

The experiences of fathers on fathering children with disabilities: *“a father and his daughter, that’s it”*

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Abstract

Fathers of children with disability are greatly overlooked in research due to the predominant focus on mothers. Furthermore, there is a lack of research to the diverse nature of fatherhood in this context. Therefore, this study aimed to gain insight into the experiences of fathers of children with disabilities. Data collection was performed through semi-structured interviews with twelve Dutch fathers of children (under 23 years) with disabilities. Furthermore, pilot data of eight fathers of children (under 23 years) with disabilities, who participated in the European fathers' study, was used. Categories that emerged during data analysis were similar to the factors illustrated in the conceptual framework on 'responsible fathering' by Doherty, Kouneski & Erickson (1998), including 'role identification', 'commitment', 'employment characteristics', 'cultural expectations' and 'social support'. Overall, the fathers in this study reported similar experiences; however, Dutch fathers identified less with the provider role and reported more opportunities for social support as opposed to the European fathers. Above all, 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 the transformation of expectations. Some fathers expressed that this experience has enriched their lives, which positively influenced their fathering experience.

Key words father, children with disabilities, experience, conceptual framework

Introduction

Children with disabilities are greatly dependent on their families, as governments in Western society turn to families for the provision of care (Boelsma, Schippers, Abma, & Dane, 2017; I. Brown, Anand, Alan Fung, Isaacs, & Baum, 2003). This is related to the belief that children with disabilities are served best within their families (Samuel, Rillotta, & Brown, 2012; Summers et al., 2005). Families with children with disabilities experience more complex difficulties compared to families with typically developing children (Pelchat, Lefebvre, & Perreault, 2003; Shave & 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 & Van Ommen, 2017). Family is defined as *'a system consisting of the sum of its parts with each part interrelated'* (Macdonald & Hastings, 2010), which demonstrates that individual family members are also affected by the child's disability, including fathers.

Fathers have contributed to family life in different ways over time (Williams, 2008), which is related to a shift in the societal perception of fatherhood over the last decades (Dermott & Miller, 2016). Before, fathers were viewed as an all-powerful figure and the exclusive breadwinner of the family (Brannen & Nilsen, 2006; Johansson & Andreasson, 2017; Michael E Lamb, 2010). Thereafter, in the 70s, the nurturing father emerged, who is engaged in family life (Boström & Broberg, 2014) and plays a significant role in his children's lives (Michael E Lamb, 2010). This trend contributed to the current societal perception of fatherhood. Today, besides breadwinning (Tseng & Verklan, 2008), the father figure also engages in caregiving activities (Dermott & Miller, 2016; Schmidt, 2017) and household work (Bonsall, 2014); and spends more time with his children compared to 50 years ago (Shandra, Hogan, & Spearin, 2008; Simmerman, Blacher, & Baker, 2001; Williams, 2008).

Models on fatherhood are scarce in the literature. One example of a father specific model is the conceptual framework on ‘responsible fathering’ by Doherty, Kouneski, & Erickson (1998) (Figure 1). This model stresses that fatherhood is a multilateral relationship influenced by father, child, mother and contextual factors, and the coparental relationship (Figure 1). Above all, this model highlights how fathering is ‘*uniquely sensitive to contextual influences*’ as opposed to mothering (Doherty et al., 1998). Several studies confirmed this substantial influence of contextual factors, including societal perceptions, on fatherhood (Braun, Vincent, & Ball, 2011; Cabrera, Tamis-LeMonda, Bradley, Hofferth, & Lamb, 2000; Daly, 1993; Marsiglio, Day, & Lamb, 2000; Williams, 2008). Furthermore, the universal definition of fatherhood is complicated by these contextual influences (Cabrera et al., 2000).

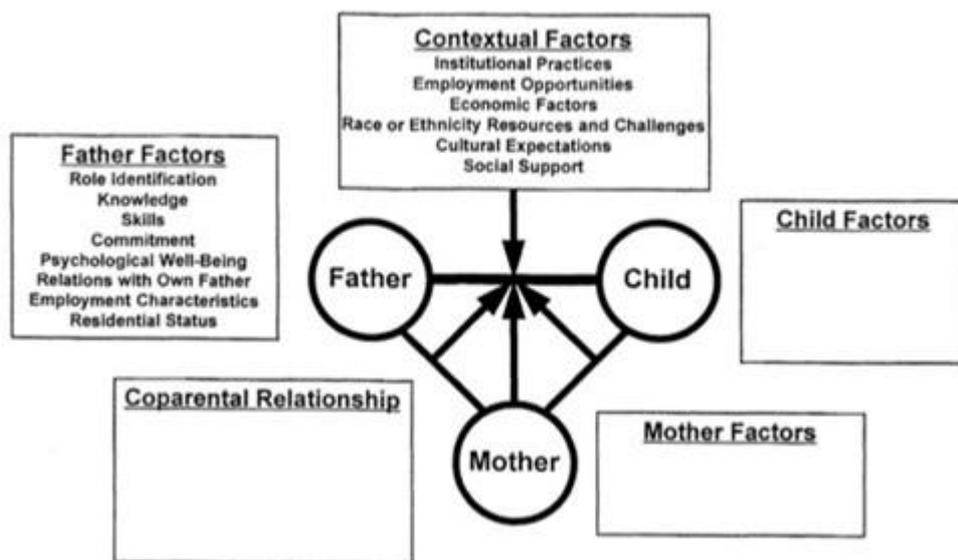


Figure 1. The conceptual framework on ‘responsible fathering’ (Doherty et al., 1998) is adapted for the purpose of this study. This conceptual model describes fathering as a multilateral relationship, which is influenced by several groups of factors, including father factors, contextual factors, mother factors, child factors and the coparental relationship. This study focuses on the father factors, including role identification, knowledge, skills, commitment, psychological well-being, employment characteristics and residential status. Additionally, contextual factors are studied, which include institutional practices, employment opportunities, economic factors, race or ethnicity resources and challenges, cultural expectations and social support.

The lack of fatherhood models can partially be explained by the predominant focus on mothers in research (Goeke-Morey & Mark Cummings, 2007; Hornby, 1995; Simmerman et al., 2001). Generally,

it is assumed that mothers are the primary caregivers (Simmerman et al., 2001) resulting in the construction of fathers as 'secondary' parents (West & Honey, 2016), which in turn might explain the underrepresentation of fathers in research. Likewise, fathers of children with disabilities are greatly overlooked in research. However, the transformed societal perception of fatherhood towards involved fathering indicates that fathers are worth studying. Moreover, several studies have shown that father involvement results in benefits for children with and without disabilities (Dyer, McBride, Santos, & Jeans, 2009; McBride et al., 2017), such as improved behavioral and cognitive functioning (Coley, 1998; M E Lamb & Lewis, 2010; McBride et al., 2017; Paquette, 2004).

Yet, research to the experiences of fathers of children with disabilities has increased over the last decades. The majority of these studies are directed to the burden and negative experiences related to the diagnosis of the child's disability (Bonsall, 2014; Hornby, 1995; Horsley & Oliver, 2015), such as parental stress (Darling, Senatore, & Strachan, 2012; Saloviita, Itälina, & Leinonen, 2003) and coping strategies (Dardas & Ahmad, 2015). Currently, there is a trend towards studying positive experiences, including how fathers of children with disabilities value their parenting role and the father-child relationship (Boyras & Sayger, 2011; Ferguson, 2002; C. A. Potter, 2016). Studies have shown that fathers of children with disabilities reported both challenging and positive perceptions of having children with disabilities simultaneously (Boström, Broberg, & Hwang, 2009; Boyras & Sayger, 2011; Broberg & Hwang, 2010; Cheuk & Lashewicz, 2016; Hastings, Beck, & Hill, 2005; Horsley & Oliver, 2015). However, not all fathers described positive experiences (Boström & Broberg, 2014; Horsley & Oliver, 2015), which underscores the diversity of experiences of these fathers.

To date, however, there is a paucity of research to the diverse nature of fatherhood (Braun et al., 2011; Marsiglio, Amato, Day, & Lamb, 2000; C. Potter, 2016). Furthermore, the experiences of fathers of children with disabilities are not yet properly defined in research (Bogossian et al., 2017;

Boström & Broberg, 2014; Darling et al., 2012; Smit, 2004). Therefore, this study aims to gain insight into the experiences of Dutch fathers of children with disabilities in order to understand their fathering nature. In addition, this study intends to discuss the experiences of the Dutch fathers from the perspective of other European fathers of children with disabilities. This comparative approach is used to review the influence of contextual factors on the experience of fathering children with disabilities.

Methodology

Study design

This research project aims to study the experiences of Dutch fathers on fathering children with disabilities in order to gain insight into the nature of fathering. Hence, in-depth data on individual experiences of a varied group of fathers is required. A qualitative study design was chosen as qualitative methods are the preferred method for gaining an understanding of the experiences of people (Lincoln & Guba, 1985). First, the experiences of fathering are studied using semi-structured interviews with Dutch fathers. Thereafter, pilot data from a European fathers' study was used to view the experiences of these fathers from a broader perspective. This 'lens' comparison approach was applied for the 'illuminating, critiquing and challenging' (Walk, 1998) of the experiences of Dutch fathers.

Participants

This study aimed to interview a diverse group of Dutch fathers of children with various disabilities (both intellectual and/or physical). Selection criteria were set that would aid the identification of this diversity among potential participants. Selection criteria included the age of the child (under 23

years); the diagnosis of the child's disability; and the father's employment status, educational level, and regional location. The demographics of the Dutch participants are depicted in **Table 1**.

A combination of sampling methods was used to recruit participants. Potential participants were contacted through a message, e-mail or phone call and the selection criteria were reviewed. Furthermore, appointments were made with the participants for an interview at a place and time convenient to them. In addition, snowball sampling was used with contacts of the participants. The procedure described above was performed before inclusion of the potential participants.

The experiences of Dutch fathers of children with disabilities are put in broader perspective using pilot data of European fathers. Therefore, this study was performed in collaboration with the Erasmus Mundus project of the Ghent University. The transcriptions of the interviews, which were translated in English, conducted by the Erasmus Mundus students were used except for one participant, who was interviewed by the author of this study. The European participants had to meet the selection criteria as described to be included in the study. The demographics of the European participants are depicted in Table 1.

Data collection

The one-to-one semi-structured interviews took place at the participants' home or workplace, depending on the participant's preference. Prior the interview, the participants were informed about the interview procedure and the participants were asked to sign a consent form (**Supplementary documents**). After permission, the interview was audio-recorded and in addition, also non-verbal communication was noted during the interview.

Prior to the interview, participants were requested to choose a video fragment with a maximum duration of 15 minutes or pictures of themselves and their children with disabilities to show at the start of the interview. These videos or pictures were used as a conversation starter in the interview. Furthermore, an interview guide (**Supplementary documents**) with several open questions, which were considered relevant to the study, was flexibly used to allow the participants to discuss themes meaningful to them. Hence, the course of the interview was determined by the participant's experiences and specific questions were asked in the context provided by the participant. All interviews lasted around 60 minutes. The scope and procedure of the interviews with European fathers were comparable to what is described previously.

Afterwards, the interviews were transcribed verbatim. In one case the interview was not recorded and notes of the interview and written responses to questions sent by email were used instead. The interviews with Dutch participants were conducted between October 2017 and January 2018 in face-to-face meetings by the author. The European participants were interviewed using Skype or in face-to-face meetings between November 2017 and January 2018 by the Erasmus Mundus students of the Ghent University. One European participant was interviewed by the author using Skype.

Data analysis

A copy or summary of the transcription was sent to the participants to check the trustworthiness of the data (Robson, 2011). Aspects of the grounded theory approach were applied in data analysis as described by Green & Thorogood (2013). The transcripts were coded using methods of open coding, axial coding and selective coding, which is based on asking questions and making comparisons for similarities, differences, and patterns in the data. NVIVO 11, a Computer Assisted Qualitative Data

Analysis Software program (CAQDAS) was used to aid the process of data analysis, through the organization and linking of the data, which in turn facilitates the formation of categories (Hutchison, Johnston, & Breckon, 2010).

Some aspects of the analysis were informed by the conceptual framework on 'responsible fathering' by Doherty et al. (1998), which is a recognized approach in grounded theory (Hutchison et al., 2010). Two groups of factors depicted in the conceptual framework emerged from the inductive analysis of the data, including 'father factors' and 'contextual factors' (Figure 1). A category that emerged from the data but could not be organized using the conceptual framework included 'new life perspective'.

The analysis was performed directly after data collection, moving from data collection, analysis and the emergence of categories. This iterative process allowed for the exploration and validation of emerging categories in following interviews. Data saturation was reached after interviewing twelve Dutch fathers (Guest, Bunce, & Johnson, 2006). Data saturation was not reached in the European pilot study. A total of eight European fathers participated in this study. The corresponding quotes were compared, and the quotes considered most suitable were selected for the final report.

Ethical considerations

This study is in accordance with the ethical standards of the Medical Ethics Committee of the VU Medical Centre and Academic Medical Centre. All participants voluntarily took part in this study and signed a consent form prior to the interview. Confidentiality was maintained through the restricted access to the data, the destruction of audio recordings following transcription and the anonymous transcription of the data.

Table 1 Demographic information of all study participants (N=20), with Dutch participants in the second column and European fathers in the third column. Two Dutch fathers had two children with disabilities. Additionally, two Dutch fathers and one European father were divorced from the mother of the child with a disability.

	Dutch fathers' study	European fathers' study pilot
Total		
Fathers	12	8
Children with disabilities	14	8
Age of father		
35-39	2	
40-44	1	2
45-49	5	1
50+	4	5
Employment status father		
Employed	11	8
Unemployed	1	
Marital status		
Married	10	7
Not married	2	1
Age of child (mean)	6-21 (11.9)	10-22 (16.5)
Gender of child		4
Son	10	4
Daughter	4	
Disability category of child		
Intellectual disability	4	4
Physical disability	1	3
Physical and intellectual disability	3	1
Severe Multiple Disabilities	6	
Country of residence	The Netherlands (12)	Belgium (2)

		Ireland (1) Italy (2) Portugal (1) Spain (1) Turkey (1)
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Results

The results section is divided into two parts. In the first part, the experiences of the Dutch fathers are reported. The subcategories derived from the ‘responsible fathering’ conceptual framework (Doherty et al., 1998) are used to organize the data. Categories and subcategories that emerged from the data included the following father factors: ‘role identification’, ‘commitment’ and ‘employment characteristics’. The contextual factors that emerged from the data included ‘cultural expectations’ and ‘social support’. The category ‘new life perspective’ emerged from the data analysis but could not be organized using the conceptual framework. In the second part, the experiences of Dutch fathers are put in a broader perspective using the data on European fathers in order to confirm, contradict, elaborate on and strengthen the experiences of Dutch fathers.

Part one: the experiences of Dutch fathers

1.0 Father factors

Fathers of children with disabilities perceived family life in a variety of ways. The majority of fathers acknowledged that their family image had changed dramatically. All fathers participating in this study agreed that family life is more difficult at some moments due to the child’s disability or health. These specific moments were related to the well-being of their children. Fathers expressed to feel like

“being in survival mode”, during periods of sickness of their children with disabilities. One father expressed great difficulties with managing his fathering role and compared his life as a father to *“environmental destruction”*. 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 of their children with his wife and *“keeping the family going”*. Feeling responsible for the family was acknowledged by other fathers, as described in the following quote:

P2: “You are an employer in a way, you have got to run a company, I really feel that way. As a father you have a company to run anyhow, but if you have a child with severe multiple disabilities you have to run an organization.”

1.2 Role identification

Fathers describe their role in the lives of their children with a disability as caregiver, educator and/or supervisor and some fathers emphasized that they have multiple roles. Fathers frequently contrast this to their role in the lives of their children without disabilities, such as P9 expressed as *“I have a completely different role as a father compared to my two other children”*.

1.2.1 Caregiver

Most fathers in this study identified themselves as a caregiver. They explained that their parenting mainly consisted of caregiving activities, as their children needed demanding care for an extended period. All fathers in this study were involved in caregiving activities. Nonetheless, there were some striking differences in how men perceived this caregiving role depending on characteristics of the child and father. One father expressed that he felt *“not like a father, but like a caregiver trying to get*

over things” and he wished to do father-son like activities. Another father explained characteristics of his son, which had an impact on the perception of his caregiving role, as follows:

P8: “And that was very hard for me at the time, as my son was very limited in making contact and emotional connection [...] you could never comfort him, he did not allow it, he pushed you away [...] so many time 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 P8, the majority of fathers explained that they felt connected with and appreciated by their children during caregiving activities. These child characteristics, which can be related to the child’s disability, influenced the father’s appreciation of his role.

Fathers in this study made a distinction between ‘caregiving’ and ‘caregiving with love’ as a father. P9 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”*. This father did not solely feel a caregiver but acknowledged this as a part of his fathering role.

1.2.2 Supervisor

Next to the caregiving role, fathers described themselves as a supervisor in the lives of their children with disabilities. Fathers explained being a supervisor during play activities, outings or while assisting in doing homework, as summarized by the following quote:

P4: “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. Guide them towards growing up, so then you have to know what they are doing.”

This quote clearly states that this supervisor role can also be perceived as a guiding role in life, for example guiding their children with disabilities in the process of growing up. However, this role is not static, but might change over time, as a father explained as follows:

P6: *"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 and that is fine when you are 10 until 16 years old. At one point I think my role has to shift towards the 'serious stuff'."*

This quote indicates that the role of this father was influenced by the age of the child, regardless of his son's disability.

1.2.3 Educator

Many fathers thought of the educator role as *"the traditional father role"*. Only a few fathers reported an educator role in the lives of their children. The majority of fathers 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 stated that he *"sometimes tries to compromise for this [father role] with his nephews and nieces"*, which he explained as follows:

P11: *"It is a different role than you would have with... like raising and teaching your children certain norms and values, yeah for us that is totally different. I can teach my sons very little [...] you have to be realistic, I can tell them nice stories about values and norms, but I will not receive any response."*

Fathers with other children without disabilities acknowledged their inability to teach their children about values and norms. Generally, the majority fathers of children with intellectual disabilities disorder could not identify with the educator role.

1.3 Commitment

All fathers in this study showed great commitment to their role as a father and emphasized their focus on the well-being of their children with disabilities. 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 with a personalized budget at the time. This father explained that he found this system very unfair and, thus, he 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. Fathers all claimed that “being there” was most important for them as a father. Fathers took days off to be there at hospital appointments or rescheduled work to be at home after school or daycare. Moreover, fathers found that taking care of their children by themselves, without the presence of their wife, of vital importance as well, as explained in the following quote:

P4: “I find it as a father important that you are there and share things. That you do not have to be informed by your wife only.”

Spending time together is considered a major constituent of fatherhood by all fathers. These activities can be one-on-one or together as a family. The majority of fathers expressed the great joy they feel when being together with their children and value their time together. Furthermore, fathers enjoyed sharing passions together with their children with disabilities. Fathers expressed the influence of sharing passion on the father-child bond, as follows:

P3: “I have two great passions: music and soccer. [...] Actually, that is not the most important thing for me, talking with him about Plato or whatever [...] Even though now his ability to

... speak is less 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 themselves and their children with disabilities. However, one father expressed that he felt like missing out on doing "father-son like things" and sharing his hobbies with his son. He explained that this inability to share his passions with his son was related to his son's disability.

1.4 Employment characteristics

Fathers explained that employment is an important part of fatherhood, as one father expressed as:

"you know, as a father, yeah you also have to work, you also have a job in addition [to fatherhood]".

Furthermore, some fathers in this study perceived the combination of work and having a child with a disability as quite hard, as participant P3 explained as:

P3: "We have been all together well... more than the half of his whole life been in the hospital. That is pretty tough if beside this you want to have a job or 'a kind of' life. Well, that's the lesser side of it, but I do not blame Down syndrome or whatever, that's just bad luck, mostly for him."

Having a child with a disability influenced the employment status and career of some of the father in this study, which will be described first. Next, the motivation to work of the fathers in this study will be reported.

1.4.1 Career choice

The majority of the fathers highlighted the influence of having a child with a disability had on their career. For some fathers *“the priority of making a career”* had changed due to this experience. Some fathers felt insecure about how to manage their working life after their child got diagnosed with a disability, like a father expressed as follows:

P1: *“After she was born, I immediately felt like ‘what will this mean for my place, can I continue doing this? I could continue, but I think looking back I did make different decisions.”*

Fathers decided to turn down promotional opportunities and they consciously chose to not make the career they had in mind. Fathers explained that this career path was no longer possible because *“my wife wants to have her own life and continue to work”* and *“also I want to put him on the bus in the morning”*. Thus, this decision was influenced by the father’s wish to be involved in the life of his child. In contrast, one father described an ‘involuntary’ effect on his career, which was caused by his unsupportive employer:

P10: *“I was not able to make 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 in this study, which included the flexible organization of time and the ability to work from home. Almost all fathers expressed the necessity of a flexible workplace 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 organization, so whether I work in the evening or morning, my employer does not care”*. Another father expressed that *“if one day something happens, you are not prevented to just be with your family so to say, that is also nice”*. The majority of fathers in highly educated jobs decided to reduce their working hours and work around 32 hours a week (not full-time). However, a few fathers decided to start working independently and thus work more hours per week. The predominant reason to switch to self-employment was to have more flexibility, as one

father explained as follows: *“which also has to do with my daughter, because now I can organize my working hours myself”*.

One father in this study gave up his full-time job to take up the care of his child with a disability. This father and this wife made this decision based on *“who earns the most and who wants to have a career the most”*. This father admitted that *“sometimes it sucks to be home, although it is also work but... [...] but I get a lot in return”*. Not all fathers in this study sample felt the need to change their job. One father explained that he would only do this if necessary to relieve the burden of his wife. These findings show that the influence on the career or employment of the fathers varied in this study.

1.4.2 Motivation to work

The fathers expressed different motivations to be employed. Their central incentive to work was to generate income for the family. Almost all fathers reported that they felt *“responsible”* as a father to financially support their family. One father explained this feeling of responsibility is enhanced because of having a child with a disability, as follows:

P8: “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, it keeps getting less less less...”

However, most fathers stated that family or quality time has the priority compared to a higher income or work in general. One father with two sons with disabilities stated that a higher income is no longer important in his life as follows: *“maybe I am less career focused than before, well 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, that is not important, but that used to be different yes”.

Next to the generation of income, working was for some father something they enjoyed doing.

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 work 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 overtaken by facts, so that was no success for me. Then I should have searched for a different job, but I did not want to compromise for this, I was thinking ‘no, this makes me happy”.* The employed fathers in this study felt like working was necessary for them in life because they had *“ambitions”.*

A minority of fathers expressed their need to work to distract themselves. A few fathers explain that they felt like *“only being with the kids”* is not something they would like in life. Other fathers expressed that they ran away from a difficult situation at home, as one father expressed as follows:

P8: “I was running away from a situation I think I found very difficult, I felt very responsible, but I expressed this mostly by working and providing income [for the family] and those kinds of things.”

Additionally, fathers explained that there were almost always care providers at home. Due to this amount of support that is usually present at home, one father expressed that *“I mean if I do not have to be at work, I usually am at home, but sometimes I did not because I wanted to get away from [home].”* In sum, for some fathers, work was in a way a strategy to ‘escape’ from home for different reasons.

2.0 Contextual factors

2.1 Cultural expectations

Fathers in this study reflect on how they are viewed in society. One father, who is the primary caregiver of his child with a disability, described his experience that activities for caregivers of children with disabilities are, to his surprise, generally aimed at women. A divorced father explained that he feels that in the Netherlands it is not common for a father to participate in household chores to the extent as he does, as people are often pleasantly surprised when they hear about this. A few other fathers expressed their appreciation for the reward 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 child with a disability. Moreover, all fathers were bothered by the usual ‘staring and gazing’ at their children’s physical characteristics. One father used the following words to describe his frustration of just wanting to be a father, as follows:

P10: “I find it important that she is part of society, so that people do not think ‘o 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 while their child was younger this ‘staring and gazing’ was very hard on them, now they have learned to deal with it and they decided to ignore it. Notably, fathers stated that this ‘staring and gazing’ would only bother them, if it would hurt their children. The fathers explained that for now this was not an issue, as their children were not able to understand this due to their disability or age.

2.2 Social support

All fathers mention the support in ways of the personalized budget (PGB in Dutch). This budget which is funded by the Dutch government intends to give the freedom to parent/child to decide on and pay for health services and care providers, such as at home care providers during day and night time; and (medical) day care on weekdays and weekends. All fathers really appreciated this help from the government. Nevertheless, some fathers explained that receiving care providers in their home sometimes felt like invasion of their privacy, as one father expressed as follows:

P3: "For example if during the night, I sleep in my boxer short, then I have to put on jogging pants 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. Thus, it feels very mixed actually."

A few fathers explained that it is hard on them to hand over the care of their children to care providers. Fathers expressed that they sometimes *"quickly take over and do it themselves"* instead of the care provider. They try their best to stay seated, as they know that this support is also aimed at giving themselves some time off caring for their children with disabilities. This is in accordance with other fathers reporting great difficulty with *"sending away their child"* for day care or an overnight weekend.

None of the interviewed Dutch fathers expressed their interest in support groups for parents of children with disabilities. The following quote describes the perception of these fathers as follows:

P10: "We are doing this in our own way, I do not know if that is comparable to what others do, but I do not care at all, I like to learn from others but not in this setting."

3.0 New life perspective

All fathers in this study expressed that the experience of fathering a child with a disability has changed themselves in a way as *“you learn a lot about yourself as well”*. Most of the fathers in this study claimed that this experience has enriched their lives, as one father said: *“I always like to say, like yes, it also brought us a great deal of [positive] things”*. Less than half of the father explained that they have changed as a person through this experience; however, most fathers stated that this change could partly be caused by the experience of fatherhood itself or as P6 explained *“but it that can 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 a positive attitude.

3.1 Appreciation of the little things

A minority of the fathers in this study reported their new ability to appreciate the little things in life. One father explained that before he was more *“materialistic”* and explained this as follows *“it is a pity that sometimes you need to suffer, if I could I rather would have had a different choice, but it did bring us many things”*. However, one father explained the difficulty he experienced with opening himself up to appreciate the little things as follows:

P8: *“For one part that was related to the fact that I did not have any room [emotionally] to take time to experience the little things and to enjoy it.”*

It took this father some time to change his perspective and learn how to appreciate the little things in life, which suggest that this is not an easy thing to do for all fathers.

3.2 Transformation of expectations

All fathers explained the need to transform or let go of their expectations of their children with disabilities or life in general. Fathers explained that this experience made them realize the expectations they unconsciously had about their children and made them reflect on *“what they want for their children”*.

P5: *“That is the strange thing. You always have expectations about everything.”*

The fathers explained that they had to transform their expectations of their child and the relationship with their child, especially shortly after diagnosis of the disability. Some fathers in this study experienced this as a *“phase of mourning”*, but also claim that they have grown out of this phase as one father said as follows: *“the degree to which I regarded [these expectations] as important has changed dramatically over time”*. In contrast, P1 stated that his diminutive expectations of his daughter hampered her development. The father called himself a *“disabling factor”* in her development, as several events now made him recognize that *“she can do much more than we notice all together”*.

3.3 Living in the moment

The majority of fathers claimed that their children with disabilities forced them to live in the moment as well. Half of the fathers mentioned insecurity of 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, as illustrated in the following quote:

P11: *“We live from day to day [...] I think more people should do this, not looking forwards and looking backwards also does not make sense much, I think that has positively impacted our lives. Just more living in the moment”*.

The amount to which the fathers in this study prepared for the future varied greatly. Most fathers explained that they lived by the day and decided to prepare for the future of their children by saving money. One father mentioned the importance of also taking care for the future for his child. Others explained that they do think in the long term depending on the issue, as this father explained as follows:

P12: "The only thing for which we think in the long term is the annex of our son [...] for the rest we live per week, we make a weekly schedule and I also have a monthly schedule with the care providers."

3.4 Positive attitude

To conclude, all fathers in this study tried to make the most of the situation they were in. They tried to see the bright side of their new situation and had a very positive attitude. Again, some fathers explained that this positive attitude had been natural to their character all their life, whereas others learned to deal with this over time. This positive attitude is also related to 'not giving up', as fathers claimed that the positive attitude was necessary for them in order to keep going. Some fathers explained that they had to "*flip a switch*" in order to gain this positive attitude, as described as follows:

P11: "As long as they are healthy, feel comfortable in their skin, in their own little world, well, they do not know better. It is for us, we must flip a switch. If every time we compare ourselves to other parents, other children, well then you get sad. Why don't we have that? If you can manage to flip this switch, you can still do great thing together with children with disabilities."

The fathers stated that their children's ability to "*make contact*" and their children's well-being, including happiness and health, greatly influenced their ability to remain positive. One father

expressed this as *“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”*.

Part two: putting the experiences into context of other European fathers

Albeit the data of the small pilot study with European fathers in itself is not sufficient to generalize or develop conclusions, the data is used to view the experiences of Dutch fathers from a broader perspective.

1.0 Father factors

1.1 Role identification

European father described their role as a provider in the lives of their children with disabilities. Some European fathers explained the great responsibility they feel to be the financial provider of the family, which is also stated by Dutch fathers in this study. A Flemish father clearly acknowledged being the providers as of one of his roles as a father, even though his wife was also employed. Moreover, the father experienced his role is to keep the family running, as is explained in the following quote:

P17: “Fatherhood, it pressures me, not directly fatherhood itself is the problem, but it is more the taking care of putting food on the table [...] the father has the final responsibility to run the whole business. That is how I feel it. I feel responsible for that. The child-rearing comes after this, and I try to do that the best I possibly can.”

None of the Dutch fathers expressed their fathering role as a provider, even though some felt responsible for the financial provision of their family.

Dutch fathers reported similar roles as European fathers. A Flemish father made a distinction when asked what fatherhood meant to him, between his children without disabilities and his child with a disability, as follows:

P17: *"I try to teach my children, well at least my 'normal' children, to think critically, open-mindedness and also to laugh, a lot and humor".*

His educator role did not apply to his child with a disability, which was comparable to the role identification of most Dutch fathers. The supervisor role was described by a few fathers in this European study through providing guidance, as a Portuguese father expressed as *"we are always watching, trying to help and correct the paths she chooses"*. The Irish father made a clear distinction between fathering and mothering, with fathering being *"more like a kind of mentor"*. This father also explains his role in the life of his son as a *"good buddy"*.

1.2 Commitment

The European fathers felt great responsibility for their paternal role, which a Flemish father described as *"making time to be there"*. Fathers were deeply concerned and involved with their children's schooling. Furthermore, most fathers joined an association for children with disabilities or set up one themselves, if they felt that their children with disabilities had limited opportunities in their area. An Irish father set up a company to work together with his son with a disability, which aims to *"shift the stereotypes"* of people with Down syndrome.

The European fathers found it important to spend time together with their children. A Spanish father expressed the importance of being able to share a passion together as follows:

P14: *"I've always liked running, but with the child I couldn't. Then I heard that in the school there was an athletic club, for running with running chairs and all that. I heard about it, I bought the chair and it's a way to go out and make some exercise."*

In contrast, two European fathers adapted to their children's interests; however, an Italian father confessed that he decided to quit at some point: *"I had to take her to this town, she had to do an hour of lessons and then I said to myself 'I will try it too, maybe I'll learn something too'. After two lessons [my daughter] played the piano, and I stopped (he laughs)"*.

Dutch fathers also found creative ways of interacting with their children in activities that were pleasant for both. The data on European fathers suggest that this fathering nature is not dependent on contextual factors, as all fathers that participated in this study showed great commitment to their children with disabilities. Even if money is tight, the fathers indicated that there is always a solution when you are persistent and creative.

1.3 Employment characteristics

All European fathers are employed and most described themselves as the financial provider of the family. An Italian father explained that it was quite stressful to him when he lost his job to *"support his family, especially financially"*. A Turkish father worked six days per week and, thus, he was not able to spend much time with his child, as follows: *"because I work most the time I have and that's why her mother has to do it"*. Nevertheless, most European fathers try to *"be flexible with work situations"* and prioritize family over work whenever this is possible. A Portuguese father explained that he *"never failed an appointment"* of his daughter at the hospital. Additionally, a Spanish father claimed that he prioritizes his children over his job as follows:

P14: *"I adapt my work life according to my children's necessities, and here I talk about both of them not only my son with a disability".*

Comparable to some Dutch fathers, an Italian father expressed that his job served as a distraction for him in the period after the diagnosis of the disability of his child: *"I went to work and even there I wandered a bit, in the sense that... the issues help to distract a bit and focus on other things".*

The opportunity to spend time with their children varied greatly between the European fathers. The extent to which they managed to adapt their work life to their family life, seemed to be related to the fathers' employment opportunities and related contextual factors. Dutch fathers showed a broad range of experiences in relation to balancing their family and working life, but all reported opportunities to spend time with family due to, for instance, flexible workplaces. However, not all Dutch fathers felt the need to adapt their work to their children. In summary, these findings suggest that the experiences as an employed father vary greatly depending on the individual and are also influenced by employment opportunities in the country of residence.

2.0 Contextual factors

European fathers reported identical experiences in public life including the 'staring and gazing', which still bothered these fathers, even though they have learned to deal with this over time. A Flemish father expresses his opinion on the pity he receives from people around him as follows:

P17: *"Society is viewing us as 'oh you poor thing...', but then I always think 'you should know how happy we are!'"*

None of the fathers shared cultural expectations about fathering in general. The data of the European fathers highlights the universal experience of 'staring and gazing' in relation to having children with disabilities.

Social support is provided by the government to a lesser extent, depending on the country, compared to the Netherlands. A Spanish father explained that *"it is expensive even to adapt a house [...] we have to adapt ourselves because there is no help, but it is worth it"*. Most European fathers count on the support of their families, especially grandparents, for taking care of their children with disabilities. An Italian father stated that they *"do not really count on anyone, we have family here, but we are not so close"*. This Italian father, who is originally from Romania, moved to Italy because of better employment opportunities and health care. This father explained that his Romanian family is unable to understand his situation, as follows:

P19: *"There are very few people who stay around the families with a disabled person in it. Mainly because we can't really do some things, for instance, a party. We have our problems and we have to interrupt what we are doing to do what he [the child with a disability] needs and of course people do not like that."*

This father stated that his social life is negatively influenced by the care for his son. Some Dutch fathers have reported similar limitations in their social life. However, support by care providers solved most problems of these fathers, in contrast to this Italian father, who has no options for support. The support opportunities of fathers and the overall acceptance of disability in the Dutch fathers' families might influence the experience of fathering of Dutch fathers substantially.

To conclude, an Italian father explained the comfort he receives from support groups for parents of children with disabilities. A majority of the European fathers is actively involved in support groups. In

contrast, Dutch fathers seem to rather do things in their way without the help of these groups or associations.

3.0 New life perspective

The European fathers in this study reported a relatively positive attitude. The Flemish, Italian, Portuguese and Spanish fathers explained that having a child with a disability changed their perspective on life, including ‘transformation of expectations and ‘appreciation of the little things’. Some fathers explained that the experience of fathering a child with a disability had changed themselves, as worded by an Italian father as follows:

P20: “I think I have grown, by changing my baseline values. The material aspirations proved to be empty, superficial, and I looked for appreciation of the little things, rethinking my priorities.”

The Dutch fathers reported that the experience of having children with disabilities increased reflection and caused reassessment of important values in their lives, which was also reported by the small sample of European fathers.

Discussion

This study aimed to gain insight into the experiences of Dutch fathers of children with disabilities. This study draws on the conceptual framework on ‘responsible fathering’ (Doherty et al., 1998) using a grounded theory approach. The ‘father factors’ and ‘contextual factors’ illustrated in the model (Figure 1) to describe the experiences of fathers of children with disabilities. It should be noted that the conceptual model on ‘responsible fathering’ is directed to fathers of typically developing children. Moreover, the term ‘responsible’ adds a value to the model, which is beyond the scope of

this study. Yet, categories similar to the factors described in this model emerged from the data, including 'role identification', 'commitment', 'employment characteristics', 'cultural expectations' and 'social support'.

A key finding of this study was the substantial influence of the 'new life perspective' on the fathering experience. However, this factor was not depicted in the conceptual model on 'responsible fathering' (Doherty et al., 1998), which suggests that this is an additional or specific factor influencing the experiences of fathers of children with disabilities. Some fathers expressed the enrichment of their lives due to this fathering experience and their new perspective on life, which concurs with a previous study by Bonsall (2014). Subcategories that emerged from this category included 'appreciation of the little things', 'transformation of expectations', 'living in the moment' and a 'positive attitude'. Recent studies have reported the transformation of the fathers' expectations of their lives and their children with disabilities (Baumann & Braddick, 2016; Shave & Lashewicz, 2016), which agrees with the majority of the fathers in this study. Moreover, the 'pace of life' found in this study agrees with the day-to-day life of families with a member with a disability reported by Schippers & Van Boheemen (2009). Thus, it could be suggested that the 'new life perspective' is universal to all fathers of children with disabilities.

This study used pilot a study on the experiences of European fathers of children with disabilities to put the experiences of Dutch fathers in a broader perspective. Hence, this is not a comparative study between Dutch and other European fathers, as the European data is merely used to study the influence of contextual factors on the Dutch fathering experiences. Moreover, this study did not intend to compare the experiences of fathering children with disabilities to typically developing children. Instead, this study focuses exclusively on the experiences of fathers of children with disabilities. Nevertheless, the fathers in this study emphasized that some aspects of their fathering

experience were identical to fathering of their typically developing children, which was also reported in previous research (Dyer et al., 2009). The fathers in this study did mention a distinct father role in the lives of their children with disabilities compared to their other children. This finding indicates that there are striking differences to the fathering experience in the presence and absence of disability, which agrees with the literature (Cheuk & Lashewicz, 2016). However, this is beyond the scope of this study.

The fathers considered the well-being of their children with disabilities their primacy regardless of the father's positive or challenging experiences. Furthermore, spending time together was a priority of all fathers in this study, which is in coherence with a study by Bonsall (2014). Of note, the ability or lack of sharing passions with their children significantly influenced the fathering experience. One father specifically expressed his 'grief' of not being able to share a typical father/son relationship, which agrees with previous research (Thackeray & Eatough, 2016), whereas the majority of fathers found creative ways to spend time together. This possibility of 'sharing of interests' might depend on child characteristics and in turn influence the experiences of these fathers.

Krauss (1993) suggested that the child's temperament and feeling of attachment to the child are related to the fathering experience, which is also supported by the findings of this study. The feeling of attachment to the child could be related to the type of disability; however, the literature is inconclusive whether the severity or type of disability influences the parenting experience (Blacher, 2007; Boström & Broberg, 2014; Krauss, 1993), which indicates that further research is necessary. The findings suggest that child factors can influence the fathering experience, as depicted in the 'responsible fathering' conceptual model. Moreover, Potter (2016) claimed that the diversity of experience can affect the challenges and needs of fathers of children with disabilities, which together with the findings of this study, underscores the need for further research to these fathers.

Fathers in this study reported diverse perceptions of their fathering roles. The fathers described different roles in the lives of their children with disability, including caregiver, supervisor, and to a lesser extent educator. These roles have also been described in studies with fathers of typically developing children (Olmstead, Futris, & Pasley, 2009; Summers et al., 1999); however, this is the only studies, to the author's knowledge, reporting the perceptions of the father role by men with children with disabilities. The findings of this study reveal that men hold multiple roles simultaneously, which complies with a recent study on fathers of typically developing children (Humberd, Ladge, & Harrington, 2015). Attachment to the child determined the appreciation of the caregiving role and feeling appreciated by the child enriched the caregiving experience. These findings indicate that further research is required to elucidate the role identification of fathers of children with disabilities and the influence of child factors.

All fathers, except for one, who took up the full-time care of his child with a disability, fulfilled the breadwinner role in their families. This finding coincides with several studies reporting a 'traditional parental role division' in families with children with disabilities (Di Giulio, Philipov, & Jaschinski, 2015; Hornby, 1995). Financial support is generally viewed as an essential element of parenting by men (Rane & McBride, 2000). However, Dutch fathers were less inclined to describe their role as a provider when viewed from the perspective of European fathers. Yet, Dutch fathers felt responsible for the generation of income for the family, which was a central incentive to work. However, the findings suggest that financial provision was not related to their father role but might be related to masculinity or gender roles. More research is warranted to elucidate the meaning of the 'provider' role for fathers of children with disabilities. Besides the generation of income, work also served as a coping strategy or distraction for the situation at home for some fathers, which agrees with recent research (Davys, Mitchell, & Martin, 2017).

The fathers in this study adapted their work life to their family life, which was partially related to the increased demands of care due to the child's disability. Only a few of studies have explored the experiences of employed fathers of children with disabilities. The literature is inconclusive on the nature of the impact on the labor market participation. A recent study by Wright, Crettenden, & Skinner (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 & Towers, 2008; Crowell & Leeper, 1994; Golden, 2007; Shave & Lashewicz, 2016; Venter, 2011; Wright et al., 2016) and the choice of self-employment to provide flexibility for the 'unplanned demands of caring' (Wright et al., 2016), which agrees with this study. Remarkably, Brown & Clark (2017) claimed that employment changes are less likely in parents of school-aged children with disabilities as compared to younger children, which disagrees with the findings of this study.

To conclude, the conceptual framework on 'responsible fathering' highlights how fathering is uniquely influenced by contextual factors, including 'cultural expectations' and 'social support' (Doherty et al., 1998). All fathers reported their struggle with stigmatization due to their children's disability, which agrees with the literature (Pelchat et al., 2003; Thackeray & Eatough, 2016). Above all, Dutch fathers had more options for governmental support, which affected their fathering experience in a positive way. There are striking differences in policies between European countries (Nordenmark, 2015) and research shows that policies and regulations greatly affect the fathering experience (Dermott & Miller, 2016; Johansson & Andreasson, 2017), which in turn can influence the experience of fathering. The personalized budget and the flexible organizational culture in the Netherlands enhanced the fathers' ability to spend time with their families. The financial contributions by the government also compensate for costs related to the child's disability, which

might decrease the 'breadwinner' burden for the Dutch fathers. However, Dutch fathers expressed their worries because the long-term future of these budgets is insecure. However, further research is warranted to the experiences of fathers of children with disabilities.

Limitations

This study is subject to several limitations that may have reduced the reliability and validity of the findings. The findings of this study are based on twelve Dutch participants and may not fully reflect the experiences of fathering children with disabilities. The pilot data of the European fathers' study is solely used to criticize and strengthen the findings of the Dutch fathers and these findings should not be generalized. In addition, the age range of the children with disabilities varied from 6 to 22 years, which limits the generalization of the findings to this age group.

Overall, fathers shared relatively positive experiences and were involved in their children's lives, which might be related to the fact that involved fathers are more likely to participate in research (Higgins, 2005). Moreover, it is possible that father presented themselves in socially desirable ways during the interviews, which might also result in more positive experiences than might be the case. Fathers had relatively homogenous backgrounds, as highly educated, married, Caucasian men were overrepresented in this study. Thus, innovative and inclusive recruitment strategies are warranted in future studies with fathers.

Conclusion

The findings of this study indicate that the conceptual model on 'responsible fathering' by Doherty et al. (1998) can be used to study fathering experiences in the presence of disability. The experiences of

fathers of children with disabilities are challenging, but overall positive. Some fathers emphasized the enrichment of their lives through their 'new life perspective'. This study highlights the additional influence of the 'new life perspective' on the fathering experience, which was frequently reported by these fathers and is not mentioned in the conceptual model. The European fathers' pilot study showed a comparable recognition of the 'new life perspective', which suggest a universal influence of this aspect on the fathering experience.

Acknowledgements

First of all, the author would like to thank the fathers for participating in this study and sharing their experiences. Furthermore, the author would like to thank Geert van Hove from Ghent University for the pleasant collaboration and the Erasmus Mundus students for sharing their interviews with European fathers. Lastly, sincere thanks to Minne Bakker and Alice Schippers for their supervision and support during this research project and their insightful comments on this report.

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Supplementary documents

1.0 Interview guide

Interview guide English

Thank you for participating in the Father's Project (short description)

I would like to ask you to read the consent form and sign it if you agree. There is an option for the sharing of the videoclips, you can decide whether you'd like to share the videoclips. You can send it to me after.

Furthermore, I would like to emphasize that you're allowed to stop the interview or take a break at any time. There are no 'wrong' answers, but you are not obliged to answer all questions.

I will start with the recording of the interview, only audio, once the interview starts. I will also write down some notes. Do you have any questions for now?

Videoclip

I would like to watch the videoclips you've chosen first. After watching the clip(s), we'll go into more detail of the video and other questions regarding fatherhood and family life.

Video

1. Why did you choose this video?
2. What do you see in this video?
3. Can you tell me how and when this video was made?

Video sharing?

4. If you could share this video with someone, who would that be? Family, teacher why?
5. Do you think this video shows your child in the way he/she really is? Is this a regular (weekly/monthly) activity?

Father-child relationship

I would like to continue with questions regarding fatherhood. Sometimes I will go back to the examples in the video.

Activities

1. Can you tell me something about the time you spend together with your child? Activities you do together? Passions you share?
2. What are the best moments as a father with your child? And the hardest moments?

Father-child relationship

3. Can you tell me about the relationship you have with your child? Can you describe it for me?
 - a. Did the decision of the videoclip make you think about this relationship? Do you want to share your thoughts with me?

4. What are the biggest challenges in the relationship with your child? Can you give an example?

Fatherhood

1. **Did the decision of the video make you think about being a father?**
2. Could you describe your role in your child's life?
3. What does fatherhood mean to you?
4. **Did the experience of being the father of a child with a disability change your perspective or as a person? Can you explain/elaborate on that?**

Employment

1. Are you employed? Has your employment/job/work changed after the birth or during the life of your child?
2. Do work obligations allow you to spend time or be here for your child? Does/did your employer support you when necessary?
3. Did fatherhood/becoming a father change your employment?
4. How do you balance family and working life? Do you feel like you have to?

Country context

Very important for me is the context. I am not familiar with Irish culture et cetera, so I am interested in whether ...

1. **You think you could be considered as a "typical (country) father"? And why?**
2. What is expected of you (from wife/work/society) as a father?
 - a. Can you name some important parts for you of fatherhood?
 - b. What factors influence fathering or fatherhood?
3. Is there anything that prevents you from spending time with your child like you would want to? At home, public spaces, work, strangers/family's opinion?
4. Did you ever deal with a difficult situation concerning being a father of a child with special needs? Can you elaborate on that?
5. Do you meet other parents/fathers with a child with a disability? Do you feel the need to?

End of interview

Thank you for answering all of my questions. I have 2 questions left. First, what is your age? And lastly, is there something I did not ask that you wish to share with me?

Demographic questions / checklist

Thank you for all the information you provided. I would like to ask you some additional factual questions.

1. Can I ask you your age?
2. What is the relationship with your child, are you the biological father, stepfather, adoptive father?

3. Are you married? If so, are you married with the mother of the child? If not, do you live together with or are you in a relationship with the mother of the child? If not, does the child live with you?

2.0 Consent form

The Father's Project

Short project description

The Father's Project is a collaboration between (European) universities, including Ghent University, University of Iceland, University of Akureyri, Lillehammer University, Open University UK and Disability Studies in the Netherlands.

The aim of this project is to gain insight into the experiences of fathers with a child with a disability. To date, research to families with child(ren) with a disability has been mostly directed to the mothers. Therefore, fathers are largely overlooked in this research field, although they too have an important influence on (the development of) their children.

Therefore, we would like to gain more insight into your experiences of being a father of a child with a disability. This interview will focus on fathering and fatherhood and will last around one hour. We ask you to select video fragments of your choice depicting the relationship with your child with a disability, a special moment or "normal" day: any video (max. 15 minutes) you wish to share with me during the interview session.

I would like to thank you again for participating in the Father's Project!

Other questions?

If you have any questions after this interview, you can contact the student interviewer Majoska via e-mail mhm.berkelaar@gmail.com or one of her supervisors Minne Bakker mi.bakker@vumc.nl and Alice Schippers alice.schippers@disabilitystudies.nl. Prof. Dr. Geert van Hove of the Ghent University has the final responsibility of this project. Geert van Hove can be reached via Geert.VanHove@UGent.be.

Informed consent English

This is to certify that Mr..... is a participant in the “Fathers Research Project” in collaboration with Ghent University, Belgium.

Mr..... is for this project working together with a student-interviewer called Majoska Berkelaar, intern at Disability Studies in the Netherlands.

The participant is well informed and agrees with the following elements of this research project.

1. This project is a part of a larger European Father’s Project. (see: short project description)
2. This project is looking for the perspectives of fathers on their son/daughter with special needs.
3. The participant can leave the interview at any given time.
4. In the results of this project the information of the participant will be anonymized.
5. The participant **AGREES / DOES NOT AGREE** that his video-clip(s) are collected in a larger collection that can be used for analysis in the larger research project.
6. The participant has done everything to make sure his child is not opposed to the use of the video clips.
7. The participant agrees that the interview is collected into a larger interview collection that can be used for analysis and publication in the larger project.
8. The participant agrees that the student-interviewer records the interview to make sure that his words are well captured. All records will be destroyed after the transcription of the interview.
9. If the participant has particular questions after the interview he can always reach the student-interviewer via email mhm.berkelaar@gmail.com or her supervisors mi.bakker@vumc.nl and alice.schippers@disabilitystudies.nl.
10. The participant knows that Prof. dr. Geert Van Hove, working at Ghent University, has the final responsibility of the project. He can be contacted with questions about this project on Geert.VanHove@UGent.be.
11. The participant will receive a short research report with an overview of the results of this project

The participant

Signature and date

The student-interviewer

Signature and date