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Imagined futures: how experiential knowledge of disability affects parents' decision making about fetal abnormality

Emma F. France PhD,*† Louise Locock PhD,‡ Kate Hunt PhD,§¶ Sue Ziebland MSc,**†† Kate Field PhD,‡‡ and Sally Wyke PhD§§

*Research Fellow, School of Nursing, Midwifery and Health, Alliance for Self Care Research, University of Stirling, Stirling, †Research Fellow, Department of Politics and International Relations, University of Edinburgh, Edinburgh, ‡Senior Researcher and Lecturer, Department of Primary Health Care, Oxford University, Oxford, §Honorary Professor, School of Nursing, Midwifery and Health, Alliance for Self Care Research, University of Stirling, Stirling, ¶Senior Research Scientist and Leader of Gender and Health Programme, Medical Research Council (MRC) Social and Public Health Sciences Unit, University of Glasgow, Glasgow, **Honorary Professor, School of Nursing, Midwifery and Health, Alliance for Self Care Research, University of Stirling, Stirling, ††Research Director, DIPEX, Department of Primary Health Care, Oxford University, Oxford, ‡‡Senior Research Fellow, Department of Primary Health Care, Oxford University, Oxford and §§Professor of Health and Social Care, and Director of Alliance for Self-care Research, School of Nursing, Midwifery and Health, Alliance for Self Care Research, University of Stirling, Stirling, UK

Abstract

Correspondence

Emma F. France PhD
School of Nursing
Midwifery and Health
Alliance for Self Care Research
University of Stirling
Stirling FK9 4LA
UK
E-mail: Emma.France@stir.ac.uk

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Background Knowledge of disability is considered key information to enable informed antenatal screening decisions by expectant parents. However, little is known about the role of experiential knowledge of disability in decisions to terminate or continue with a pregnancy diagnosed with a fetal abnormality.

Objective To explore the role that expectant parents' experiential knowledge of disabilities and conditions can play in real-life decisions to continue or end a pregnancy with a fetal abnormality.

Design Secondary analysis of qualitative narrative interview data informed by contextual systems framework.

Setting Participants were recruited throughout the United Kingdom and interviewed between 2004 and 2006.

Participants Twenty-four women and four of their male partners who had direct or indirect experience of disability or illness and who had proceeded with or ended a pregnancy diagnosed with a fetal abnormality.

Findings Most respondents recounted using their experiential knowledge of disability, whether of their unborn baby's condition or of a different condition, to try to imagine the future for their unborn child, themselves and their family when making their decision. Some, who were considering continuing their pregnancy and had little or no experience of their unborn baby's specific disability, sought out others' experiences of the condition following antenatal diagnosis. The nature of a parent's experiential knowledge did not predict whether they continued with or terminated their pregnancy.

Discussion Prospective parents may find it helpful to discuss their existing knowledge of their unborn baby's condition with health professionals who are aware of the influence this might have on parents' decisions.

Introduction

Knowledge of disability or illness is often considered key information to enable informed antenatal screening decisions by expectant parents,^{1,2} but little attention has been paid to what information on disability people use, need or prefer when considering termination or continuation of a pregnancy affected by fetal abnormality. Some argue^{3–5} that prospective parents need more comprehensive, balanced information 'for example, on what it might be like to bring up a child with Down's syndrome' (pp16).³ Following antenatal diagnosis, most parents in the United Kingdom (UK) choose to end a pregnancy affected by fetal abnormalities including Down syndrome¹ and spina bifida.^{6,7} However, little is known about the role of information/knowledge of disability, gained through first- or second-hand experience, in decisions to continue or terminate pregnancies affected by fetal abnormality.

Studies using hypothetical scenarios to investigate the attitudes of people with experiential knowledge^{II} of disability (either through having a disability/serious condition themselves or through contact with disabled^{III} people) towards antenatal screening and/or termination of pregnancy for various conditions have found both positive and negative attitudes.^{10–23} There is also some evidence that experience of disability influences decisions to decline antenatal tests.^{17,23} However, few studies investigate how

real-life decisions to continue with or terminate a pregnancy following antenatal diagnosis are influenced by prospective parents' experiential knowledge of disability.

Qualitative studies in Australia²⁴ and America^{24–26} and a small American survey²⁷ of expectant parents who continued with their pregnancy revealed that after antenatal diagnosis of holoprosencephaly (a brain abnormality),²⁵ spina bifida, hydrocephalus,²⁴ sex chromosome abnormalities²⁷ or other unspecified conditions,²⁶ some parents who continued their pregnancy sought out other people's experiences of disability to aid decision making^{24,25,27} or cited experiential knowledge as influential in their decision.^{25,26} Having experience of disability was not cited as influential in decisions to terminate affected pregnancies in one aforementioned study that also investigated this.²⁶ However, a UK qualitative study²⁸ and small UK²⁹ and Australian surveys³⁰ indicate that, amongst parents who have had a child with haemophilia, muscular dystrophy²⁸ or cystic fibrosis,^{29,30} some become less inclined to terminate subsequent affected pregnancies, while others become more inclined to terminate because of concerns about the child's and family's quality of life and about coping with another affected child.^{28–30} These studies suggest that people's experiential knowledge of disabilities may be influential in continuing or ending an affected pregnancy.

Thus, very few studies have explored how experiential knowledge of a serious condition or disability influences *actual* rather than hypothetical decisions to continue or end a pregnancy affected by fetal abnormality. This paper presents secondary analysis of UK qualitative data to further our understanding of the role that women's and couple's experiences of disabilities and serious conditions can play in such decisions.

^IIn line with recent convention, we refer to congenital syndromes without an apostrophe S, e.g. 'Down syndrome', verbatim quotes excepted.

^{II}Knowledge gained from first- or second-hand personal experience.^{8,9}

^{III}In the UK, 'disabled people' is the preferred terminology 'signifying that people with impairments are disabled by an exclusionary society' (pp686).⁴

Methods

This study employed secondary analysis of narrative interviews to explore how people describe the role of experiential knowledge of serious illness or disability in their decisions to continue or end a pregnancy affected by fetal abnormality. It forms part of a wider study on information use in health-related decisions. The qualitative data were collected in the UK by the Oxford Health Experiences Research Group for three 'modules' (studies) of the 'HealthTalkOnline'³¹ website that provides access to people's experiences of health and illness. The three modules were as follows: ending a pregnancy for fetal abnormality (40 interviews); experiences of antenatal screening (37 interviews); and screening for sickle cell disorders and thalassaemia (30 interviews). LL and KF conducted interviews in participants' homes in 2004–06. They carried out narrative interviews that allowed respondents to tell their own stories with subsequent prompting on certain topics; conducted initial data analysis for each module; wrote thematic topic summaries for the HealthTalkOnline website; summarized key interview features; and undertook some detailed analysis.³²

HealthTalkOnline's aims and methodology are described in more detail elsewhere.³³ For each module, a diverse purposive sample³⁴ is selected including people with 'typical' and more unusual experiences of the health issue. For the modules of interest here, variation was sought in length of time since pregnancy/termination, geographical location, occupation, age and ethnicity. Recruitment was via general practitioners, hospital consultants, nurses, support groups and word of mouth. The research methods were approved by the UK Multi-centre Research Ethics Committee. With participant consent, interviews were audio and video recorded, transcribed, checked by the interviewee and copyrighted to the University of Oxford which can grant access to full interview transcripts for secondary analysis. The website features only short extracts from interviews.

In our secondary analysis, we analysed 26 full interview transcripts with 24 women and four of their male partners (two male partners were interviewed individually, and two with their wives) in which respondents reported having prior first- or second-hand experience of a disability/condition, and who had continued with or ended a pregnancy following suspected or diagnosed fetal abnormality. Fifteen interviews were collected for the 'Ending a pregnancy' module, six for the 'Antenatal screening' module and five for the 'Sickle cell' module. Nineteen interviewees spontaneously raised their experiential knowledge of disability, nine mentioned their experiences of disability in response to questions by the interviewer. The 26 interviews took place one to 12 years after a pregnancy (mean: 5 years, mode: 2 years) and lasted one to three hours. Seventeen women terminated (most by artificially induced labour) and seven women continued with one or more abnormal pregnancies. Table 1 provides details of respondents' pregnancies and experiences of disability; Table 2 gives respondents' biographical details. Pseudonyms are used throughout.

Our initial interest was in the types of information people used in reaching decisions, so we could compare this across health contexts for the wider study. Using framework analysis,³⁵ initially, each transcript was analysed separately; EF summarized in a framework pre-determined aspects of every decision discussed in the interview (including whether to end a pregnancy affected by fetal abnormality) by recording whether the respondent saw the decision as a 'choice'; the type and format of any information mentioned; the method and manner of information delivery; and any perceived information gaps. Frameworks included salient verbatim quotations from transcripts. Table 3 presents an illustrative, abridged framework. SZ, KH or SW verified the accuracy of data extraction in 12 of 26 frameworks. Subsequently, using constant comparison,³⁶ similarities and differences across transcripts were explored and themes identified in terms of how respondents described the role of experiential knowledge in their decision to end or continue their pregnancy. A gendered

Table 1 Pregnancy details and outcome, baby's diagnosis and person's experiential knowledge of disability

Respondent Pseudonym	Pregnancy details and outcome	Involvement in decision*	Nature of baby's condition	Nature of woman's/couple's disability experience	Respondent raised their experiential knowledge of disability?
Jenny	Terminated pregnancy 3 (surgical termination)	Alone	Down syndrome	Jenny had met children with Down syndrome as a public auditor	Yes
Rachel	Went ahead with pregnancy 2	Joint/agreed	Hypoplastic left heart	Colleague's daughter had Down syndrome. Met other families of 'heart children' after antenatal diagnosis at AGM of 'Left Heart Matters' charity	Yes
Kelly	Terminated pregnancy 1	Joint/agreed	Edward syndrome (lethal)	Couple knew other couple's with disabled children. Read parents' accounts about their babies with Edward syndrome after diagnosis	Yes
Amanda	Terminated pregnancy 5	Joint/disagreed	Down syndrome	Amanda has sibling with autism and lives next door to disabled centre	No
Tanya	Terminated pregnancy 4	Alone	Down syndrome	Tanya knows people who have children with Down syndrome	No
Vanessa	Terminated pregnancies 2 and 4	Joint/agreed	2: multiple, severe abnormalities (post-mortem diagnosis: lethal multiple pterygium syndrome). 4: suspected pterygium syndrome (post-mortem diagnosis: Down syndrome)	Vanessa knows couples with disabled kids and had had a school friend with a sibling who had cerebral palsy	Yes
Melanie	Terminated one twin in pregnancy 5 (fetal reduction)	Joint/agreed	Down syndrome	A family friend's brother has Down syndrome. Have friends with disabled children.	Yes
Helen	Terminated pregnancy 1	Joint/agreed	Anencephaly (lethal neural tube defect)	Melanie is nurse with experience of children with Down syndrome	Yes
Lucy	Went ahead with pregnancy 5	Joint/agreed	Pulmonary stenosis and a VSD (heart defect)	Helen had disabled foster siblings including those with physical and learning disabilities	Yes
Anne and David [†]	Went ahead with pregnancy 1	Joint/agreed	Down syndrome and heart defect	Lucy's uncle has Down syndrome	Yes
Jane and Steve [‡]	Terminated pregnancy 3	Joint/agreed	Lower limb deformity	David at boarding school with disabled children and had foster siblings with disabilities. Couple met people with various disabilities including Down syndrome prior to decision	No
				Jane has congenital heart condition. Contacted parents with children with same condition as their baby	Yes

Table 1 (Continued)

Respondent Pseudonym	Pregnancy details and outcome	Involvement in decision*	Nature of baby's condition	Nature of woman's/couple's disability experience	Respondent raised their experiential knowledge of disability?
Cathy	Terminated pregnancy 2	Joint/disagreed	Down syndrome	Husband had older brother with spina bifida who died at 16. Cathy is nurse on a learning disability placement at time of termination	Yes
Sarah and John [†]	Terminated pregnancy 2	Joint/agreed	Alobar holoprosencephaly (possibly lethal brain abnormality, severity varies)	Sarah's uncle has Down syndrome and she works with people with disabilities	Yes
Marie	Went ahead with pregnancies 1, 2 and 3	Alone	1 and 2: sickle cell disease 3: sickle cell anaemia	Marie and her 1st and 2nd children have sickle cell disease	No
Afiyah	Went ahead with pregnancy 1 and 3	Not stated	1: Sickle cell disease 3: sickle cell anaemia or sickle cell disease (no diagnosis but 1 in 2 chance)	Afiyah has sickle cell disease	No
Selina	Terminated Pregnancy 2 (surgical termination)	Alone	Sickle cell anaemia (no diagnosis but 1 in 4 chance)	First child has sickle cell anaemia – diagnosed after birth	Yes
Bayo	Went ahead with Pregnancy 3	Not stated	Sickle cell anaemia	Bayo's uncles have sickle cell anaemia	Yes
Ameena	Went ahead with Pregnancy 2	Joint/agreed	Beta thalassaemia major	Parents-in-law had baby and her other relatives have children with beta thalassaemia major	Yes
June	Terminated pregnancy 5	Joint/agreed	Down syndrome	June worked with disabled children and people with Down syndrome as speech therapist	No
Paula	Terminated pregnancies 2 and 3	Joint/agreed	Walker-Warburg syndrome (lethal). (pregnancy 2 initial diagnosis: neural tube defect).	Paula had been a nurse and had nursed babies with hydrocephalus, a neural tube defect	Yes
Nicola and Mike [‡]	Terminated pregnancy 3	Joint/agreed	Multiple organ and limb defects (diagnosis uncertain)	Couple worked with disabled people 15 years ago. Nicola had worked with children with learning difficulties	Yes
Julia	Terminated pregnancy 2	Joint/agreed	Patau syndrome (lethal)	Julia is nurse and had nursed sick children	Yes
Suzy	Terminated pregnancy 1	Joint/agreed	Severe spina bifida	Suzy is health professional who worked with complex cases of spina bifida in children and adults	Yes
Debbie	Terminated pregnancy 3 (surgical termination)	Alone	Severe heart and kidney deformity (diagnosis uncertain)	Debbie is nurse with experience of various conditions and disabilities	Yes

*'Joint' = decision made with baby's father; 'Alone' = woman made decision alone; 'agreed' = couple agreed over decision; 'disagreed' = couple disagreed over decision.

[†]Couple interviewed together.

[‡]These two couples who were interviewed separately have been described jointly.

Table 2 Respondents' demographic and biographical details

Respondent Pseudonym	Age at interview	Ethnic origin	Marital status	Time since pregnancy termination or continuation	Had children before affected pregnancy
Jenny	36	White	Married	8 years	No
Rachel	41	White	Living with partner	2 years	Yes – 2
Kelly	38	White	Married	< 1 year	No
Amanda	37	White	Married	3–4 years	Yes – 1
Tanya	37	White	Married	2 years	Yes – 3
Vanessa	43	White	Married	8 and 4 years	Yes – 1
Melanie	43	White	Married	9 years	Yes – 2
Helen	23	White	Married	2 years	No
Lucy	37	White	Married	4 years	No
Anne and David	Both 28	White	Married	1 year	No
Jane	43	White	Married (to Steve)	3 years	Yes – 1
Steve	49	White	Married (to Jane)	3 years	Yes – 1
Cathy	44	White	Married	6 years	Yes -1
Sarah and John	Both 37	White	Married	6 years	Yes – 1
Marie	41	Black Nigerian	Married	12, 8 and 6 years	No*
Afiyah	38	Black Nigerian	Single	10 and 4 years	No*
Selina	30	Black Sierra Leone	Single	1 year	Yes -1
Bayo	37	Black Nigerian	Living with partner	9 years	Yes-2
Ameena	31	Pakistani	Married	9 years	Yes – 1
June	52	White	Married	11 years	Yes – 4
Paula	40	White	Married	3 years	No
Nicola	38	White	Married (to Mike)	2 years	Yes – 2
Mike	41	White	Married (to Nicola)	2 years	Yes – 2
Julia	32	White	Married	5 years	Yes – 1
Suzy	25	White	Living with partner	1 year	No
Debbie	34	White	Married	4 years	Yes – 2

*They did not have any children prior to their first pregnancy that was diagnosed with an abnormality but did have children in subsequent affected pregnancies.

analysis was not possible because the sample had only four men.

Our conceptual approach was influenced by Bury's³⁷ framework for analysing illness narratives which distinguishes between contingent narratives (what respondents said about events and what happened to them), moral narratives (accounts of relations between the person, their decision and social identity) and core narratives (deeper cultural meanings). We focused on contingent narratives to analyse people's perceptions of their experiences while recognising that the interviews are 'factions' (pp282),³⁷ i.e. accounts combining fact and 'fiction' as people retrospectively reconstruct events. We were also influenced by Lawson and Pierson's³⁸ 'contextual systems framework' (developed using research regarding antenatal testing decision

making) that emphasizes the importance of social and psychological factors, such as attitudes, beliefs, values (individual level factors), one's family (the proximal social context) and societal norms (the distal social context), in antenatal decision making.

Findings

Most people described using various types of information from a range of sources in reaching a decision about the pregnancy (see Table 4). We focused on experiential knowledge of conditions and how respondents described its influence on them.

All respondents described the decision to end or continue their pregnancy as their own. Most partnered respondents recounted sharing the

Table 3 Abridged excerpt of an analytical framework for one respondent

Decision event	Seen as choice? (yes, no, unclear)	Information type and format (data/evidence)	Method and manner of information delivery (data/evidence)	Evaluation of information (data/evidence)	Evaluation of decision (data/evidence)	Information gaps (data/evidence)
Decision to terminate one twin who had Down syndrome (DS)	Yes – ‘we did have options, we could have continued and taken our chances’ p25*	One twin has DS – results of first of two CVSs (Chorionic Villus Sampling), verbal over phone from midwife/counsellor	R was at home alone when a midwife or counsellor from the hospital rang up 2 weeks after the CVS to tell her that she was having a boy and a girl and that only one twin had DS. R could not wait for someone to be with her to hear the results and wanted to know immediately. p4*	The news invoked conflicting emotions in couple- ‘immense relief’ that one baby was ok, but they were ‘devastated’ that one had DS. R called her husband at work to tell him the results. Couple went to see the consultant again the next week (he was on leave so they had to wait 6 days). p4* No data in transcript	R felt lucky she was leaving after the termination with ‘something’ because she was still pregnant with one twin p6 ‘part of me thought we were very lucky in a bizarre sort of way.’ p6.* R was ‘absolutely thrilled’ when she gave birth to one twin but was sad too and felt something was missing- she did not realize she needed to grieve for her lost baby boy. p8. R called ARC (Antenatal Results and Choices) after termination – they gave her ‘permission’ to grieve for her lost baby. ‘And it was like this “light-bulb moment.”’p9	R wasn’t given any literature – wasn’t told about ARC (Antenatal Results and Choices) either but she knew of them and found their number herself p24* ‘I didn’t have anything at all. [um] Probably if I hadn’t, I mean if I hadn’t known about ARC, or SATFA as it then was, nobody gave me the information at all. I literally. I think I went on the internet, and I found their number.’ P24
		Option of termination or continuing pregnancy – verbal from consultant at local hospital	At some point before getting the CVS results, couple talked face-to-face to a consultant at their local hospital – he told them that they could either terminate (both babies) or continue with the pregnancy. p3	No data in transcript		
		Risk of miscarriage if woman continued with pregnancy – verbal from local hospital consultant	When the consultant at the local hospital told the couple their options of either terminating or continuing with the pregnancy he told them that if both babies had DS they were at ‘very high risk of miscarriage.’ p3	No data in transcript		
		R’s father’s attitude to termination – verbal from her father over phone p33	‘And even now I remember my father ringing me when we’d found out that we had a problem, and him saying to me, “Well, I really think you ought to have a termination.”’p33 Personal experience of having twins already			
		Imagining coping with twins when one has DS				
			R felt that having another set of twins combined with one twin having DS would be too much to cope with. p3 and P10			

Table 3 (Continued)

Decision event	Seen as choice? (yes, no, unclear)	Information type and format (data /evidence)	Method and manner of information delivery (data /evidence)	Evaluation of information (data /evidence)	Evaluation of decision (data /evidence)	Information gaps (data /evidence)
		Imagining burden of child with DS on their other children p10	Not applicable	'We were slightly older parents so it would obviously fall on our younger children [um] to actually be looking after him. We weren't, we didn't think it was fair on our other children to have that burden on.' P10		
		Experience of their friends who have disabled children p10-11	Personal experience	R didn't want that life for her baby – 'We've got some experience with friends with very disabled children, and though I wouldn't, I'm not belittling their life as it is, I didn't think it was fair. I didn't want it for my child I think is, is probably the bottom line.'		
		R's experience of DS as a nurse	Personal experience	P10-11 R has nursing experience of children with DS in 'very difficult' and 'very sad situations' and did not want that for herself. p3		
		People with DS know they are different – verbal from a family friend p11	A family friend has a brother with Down syndrome. When R got diagnosis of DS she told R that her brother knew he was different and was hurt by how people sometimes treated him p11	This info really 'struck' R – she had previously assumed that people with DS weren't aware of being treated badly. R didn't want her son to be hurt. P11		
		Risk of miscarrying both babies when one has DS – verbal from consultant	At one of their appointments, the consultant told couple they might risk miscarrying both babies because one had DS. p22	R feels that knowing they might have lost both babies if they hadn't had fetal reduction – R feels like this took a bit of the responsibility for the decision away from couple although R knows that really she was responsible for the decision in the end. p22		

Table 3 (Continued)

Decision event	Seen as choice? (yes, no, unclear)	Information type and format (data /evidence)	Method and manner of information delivery (data /evidence)	Evaluation of information (data /evidence)	Evaluation of decision (data /evidence)	Information gaps (data /evidence)
		Information on 'selective reduction' – verbal from consultant and R's knowledge as nurse p5	Once couple had decided to terminate they were told about the procedure for terminating one twin by lethal injection (but R already knew this info) p5	R already knew about this procedure as a nurse working with babies but she listened to the info about it for her husband's sake because he didn't have any medical knowledge. R says the explanation for her husband was very good. p24		

*All page numbers in the framework refer to the pages of the respondent's transcript from which the evidence was drawn.
R, respondent

decision with the baby's father except for four women who decided alone to terminate (Debbie, Jenny and Marie at their husband's request, and Tanya who interpreted her husband's silence as tacit acceptance). Two women did not state whether the decision was shared. Most respondents said they and their partner agreed about the decision; the exceptions were Amanda and Cathy who initially disagreed with their husband's preference to terminate but both eventually ended the pregnancy.

People's experiential knowledge of disability included having a disorder themselves, living with a disabled sibling, and talking to or observing family, friends, acquaintances or clients who had a disability or a disabled relative.

While around half of the women/couples had prior experience of the same condition as their unborn child, others had experience of a different condition or referred to experience of 'disability' more generally. Six of this latter group described seeking out other people's experiences of their child's condition after antenatal diagnosis.

Imagining possible futures

The most common story women and couples told, both those who ended and continued their pregnancy, was of 'imagined futures': they used experiential knowledge of disability to try to imagine how life might be for their unborn child, themselves, and their family. Table 5 summarizes which key aspects of the future participants mentioned.

Most respondents discussed what the baby's life might be like. Some focused on the likely extent and manageability of any physical or emotional suffering, others on what the child's day-to-day life or prognosis might be like. Fewer talked about whether the baby might experience the stigma of disability, and the nature of health and care services for disabled children and adults. Some parents concluded that their baby could have a reasonable quality of life despite her/his condition, while others felt it would be poor. Parents in both categories ended and continued their pregnancy.

Table 4 All reported influences on the decision to terminate or continue an affected pregnancy

Experiential knowledge of disability
Biomedical information on baby's condition and possibility of treatment/surgery
Information on option to continue pregnancy
Information on legality of termination /option to terminate
Information on process and procedure of termination
Attitudes of health professionals to termination and disability
Attitudes of significant others to termination and disability
Emotional attachment to unborn baby
Importance of having a child (e.g. cultural, personal)
Fertility history (e.g. history of miscarriage)
Own age and health as parents
Religious influences

In bold are factors which parents described as affecting their perceptions of the potential future of their unborn baby, their family and themselves.

The decisions of three women were influenced by how 'bearable' their child's potential pain or suffering might be. For instance, Marie and Afiyah, who had sickle cell (SC) disorder,^{IV} felt they understood what it would be like for their child to live with the condition. They knew how painful it could be, as Marie describes:

I'd been through so many pains, I know what it means to have pain. And my idea is that I don't want to bring someone to the world and have so much pain.

However, when they discovered their baby had SC disorder, they both concluded that the disease was manageable because if they could cope, so could their child. They also spoke about the importance to them of having a child. Both continued with their first pregnancy. Marie also continued with her similarly affected second pregnancy (see below for Marie's decision making in her third pregnancy).

Rachel, whose unborn baby was diagnosed with a serious heart abnormality, did not have prior experience of this condition, but she was

familiar with and positive about other disabilities including Down syndrome. After antenatal diagnosis, she and her husband met other families whose children had the same heart defect. From this, she felt hope that her child too would be able to cope ('He could be one of the ones that gets to 18 without needing anything more than an aspirin occasionally') and also that her family would cope, whereas she felt her health professionals had given her little optimism. She also chose to continue with her pregnancy.

In other circumstances, the child's likely level of pain and suffering was perceived to be too great. In her third pregnancy, Marie's baby was diagnosed with sickle cell anaemia. She felt this was much worse than SC disorder having met people with sickle cell anaemia while in hospital. She intended to terminate this pregnancy, but changed her mind during an ultrasound scan when she saw the child moving ['Oh, this is lovely and even if she has SS, how can I do this (terminate)?']. Further encouragement came from church pastors who said that God would only give a person what they could cope with.

More often though, people chose to end their pregnancy when they believed that their baby would have a poor quality of life. For instance, Suzy had professional knowledge and experience of caring for people with severe spina bifida. This meant she understood the diagnosis and its implications leading her to question her child's potential quality of life and quality of care as an adult:

I knew how serious this was and as a professional I knew what the outcomes were going to be. I've seen these kids just exist. And worst of all I've seen these adults, once the parents have gone, basically with no-one to take responsibility for them, no-one to care.

She was sure she could cope with the care of her child. However, the baby's quality of life was her major concern; she reflected that proceeding with the pregnancy would be 'to what end, and for what purpose?'

Sometimes, as above, there was a tension between the child's perceived quality of life and the couple's anticipated ability or willingness to parent a disabled child. Only one couple who

^{IV} Sickle cell disease is a group of related genetic conditions affecting blood haemoglobin levels. The most serious form is sickle cell anaemia (also known as Hb-SS). Other conditions requiring treatment include Hb-SC or SC disorder. This often has milder effects than sickle cell anaemia, but can still cause most of the same symptoms and complications.

Table 5 Use of experiential knowledge of disability to inform key aspects of the future

Respondent Pseudonym	Contextual information		Aspects of future mentioned		
	Decision	Seek others' experiences	Baby's life	Parent's life	Family life (including marriage and existing children)
Jenny	TOP		✓	✓	
Rachel	Continued	✓	✓		✓
Kelly	TOP	✓	✓	✓	✓
Amanda	TOP		✓	✓	✓
Tanya	TOP		✓		✓
Vanessa	TOP × 2		✓	✓	✓
Melanie	TOP		✓	✓	✓
Helen	TOP	✓	✓		
Lucy	Continued			✓	
Anne and David	Continued	✓			
Jane and Steve	TOP	✓	✓	✓	
Cathy	TOP			✓	✓
Sarah and John	TOP		✓	✓	✓
Marie	Continued × 3		✓	✓	
Afiyah	Continued × 2		✓		
Selina	TOP			✓	
Bayo	Continued		✓	✓	
Ameena	Continued				
June	TOP			✓	✓
Paula	TOP × 2		✓		
Nicola and Mike	TOP		✓	✓	✓
Julia	TOP	✓	✓		✓
Suzy	TOP		✓	✓	
Debbie	TOP		✓		

TOP, termination of pregnancy; Continued, continued with an affected pregnancy.

openly acknowledged that their baby could have a good life decided to terminate the pregnancy. Jane and Steve carried out extensive research into their son's lower limb deformity, seeking out medical advice and other families' experiences. Jane, who had a congenital heart condition, concluded:

I've managed with it, I have got a good life, and I'm happy and he probably would have been happy and so on. [...] He wasn't going to have a dismal life at all – I knew that because of the conversations I've had with people.

Their reasons for termination centred on Jane's perceived inability to 'cope with it all' because of the pressures of her own health condition. Steve came to the same conclusion as his wife:

As much as I could suggest, "Of course I'll share it [the burden] with you," the reality is that it would have fallen on her mainly.

The baby's perceived quality of life was even a consideration for some of the six people given an antenatal diagnosis 'incompatible with life', usually suggesting that the baby will die before or soon after birth. None had previously encountered such a condition, but four tried to apply their prior experiential knowledge of more common disabilities or illnesses to anticipate what their baby's brief life might be like. Julia, for example, drew on her experience of nursing very ill babies, combined with other parents' experiences of the syndrome:

I read a few stories of people's experience of living with a child with Patau's Syndrome and as I read it I just thought, "Not for my daughter, no way". I just thought, there's no quality here. And plus I suppose my experience of looking after some children at work, that I've seen that are so poorly, and it's terrible and you just think, "not for my child".

Julia knew she would not be raising a disabled child for long, if at all, so focused on the immediate future. She initially wanted to have the baby but as she learned more about Patau syndrome she opted for termination. Some other people in situations like Julia's also sought out other people's personal experiences of rare, fatal conditions and also ended their pregnancies.

Another aspect of the baby's potential life was the likelihood that he/she would encounter prejudice because of his/her disability. Two women who ended their pregnancy spoke about this. For instance, Melanie, whose unborn baby was diagnosed with Down syndrome, was 'struck' by her friend's description of what her brother with Down syndrome had experienced:

He would regularly say to her, "Why am I different? Why are people so horrible to me?" Because as a child, children are cruel, and therefore he had a very difficult time I think.

From this, Melanie believed that her child would suffer from unkind, discriminatory behaviour. She did not want that for her son and ended her pregnancy.

Some people described trying to use their experiential knowledge to imagine what their baby's life could be like but, because their baby's condition was rare and unfamiliar to them or the diagnosis was unknown, they struggled. In three pregnancies, couples who were considering continuing with the pregnancy wanted to know how long their baby might survive and his/her likely quality of life. For example, Sarah and John tried to apply their own and other people's experiences of common disabilities to their situation, but they did not seem relevant to their unborn baby's rare brain abnormality, as Sarah describes:

I just couldn't even really identify with people who'd had children with hydrocephalus, or people who had children with Down's syndrome, there didn't seem to be any kind of link.

For them and others, the uncertainty of the diagnosis or of its severity made it difficult to apply their experiential knowledge of disability to their baby's potential future life. These couples all ended their pregnancy.

Most people also talked about other potential consequences of having a disabled child. Over half of the respondents described drawing on experiential knowledge of disability to judge how a disabled child might affect their life and/or whether they could cope emotionally and practically: they imagined how they might manage when they had their own serious health condition; or when they already had healthy or disabled children to care for; how capable they felt of providing specialized care for a sick child; or of coping with the stigma of disability.

Three women already had a child with a serious condition (a sickle cell disease) when they faced another potential fetal abnormality. For Selina, it was so difficult being the single parent of one young child with sickle cell anaemia that she felt she could not cope with another:

I'm so scared that I don't want to have another child with sickle cell again.

[Later in the interview]

Because I thought it was something so shameful and I don't want anybody to know.

The disease is greatly stigmatized in Sierra Leone, her country of origin. Consequently, Selina ended her second pregnancy, where her baby's risk of having the condition was one in four, without seeking a diagnosis. As presented earlier, Marie and also Afyah continued with subsequent affected pregnancies (although, like Selina, Afyah only knew there was a high probability her unborn baby was affected).

Having doubts about how one would cope with a disabled child when one had other children without a disability was also raised by a few people because they had witnessed the extra demands disabled children make on their parents.

Others said that having a disabled child was not the life they had envisaged for themselves or their family. For instance, from her observations, Vanessa felt sure that a disabled child would be a 'burden'.

I'm very sure that I couldn't bring up a disabled child, I don't want to bring up a disabled child. I've got friends with disabled children, and I can see what a very, very difficult life they have.

Unlike Sarah and John, above, she did not describe it as difficult to draw on her experiential knowledge of common disabilities (including cerebral palsy) when deciding to end two pregnancies, even though she did not have definite antenatal diagnoses. She had been sure from the outset that she would terminate for any serious fetal abnormality.

In contrast to Vanessa, Bayo, who also perceived a seriously sick child as something she did not want to be 'lumbered with', continued with her pregnancy. She understood the implications of sickle cell anaemia because she had relatives with the disorder:

I had people in my family that have had sickle cell, I've seen the way some of them cope. I've seen the way some of them couldn't really cope, have had stroke, have died.

Because her pregnancy was too advanced for her to consider termination, she opted for adoption during pregnancy but ultimately could not part with her baby.

Another widespread concern was how a disabled child might affect family life. The majority of the 15 women/couples who already had children talked about this. Amongst this sample, imagining one's future family or married life was mentioned only in relation to negative impacts of continuing the pregnancy and by those who terminated.

Some people felt their other children would suffer through being deprived of parental attention or having to care for their disabled sibling now or in the future. One such example is Cathy whose husband's brother died of spina bifida aged 16 years. According to Cathy, her husband (who was not interviewed) was sure he did not want a disabled child. Because of his own childhood, he was very concerned about the impact on his existing daughter:

My husband missed out an awful lot, his brother was in and out of hospital, he felt a lot of guilt when his brother died. And his mum was so badly affected that my husband suffered as a teenager really, because she was so badly affected by losing her other son.

He had also been heavily involved in day-to-day care for his brother. Although Cathy says

she initially wanted to keep her baby who had Down syndrome, she ended the pregnancy. She emphasizes the considerable influence on the decision of her spouse's experience of a disabled sibling rather than her own nursing experience of Down syndrome. This example illustrates how these decisions can be presented as a negotiation between partners who may have different experiences of and attitudes to disability, and different preferences regarding termination.

Another related issue raised explicitly by two women included the potential impact on their marriage. Having seen other couple's relationships 'crumble' under the 'strain' or 'burden' of caring for a disabled child, they were not willing to risk their relationship in this way. Respondents also considered the prospect of poor or non-existent professional care services on the family and on the disabled child's siblings after the couple died.

It is clear that respondents generally tried to draw on whatever experiential knowledge of disability they had to imagine the future for, and with, a disabled child. Even people without experience of their unborn baby's condition tried to apply what they knew of other disabilities to their decision making, and in some cases (e.g. Cathy, Vanessa), this kind of knowledge appeared highly influential. When people had no, or very limited experience of their baby's condition and were considering continuing their pregnancy, they tended to seek out other people's experiences after antenatal diagnosis to help decision making.

Stories of drawing on experiential knowledge of disability to imagine the future life of the family and child predominated in respondents' narratives, with three exceptions. Helen, raised in a religious family that was against termination and that had fostered disabled children, talked about her exposure to disability in terms of a right to life, despite knowing her baby's condition was lethal:

That person is still a person, at the end of the day you wouldn't kill a healthy child so why would you kill, in inverted commas "kill", a disabled child?

Therefore, Helen was initially certain that she wanted to continue with her pregnancy. However, she ended the pregnancy after her parents and parents-in-law questioned her decision to go ahead.

Two other women/couples believed that they 'did not know anything' (Amanda) or knew 'a little bit' (David) about their unborn child's Down syndrome. Amanda does, however, refer to her autistic sibling's poor quality of life, when talking about why she ended her wanted pregnancy (her husband wanted a termination). Anne and David, who continued their pregnancy, sought out other people's experiences of Down syndrome and related heart defects, as Anne says, 'to help with the decision making'. Neither woman/couple talked much about what experience they did have, nor did they spontaneously raise their prior experiential knowledge of disability.

Discussion

In how they described their real-life decisions to end or continue a pregnancy, most respondents told stories of imagined futures grounded in real experiences of disability. Other studies have also found that couples who terminated because of fetal abnormality considered issues such as the baby's welfare, impacts on his/her siblings and the parents' perceived coping ability,^{39–41} but they did not explore whether parents' experiential knowledge of disability informed these considerations. Our study shows that such knowledge (where it exists) is commonly part of the repertoire of information drawn on to inform decisions both to continue *and* to end a pregnancy with a fetal abnormality. This reflects research findings that some people with direct experience of a condition terminated while others proceeded with affected pregnancies,^{28–30} but is in contrast to a study in which parents did not report experiential knowledge as an influence on termination decisions.²⁶

However, people did not report using experiential information in isolation but described it interacting with other information, influences

and beliefs (e.g. religious beliefs, spouse's wishes). Previous research has also found a range of influences on decision making regarding termination.²⁴

Our findings confirm that information on what it is like to live with a condition is associated with decisions to terminate or continue pregnancies which has previously been found for pregnancies affected by cystic fibrosis,³⁰ haemophilia and muscular dystrophy²⁸ but extends this to a wider range of antenatal diagnoses (e.g. Down syndrome, spina bifida, heart defects) and a greater range of experiences (e.g. having a condition oneself, having a disabled sibling or friend), not just being the parent of a disabled/ill child.

The apparent influence of experiential knowledge of one condition (e.g. spina bifida) on an antenatal decision about a different condition (e.g. Down syndrome) seen in our analysis has not been explored previously as studies have usually focused on how familiarity with a specific condition affects attitudes towards termination for that same condition,^{14,17,25,28–30} or have investigated hypothetical decisions.¹⁹ This merits further exploration to better understand how different kinds of exposure to disability influence real antenatal decisions for a range of conditions.

Our findings suggest that in certain circumstances, people may feel they need or prefer to access other people's experiences of their unborn baby's condition following antenatal diagnosis (particularly if they are considering proceeding with a pregnancy but have little or no experience of their baby's condition) and that this information can play a role in decisions to end *and* to proceed with an affected pregnancy. Other studies have found that couples look for people's personal experiences regarding the decision to *continue* with a pregnancy affected by a neural tube defect,²⁴ sex chromosome abnormality,²⁷ or brain abnormality²⁵ and for other health decisions.⁴² At least one UK website⁴³ provides information on other people's experiences of disability specifically for antenatal decisions, and some research has explored how best to present experiential health infor-

mation to people who want it,^{44–46} but this area needs further research.

Our study, using Bury's contingent narratives,³⁷ confirms contextual systems framework's³⁸ relevance for decisions about pregnancy termination, not just antenatal testing decisions. Experiential knowledge informed people's perceptions of the future related to the life contexts the framework describes: individual factors (e.g. beliefs about how a child might experience disability), and proximal (e.g. impact on family) and distal social contexts (e.g. stigma of disability). It also highlights that experiential knowledge forms part of people's life contexts and supports the theorized 'inter-connectedness' (pp245)³⁸ of different contextual influences.

Limitations of the data

The 26 interviews analysed here were selected from three HealthTalkOnline modules on the basis of people's self-described, pre-existing experiential knowledge of disability in relation to deciding whether to terminate therefore the findings are not intended to be predictive of attitudes and behaviour in the wider population.⁴⁷ We cannot know whether others in the modules had experiential knowledge of disability that was not mentioned (although some were asked about this if they did not raise it). This limits the insights we can offer into some situations in which prior experiential knowledge did *not* play a role, although some respondents said their prior knowledge was too limited or not relevant enough to be useful in their decision making.

The interviews covered the topic of personal experience of disability and its influence on antenatal decisions in varying depth depending on how important the topic was to the interviewee. Nonetheless, they provide in-depth data on a variety of experiences around whether to end a wanted pregnancy.

It is important to note that these are retrospective accounts of actual decisions taken between one and 12 years previously which are likely to involve some 'moral identity' manage-

ment, given societal attitudes towards disability and pregnancy termination. In such difficult circumstances, we would expect people to 'rehearse' an account of their decision that they can live with and/or legitimate to others. Hence, we focused on how people talked about their decisions, their contingent narratives about 'what happened'.³⁷ We accept that on one level, these accounts are 'performative' and contain both fact and 'fiction' in Bury's terms,³⁷ but we cannot know to what extent describing experiential knowledge of disability as a factor in decision making is moral justification or faithful reporting of decision making.³⁷ We would, however, argue that the need for positive self-presentation is not limited to retrospective accounts.

Although some interviews occurred many years after pregnancy, because the purposive sampling method aims to cover diverse experiences, most interviews were within a few years of pregnancy and respondents generally appeared to have vivid recollection of these traumatic decisions.

Some may argue that a condition's severity or visibility is a key factor in antenatal decisions, with termination more likely for more severe or visible conditions.^{6,19,48} We acknowledge this potential influence on decisions, but severity is a subjective perception, and medical and parental assessments of severity may differ. We do not claim that experiential knowledge is the only influence on antenatal decisions, but it can be a powerful influence on perceptions of 'severity' and thus plays a significant role in decision making.

Conclusion

This research has found that experiential knowledge of disability (gained from prior experiences and other people's experiences sought out after antenatal diagnosis) is an important aspect of people's accounts of their decision making following diagnosis of a fetal abnormality, at least for these respondents. The perceived consequences of the abnormality on the life of the child, the family and the parents

can heavily influence parents' decisions. However, experiential knowledge often interacts with other influences, and there is no simple predictive relationship between the nature of a person's experiential knowledge and the decision to continue or end an affected pregnancy. Prospective parents may find it helpful to discuss their existing knowledge of their unborn baby's condition with health professionals who are aware of how this might influence parents' decisions.

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Conflict of interest

None declared.

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