their children.

Social support

All fathers mentioned the support provided by the Dutch personalised budget system. This budget is organised by the Dutch government with the intention of giving parents the freedom to choose and pay for health services and care providers, such as at home care providers and (medical) day care on weekdays and weekends. All fathers indicated that they highly appreciated this budget. Nevertheless, some fathers explained that welcoming care providers into their homes sometimes felt like an invasion: 'For example, if during the night, I sleep in my boxer shorts, then I have to put on jogging bottoms if I want to grab a glass of water from downstairs. [...] Just an example that sometimes for me, this is hard. But on the other hand, I am happy that, for once, I do not

have to look after my son and I can have a good night of sleep’.

A few fathers explained that it is difficult for them to hand their children over to care providers. Fathers sometimes ‘quickly take over and do it themselves’. They try to stay seated, as they know that this support is also aimed at giving themselves some time off. This is in accordance with other fathers reporting experiencing great difficulty with sending away their child away for day care or an overnight weekend.

None of the interviewed fathers expressed interest in attending support groups for parents of children with disabilities.

New life perspective

All fathers in this study stated that the experience of fathering a child with a disability has changed them, as ‘you learn a lot about yourself as well’. Most fathers in this study claimed that this experience has enriched their lives: ‘I always like to say, it also brought us a great deal of [positive] things’. Most fathers said this change could partly be caused by the experience of fatherhood itself ‘but it may also be that this developed over the years, as I grew older’. Fathers frequently mentioned that their perspective on life has changed in ways such as *appreciation of the little things*, *transformation of expectations*, *living in the moment* and *keeping a positive attitude*.

Appreciation of the little things

Four fathers in this study reported their new ability to appreciate the little things in life. One father explained that while in the past he was more ‘materialistic’, now he had other priorities and pleasures: ‘It is a pity that sometimes you need to suffer, if I could I rather would have had a different choice, but it brought us many things.’ This change did not always occur easily. One father explained the difficulty he experienced with opening himself up to appreciate the little things as follows: ‘It was partially related to the fact that I did not have energy left to take time to experience and to enjoy the little things’.

Transformation of expectations

All fathers explained the need to transform or to let go of their expectations about their children with disabilities or about life in general. They explained

that as these new realisations emerged, they became aware of their subconscious expectations that they previously had about their children, which made them reflect on ‘what they want for their children’.

The fathers clarified that they had to transform their expectations of their child as well as the relationship with their child, especially shortly after the diagnosis. Some fathers in this study experienced this as a ‘phase of mourning’ but added that they have since grown out of this phase: ‘The degree to which I regarded [these expectations] as important has changed dramatically over time’. Sometimes expectations changed yet again. For example, one father stated that his lowered expectations of his daughter hampered her development. This father called himself a ‘disabling factor’, as several events made him realise that his daughter ‘can do much more than we notice all together’.

Living in the moment

The majority of fathers claimed that their children with disabilities forced them to live in the present. Half of the fathers mentioned insecurity regarding the life expectancy of their children as a reason for their altered ‘pace of life’. Most fathers explained that this new perspective on life has enriched their lives: ‘We take it one day at a time. [...] I think more people should do this; not focussing on the future or looking back, I think that has positively impacted our lives. Just more living in the moment’.

The degree to which the fathers in this study prepared for the future varied considerably. Most explained that they lived day by day and decided to prepare for the future of their children by saving up money. One father mentioned the importance of also ensuring a future for his child. Others explained that they think in the long term depending on the issue: ‘The only thing for which we plan for the long term is the construction of the annexe for our son. [...] Apart from this, we live per week; we make a weekly schedule, and I also create a monthly schedule with the care providers’.

Maintaining a positive attitude

All fathers in this study tried to make the best of their situation. They tried to see the bright side of their changed lives and had a very positive attitude. Again, some fathers explained that keeping a positive attitude

had been natural to their character for all their lives, whereas others made a shift over time. Maintaining a positive attitude is related to the desire not to give up and was seen as essential to keep going. Some fathers explained that they had to ‘flip a switch’ in order to maintain this positive attitude: ‘As long as they are healthy, feel comfortable in their skin, in their own little world, well, they do not know any better. We do know better [and] we must flip a switch. If you keep on comparing yourselves to other parents and children, time and time again, well, you will get sad. Why do we not have that? If you can manage to flip this switch, you can still do great things together with children with disabilities’.

The fathers stated that their children’s ability to ‘make contact’ and their well-being, including happiness and health, greatly influenced their ability to remain positive: ‘First thing in the morning, he smiles at you, he goes to bed happy and that is most important to us. Then we feel like we are doing well, and he is doing well’.

Conclusion and discussion

This study was conducted with the aim of gaining insight into the experiences of Dutch fathers of children with disabilities. It draws on the conceptual framework of ‘responsible fathering’, a model directed towards fathers of typically developing children (Doherty *et al.* 1998). The *father factors* and *contextual factors* of the model were deemed reliable also for mapping the experiences of fathers of children with disabilities. Categories such as *role identification*, *commitment*, *employment characteristics*, *cultural expectations* and *social support* were found in the data and will subsequently be described and discussed below. Additionally, fathers in this study gained a *new life perspective* through fathering a child with a disability.

Role identification

Fathers in this study reported various perceptions of their fathering roles, including caregiver, educator and supervisor. These roles have also been described in studies of fathers with typically developing children (Olmstead *et al.* 2009; Summers *et al.* 1999). The findings in this study reveal that fathers of children with disabilities hold multiple roles simultaneously,

which also mirrors a recent study on fathers of typically developing children (Humberd *et al.* 2015). Nevertheless, several fathers in this study expressed that the educator role in the case of children with intellectual disabilities is different or non-existent compared with typically developing children.

Commitment

The fathers considered ensuring the well-being of their children with disabilities to be their responsibility. Furthermore, spending time together was a priority for all fathers in this study, which is in line with findings by Bonsall (2014). The ability to share interests with their children, or not, significantly influenced their fathering experience. One father specifically expressed his ‘grief’ at not being able to have a typical father–son relationship with his child, which agrees with previous research conducted on this subject (Thackeray and Eatough 2016), although the majority of fathers were able to find creative ways to spend time together. This suggests that the possibility of sharing interests might depend on individual child characteristics and capabilities, which corresponds with the ‘responsible fathering’ conceptual model (Doherty *et al.* 1998).

Employment characteristics

All but one of the fathers fulfilled the breadwinner role. This finding coincides with several studies reporting a ‘traditional parental role division’ in families with children with disabilities (Di Giulio *et al.* 2014; Hornby 1995). In addition to generation of income, employment also serves as a coping strategy, which agrees with recent research (Davys *et al.* 2017). Only a few other studies have explored the experiences of employed fathers of children with disabilities, which are inconclusive as to the nature of the impact on the labour market participation. The fathers in this study adapted their work life to their family life, which was partially related to the increased demands of care for their child. A recent study by Wright *et al.* (2016) showed that fathers chose to reduce their working hours and refrain from promotional opportunities, which concurs with the findings of this study. Several studies have mentioned the need of a flexible workplace (Carpenter and Towers 2008; Crowell and Leeper 1994; Golden 2007; Shave and Lashewicz 2016; Venter 2011) and

the choice of self-employment to provide flexibility for the ‘unplanned demands of caring’ (Wright *et al.* 2016), which highlight the need for flexibility at companies and organisations to support their employees with children with disabilities.

Cultural expectations and social support

All fathers reported their struggle with stigmatisation because of their children’s disability, as indicated by other authors (Pelchat *et al.* 2003; Thackeray and Eatough 2016). Many challenges that families face are experienced in the interaction between the differences caused by disabilities and a society that is not accepting or accommodating (Fisher and Goodley 2007). In a recent study on families with a family member with disabilities (Boelsma *et al.* 2018), it was found that families felt confronted by what is considered to be normal in their daily lives through their interactions with others. To reduce this form of stigma, referred to as associative or family stigma, interventions need to include families where disability is the case (Mitter *et al.* 2018). A study in Indonesia proved the success of combining interventions that focus on a family as well as a societal level (Dadun *et al.* 2017).

Dutch fathers have access to governmental support, which affected their fathering experience in a positive way. The Dutch personalised budget and the flexible organisational culture in the Netherlands enhance the fathers’ ability to spend time with their families. The financial contributions also compensate for costs related to the child’s disability, which might decrease the ‘breadwinner burden’. However, Dutch fathers expressed their worries because the long-term future of these budgets is unsure, which emphasises the importance of this support system on the experience of fathering children with disabilities.

New life perspective

The key finding of this study was the substantial influence of a *new life perspective* on the fathering experience. This factor was not depicted in the “responsible fathering” conceptual model of Doherty *et al.* (1998). Some fathers expressed the enrichment of their lives, which concurs with a previous study by Bonsall (2014). Subcategories of this category included *appreciation of the little things*, *transformation of expectations*, *living in the moment* and *maintaining a*

positive attitude. Recent studies have reported a transformation of fathers’ expectations of their lives and their children with disabilities (Baumann and Braddick 2016; Shave and Lashewicz 2016), which agrees with the majority of the fathers in this study. Moreover, the ‘pace of life’ found in this study is similar to the day-to-day life of families with a member with a disability as reported by Schippers and Van Hoheemen (2009). Thus, it could be suggested that this *new life perspective* is a new insight into the lives of fathers of children with disabilities.

The addition of the category *new life perspective* offers extra insights into the life of men who engage differently with their children. Instead of an emphasis on the physically active and play-centred parenting style typical for men (the ‘embodied habitus’, Doucet 2013), we learned that fathers in this study, through their specific care activities, assumed new embodied and relational positions vis à vis their children.

Understanding the importance of this *new life perspective* can inform fathers of children with disabilities and those who support them, suggesting an approach that focusses on the benefits associated with having a child with a disability. By providing an alternative and more empowering perspective, negative contextual factors, such as the pitying that the fathers in our study experienced, can be countered (Allred 2014; McConnell *et al.* 2014).

Acknowledgements

We would like to thank the fathers who participated in the study. We are grateful for the insightful suggestions by Dr Ekas and the anonymous reviewers.

Source of funding

No external funding was received for the research reported in the paper.

Conflict of interest

The authors report no conflict of interests.

References

- Allred K. (2014) Engaging parents of students with disabilities: moving beyond the grief model. *Improving Schools* 18, 46–55.

A. Schippers *et al.* • Experiences of fathers

- Baumann S. L. & Braddick M. (2016) On being a father or sibling in light of the human becoming family model. *Nursing Science Quarterly* **29**, 47–53.
- Blumer H. (1954) What is wrong with social theory? *American Sociological Review* **19**, 3–10.
- Boelsma F., Schippers A., Dane M. & Abma T. (2018) "Special" families and their "normal" daily lives: family quality of life and the social environment. *International Journal of Child, Youth and Family Studies* **9**, 107–24.
- Bogossian A., King G., Lach L. M., Currie M., Nicholas D., McNeill T. *et al.* (2017) (Un)packing father involvement in the context of childhood neurodisability research: a scoping review. *Disability and Rehabilitation* **41**, 110–24.
- Bonsall A. (2014) Fathering occupations: an analysis of narrative accounts of fathering children with special needs. *Journal of Occupational Science* **21**, 504–18.
- Boström P., Broberg M. & Hwang C. P. (2010) Different, difficult or distinct? Mothers' and fathers' perceptions of temperament in children with and without intellectual disabilities. *Journal of Intellectual Disability Research* **54**, 806–19.
- Boström P. K. & Broberg M. (2014) Openness and avoidance – a longitudinal study of fathers of children with intellectual disability. *Journal of Intellectual Disability Research* **58**, 810–21.
- Boström P. K., Broberg M. & Hwang P. (2009) Parents' descriptions and experiences of young children recently diagnosed with intellectual disability. *Child: Care, Health and Development* **36**, 93–100.
- Boyraz G. & Sayger T. V. (2011) Psychological well-being among fathers of children with and without disabilities: the role of family cohesion, adaptability, and paternal self-efficacy. *American Journal of Men's Health* **4**, 286–96.
- Brannen J. & Nilsen A. (2006) From fatherhood to fathering: transmission and change among British fathers in four-generation families. *Sociology* **40**, 335–52.
- Braun A., Vincent C. & Ball S. J. (2011) Working-class fathers and childcare: the economic and family contexts of fathering in the UK. *Community, Work and Family* **14**, 19–37.
- Brown I., Anand S., Alan Fung W. L., Isaacs B. & Baum N. (2003) Family quality of life: Canadian results from an international study. *Journal of Developmental and Physical Disabilities* **15**, 207–30.
- Cabrera N. J., Tamis-LeMonda C. S., Bradley R. H., Hofferth S. & Lamb M. E. (2000) Fatherhood in the twenty-first century. *Child Development* **71**, 127–36.
- Carpenter B. & Towers C. (2008) Recognising fathers: the needs of fathers of children with disabilities. *Support for Learning* **23**, 118–25.
- Charmaz K. (2000) Grounded theory: objectivist and constructivist methods. In: *Handbook of Qualitative Research* (eds N. K. Denzin & Y. S. Lincoln 2nd ed.), 509–35. Thousand Oaks, CA, SAGE Publications Inc.
- Cheuk S. & Lashewicz B. (2016) How are they doing? Listening as fathers of children with autism spectrum disorder compare themselves to fathers of children who are typically developing. *Autism* **20**, 343–52.
- Coley R. L. (1998) Children's socialization experiences and functioning in single-mother households: the importance of fathers and other men. *Child Development* **69**, 219–30.
- Crowell N. & Leeper E. (1994) *America's fathers and public policy: report of a workshop*. Washington DC: National Academy press.
- Dadun D., Van Brakel W. H., Peters R. M., Lusli M., Zweekhorst M. & Bunders J. G. (2017) *Leprosy Review* **88**, 2–2.
- Daly K. (1993) Reshaping fatherhood: finding the models. *Journal of Family Issues* **14**, 510–30.
- Dardas L. A. & Ahmad M. M. (2015) For fathers raising children with autism, do coping strategies mediate or moderate the relationship between parenting stress and quality of life? *Research in Developmental Disabilities* **36**, 620–9.
- Darling C. A., Senatore N. & Strachan J. (2012) Fathers of children with disabilities: stress and life satisfaction. *Stress and Health* **28**, 269–78.
- Davys D., Mitchell D. & Martin R. (2017) Fathers of adults who have a learning disability: roles, needs and concerns. *British Journal of Learning Disabilities* **45**, 266–273.
- Dermott E. & Miller T. (2016) More than the sum of its parts? Contemporary fatherhood policy, practice and discourse. *Families, Relationships and Societies* **4**, 183–95.
- Di Giulio P., Philipov D. & Jaschinski I. (2014) Families with disabled children in different European countries. *Families and Societies*, Working Paper 23–8.
- Doherty W. J., Kouneski E. F. & Erickson M. F. (1998) Responsible fathering: an overview and conceptual framework. *Journal of Marriage and the Family* **60**, 277–292.
- Doucet A. (2013) A "choreography of becoming": fathering, embodied care, and new materialisms. *Canadian Review of Sociology* **50**, 284–305.
- Dyer W. J., McBride B. A., Santos R. M. & Jeans L. M. (2009) A longitudinal examination of father involvement with children with developmental delays: does timing of diagnosis matter? *Journal of Early Intervention* **31**, 265–81.
- Faragher R. & Van Ommen M. (2017) Conceptualising educational quality of life to understand the school experiences of students with intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities* **14**, 39–50.
- Ferguson P. M. (2002) A place in the family: a historical interpretation of research on parental reactions to having a child with a disability. *The Journal of Special Education* **36**, 124–30 147.

A. Schippers *et al.* • Experiences of fathers

- Fisher P. & Goodley D. (2007) The linear medical model of disability: mothers of disabled babies resist with counter-narratives. *Sociology of Health Illness* **29**, 66–81.
- Goeke-Morey M. C. & Cummings E.M. (2007) Impact of father involvement: a closer look at indirect effects models involving marriage and child adjustment. *Applied Developmental Science* **11**, 221–5.
- Golden A. G. (2007) Fathers' frames for childrearing: evidence toward a "masculine concept of caregiving". *Journal of Family Communication* **7**, 265–85.
- Green J. & Thorogood N. (2013) *Qualitative methods for health research*, 3rd edn. London: SAGE Publications Inc.
- Hastings R. P., Beck A. & Hill C. (2005) Positive contributions made by children with an intellectual disability in the family. *Journal of Intellectual Disabilities* **9**, 155–65.
- Hornby G. (1995) Fathers' views of the effects on their families of children with Down syndrome. *Journal of Child and Family Studies* **4**, 103–17.
- Horsley S. & Oliver C. (2015) Positive impact and its relationship to well-being in parents of children with intellectual disability: a literature review. *International Journal of Developmental Disabilities* **61**, 1–9.
- Humberd B., Ladge J. J. & Harrington B. (2015) The "new" dad: navigating fathering identity within organizational contexts. *Journal of Business and Psychology* **30**, 249–66.
- Hutchison A. J., Johnston L. H. & Breckon J. D. (2010) Using QSR-NVivo to facilitate the development of a grounded theory project: an account of a worked example. *International Journal of Social Research Methodology* **13**, 283–302.
- Johansson T. & Andreasson J. (2017) Breadwinners and new fathering practices. In: *Fatherhood in Transition*, pp. 81–101. Palgrave Macmillan, London.
- Lamb M. E. (2010) How do fathers influence children's development? Let me count the ways. In: *The role of the father in child development*, pp. 1–26. John Wiley & Sons Inc., Hoboken, New Jersey.
- Lamb M. E. & Lewis C. (2010) The development and significance of father-child relationships in two-parent families. In: *The role of the father in child development*, 5th edn, pp. 94–153. John Wiley & Sons Inc., Hoboken, New Jersey.
- Lincoln Y. S. & Guba E. G. (1985) *Naturalistic inquiry*, 2nd edn. SAGE Publications Inc.
- Macdonald E. E. & Hastings R. P. (2010) Fathers of children with developmental disabilities. In: *The role of the father in child development*, 5th edn, pp. 486–516. John Wiley & Sons Inc., Hoboken, New Jersey.
- Marsiglio W., Amato P., Day R. D. & Lamb M. E. (2000) Scholarship on fatherhood in the 1990s and beyond. *Journal of Marriage and Family* **62**, 1173–91.
- McBride B. A., Curtiss S. J., Uchima K., Laxman D. J., Santos R. M., Weglarz-Ward J. *et al.* (2017) Father involvement in early intervention: exploring the gap between service providers' perceptions and practices. *Journal of Early Intervention* **39**, 71–87.
- McConnell D., Savage A., Sobsey D. & Uditsky B. (2014) Benefit-finding or finding benefits? The positive impact of having a disabled child. *Disability and Society* **30**, 29–45.
- Mitter N., Ali A. & Scior K. (2018) Stigma experienced by family members of people with intellectual and developmental disabilities: multidimensional construct. *BjPsych Open* **4**, 332–8.
- Noble H. & Smith J. (2015) Issues of validity and reliability in qualitative research. *Evidence-Based Nursing* **18**, 34–5.
- Olmstead S. B., Futris T. G. & Pasley K. (2009) An exploration of married and divorced, non-resident men's perceptions and organization of their father role Identity. *Fathering: A Journal of Theory, Research, and Practice about Men as Fathers* **7**, 249–68.
- Paquette D. (2004) Theorizing the father-child relationship: mechanisms and developmental outcomes. *Human Development* **47**, 193–219.
- Patton M. Q. (1990) *Qualitative evaluation and research methods*. SAGE Publications inc.
- Pelchat D., Lefebvre H. & Perreault M. (2003) Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability. *Journal of Child Health Care* **7**, 231–47.
- Potter C. A. (2016) "I accept my son for who he is – he has incredible character and personality": fathers' positive experiences of parenting children with autism. *Disability and Society* **31**, 948–65.
- Robson C. (2011) *Real world research*, 3rd edn. Wiley, Chichester.
- Saloviita T., Itäläinen M. & Leinonen E. (2003) Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a double ABCX Model. *Journal of Intellectual Disability Research* **47**, 300–12.
- Samuel P. S., Rillotta F. & Brown I. (2012) The development of family quality of life concepts and measures. *Journal of Intellectual Disability Research* **56**, 1–6.
- Schippers A. & Van Boheemen M. (2009) Family quality of life empowered by family-oriented support. *Journal of Policy and Practice in Intellectual Disabilities* **6**, 19–24.
- Schmidt E. M. (2018) Breadwinning as care? The meaning of paid work in mothers' and fathers' constructions of parenting. *Community, Work and Family* **21**, 445–62.
- Shandra C. L., Hogan D. P. & Spearin C. E. (2008) Parenting a child with a disability: An examination of resident and non-resident fathers. *Journal of Population Research* **25**, 357–77.
- Shave K. & Lashewicz B. (2016) Support Needs of Fathers of Children with ASD: Individual, Family, Community and Ideological Influences. *Journal of Applied Research in Intellectual Disabilities* **29**, 495–507.

A. Schippers *et al.* • Experiences of fathers

- Simmerman S., Blacher J. & Baker B. L. (2001) Fathers' and mothers' perceptions of father involvement in families with young children with a disability. *Journal of Intellectual and Developmental Disability* **26**, 325–38.
- Summers J. A., Poston D. J., Turnbull A. P., Marquis J., Hoffman L., Mannan H. *et al.* (2005) Conceptualizing and measuring family quality of life. *Journal of Intellectual Disability Research* **49**, 777–83.
- Summers J. A., Raikes H., Butler J., Spicer P., Pan B., Shaw S. *et al.* (1999) Low-income fathers' and mothers' perceptions of the father role: a qualitative study in four early head start communities. *Infant Mental Health Journal* **20**, 291–304.
- Thackeray L. A. & Eatough V. (2016) "Shutting the world out": an interpretative phenomenological analysis exploring the paternal experience of parenting a young adult with a developmental disability. *Journal of Applied Research in Intellectual Disabilities* **28**, 265–75.
- Tseng Y. & Verklan M. T. (2008) Fathers in situational crisis: a comparison of Asian and Western cultures. *Nursing and Health Sciences* **10**, 229–40.
- Venter K. (2011) Fathers "care" too: the impact of family relationships on the experience of work for parents of disabled children. *Sociological Research Online* **16**, 1–6.
- West C. & Honey A. (2016) The involvement of fathers in supporting a young person living with mental illness. *Journal of Child and Family Studies* **25**, 574–87.
- Williams S. (2008) What is fatherhood? Searching for the reflexive father. *Sociology* **42**, 487–502.
- Willingham-Storr G. L. (2014) Parental experiences of caring for a child with intellectual disabilities: a UK perspective. *Journal of Intellectual Disabilities* **18**, 1–3.
- Wright A., Crettenden A. & Skinner N. (2016) Dads care too! Participation in paid employment and experiences of workplace flexibility for Australian fathers caring for children and young adults with disabilities. *Community, Work and Family* **19**, 340–61.

Accepted 23 December 2019