

The views and experiences of fathers of young children with intellectual and developmental disabilities: Findings from a qualitative study

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ABSTRACT

Aims and objectives. The aim of this paper is to report on fathers' responses to their child's diagnosis of intellectual and developmental disability (IDD), their expectations of fatherhood and their motivation for participating in research.

Background: There is a growing interest in understanding the experiences of fathers of children with IDD given the transformation of the structural change of fathers' roles within the family and wider society. Therefore, their voices need to have a more dominant research focus regarding learning of a child's diagnosis, their expectations of fatherhood and their motivations for participating in research.

Design: A secondary analysis of a qualitative study that initially explored the views and experiences of fathers of young children with intellectual and developmental disabilities (IDD) was used to address the new research questions.

Methods: A total of 10 fathers(n=10) consented to participate in semi-structured interviews. Secondary analysis of data were thematically analysed.

Results: This paper specifically reports on three themes following a secondary analysis of the primary data (i) learning of a child's diagnosis (ii) expectations of fatherhood and (iii) what motivates fathers to share their story.

Conclusions: The study inform and develops further understanding the international evidence-base of learning of a child's diagnosis, the expectations of fatherhood and what motivates fathers to share their story of being a father of a young children with IDD. Nurses have important contributions to make in meeting the needs of fathers and there are specific areas to consider in terms of practice, education and research that require further attention and development to ensure fathers distinct needs regarding their child's diagnosis of IDD are known and responded to effectively.

Relevance to clinical practice.

This study highlights that from the time a diagnosis of a child's disability is confirmed, fathers experience a competing range of mixed emotions. Healthcare professionals including nurses must be aware that even the words used at a disclosure can impact on how fathers process the news. Therefore, it is critical that healthcare professionals are aware and educated about their roles, responsibilities and best practice guidelines that could be used to underpin their practice at the time of disclosure to improve future care and support for fathers and the wider family.

Keywords: fathers, families, children, diagnosis, education, intellectual and developmental disabilities,

What does this paper contribute to the wider global clinical community?

This study highlights how important it is for healthcare professionals to recognise that the diagnosis of IDD is a very emotional time and the words that are used as well as who is involved in the disclosure can influence how fathers adapt in the proceeding days, months or years. Further, fathers are often reticent to talk to others about themselves or their child and may find it difficult to access supports such as counselling or disability support groups. Therefore, fathers should be afforded an opportunity to discuss their feelings regarding a child's diagnosis of IDD and their changing expectations of fatherhood so that healthcare professionals recognise and support them across the caring trajectory.

1. INTRODUCTION

Major transformations in the roles of mothers and fathers within families had evolved and families now compose of diverse elements that include gender differences, single parents, co-parenting and same-sex couples (Carroll 2018; Gates 2015; Golombok 2015; Goldscheider, Bernhardt & Lappegård, 2015). Additionally, the change from traditional family structures have been influenced by socio-political and economic factors. These changes have seen women return to the workplace thereby necessitating the need for shared parenting (Christopher et al., 2015; Doss & Rhoades 2017). While it is recognised that traditional approaches to child-rearing and parenting have historically focused on the role and experiences of mothers, fathers are playing an increasingly central and important role in child rearing. For example, evidence highlights the positive effect that the involvement of fathers has on social and psychological development and academic achievement (Cohen et al., 2016, Jeynes 2016).

Becoming a father is a life changing event and a significant milestone (Gage & Kirk, 2016; Yarwood 2011) in which a man's status changes from that of being a son, a brother, a partner or a husband to that of being a father (Chin et al., 2011). Transition to fatherhood is often a mixture of excitement and apprehension and can be extremely rewarding (Huang et al., 2011). Despite positive policy initiatives spanning over 50 years, a meta-ethnographic analysis of 62 research studies found that fathers are still not fully accepted and supported to fulfil their parental roles (Wells 2016).

However, societal changes and expectations of men has witnessed the more involved father, who takes on considerable responsibility for the rearing of a child and this increased involvement is recognised more globally in the wider family context (Allport et al., 2018; Banchefsky & Park 2016; Broomhill & Sharp 2012; Shapiro et al., 2019). Indeed, this increased involvement is reflective of fathers of children with IDD (Boström & Broberg 2014; Davys et al., 2017; MacDonald & Hastings 2010; Takataya et al., 2016).

The focus in the past, however, is one of the negative aspects of parenting a child with IDD such as stress (Findler et al., 2016; Giallo et al., 2015; McConnell & Savage 2015; Thompson, Coleman & Olmos 2018) marital disharmony (Namkung et al., 2015; Robinsonn & Neece 2015), and financial pressures (Trentacosta et al., 2018; İnanç et al., 2018; Isa et al., 2016). In addition, much of the research is presented through the lens of mothers (Findler et al., 2016) with a reduced focus on fathers' experiences (Davys et al., 2017; "Author Blinded (2018a)"; Marshak et al., 2018) despite the growing recognition of fathers' involvement in the caring roles for their children from the moment of the diagnosis of IDD. Yet, the diagnosis of a child's IDD requires a man to reposition himself as a father of a child with a disability (Davys et al., 2017). Therefore, the aim of this study is to report on fathers' responses to their child's diagnosis of IDD, their expectations of fatherhood and their motivation for participating in research following a secondary analysis of a qualitative study.

1.1 Aims

The aim of this paper is to report on fathers' responses to their child's diagnosis of IDD, their expectations of fatherhood and their motivation for participating in research.

2. METHODS

A secondary analysis of a qualitative study that initially explored the views and experiences of fathers of young children with intellectual and developmental disabilities (IDD) was used to address these new research questions (Long-Sutethall, Sque & Addington-Hall 2011; Ruggiano & Perry 2019). Each transcript was read and re-read for the quality of the data. This exploratory qualitative research study employed one-to-one interviews with fathers of children with intellectual disabilities in the Republic of Ireland. A qualitative design was identified as

appropriate to uncover intimate and sensitive personal experiences that can advance new knowledge and understanding and benefit wider society (Ruggiano & Perry 2019).

2.1 Ethics statement

Full and independent ethical review and approval was sought and provided by the relevant organisations with all research ethics and governance procedures adhered to throughout.

Consent was gained from all participant fathers.

2.2 Study question

1. What were fathers' responses to their child's diagnosis of IDD?
2. What were their expectations of fatherhood?
3. What motivated them to participate in the research?

2.3 Sampling and inclusion criteria

This study was undertaken with 10 fathers drawn from an early intervention intellectual disability service in Southern Ireland. A convenience sampling (Haber 2013) approach was used to identify 25 potential fathers of children with ID who met the inclusion criteria. Fathers were invited to participate (i) if they were living with their child who had IDD, (ii) their child was younger than six years of age, (iii) their child was being supported by the Early Intervention (EI) services and (iv) were able to communicate their stories in English. Ten fathers responded directly to the researcher and consented to participate in this study.

2.4 Data collection and recruitment

Participants were recruited from an early intervention intellectual disability service in Southern Ireland through a Registered Nurse Manager who acted as gatekeeper in an early intervention

service. The gatekeeper disseminated the study information on behalf of the first researcher including the researcher's contact details, to 25 fathers availing of early intervention services and who met the inclusion criteria. As per the guidance, a total of 10 fathers contacted the researcher directly by via email, phone calls or texts consenting to participate in the study and interviews with the primary researcher were scheduled at a date and time that was suitable to both parties. Neither participants nor their children were known to the researcher prior to their participation in the study. As the other 15 fathers did not contact the researcher, their specific reasons for not participating were never made know.

As the focus of the original study was to explore the views and experiences of fathers of young children with IDD, a qualitative interpretative design was adopted involving semi-structured interviews ($n=10$). Interviews were conducted with the female researcher in fathers' own homes ($n=3$), the primary researcher's office ($n=4$), an office in the early intervention service ($n=2$) or the workplace ($n=1$). Each interview was digitally recorded and lasted for approximately 49-76 minutes, with the average interview lasting one hour. Following data collection, pseudonyms were assigned to provide anonymity and confidentiality was assured.

2.5 Data analysis

Thematic analysis was used to conduct a secondary analysis (Johnston 2017; Long-Sutehall, Sque & Addington-Hall 2011; Ruggiano & Perry 2019) of the data across and within transcripts which addressed fathers' responses to the child's diagnosis of IDD, their expectations of fatherhood and what motivated them to participate in research (Clarke & Braun 2017). All interviews had been transcribed verbatim by a professional transcribing company. They were then initially analysed individually, and then collectively, using an analytical framework developed by the three members of the research team to address the new research questions. Further, *QSR NVivo 12* software was used to manage all of the data and support the systematic

approach to analysis (QSR International 2018). During the interviews field notes were recorded and some analytic thoughts began emerging. Immersion in the data was critical to generate these themes and this was achieved through repeated listening to the audio-recordings and re-reading the transcripts for the quality of data (Long-Sutehall, Sque, & Addington-Hall 2011). Emergent themes were identified independently by all researchers and following discussion consensus agreed that represented coherency of fathers' stories in relation to the research questions. The use of rich descriptions added to the richness of fathers' stories (Nowell et al., 2017).

2.6 Validity, reliability and rigour

A transparent process of decision making was established by the research team to ensure confirmability the findings. To enable this, a detailed description of the participant experiences was undertaken, thereby establishing the potential transferability of the secondary findings from the study (Graneheim et al., 2017). From a credibility perspective, robust data collection methods, data analysis and synthesis were employed throughout. As part of the secondary data analysis procedure, the researchers undertook detailed cross-checking and confirmation to enable the identification of the emergent themes. The application of the principles of qualitative rigour were fully applied throughout the data analysis process to ensure the trustworthiness of the findings (Noble & Smith 2015).

3. RESULTS

The study involved 10 fathers who completed semi-structures interviews providing rich qualitative data. The demographic characteristics of the participants and their children with IDD included 8 fathers who were married and 2 who were co-habiting, with ages ranging from 31-48 years. Of the children with IDD, 6 were boys and 4 were girls, with ages ranging from

13 months to 5 years. One boy had severe physical and intellectual impairment and one boy was being tested for autism. Six children had Down syndrome and one boy had Global Developmental Delay. One girl remained without a specific diagnosis. A total of nine children with IDD had siblings and one was an only child.

Table 1: Demographics of fathers and their child with IDD

Participant pseudonym & age	Relationship, pseudonym and age of child	Child's Diagnosis
Andy Age 37	Daughter Molly 2½ years	Down syndrome
Brian Age 31	Daughter Abbie 2 years	Undetermined
Charlie Age 39	Daughter Lucy 3 years	Down syndrome
David Age 44	Son Matthew 13 months	Down syndrome
Eoghán Age 38	Son Leo 2¾ years	Down syndrome
Fionn Age 41	Son Rory 2 years	Down syndrome
Greg Age 43	Son Dylan 4 years	Unknown- Autism query
Harry Age 48	Son Vincent 5 years	Unknown - Associated severe physical disability
Ian Age 35	Son Peter 3 years	Global Developmental Delay
Jack Age 41	Daughter Jess 2½ years	Down syndrome

Following secondary analysis of the qualitative data, three themes emerged: (i) learning of a child's diagnosis (ii) expectations of fatherhood and (iii) motivation to tell their story.

Learning of a child's diagnosis

The narratives presented by fathers clearly articulated the emotions associated with being informed of their child's IDD and resonated across each and every fathers' personal experience. Even recalling the story of receiving the diagnosis was full of raw emotion. One father, Andy, explained how he was *'reliving the experience as if it were yesterday'* and this sharing of his personal story was *'not easy'*. Andy then went on to describe how he was *'heartbroken'* when the doctor confirmed within a half hour of his daughter's birth that Molly had Down syndrome. For Charlie, the confirmation for him was when the doctor said not long after his daughter's birth when the doctor went on to describe the visible and typical features of Down syndrome such as 'the low ears and the eyes.

Similarly, Eoghán who was in the in the delivery room at the birth of his first child, said that it was good that the midwife confirmed that their son had Down syndrome almost immediately which was a value he appreciated:

I sort of knew it straight away you know when I saw the eyes... the midwife actually said it straight away...which was good...

While the diagnosis of Down syndrome described to Charlie and Eoghán by doctors of the typical features of the condition was in a manner they understood, the power of negative language used by one doctor who provided a second opinion to confirm the diagnosis of Down syndrome to Andy was almost destructive:

I will never forget it he kept using the term limp and I hated it at the time, I just wanted to kill him...she is very limp, and he kept repeating it...

For these fathers' a conclusive diagnosis of Down syndrome was within a few hours of birth while for other fathers, it was delays in reaching the developmental milestones that propelled them to seek healthcare professional's opinions. The lack of a visible diagnosis resulted in lengthy delays as concerns were not raised until two to four years following their child's birth. Similar to Andy whose daughter had Down syndrome, the way the diagnosis of a less visible disability was disclosed by healthcare professionals was particularly harsh because of the words used. In addition, Brian was distressed as his wife was alone at the time of the disclosure:

...it was just completely wrong the way it was put across, it was just blunt, and it was just thrown at [partner], she was there on her own...

Similarly, Jack recounted how his wife was told alone that their baby had Down syndrome during a planned scan of the baby at 13 weeks, which he perceived to be a harsh way of hearing such news:

...they told her at the scan when she was on her own... I thought it was a bit harsh but then when was she going to be told ... we got an awful shock...

Irrespective of how fathers were told of their child's disability, the primary source of disclosing the diagnosis to the wider family and friends was through mothers and sisters as fathers themselves were too emotionally overwrought at this time. Andy said:

I just broke down and I put my arms around my Mom and I just said it, that was it. I just said I don't want to tell anybody. I said you can tell people...

Reticence to disclose their child's diagnosis to wider family and friends was very difficult for the majority of fathers and was further compounded by the later diagnosis. Fathers like Brian and Greg did not want to be constantly asked about their child once the news was made public.

This was related to needing more time for themselves as fathers to come to terms with their child's diagnosis. Greg, whose son was four when there was a suspicion of autism, was just 'not ready' to tell people about his son's diagnosis yet there was a sense that he was more ready and accepting as time went by. He said:

I don't talk about it with anyone else ... now I am ready to tell people, 6 months ago I wasn't...

Expectations of fatherhood

It is recognised that becoming a father comes with personal and societal expectations and for some these expectations have to change when a child is diagnosed with IDD. These fathers' narratives were no different as for the majority of these men, there was an expectation of becoming a father and looking forward to the experience of fatherhood, other than David, who had never expected to become a father, because of 'getting married later in life'. Fathers used the phrase '*hands on dads*' to capture these experiences of being involved with their children. There was no manual to instruct them on how to be a dad and for most part, fatherhood just came naturally as captured here in Fionn's narrative:

...you go into a hospital you are just given a child and boom you are a father or boom you are a mother and when you have a typical developing child everything is just easy; you literally fall onto the roller coaster and go with it...

Fathers also became more aware of people with disabilities because of their personal experiences with their disabled child. While previously they would have been oblivious to people with disabilities, now as fathers of children with disabilities, they made considerable effort to communicate with people with disabilities, to be helpful and were more appreciative of others in similar situations to themselves. For instance, Brian said:

...now I know the score I would actually talk to them and not talk to the person with them, but it would make you more aware of it anyway especially then when you are dealing with your own because you can appreciate more what people are dealing with...

A heightened awareness of disability led to changes in how they had perhaps previously 'judged or misjudged' others with disabilities. They were now more aware of their position in the world of disabilities, a positive change acknowledged from their experiences.

Motivation to tell their story

Fathers were motivated to be involved in this study for a number of reasons including the focus on father's views and opinions. For David:

I believe research needs to happen and what interested me in your letter was the fact there was a focus on fathers because I know a lot of the focus is usually on mothers....

For Greg, it stemmed from a father's opportunity to vent:

I have to vent I am going have to get this off my chest I said it is building up and I have been through so much. I said I don't know the girl it will be confidential I said I just want to get it off my chest I said it is killing me...

Charlie's drive to participate in the study stemmed from his curiosity as to why after three years anyone would want to talk to him about his experiences as a father of a child with IDD:

I think Dads are put in the background as such ...there was nobody ever said anything to me about do you want to talk to somebody or whatever... I was a bit weary because nobody has ever in 3 years wanted to talk to me and I thought why now...

4. DISCUSSION

The aim of this paper is to report on fathers' responses to their child's diagnosis of IDD, their expectations of fatherhood and their motivation for participating in research as part of a secondary analysis of qualitative interviews with 10 fathers of young children with IDD. The findings from the current study reflect the existing body of international research that highlights how from the time the diagnosis of a child's disability is confirmed, fathers' emotional responses are varied (Carpenter & Towers 2008; Hannon & Hannon 2017). While fathers were not specifically asked about their child's diagnosis, all of them began their story at that point, which for them was the central tenet to becoming a father of a child with IDD. In the current study, fathers spoke in depth about the initial confirmation of the child's diagnosis of IDD, the words that were used and who was involved in the disclosure, a finding resonating in Huang et al's., (2011) phenomenological study with 16 Taiwanese fathers of children with a developmental disability.

For some, being informed by healthcare professionals of their child's Down syndrome was direct and was an approach that was perceived as useful, reflective of many Japanese fathers' experiences in Takataya et al's., (2016) qualitative study. For others, the provision of a diagnosis in later months or years by healthcare professionals was insensitive and blunt, a finding that resonated across other studies in which parents were dissatisfied with healthcare professionals' disclosure of a child's disability (Close et al., 2016; Crane et al., 2016; Coons et al., 2016; Nelson Goff et al., 2013). Appropriate and positive terminology and the impact of negative language is therefore an important practice consideration for healthcare professionals and warrants further research (Cadwgan & Goodwin 2018). Thus, it is critical that healthcare professionals are aware of the influence they have in their disclosures of IDD and the subsequent impact that this type of disclosure could have on fathers across the trajectory of

their child's life. Therefore, education of healthcare professionals of best practice guidelines at the time of disclosure of IDD is required, such as *Informing Families of a Child's Disability* (National Federation of Voluntary Bodies 2007) or the National Institute for Health and Care Excellence (NICE 2011) guidance in relation to recognition, referral and diagnosis of autism spectrum disorder in children, to help ensure that parents are appropriately supported and signposted at this emotional time in their lives (Byrne et al., 2017).

Within the theme of *expectations of fatherhood*, there was an assumption that fatherhood would come naturally and the anticipation of a 'healthy' child in keeping with societal expectations and cultural norms (Petts *et al.*, 2018). In the current study, fathers were unprepared for the diagnosis of IDD. Fatherhood, for most, was being present for the birth of the 'perfectly healthy' child and having that expectation of '*normal*' (Riley & Rubarth 2015). Thus, the concept of fatherhood for some, meant taking on a role of caring across the child's lifespan, a role that was not anticipated or expected, reflective of other fathers' experiences of children with disabilities (Bonsall 2018). Further, the concept of fatherhood was repositioned with a new understanding of fatherhood through a different experience emerging as a father of a child with IDD, a view further supported by Bonsall (2018). Thus, evolving societal beliefs and attitudes regarding fatherhood requires a fresh understanding of the different forms it takes and that no single view of fatherhood exists. Rather, transition within fatherhood evolves over time and considerable time for some towards that acceptance of being a different father of a child with IDD.

Fathers participation in research remains a considerable challenge for researchers and this current study provides some concrete reasons for fathers' motivations to be involved which has been largely underreported. Rather many of the reasons purporting why fathers' voices are

absent are largely speculative and also unfortunately reflected in this study. However, an important and recurring theme from these findings is that fathers they are in the background and are generally not invited to talk about their child. However, when presented with an opportunity, motivation stemmed from a multitude of factors including a realisation that most of the research focuses on mothers, a belief that research needs to happen with fathers, curiosity itself in why they were invited as well as a desperate desire to talk to someone unknown to them. The term the '*forgotten man*' was coined by Paytner et al., (2018) in which fathers reported how they were ignored by healthcare professionals and removed from decision making processes about their children, a finding resonating across our study and the international research (Takataya et al., 2016). While policy attention with fathers is now growing, a key learning point is that they have to be asked and be included on the decisions that affect themselves, their child and family.

Limitations

This current study expands the evidence base relating to fathers' responses to their child's diagnosis of intellectual and developmental disability (IDD), their expectations of fatherhood and their motivation for participating in research. The authors recognise that the study has several limitations including the restriction to one country and limited to one service provider, therefore, the findings may not be reflective of fathers experiences elsewhere. Additionally, as all fathers in this study had young children a future comparison study of experiences between such fathers and those with older adult children with IDD would be helpful. However, an important strength of this qualitative study is the inclusion of the unique subjective experiences of fathers of children with IDD.

5. CONCLUSION

It is evident from our findings and the wider international research that fathers of young children with IDD require healthcare professionals to be knowledgeable and responsive to their needs particularly at the time of a disclosure of IDD and are therefore, required to embrace a culture of respect, inclusivity and collaborative working with all members of the family, including fathers. Changes in family structures and societal beliefs and values has witnessed a reframing of the concept of fatherhood. While becoming a father is a major life transition, fathers are now more involved in their child's care, an involvement that transcends to fathers of children with IDD. There is scope for nurses and healthcare professionals to work with fathers as they are well placed to make an important contribution to meeting the needs of fathers and specific areas of practice, education and research will contribute to ensuring fathers distinct needs are responded to effectively.

6. RELEVANCE TO CLINICAL PRACTICE

Future research priorities should include studies that increase our knowledge and understanding of the unique needs of fathers and how nurses can better support them. There is an opportunity for nurses to add to the body of research evidence regarding fathers by understanding, for example, how parents should be informed about a child's disability diagnosis. While fathers are often reticent to talk to others, nurse researchers could also undertake further studies that focus on both mothers and fathers thereby recognising and responding to the distinct individual needs of parents, and as a couple.

It is apparent from the wider literature and the findings from the current study, that there is a need for nurses to develop their knowledge, skills and confidence in supporting fathers and families of children with IDD. This is required to respond to the concerns of fathers regarding their potential limited involvement in decision making about their child. Therefore,

nurses can create collaborative alliances with fathers to meet their individual needs and those of their family. From the perspective of undergraduate and postgraduate nurse education, there is a need to specifically reflect the needs and concerns of fathers and families, thereby ensuring their aspirations and hopes are included and responded to at a clinical, education, research and policy level.

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REFERENCES

- Allport, B.S., Johnson, S., Aqil, A., Labrique, A.B., Nelson, T., Angela, K.C., Carabas, Y. & Marcell, A.V. (2018). Promoting father involvement for child and family health. *Academic Pediatrics*, 18(7), 746-753. doi.org/10.1016/j.acap.2018.03.011
- Banchefsky, S., & Park, B. (2016). The “new father”: Dynamic stereotypes of fathers. *Psychology of Men & Masculinity* 17(1), 103. doi.org/10.1037/a0038945
- Bonsall, A. (2018). Narrative transitions in views and behaviors of fathers parenting children with disabilities. *Journal of Family Studies* 24(2), 95-108. doi.org/10.1080/13229400.2015.1106336
- 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(9), 810-821. doi.org/10.1111/jir.12093
- Broomhill, R. & Sharp, R. (2012). *Australia’s parental leave policy and gender equality: an international comparison*. Australian Workplace Innovation and Social Research Centre: The University of Adelaide.
- Byrne, R., Noritz, G., Maitre, N. L. & Group, N. E. D. (2017). Implementation of early diagnosis and intervention guidelines for cerebral palsy in a high-risk infant follow-up clinic. *Pediatric Neurology*, 76, 66-71. doi.org/10.1016/j.pediatrneurol.2017.08.002
- Cadwgan, J. & Goodwin, J., 2018. Helping parents with the diagnosis of disability. *Paediatrics and Child Health*, 28(8), pp.357-363.
- Carpenter, B. & Towers, C. (2008). Recognising fathers: The needs of fathers of children with disabilities. *Support for Learning* 23(3), 118-125. doi.org/10.1111/j.1467-9604.2008.00382.x
- Carroll, M. (2018). Gay fathers on the margins: Race, class, marital status, and pathway to parenthood. *Family Relations*, 67(1), 104-117. doi.org/10.1111/fare.12300

Chin R. Hall P. & Daiches A. (2011). Fathers' experiences of their transition to fatherhood: a metasynthesis. *Journal of Reproductive and Infant Psychology* 29(1), 4-18.
doi.org/10.1080/02646838.2010.513044

Christopher, C., Umemura, T., Mann., Jacobvitz, D. & Hazen, N. (2015). Marital Quality over the Transition to Parenthood as a Predictor of Co-parenting. *Current Opinion in Psychology*, 13(12), 3636–3651. doi.org/10.1007/s10826-015-0172-0

Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology* 12(3), 297–298.

Close, S., Sadler, L. & Grey, M. (2016). In the dark: challenges of caring for sons with Klinefelter syndrome. *Journal of Pediatric Nursing*, 31(1), 11-20.
doi.org/10.1016/j.pedn.2015.05.002

Cohen, S. R., Zeedyk, S. M., Tipton, L. A., Rodas, N. V. & Blacher, J. (2016). Fathers of children with or without ID: Understanding long-term psychological symptoms. *Journal of Intellectual Disability Research*, 60(4), 295-307. doi.org/10.1111/jir.12232

Coons, KD., Watson, S.L., Schinke, R.J. & Yantzi N.M. (2016). Adaptation in families raising children with fetal alcohol spectrum disorder. Part I: What has helped? *Journal of Intellectual & Developmental Disability*, 41(2), 150-165.
doi.org/10.3109/13668250.2016.1156659

Crane, L., Chester, J.W., Goddard, L., Henry, L.A. & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, 20(2), 153-162.
doi.org/10.1177/1362361315573636

Davys, D., Mitchell, D. & Martin, R. (2017). Fathers of people with intellectual disability: A review of the literature. *Journal of Intellectual Disabilities*, 21(2), 175-196.
doi.org/10.1177/1744629516650129

Doss, B.D. & Rhoades, G.K. (2017). The transition to parenthood: Impact on couples' romantic relationships. *Current Opinion in Psychology*, 13, 25-28.

doi.org/10.1016/j.copsyc.2016.04.003

Findler, L., Jacoby, A.K. & Gabis, L. (2016). Subjective happiness among mothers of children with disabilities: The role of stress, attachment, guilt and social support. *Research in Developmental Disabilities* 55, 44-54. doi.org/10.1016/j.ridd.2016.03.006

Gage, J.D. & Kirk, R. (2016). First-time fathers: perceptions of preparedness for fatherhood. *Canadian Journal of Nursing Research Archive* 34(4), 15-24.

Gates, G.J. (2015). Marriage and family: LGBT individuals and same-sex couples. *The Future of Children* 25(2), 67-87. doi:10.1353/foc.2015.0013

Giallo, R., Seymour, M., Matthews, J., Gavidia-Payne, S., Hudson, A. & Cameron, C. (2015). Risk factors associated with the mental health of fathers of children with an intellectual disability in Australia. *Journal of Intellectual Disability Research*, 59(3), 193-207. doi.org/10.1111/jir.12127

Goldscheider, F., Bernhardt, E., & Lappegård, T. (2015). The gender revolution: A framework for understanding changing family and demographic behavior. *Population and Development Review*, 41(2), 207-239. doi.org/10.1111/j.1728-4457.2015.00045.x

Golombok, S. (2015). *Modern Families: Parents and Children in New Family Forms*. Cambridge University Press: Cambridge.

Graneheim, U.H., Lindgren, B.M., & Lundman, B. (2017). Methodological challenges in qualitative content analysis: A discussion paper. *Nurse Education Today* 56, 29-34.

doi.org/10.1016/j.nedt.2017.06.002

Haber, J. (2013). Sampling In: *Nursing research: Methods and critical appraisal for evidence-based practice* (LoBiondo-Wood G. & Haber J. eds). Elsevier Health Sciences: New York, pp.231-253.

Hannon, M.D. & Hannon, L.V. (2017). Fathers' orientation to their children's autism diagnosis: A grounded theory study. *Journal of autism and developmental disorders*, 47(7), pp.2265-2274.

Huang Y.P., St John W., Tsai S.W. & Chen H.J. (2011). Taiwanese Fathers' Experiences of Having Their Child Diagnosed with a Developmental Disability. *Journal of Nursing Research* 19(4), 239-249. doi: 10.1097/JNR.0b013e3182389e34

İnanç, B., Topal, Y. & Topal, H. (2018). Evaluation of health situation and problems of the families having disabled child: quantitative study. *Annals of Eurasian Medicine* 6(1), 1-4. doi:10.4328/AEMED.116

Isa, S.N.I., Ishak, I., Ab Rahman, A., Saat, N.Z.M., Din, N.C., Lubis, S.H. & Ismail, M.F.M. (2016). Health and quality of life among the caregivers of children with disabilities: A review of literature. *Asian Journal of Psychiatry* 23, 71-77. doi.org/10.1016/j.ajp.2016.07.007

Jeynes, W.H. (2016). Meta-analysis on the roles of fathers in parenting: Are they unique? *Marriage & Family Review* 52(7), 665-688. doi.org/10.1080/01494929.2016.1157121

Johnston, M.P. (2017). Secondary data analysis: A method of which the time has come. *Qualitative and quantitative methods in libraries*, 3(3), pp.619-626.

Long-Sutethall, T., Sque, M. & Addington-Hall, J. (2011). Secondary analysis of qualitative data: a valuable method for exploring sensitive issues with an elusive population?. *Journal of Research in Nursing*, 16(4), pp.335-344.

“Author Blinded (2018a)”

MacDonald, E.E. & Hastings, R.P. (2010). Mindful parenting and care involvement of fathers of children with intellectual disabilities. *Journal of Child and Family Studies*, 19(2), pp.236-240.

Marshak, L.E., Lasinsky, E.E. & Williams, C. (2018). Listening to fathers: Personal impacts of raising children with Down syndrome. *Journal of Intellectual Disabilities*, p.1744629518801112.

McConnell, D. & Savage, A. (2015). Stress and resilience among families caring for children with intellectual disability: expanding the research agenda. *Current Developmental Disorders Reports* 2(2), 100-109. doi.org/10.1007/s40474-015-0040-z

Namkung, E.H., Song, J., Greenberg, J.S., Mailick, M.R. & Floyd, F.J. (2015). The relative risk of divorce in parents of children with developmental disabilities: impacts of lifelong parenting. *American Journal on Intellectual and Developmental Disabilities* 120(6), 514-526. doi.org/10.1352/1944-7558-120.6.514

National Federation of Voluntary Bodies (2007). *Informing Families of their Child's Disability. National Best Practice Guidelines*. National Federation of Voluntary Bodies, Galway, Ireland.

Nelson Goff, B.S., Springer, N., Foote, L.C., Frantz, C., Peak, M., Tracy, C., Veh, T., Bentley, G.E. & Cross, K.A. (2013). Receiving the initial Down syndrome diagnosis: a comparison of prenatal and postnatal parent group experiences. *Mental Retardation* 51(6), 446-457. doi.org/10.1352/1934-9556-51.6.446

NICE (2011). Autism spectrum disorder in under 19s: recognition, referral and diagnosis. <https://www.nice.org.uk/guidance/cg128/resources/autism-spectrum-disorder-in-under-19s-recognition-referral-and-diagnosis-pdf-35109456621253>. Accessed 6th September, 2019

Noble, H. & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence-based Nursing* 18(2), 34-35. doi.org/10.1136/eb-2015-102054

Nowell, L.S., Norris, J.M., White, D.E. & Moules, N.J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods* 16(1), 1-13. doi.org/10.1177/1609406917733847

Paynter, J., Davies, M. & Beamish, W. (2018). Recognising the “forgotten man”: fathers’ experiences in caring for a young child with autism spectrum disorder. *Journal of Intellectual & Developmental Disability*, 43(1), pp.112-124.

Petts, R. J., Shafer, K. M., & Essig, L. (2018). Does adherence to masculine norms shape fathering behavior? *Journal of Marriage and Family*, 80(3), 704-720.
doi.org/10.1111/jomf.12476

QSR International (2018). *NVivo qualitative data analysis Software*: QSR International Pty Ltd. Version 12, 2018.

Riley, C., & Rubarth, L. B. (2015). Supporting families of children with disabilities. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 44(4), 536-542. doi.org/10.1111/1552-6909.12660

Robinson, M. & Neece, C.L. (2015). Marital satisfaction, parental stress, and child behavior problems among parents of young children with developmental delays. *Journal of Mental Health Research in Intellectual Disabilities* 8(1), 23-46.
doi.org/10.1080/19315864.2014.994247

Ruggiano, N. & Perry, T.E. (2019). Conducting secondary analysis of qualitative data: Should we, can we, and how? *Qualitative Social Work* 18(1), 81-97.
doi.org/10.1177/1473325017700701

Shapiro, A.F., Gottman, J.M. & Fink, B.C. (2019). Father’s Involvement When Bringing Baby Home: Efficacy Testing of a Couple-Focused Transition to Parenthood Intervention for Promoting Father Involvement. *Psychological Reports* Early view: p.0033294119829436.

Takataya, K., Yamazaki, Y. & Mizuno, E. (2016). Perceptions and feelings of fathers of children with Down syndrome. *Archives of Psychiatric Nursing* 30(5), 544-551.
doi.org/10.1016/j.apnu.2016.04.006

Thompson, T., Coleman, J. & Olmos, A. (2018). The expressed emotion of parents of children with developmental disabilities: A meta-analysis. *Life Span and Disability* 21(2), 177-189.

Trentacosta, C.J., Irwin, J.L., Crespo, L.M. & Beeghly, M. (2018). Financial hardship and parenting stress in families with young children with autism: opportunities for preventive intervention. In: *Handbook of Parent-Implemented Interventions for Very Young Children with Autism* (pp. 79-91). Springer, Cham.

Wells, M. B. (2016). Literature review shows that fathers are still not receiving the support they want and need from Swedish child health professionals. *Acta Paediatrica*, 105(9), 1014-1023. doi.org/10.1111/apa.13501

Yarwood, G.A. (2011). The Pick and Mix of Fathering Identities. *Fathering: A Journal of Theory, Research, and Practice about Men as Fathers* 9(2), 150-168.

<https://www.nice.org.uk/guidance/cg128/resources/autism-spectrum-disorder-in-under-19s-recognition-referral-and-diagnosis-pdf-35109456621253>