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“Perceptions and discourses relating to genetic testing: Interviews with people with Down syndrome”

Running Head: Down Syndrome and Prenatal Testing

Barter, B., Hastings, R. P., Williams, R. R., & Huws, J. (in press). Perceptions and discourses relating to genetic testing: Interviews with people with Down syndrome. *Journal of Applied Research in Intellectual Disabilities*.

Abstract

Background

The perceptions of individuals with Down syndrome are conspicuously absent in discussions about the use of prenatal testing.

Method

Eight individuals with Down syndrome were interviewed about their views and experience of the topic of prenatal testing.

Results

Interpretative Phenomenological Analysis revealed two major themes with sub themes: 1) A devalued condition and a valued life and 2) A question of 'want?' Foucauldian Discourse Analysis highlighted two main discursive practices: 1) Social deviance and 2) Tragedy and catastrophe of the birth of a baby with Down syndrome.

Conclusions

The findings suggest that individuals with intellectual disabilities can make a valuable contribution to discussions surrounding the use of prenatal testing. Implications for clinical practice include the use of information about Down syndrome given to prospective parents, and the possible psychological impact of prenatal testing practices on individuals with Down syndrome.

Keywords: Down syndrome, qualitative methods, discourse analysis, prenatal genetic testing

Introduction

Down syndrome is a condition caused by trisomy of chromosome 21 and represents the most common single genetic cause of intellectual disability occurring in approximately 1 in 600 to 800 births (St-Jacques et al., 2008). The life expectancy and quality of life for individuals with Down syndrome has improved dramatically in the last 40 years (Bittles, Bower, Hussain & Glasson, 2007) and continues to do so as a result of better medical care (Buckley & Buckley, 2008), and increased access to education and employment opportunities (Buckley, Bird, Sacks & Archer, 2006).

Screening and testing policies for Down syndrome vary internationally. In the USA, UK and many countries in Europe, including France, Sweden, and Denmark, all pregnant women are offered screening and diagnostic tests. Other European countries, such as Latvia, Lithuania, and Bulgaria, offer screening and tests to high risk groups, while in parts of Southern Europe, such as Italy, and developing countries such as India and China there are currently no national screening policies (American College of Obstetricians and Gynaecologists, 2007; Hall et al., 2007; Hewison, et al., 2007). Termination rates of 90-92% following a prenatal diagnosis of Down syndrome have been reported in the UK (Morri & Springett, 2014), 90% in the USA (Britt et al. 1999), 88% in Europe, with lower rates in countries without national screening policies (Boyd et al., 2008). In a survey of prenatal policies in 18 countries in Europe, Boyd et al. identified that six countries had a legal gestational age for termination and that in two countries termination of pregnancy was illegal at any gestational age (Boyd et al., 2008).

In an international study, Cocchi et al. (2010) concluded that although an increase in maternal age and higher prevalence of Down syndrome was observed in most of the 20 countries included, the number of Down syndrome births remained stable as a result of an increased use of prenatal diagnostic procedures and subsequent terminations. Raz (2004) argues that there is potentially paradoxical situation whereby the life expectancy and quality of life for individuals with Down syndrome continues to improve so too do the number of terminations.

Prenatal testing for Down syndrome is viewed favourably by the general public in the UK and USA (Evers-Kiebooms, Denayera, Decruyenaerea & Van Den Berghea, 2003; Marteau, Michie, Drake & Bobrow, 1995; Singer, 1993). There is less overall support for termination than for testing (Evers-Kiebooms et al., 1993; Singer, 1993), and the perceived burden of caring for a child with a disability has been a consistent factor in predicting these attitudes (Abramsky, Hall, Levitan & Marteau, 2001; Mansfield, Hopper & Marteau, 1999). Existing research reveals that mothers and siblings of individuals with Down syndrome have less positive attitudes to testing than the general public (Bridle, 2000; Bryant, Hewison & Green, 2005; Felker, 1994).

The literature relating to Down syndrome in the areas of medicine, psychology, social science, and in the general media tends to present the condition negatively, and it is often referred to as an 'untreatable disorder' (Alderson, 2001). A recent UK newspaper article suggested that a new test for Down syndrome could save hundreds of 'normal lives' through the reduction of false positive results (Campbell, 2009), thereby highlighting the worth that is placed on 'normality'. Shakespeare (2006) suggests that more research into the experience of individuals with intellectual disabilities is imperative to understand the

diversity of living with any type of disabling condition. However, we could find only two published studies exploring the views of prenatal testing from the perspectives of individuals with intellectual disabilities. Ward, Howarth and Rodgers (2002) reported on two workshops explaining the use of prenatal testing to people with intellectual disabilities. They concluded that the discussions were accessible, but made little comment on the views of the attendees. Alderson (2001) interviewed five participants with Down syndrome to assess if the condition involved costs, limitations, and suffering. A number of issues relating to quality of life were outlined, and Alderson concluded that people with Down syndrome could lead fulfilling lives, but that more research was required if prenatal policies were to be evidence-based and fair.

The voice of individuals with Down syndrome and intellectual disability is thus effectively absent in research that focuses on perceptions of, and attitudes towards, prenatal testing for Down syndrome. Existing research on the views of people with an intellectual disability lacks detail and methodological rigor and is concerned with understanding the extent of knowledge rather than understanding the lived experience. Thus, the aim of the present study was to explore the perceptions and experience of individuals with Down syndrome of prenatal testing for Down syndrome.

Method

Methodological Approach

We used a combination of Interpretative Phenomenological Analysis (IPA) and Foucauldian Discourse Analysis (FDA). IPA is an approach to qualitative analysis informed by phenomenology, hermeneutics, and idiography (Smith, Flowers & Larkin,

2009). Using IPA, researchers aim to explore, through interpretation, the unique lived experience of an individual in a particular context, to a particular phenomenon. IPA has been used successfully within the field of intellectual disability and with individuals with intellectual disabilities themselves (Baum & Burns, 2009; McDonald, Sinason & Hollins, 2003; Reilly, Huws, Hastings and Vaughan, 2010). The purpose of FDA is to highlight and understand the relationship between broad cultural discursive resources, the social relationships which shape these discourses, and the power relationships that are reflected in, and shaped by, these discourses (Parker, 1992). The use of IPA and FDA enables insights to be made into the lived experiences of individuals, and the discourses that are used to describe these experiences. This combined approach has been used successfully in previous research (Boyle, Smith & Liao, 2005; Johnson, Burrows & Williamson, 2004). While IPA can offer an interpreted account of individuals' personal and collective experiences of a phenomenon, FDA can offer an account of why the individuals may employ certain language to describe these experiences and how these discourses can themselves shape those experiences.

Participants

Eight people with Down syndrome, four males and four females, consented to participate in the study. All were adults (aged 24 - 46 years) and were identified by professionals or carers as having Down syndrome. Participants are described in Table 1, and pseudonyms have been adopted throughout.

-----Insert Table 1 about here-----

Procedure

Following local University Research Ethics Committee review and approval, a local intellectual disability non-profit organisation agreed to facilitate this study. A staff member of this organization who had Down syndrome acted as a consultant to consider the feasibility and design of the study. Following this initial pilot consultation, 10 individuals with Down syndrome were identified by members of the organisation. Each individual was known by the organisation's staff. The individuals were identified on the basis that they were over the age of 18 years, had the receptive and expressive ability to take part in an interview, and had ongoing contact with the supporting organisation. The latter criterion was significant in case ongoing support was required resulting from the topic and conduct of the research. These individuals were invited (along with family members or carers) to voluntarily attend an initial information session about prenatal testing for Down syndrome.

The purpose of the information session was for the potential participants to meet with the researcher, to have a preliminary discussion about the topic, and to provide information about the study prior to being invited to take part. Individuals with Down syndrome and carers were assured that participation in the information session did not oblige them to take part in the study. Five individuals, four of whom were male, attended a group information session. Three other individuals, who wished to attend but had been unable for practical reasons, attended individual information sessions with the primary investigator at a later date. Two individuals, who had been approached initially, did not take up the invitation to participate in the project.

The material for the information sessions was designed by the first author and was presented to members of the local non-profit organisation, including the consultant with

Down syndrome, to gain feedback about the content and methods of presentation. The information sessions covered material such as sex and reproduction, with an emphasis on 'keeping safe', diversity, difference and disability, and finally testing for Down syndrome (see Table 2 for information about topics covered). The material was presented in verbal, written, and pictorial formats and there were a series of activities to promote interaction and the assimilation of information. The information sessions were led by the first author and supported by members of the non-profit organisation who were familiar with the participants. The individuals were provided with summary information at the end of the session in written and pictorial versions. Each participant had access to a supporter from the organisation if they wished to discuss the topics further.

-----Insert Table 2 about here-----

Following participation in the information session, each individual was invited to take part in an interview with the first author. All participants who had attended the sessions consented to participate. Six interviews were carried out in a private space in the participants' homes, and two interviews were carried out at the participants' places of work, at their request. Prior to the interviews, each participant met with the first author who re-explained the purpose of the research. A copy of the resources, including those that were used during and presented after the information session, was re-introduced to the participant. The process of the interview, aim of the research, confidentiality, and the right to withdraw at any time were explained. The participant was deemed to have capacity to consent to the interview process if he or she could demonstrate that they understood the main theme of the research (talk about prenatal testing for Down

syndrome) and could demonstrate the ability to weigh up and communicate the decision to take part.

Throughout the information sessions, notes were made about the communication needs of each individual so that subsequent interviews could be tailored to that individual's needs. For example, participants had access to materials such as pictures, emotion picture cards, and pens and paper if they wished to express their thoughts and feelings in non-verbal ways. Throughout the information sessions, attention was also paid to cognitive and emotional understanding and reaction to the topics in question and interviews were also tailored to the individual's level of comfort or familiarity with the topics. For example, during two of the individual information sessions it became clear that the participants did not consider that they had Down syndrome and the subsequent interviews were carried out with this in mind. In this way, the interviews continued to use broad and open-ended questions, and did not make reference to that individual being labelled with Down syndrome or an intellectual disability. It was considered that these individuals continued to demonstrate informed consent to participate as they knew that their perceptions and experiences were of interest, the fact that they did not identify with the label was of less importance.

The interview addressed a number of key areas including sex, reproduction and pregnancy, Down syndrome, and prenatal testing (for example; Do you remember what we talked about during the last time we met?; Do you know anybody who has Down syndrome/intellectual disability?; What would you say if someone you knew wanted to have a test to see if their baby would have Down syndrome?; Or end a pregnancy because they were worried about the foetus having Down syndrome?). The interview schedule

was flexible and tailored to the individual's communication needs. The mean interview time was 50 min (range 20-90 min). Each participant completed one interview, with the exception of one participant who, on request, also accompanied his girlfriend to her interview as support, but only the data from the primary participant was subsequently included in the analysis. Following each interview, the researcher ensured that the participant still consented to involvement in the research. Each participant had access to a supporter from the supporting organisation if they had any further questions or concerns. Each interview was audio recorded and transcribed verbatim following the interview.

Analysis

The first author (BB) completed the process of IPA following Smith et al. (2009). Each interview was transcribed verbatim, and the transcripts were then analyzed on a line-by-line basis. Exploratory comments were made about the content and language in the left hand margin, and emergent themes were recorded in the right-hand margin. Chronological lists of all emergent themes for each participant were compiled, and emergent subordinate-themes were identified within, and across, each transcript. A second researcher with experience of IPA (JH) was consulted during this process to ensure that the themes were grounded in the data and reflected the experience of the participants. The analysis was continually refined and edited throughout the process of writing the results.

The procedure for FDA is not generally completed in accordance with a protocol, and instead it relies on the development of analytic mentality rather than on any particular methodology (Willig, 2001). To aid such analysis, Willig's six-stage approach to FDA

was employed. All transcripts were analysed on a line-by-line basis by the first author, and common discursive practices were outlined. In line with Willig's model the initial stage of analysis involved identifying the various ways in which the topic of prenatal testing was constructed, either implicitly or explicitly. The second stage aimed to locate the various discursive constructions within wider discourses, for example participants drew on discourses of power and difference. The third stage of analysis involved a closer examination of the discursive contexts within which the different constructions occurred. This focus allowed a hypothesis of the function of various discourses, for example that of difference which may serve the function of rationalising any sense of stigma. This case was closely linked with stages four and five which are concerned with conceptualising the relationships between discursive constructions and the positions contained within them and how they open up or close down opportunities. Stage six involved considering how the analysis traced the consequences of taking up various subject positions for the participants' subjective experience. It involved considering what could be felt, thought and experienced from within various subject positions for example the subjective experience within a discourse of valued or devalued condition.

Findings/Results

Five of the eight participants, Luke, Tom, Jen, Becky, and Pete considered themselves to have Down syndrome and Ann, Jane, and Sam did not refer to identifying with having Down syndrome. Although there were differences in their personal perceptions, the group was and analyzed as a whole on the basis that they did all have the condition.

Each IPA theme is presented to provide an interpreted account of the lived experience of the individuals, and is followed by an account of the discourse that underpinned these experiences. The interplay between experience and discourse is then discussed in relation to each theme. The themes and discourses are summarized in Table 3. The themes are discussed below and specific points are illustrated with verbatim quotes. The quotes are merely used as an example. When providing extracts from the interviews, the following transcript conventions are used:

.... Short pause. (...) Words omitted to shorten a quote (Text) Provides context information.

-----Insert Table 3 about here-----

1. A devalued condition and a valued life

When considering prenatal tests for Down syndrome, the participants drew upon their own experience of living with a devalued label of disability. This led them to question their own sense of self worth, and to hypothetically draw parallels between their own experiences and those of an already labelled foetus.

All participants described their experience of Down syndrome or disability as something chronic, negative, and limiting that was referred to in terms of devalued difference. This led to the assumption that fetuses with Down syndrome would also experience the same level of limitation. Luke, Jen and Becky referred to Down syndrome as something biologically wrong and chronic. Tom referred to Down syndrome as abnormal; in reference to a question if the interviewer had Down syndrome, Tom answered ‘(...) you’re normal.... what it is eh, normal people they cope...’ Later he

describes it as a defining part of his identity, and placed a particular emphasis on a need for care from capable others.

Pete made the assumption that babies with Down syndrome would also experience the same sense of wrongness, demonstrating his experience of the condition as something fixed and uncompromising: ‘the syndrome is about the baby... is about the head’ and ‘...cos that’s the syndrome it’s a bad thing’. Luke found it difficult to express his thoughts about Down syndrome, but referred to his experience as an unnamed sense of wrongness. Sam used graphic language and a tone of sadness and regret to convey his view of Down syndrome as damage that affected other people. He was well socialised to the concept of the condition, and demonstrated an awareness of others with Down syndrome, but did not consider himself affected by the condition. Given the language and emotional content of his descriptions, it is possible that this could be interpreted as a protective denial of impairment. For example he said, ‘I think that... or brain I think that’s inside a baby, it’s like that (showing an empty sign with his hands)’ and ‘like a soft ball’ and ‘it’s (Down syndrome) so horrible’.

In response to questions about disability and prenatal testing for disability, the participants referred to aspects of themselves that they valued, and that were also valued by others. This included a sense of self beyond impairment, personal achievement, and personal relationships. The participants referred to feeling valuable in numerous ways. Tom placed emphasis on a valuable life in terms of happiness. When asked about a parent considering a termination based on a positive prenatal test result, he replied, ‘me happy... and friends (happy) too’, implying that, in his experience, Down syndrome did not necessarily equate to suffering.

Many of the participants viewed their personal relationships as mutually beneficial to themselves and others, suggesting a personal sense of self worth. This implied that a baby born with Down syndrome could be a valuable addition to families and society as a whole, as exemplified by the following extract from Becky ‘...me and my sister have been joined from the hip... ..she supported me, I supported her’.

There was a collective emphasis on personal achievement as a means of proving self-worth, or value, among the majority of the participants. For example, Jen referred to her own achievements and successes, and viewed these as a fundamental aspect of proving her self-worth. She referred to a child with Down syndrome as valuable since he or she may achieve things in their life, saying ‘...keep it, I mean and you know, you know he or she might gain experience, um and emmm gain everything in life in general, you know, yes’.

Becky, Jen and Tom also considered the idea of a self beyond the disability to varying degrees. Becky referred to a sense of self that lay at a deeper personal level, and how others also valued this, ‘... I can remember quite a few situations where, um, the pupils in mainstream especially, look at my supporter... ..whereas at special needs school you won’t get that kind of connection with my supporter because they see me’.

Tom considered Down syndrome a defining and important aspect of his identity, and struggled with the concept of being both ‘normal’, and having Down syndrome. His comments suggested that he felt ‘normal’ in some ways, and that this may be due to a sense of self apart from the disability, ‘emmm well you see, being normal eh... Down syndrome emmm and I’m a bit of both’. Likewise, Jen referred to the biological aspect of Down syndrome as meaningless, for example, (referring to an extra chromosome) – ‘I

don't think it means anything', therefore implying that she held a personal sense of self beyond disability.

Discourse associated with Theme 1: A discourse of social deviance.

Social deviance has been conceptualized as a means of maintaining social order. It defines societal shared reality, cultural norms, and expectations by defining what is acceptable and real (Pofhl, 1994). The long-standing social deviance theory of disability appears to mirror the medical view of normality and pathology as a means of understanding impairment. Deviance is a phenomenon situated in power. The deviant group are labelled as different, less valuable, and powerless.

It is clear that all of the participants used adjectives of difference, damage, and abnormality to highlight their collective experience of deviating from the norm in some way, which reflected the dominant wider discourse of social deviance. They also referred to dependence and a lack of autonomy in life choices, indicating a perceived level of social control by others. Jen, in particular, used language that displayed a lack of social power in terms of her description of having no control over other people's views of Down syndrome. Tom's language of normality undermined his autonomy, and by virtue of a defining label, he handed power to the 'staff', in terms of his decision-making and life choices. However there was also a positive discourse. The participants defined personal valued experiences by rejecting aspects of the negative discourse; in this way, a positive discourse about living with a disability (in terms of acceptance) and a valued life (in spite of a disability) emerged. For example, Becky demonstrated her refusal to accept the negative dominant discourse by constructing an alternative discourse of 'Down

syndrome, so what?’ that underpinned her battle to gain personal achievements in spite of impairment.

The IPA and FDA indicated that participants, and any other people with Down syndrome, could live a valued and valuable life with, and in spite of, impairment and a devalued label.

2. A question of ‘want’

The participants grappled with the idea of Down syndrome as a condition that they wanted for themselves, and a condition that is wanted by others. This led to an implicit question of a ‘wanted life’ both in terms of a ‘wanted baby’ and themselves as ‘wanted’.

Becky and Jen grappled with the idea of Down syndrome being something that they would hypothetically choose. Becky referred to her lack of choice about having the condition, and accepted the chronic nature of impairment: ‘...you live with it and you have Down syndrome from birth, it’s not something that will just go away’. This contradicted her explanation of Down syndrome as something she hypothetically chose to have since birth: ‘when I was born I was greedy and asked for one extra (chromosome)’. Jen referred to Down syndrome as something very positive, and implied that it was a condition she now accepted,

Becky, Jen, Pete, and Sam considered whether Down syndrome was something that parents wanted their children to have, and referred to the shock and disappointment in having a child with Down syndrome. Overall, this appeared to be a painful topic for those who considered it consciously. The emotional difficulty of thinking about Down syndrome as something unwanted is illustrated by Becky: ‘...as soon as the doctor or

someone says there's complications around your baby... some people kind of take the oh my god I don't want that baby...'

Luke displayed an unsure reaction when asked about the mother knowing that her baby would have Down syndrome. The interviewer explained that the mother in a picture has found out that the baby will have Down syndrome, and Luke's reaction was: '(nervous laugh) em, right... got me there... (laugh)'. It was interpreted that he expressed discomfort with the subject, and found it very difficult to express himself.

Even though Pete said that he did not have Down syndrome, he believed that it was a bad thing that would cause a baby to die, and that this would lead to sadness in the family. It would appear that he did not consider the question of want, and saw Down syndrome as something that caused the baby's death, rather than the parents not choosing to have that baby. This is illustrated in the following extracts, (following discussion about the testing and termination): '...cos its about the baby' and 'eh mother and a father they crying'. And 'cos the syndrome cos that's the syndrome it's a bad thing'. When asked how he was feeling, Pete replied, 'heart'.

Sam focused on the concept of want, and made a connection between the mother knowing that the baby will have Down syndrome, and thinking that the mother would be disappointed with this: '... women having baby....before baby be born... and have Down sysdom....she the mother is not happy with it.'

Jane focused on the idea of wanting a baby with Down syndrome as a salient issue in terms of the care that baby would require. She connected with this idea on a cognitive level, and did not display any emotional reaction to it, which could possibly be explained by the fact that she did not present any reason to assume that she considered herself to

have Down syndrome: 'The man and woman have sex ...Down syndrome and they say... I don't want a baby said I don't want one...yes I know that one'.

Jen, Becky, and Sam all viewed Down syndrome as unwanted due to lack of knowledge and education in society in general, and also due to parents' lack of knowledge. This stems from their views that life is worth living with a disability. For example Sam said: 'I think it's to do with the family 'cos they don't know the Down sysdom'.

Sam and Becky referred to testing for Down syndrome as something positive, since parents have time for preparation. Becky demonstrated this by saying: '...kind of positive stories about, um, how mothers were having these tests and accepting the baby themselves'.

It is not surprising that Luke, Becky, Jen and Tom, who all considered themselves to have Down syndrome, and who questioned Down syndrome as something wanted or unwanted, would refer this question of want in their own lives. This might explain why the other participants did not consider these issues. Sam, Ann, and Jane did not consider the issues as relevant to them, and Pete did not consider that the baby with Down syndrome was not born due to the parents' decision.

Neither Becky nor Jen were sure if their mother had had a test or not, and referred to this, a few times throughout the interview. For example, Jen said: '...because they had the test for Down syndrome for me, and yes she had the test for Down syndrome and that's me (laughs)'. In both cases, this led to the consideration of themselves as wanted babies and wanted adults. Becky said: 'I've got quite a big family and um, everyone kind

of wanted to kind of offer help when they can' and '...my mum had me and still wants to have me and still loves me'.

Tom referred to his family wanting to support and care for him: 'my family want ...and give me more support in my life'. When asked a hypothetical question about a parent considering a baby with Down syndrome, he automatically connected this to his family's wish to support him, thereby implying that he was wanted and there was proof of this want through care. Luke did not consider the issue of being wanted, but he did refer to his own infancy when speaking about tests for Down syndrome: 'I was a baby once.' It is possible that he has made an association on some level between a parent's decision to test and his own infancy.

Discourse associated with Theme 2: The Discourse of Tragedy and Catastrophe. Clapton (2003) refers to a dominant discourse of personal tragedy and public catastrophe surrounding the principles of bioethics and intellectual disabilities. He describes catastrophe as public upset due to a disruption to an established social order. The language surrounding the birth of a child with an intellectual disability, or Down syndrome, is often considered a private tragedy, and a catastrophe in public terms. In this way, the discourse allows for the rationalization of terminations of pregnancy based on the assumption that the birth of a child with a disability causes social disruption.

Becky, Sam, and Jen all reflected this public discourse in their language of parents being 'shocked' by Down syndrome. For example, Becky referred to her own parents as needing support for the shock. She also viewed a test as a positive means of preparing a parent with the news, and referred to her own hypothetical wish to know that her child would be disabled before birth to prevent shock. Becky and Jen, in spite of their personal

views, both used language of understanding to identify with a mother's wish to terminate a baby with Down syndrome, highlighting the extremely powerful discourse of private tragedy and public catastrophe which serves the function of rationalizing the choice to terminate.

The interplay between the social discourse of tragedy and catastrophe, and the participants' own personal experiences, highlights the highly painful topic of the self as wanted. The participants reflect the social discourse of the tragedy of the birth of a baby with Down syndrome, and identify with the implicit argument that termination is a rational option. In terms of their personal experience, they view themselves as wanted by their own families, but the consideration of the social discourse may possibly them to question their own births as a tragedy to their families. This is a highly painful topic for all of the participants who considered it on any level. Those who did not believe themselves to have Down syndrome had a distance from this emotion. On the one hand, this leaves them more disabled by not being able to engage in the debate, but on the other, it protects them from the consideration of the self as a tragedy. The participants make sense of the tension between the discourse of tragedy and themselves as wanted by assuming that a test will provide a parent with the time needed to come to terms with the shock of Down syndrome.

Discussion

Overall, our findings have resonance with Ward et al. (2002) and Alderson (2001) and further their original findings by highlighting that assessing the perceptions of individuals with intellectual disabilities about a seemingly complex and sensitive topic of prenatal

testing was both possible and beneficial in terms of providing a greater understanding of the views of individuals who live with the condition in question. A number of practical implications and methodological issues can be derived from our findings and the process of carrying out this research.

Overall, the participants supported the right for prospective parents to have a choice about prenatal testing for Down syndrome. There are ongoing debates about the level of informed choice that women have about the uptake of prenatal tests. Although there is a consensus about the importance of informed choice, there are few definitions and measures of this construct (Marteau & Dormandy, 2001). A neglected dimension is the presentation of information from the perspective of those with a genetic disorder, especially individuals with Down syndrome. Individuals with genetic conditions may not always be opposed to genetic testing, but call for information about the condition to be presented to prospective parents (Chapman 2002). The participants in our study felt that prospective parents did not understand or have knowledge of Down syndrome. Information about Down syndrome from people with Down syndrome (e.g., the perceived value of life with a disability) could be presented to prospective parents, not as a means of persuasion, but as a means of providing a more balanced view of disability.

Our findings suggest that the individuals in the sample referred to the benefit of testing as a means of 'preparation' for the birth of a baby with Down syndrome, which demonstrates that the views of individuals with Down syndrome concur with other groups of individuals with genetic conditions. This suggests that an intellectual disability did not exclude people from reaching the same conclusion as other groups. However, there is little evidence that any of the groups of individuals with genetic conditions asked

about their attitudes or views of prenatal testing have considered the issue of risk to the foetus from testing. No identified study of individuals with genetic conditions has assessed the participants' knowledge of risk estimates or the possibility of false positive or false negative results. This is similar to previous research documenting that the general public have a lack of knowledge about prenatal tests and the implications (Singer, Couper, Raghunathan, Hoewyk & Antonucci, 2008). This may highlight an area for future research.

Sinason (1992) refers to the concept of the death wish, which she describes as a collective societal wish that individuals with Down syndrome had never been born. She argues that the very presence of the option to terminate, based on disability, feeds the social representation that people with intellectual disabilities are not of value and are therefore unwanted. Simpson (2004) reports that there is often familial mourning for the child or person that 'could have been', and in the extreme there is a view that some people would be 'better off dead' (Sinason, 1992). Essentially, Sinason employs very emotive language to speak about what the disability rights literature refers to as the expressivist message. This message has been criticised for lacking evidence.

Our study does provide some evidence that individuals in the sample considered the issue of Down syndrome as something 'unwanted' and also that they applied this message to their own lives. Many of the participants referred to previous experience of this message from the media. Others spoke directly about themselves as 'wanted' and grappled with existential and emotional questions around this consideration. The interview questions and structure was open and did not pose leading questions.

Individuals who entered into this dialogue did so with little direction from the researcher suggesting that there is some evidence that the individuals in the sample did take some personal message from prenatal testing and wanted to explore this. However, this finding must be interpreted with caution as not all of the individuals engaged in this dialogue and the sample may not be representative of the wider population of individuals with Down syndrome.

There may be an assumption that prenatal testing goes on without the awareness of individuals with intellectual disabilities. However, it would appear that some of the implicit and explicit messages contained within testing policies and practice do reach individuals with intellectual disabilities. Given that people with intellectual disabilities often have fragile attachment patterns (Lemma, 2003), the emotional impact from this broader message should, at the very least, be considered and contained by health professionals. Therapeutic space must be provided, and these issues could be considered as part of a broader conceptualisation of an individual's presenting difficulties.

Of additional note was the discourse of personal tragedy and public catastrophe surrounding the birth of a child with Down syndrome, which served to rationalise termination on the basis of re-establishing social order. The individuals in the sample accepted this dominant discourse to a certain extent. Clinicians who work with individuals with intellectual disabilities are themselves also subject to the power of this discourse and could use reflective practice to consider their own position and prejudices when working with individuals with intellectual disabilities. This is of particular relevance when considering the work of genetic counsellors who provide information to prospective parents about genetic conditions.

Many of the participants had communication difficulties, which made the process of collecting and analysing data more difficult. There were often inconsistencies in the presentation of the views and perceptions of the participants' account of their experiences, thoughts, or impressions of the subject in question. These inconsistencies were highlighted above as a means of demonstrating the complex nature of the topic, and the fact that the individuals may not have developed a coherent narrative that was articulated in an organised fashion. Consideration and presentation of these inconsistencies allowed for a greater understanding of the way in which each participant grappled with the topic at both a cognitive and emotional level.

A second method of overcoming some of the participants' communication difficulties was to not rely solely on the verbal material that was presented. The analysis also included non-verbal gestures, tone of voice, and emotional reactions to specific topics, which served as a means of placing an emphasis on the 'lived experience' of the participant. Future research could build on this approach and use video recordings to capture the nuances of non-verbal expressions throughout the process.

Proponents of IPA suggest that the group of participants in a sample should be homogenous, and is defined in terms of a single construct that the participants have in common. In this study, all of the participants had Down syndrome and on that basis the sample was considered homogenous. However, there was no accounting for the fact that there was a wide variety in the presentation of individuals with Down syndrome and the communication needs of each participant varied greatly. When conducting IPA with a group of individuals with varying levels of expressive and receptive communication, the challenge was to include all of the participants' experiences in a meaningful way. For

this reason, the subordinate themes were relatively broad as a means of capturing the experiences of the group as a whole.

Our study employed a combination of IPA alongside FDA. We believe that this allowed for analysis at a deeper level than either approach would have provided alone, thereby extending previous research. The combined method may be especially useful in other qualitative studies where individuals with intellectual disability are the participants, since there are such powerful discourses relating to disability that provide an important context for interpretation of any findings. A second aspect of our method that may be useful, more broadly, was to use an information session followed by an interview. The information sessions acted as a means of building rapport with the interviewer, and also allowed for some information about the study to be given, which aided the process of informed consent. The information provided in the sessions was neutral and did not give any argument for or against prenatal testing or termination. It is possible that participants had further conversations with their support networks between the sessions and interviews, which may have in some way biased the results. On balance, the risk of bias was less important than ensuring informed consent and this model may be readily applied for individuals who may require support to readily access the information about complex and emotive topics.

There were also a number of limitations that are important to consider when interpreting these findings. The participants were recruited on the basis that they had the expressive and receptive ability to partake in an interview, which excluded less able participants. They were also recruited on the basis that they had ongoing contact with a local non-profit organization and as such may have had more positive experiences of

Down syndrome and disability. The organisation in question had no particular stance toward the topic, however the participants may have already had a shared narrative as influenced by the organisation with which they were affiliated. Future research should aim to make these concepts accessible to individuals of all levels of ability. All of the participants were White, British Caucasian and aged between 24 and 49, with no children. As such, they did not represent culturally diverse groups, individuals of younger or older age groups. This is important to consider as Green, Snowdon and Statham (1993) highlighted that factors such as age, reproductive history and education were related to attitudes to prenatal testing.

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Table 1. Characteristics of participants.

Participant	Age	Living arrangement	Relationship Status and number of children	Employment
Jen	28	With family	Not married No children	Employed
Jane	24	In a supported community house with two other residents	Not married No children	Employed
Becky	26	At home with family	Not married No children	Employed
Ann		At home with family	In a relationship with Pete (participant) No children	Employed
Sam	41	At home with family	Not married No children	Employed
Tom	49	In a supported community home with two other residents	Not married No children	Employed
Mike		At home with family	In a relationship with Ann (participant) No children	Employed
Luke	36	At home with family	Not married No children	Employed

Table 2. Topics presented at the group information session

Topic	Sample of Information	Supplementary materials
Introduction	Introduction to the researcher, aim of the information session, and invitation to participate.	A written introduction sheet was presented.
Sex and Pregnancy	A basic teaching session about sex and pregnancy (with a focus on 'keeping safe').	Verbal information was presented in written format. Pictures were provided to aid the information giving. A group task to put a range of pictures in chronological order.
Down syndrome and disability	What is Down syndrome?	A short interactive discussion among the group.
Diversity and Difference	Some information and teaching about difference among individuals was presented.	Verbal information was also presented in written format. Pictures to aid with the concept of 'difference'. An interactive task to think about differences among people in the room. A true/false quiz about the meaning of difference.
Prenatal testing and implications.	An information session about prenatal testing.	Pictorial information along with a verbal presentation.

Table 3 – A summary of IPA and FDA themes

IPA Themes	IPA Sub-themes	FDA Discourses
1. A devalued condition, a valued life	A devalued condition	A discourse of social deviance
	A valued life	
	Self beyond disability	
2. A wanted condition? A wanted life?	Down syndrome as something wanted or unwanted by self and others	The discourse of tragedy and catastrophe
	Down syndrome as unwanted because people are not aware of the condition – test as preparation.	
	Self as someone who is wanted	