Views of adults with a congenital condition about prenatal tests: cost, quality and value of life in Britain and Finland
Discussion paper followed by reports of interviews with adults with Sickle cell, cystic fibrosis, thalassaemia,

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Abstract

Views of adults with a congenital condition about prenatal tests: cost, quality and value of life in Britain and Finland

Prenatal tests for congenital conditions are offered increasingly commonly. They offer prospective parents the choice of preventing lives which are likely to be of poor quality and to require costly support. We looked for evidence to support these assumptions about the value and cost of life, in semi-structured interviews with 50 adults with a congenital condition. The six conditions involved were thalassaemia, cystic fibrosis, sickle cell, spina bifida, Down's syndrome and, in Finland, diastrophic dysplasia. Interview topics included family and friends, education and employment, pleasures and dissatisfactions, and views on prenatal testing. Far from needing to be dependent, the adults described active rewarding lives, and the many ways they contribute to their families and local communities. They all said that prejudice and pessimistic expectations about their condition were the main barriers preventing them from living life more fully. They would like prenatal counselling to be more accurately informed about the reality of living with a congenital condition. The interviewees are not claimed to be typical; too little social research has yet been conducted to see how representative they might be. However, they raise urgent questions about the need for more realistic and wide-ranging evidence on which to base prenatal screening policies and counselling.

Keywords
prenatal screening, quality of life, thalassaemia, cystic fibrosis, sickle cell, spina bifida, Down's syndrome, diastrophic dysplasia

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Introduction

Prenatal tests and scans for congenital conditions are offered increasingly commonly.(1) Screening policy makers assume that life with a serious congenital condition may be better prevented, and that screening is cost effective when the price per detected pregnancy is compared with the estimated "life time costs of care"(2) or neonatal costs (3) of an affected person. We looked for evidence to support these assumptions about the value and cost of life, in exploratory interviews with 50 people with a congenital condition. They have thalassaemia (Th), cystic fibrosis (CF), sickle cell (SC), spina bifida (SB) or Down's syndrome (DS) and, in Finland, diastrophic dysplasia (DD). Although the views of carriers have been well researched, (4)(5) views on screening held by people with a full condition are less well known. We aim to provide evidence to inform people who plan, provide and use screening services.

Methods

The study was approved, in Britain, by the Institute of Education ethics committee. A leaflet, explaining the project, its topics and aims, and interviewees' rights (such as to refuse to take part in the research, to withdraw, and say "pass" to questions) was sent via intermediaries, mainly self-help organisations, to prospective interviewees with an opt-in reply form. During informal tape-recorded interviews in their homes lasting from 30 to 150 minutes, we asked open questions about their daily life to gain an impression of each person's sense of the value and quality of their life. We avoided pathologising terms (disease and illness, patient, suffering) and used more neutral ones (condition, person, experience). When problems were mentioned, possible social factors such as income or transport were discussed, besides possible physiological factors. Two people (Th and SB) became distressed and one wanted to stop talking (Th) though later she sent some notes. Three people (DS) firmly replied "pass" to some questions, and a few others seemed reticent at times, so that we moved to other topics. Most people appeared to enjoy their session.

Interviewees' responses

Background details about the interviewees are summarised in table 1. Most interviewees had attended mainstream schools. Three people with DS mentioned the names of their schools but not the type. Some single people had lived with former partners so that the number who have experienced relationships is higher than the table implies. The CF group are the most highly educated, five had been to university and two planned to go there but, with the DS group, they are the least likely to be in paid work. One Finnish person has a PhD. All the interviewees are literate, numerate and able to work; the woman with DS worked in an office for 13 years. Employment in all groups covered a wide range: computing, accountancy, administration, teaching, retail, construction, counselling, journalism, sports; those with DS

worked as an artist, actors, a caterer, they taught professionals about real life with DS, and taught people with learning difficulties about independent living and safe sex.

The "x"s in the unpaid work row denote people's contributions as carers for relatives and friends, as parents, and disability activists. Three people were writing books, including a novel about the good aspects of CF. One woman with CF did voluntary work in Argentina, and a man with DS ran a small youth club with his brother. One man with CF gave skilled learning support to disabled people in colleges; like others, he relies on disability benefits to covers his high medication bills, and cannot afford to start paid work on a low salary.

Quality of life links to enjoyments, such as seeing friends and family, travel, eating out, cinema, clubbing, music, shopping, charity work, sports, faith in God, "enjoying nature", reading, writing and painting. When asked about what they find most helpful, they tended to talk about being interdependent rather than dependent. People with Th and DD stressed their independence: "my stubborn father who would not let me get away with anything"; "If I said `I cannot do that', my mother always replied, `yes you can, if you want'." Others found helpful, "my wife/husband/partner/friends," "knowing I'm not the only one with uncertainties," "people who accept me as normal," "my car, my mobile phone and my own flat," "my positive attitude and knowing it's okay to feel happy or sad." The woman with DS said she managed her housekeeping money "except for the big things, my sister helps me with them".

They had varied hopes and plans. Those with DS want to become a champion snooker player, a college art teacher, a family man, and the co-director of a play about the 20 year history of his theatre company for people with learning difficulties. We asked, "Is there anything you would like to change or improve in your life?" Some wanted a better job, income and housing, or to find a partner, or have children. Few mentioned their condition, though some spoke of its effects, "have better lungs", (CF) "be taller", (Th) "have less pain" (SC). Several said they are happy as they are.

They had clear views on changes they would like to see in society. "Where shall I begin?" "Tear it down and start again!" They all spoke about injustice and discrimination, from the man with DS who protested against being pushed about in the street, to the woman with SB who said buildings and buses should be more accessible, to people with SC who found racism, and taunts about being lazy added to their problems when they were too ill to work. Mothers with DD said people would ask them about their children, "Is it a doll you have in your baby carriage?" They all see prejudice against their conditions as very hurtful and wasteful, preventing them from living their lives fully. "There is this sickly child image of CF. If I tell people at parties that I have CF they say, 'Why aren't you dead yet?' How can we get jobs or mortgages or pensions when people have those attitudes?"

We asked for their views on being or becoming a partner and a parent. Some people said they already enjoyed this, or looked forward to doing so. A few referred to their condition, such as the woman who said she was unlikely to get married, "thalassaemia does rule your life because of other people's attitudes." A few said they were very sad not to be married, others preferred

to be independent. One woman said she had more problems with being gay than with having CF, and she hoped to have a woman partner and two children. The most disabled person interviewed hoped to be a mother, and she discussed how taking folic acid preconceptually complicated her strong sense of identity, "I'm proud of having spina bifida." She believed her experience with her condition had greatly increased her compassion and sense of justice, and others said their condition “has made me stronger/more determined/kinder, my friends tell me their problems”. Several women said that if they had children, they would need a very supportive partner because of their poor health, and some were concerned about the strain on their health of childbearing and child care, especially if the child had a condition which needed extra care. The interviewees varied from wanting to have children, to saying "maybe one day", to not wishing to become parents. Some older women with DD felt they had been denied the chance of becoming parents, one had been sterilised, another refused proposed sterilisation.

The discussions led on to prenatal testing, and our question: "If you met a woman who has been told the baby she is expecting has (your condition) what would you say to her?" The replies varied from "I would not advise anyone," to "It's quite easy (laughs) everything, you know, the baby, it's a human being, feed it, look after it, give it lots of love, everything" (DS). The range of interviewees’ views on screening varied widely, as shown in table 2. Some were ambiguous. "Screening is good in one way but in another it's not good because sometimes it makes us think for the worse but in the end it turns out for the best" (SC). The Finnish people’s views on whose interests screening serves varied from “society’s, it is cost-effective”, to “the child’s”, and most people thought that screening primarily serves parents’ interests.

Discussion

We mainly used informal self-help networks for contacting the interviewees, rather than approaching them through health professionals, in order to emphasise the social non-medical nature of the research. We sent leaflets inviting people to take part through intermediaries, using opt-in methods, so that we cannot count the response rates. The interviewees may be unusually confident. Almost everyone talked calmly and openly about potentially painful issues, and introduced sensitive topics before we enquired about them. Whereas medical and psychological research tend to over-emphasise illness, our social research may under-report it. The interviewees are not presented as typical, because no one knows what a typical person with one of these conditions might be like, for reasons given in table 3, or how much their care might cost, for reasons given in table 4.

"Is your life worthwhile, valuable?" "Would you rather not have been born?" are inappropriate questions to ask directly, but they can be approached indirectly through questions about the aspects of life people most value or find hardest. Our descriptive interviews show how people are active, competent and enjoy many aspects of their lives, by discussing the rich detail and variety in their lives, rather than comparing them with arbitrary norms. We also asked about the impact of social and psychological conditions

(education, transport, employment, relationships, opportunities, discrimination) as well as the impact of their inherent condition, on each person's life, and the interviewees frequently pointed out the difference between social and bodily influences in their lives. As one woman said, "CF doesn't do any good, but people with CF do."

Disabled children and adults are now much more included in mainstream society, and share many more of their peers' experiences. The adults in Britain and Finland gave fairly average replies for their whole peer groups. The Thalassaemia group, for example, reflect the closer ties with parents among families of Mediterranean and Asian origin.

These exploratory social research interviews could be followed up with larger groups to see how representative they might be. Our interviews raise more questions than answers. For example, how general is the difference between most replies from the four groups, who tended to favour prenatal information and choice, and the SB and DS groups who tended to be sad, angry or appalled about terminations of pregnancy for their conditions? They all favoured prospective parents being properly informed with accurate unprejudiced knowledge.

All the group believed that their lives were restricted mainly by negative attitudes about their condition, and less by the physical or mental condition itself. Some mentioned seeing other people as more disabled than they felt themselves; some stressed “I’m normal” or said “DD isn’t a disability, but a personal quality”. They all believed that they could live their lives more fully, and in some cases the extra active years they have gained through medical advances (CF, Th), if they were less held back by negative social attitudes. They wanted progress in social knowledge and attitudes, to overcome prejudices. Prenatal screening is intended to reduce costly dependence. Yet, paradoxically, it endorses the discrimination which traps people with a serious congenial condition into unwanted dependence and prevents many from being the active contributors to society they would like to be.

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Table 1. The 50 interviewees

Conditions	thal	CF	sickle cell	spina bifida	Down's	diastrophic dysplasia
Interviewees	10	10	10	5	5	10
men	5	2	6	1	4	2
women	5	8	4	4	1	8
age range	26-39	17-30	21-33	18-33	20-43	22-70
median age		33	24	29	26	30 30
mainstream school	10	9.5	9	4.5	2?	10
special school	-	.5	-	.5	?	-
done college/ courses	6	4	8	3	5	5
university	4	5(7)	2	1	-	3
live with parents	6	3	4	3	2	1
with friend(s)	-	4	1	-	2	-
with partner	1	2	2	.5	.5	5
have children	1	1	3	1	-	4
live on own	3	1	3	1.5	.5	4
have done paid work	10	9	7	4	3	10
now do paid work	9	4	5	4	-	5
student	-	2	1	2	2	2
retired	-	-	-	-	-	3

Table 2. Interviewees' views on prenatal screening, information and choice

Screening

* Screening should be compulsory.
* Screening should be offered to everyone.
* It's too expensive and wasteful to screen everyone - and would anyone have babies?
* Prenatal tests should only be offered to individual people who ask for them if they might be carriers.
* There should not be any prenatal screening or tests.

Information

* The more information the better.
* Most people do not know enough about these conditions to decide what to do about screening results, and nor do most prenatal counsellors and doctors.
* Information about our conditions is too negative and biased.

Choice

* All disabled fetuses should be aborted (no choice).
* Everyone should have the chance to abort a fetus with my condition, and that is what I would do.
* I wouldn't put anyone through what I'm going through, but I'd give people the advantages and disadvantages of everything.
* I would draw the line at severe mental handicaps.
* I agree with abortion for some diseases, but not for my condition.
* I'm angry that abortion is advised for CF or Down's, but I respect everyone's right to choose.
* I'd go ahead and take the risk of having the baby whatever it had, you don't know how bad it will be.
* Screening is good when it helps people to prepare, if their baby will be disabled. They can learn more, and feel they have chosen the baby and that it has not been forced on to them.
* If you're old enough to decide you want the child, you should be old enough to handle the child no matter what disability or ability.
* I would advise them to have the child
* I disagree with abortion for any reason.

Table 3 Reasons for the lack of evidence about the quality of life with a serious congenial condition

* Medical and social case notes, usefully intended to record problems in order to plan treatment, are misread as comprehensive records. Medical notes are usually made when people are ill.
* Medical texts about DS and SB still echo subnormality hospital records, which say more about the effects of being institutionalised than of having these conditions. The texts tend to repeat views about CF which predate recent rapid medical advances.
* Most related research constructs sickness by using terms such as "patient", "suffer" and "disease".
* Psychometric research emphasises anxiety and depression over positive experiences.
* Some interviewees reported that, during medical checks, they felt they were perceived as “a clinical conditions” or “a research guinea pig”.
* Satisfaction in life tends to be correlated with clinical measures of health although among our interviewees it appears to be affected more by attitudes, opportunities and social networks.
* Impersonal standard questions for measuring abnormality, against an arbitrary norm, can intimidate and deter people from talking about the rich variety of their lives.
* Descriptive, social, non-medicalising research with people with serious congenital conditions reporting their own views is seldom published in medical journals.

Table 4 Reasons for the lack of evidence about the cost of life with a serious congenial condition

* Carers and carriers tend to over-emphasise difficulty and dependence in interviews with practitioners, in order to gain more help and benefits for the affected person. They are likely to repeat these negative accounts in research interviews, which are already biased towards over-estimating dependence (see table 3).
* When they are called "patients", people are portrayed as expensive dependents, and their actual or potential contributions as agents tend to be over-looked; inadvertently, language can shape logic.
* Daily problems are attributed to the person's illness or disability, instead of being seen as the possible effects of being poor, unemployed or lacking transport - social problems which could be changed.
* Unemployment and dependence are assumed to be inevitable, rather than the self-fulfilling effects of poor education, low expectations, discrimination and lack of appropriate employment. Recent changes in health care and education show that many people with these conditions are physically and mentally able to do paid work.
* Extra costs to society for medical treatment associated with these conditions could be counterbalanced by the benefits of more affected people having paid work and paying taxes..
* Cost calculations do not allow for the unpaid but highly valued contributions people make.
* Costs calculated on assumptions about dependency or on current employment rates of disabled people do not reflect their possible and optimal employment rates.
* Prenatal testing is like predictive genetic testing; it is uncertain how severely affected the fetus might be, how medical and educational support might improve, or how life chances will affect future capacities and opportunities, so that costs cannot be estimated.

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Living with Sickle Cell
Penny Scott PhD and Priscilla Alderson PhD

This article reports interviews with six men and four women who have sickle cell anaemia. They are aged 21-33 and have all had further or higher education. They enjoy many *activities,* including being with and helping other people, reading, music, dancing and clubbing, cinema and theatre, and sport. Asked about *"what is most helpful in your life?"* every one mentioned family and friends, and four mentioned their faith in God. None saw themselves as victims, though they accepted extra help when they were ill.

They were asked "*Is there anything you would like to change or improve in your life?"* Only two people said "sickle cell", but others talked about changing employers' and society's attitudes towards disabled people. Some would like to stay healthy, have fewer crises, and have more energy, or be more positive - or richer. On *changing society,* six people wanted more positive public attitudes towards sickle cell, and two wanted doctors to know what it is like to *live* with sickle cell. Five people mentioned racism.

Their *future plans* include getting qualifications or a better job, travelling, having a baby, finishing a book, finding a partner, or getting their own home and greater independence. Only one mentioned gaining better health. On *being or becoming a partner,* three are happy in their relationships, the others would like to find the right person, but seemed happy being single. Nobody mentioned sickle cell as an obstacle to a relationship beyond needing someone who understood about the condition. Nearly everyone said that they would appreciate the support of a partner, but only if they could give as much in return. *On being or becoming a parent,* the three parents were very positive, and did not mention any problems from sickle cell. Some others were keen to have children, but two thought that having and possibly passing on sickle cell was a problem. On pre*natal screening,* only one person didn't know about it. Everyone else thought it was important, two said it should be compulsory, and others said it should be optional. Proper information is vital, and some would consider abortion, but most of them saw screening as a way for parents to prepare properly for the coming child.

Comments This group may be unusually positive, although some of them have severe health problems. Even if they are unusual, they are important in giving a broader picture of the value and quality of their daily life. They challenge the social prejudices which, they believe, stop them from living as fully as they could. They helped to pilot socially-based, less medical interviews, to follow up later with larger groups. Views of sickle cell tend to be negative, dominated by medical accounts of illness. Prenatal counsellors may not know anyone with sickle cell, and may give unbalanced information. This research aims to provide a broader view of what it is like to live with sickle cell.

We thank the interviewees, and the European Commission for funding.

Living with cystic fibrosis
Priscilla Alderson PhD

Two men and eight women, aged 17 to 30, who have CF were interviewed as part of a Europe-wide project. The aims were to find out what they think about their daily life, and about prenatal screening. Everyone was interviewed at home and their names have been changed; five have degrees, and two more plan to go to university. Four do paid work, one is at school, another is a mother, the others cannot find work to suit their ability and health needs. Several have done voluntary work, one did so in Chile. Three live with their parents, four live with friends, one lives on his own and two are married.

They mostly enjoy being with friends and/or family, eating out, clubs or parties, and also caring for people, travel, writing, music and sports. Eight people said they value challenges, new experiences, excitement, freedom and independence. When asked what they find most helpful or supportive, some replied they feel inter-dependent rather than dependent on other people. Some replied, “enjoying myself”, “a positive attitude”, and "the benefits of the transplant and all the opportunities that brings,"or "being independent.”

On what they would like to change or improve in their life - if anything - some said they are fairly happy, and others want to change their personality or appearance. No one said “CF.” In society, their overwhelming wish is to change ignorance, intolerance and any discrimination against disabled and disadvantaged people, and negative attitudes toward CF, "the poor helpless crippled child.”

“The media always paint very bad pictures of CF and the text books are depressing. I want it changed."

They also want practical improvements: better benefits, housing, health care funding, work opportunities and transport for disabled people, current policies can "all make disability worse.”

Josie said, "People should know the more about CF, the good and the bad sides. I want to get a pension but they don't include people with CF."

Hopes and plans
Their main hopes and plans include more independence, a good career and relationships, and to write a novel, to be a musician, or to keep being happy. On being or becoming a partner, two said they are already happy as partners, three are "very hopeful and don't see why not", two said "yes but not yet", two said they would be happy either way, on their own or in a relationship. One said "CF wasn't very important when I got into a relationship" but another felt CF prevents her from getting married. One said, "I've had more problems about being gay than about having CF.”

One is a parent and several would like to be, others said "maybe but not yet.” Some women are concerned about the physical demands of pregnancy and parenting.

Jenny said, "Selfishly, I would love to have a child... but I don't think I would be strong enough."

One woman added, “Personally I would not have an abortion whatever condition the baby might have", but three women would consider abortion:

"I would almost certainly terminate if the baby had CF.”

Rob was sad that a doctor casually told him in his late teens that men with CF cannot be biological fathers. "I might meet someone with children, or I might not. Being a favourite uncle is rather like being a parent by proxy, all the positive aspects."

Screening
Everyone supports CF screening of newborn babies, but they have mixed views on prenatal screening. Some said, "the more the better".

Yet Josie said that when she was pregnant, a genetic counsellor came to the house to explain the risks and test her partner. "She wrote on a paper, it will have this and that. I was crying and I ran out. Basically she was saying I shouldn't have it and there was still time to do the tests. I'd like to complain but -."

They are generally cautious about prenatal counselling, "It tends to show the worst case scenario of life with CF."

Lucy said, "Television makes CF sound worse than it is, a child's disease, that's a load of rubbish. I'd give a more optimistic side. I'm not disabled. I'd go ahead and take the risk of having a baby with CF. You don't know how bad it will be, treatment and general knowledge are getting better all the time."

One said, "I'm in favour of information and choice, I would never advise anyone. I'd almost certainly terminate if the baby had CF or Down's or spina bifida."

Yet Diana said, "CF doesn't do any good but people with CF do. I'm angry that people assume abortion is advisable for CF or Down's, but I respect the right of each person to choose in their own case. I'm not sure that many can make informed decisions. The CF Trust could help with promoting a fulfilled-adults image of CF, but it uses the frail child image to bring in funds and support. It's difficult... It's too expensive and wasteful to test everyone, and if these scary policies come about, what kind of world would it be? Would anyone have babies?"

When asked what they might say to a women expecting a baby with CF, although some said they would not advise anyone, others said, "I'd try to give the positive side to redress the balance of negative counselling, and talk about the everydayness of happening to have CF."

Cathy said, "I agree with abortion for social reasons but maybe not for CF. But it is hard, how bad does a disability have to be? I'm not sure what I'd do if I were in that position. Maybe CF I could live with for my child but maybe not a very severe other condition."

Emma is for "freedom of choice, but it's got to be informed choice, with up to date images of CF."

Ben said screening "should be done but then to say I don't think you should" end the pregnancy.

Jenny, who has the least good health, said, "I would advise them to have the child because I would much rather be alive than not. And nowadays treatment is good, 20 years ago maybe I would have said no. A baby now with CF has much better chances than I have. I'm glad my mother never told me until recently about the shorter life expectancy. I don't dwell on death and illness and I just get on with doing what I want to do."

Genetic research

Though generally in favour of genetic research, they mainly said they know little about it and do not expect miracles; they are too used to being told about expected break-throughs "in five years time" which did not appear.

"I hope very much that gene therapy would produce ways to prevent further damage. I don't think it will restore or repair damage, it's not a cure..."

"I'm in favour of any treatment that will help though it will probably not be in time for me."

"I'd like to get rid of physio, but the rest is not too bad. I can cope with it."

Several would take part in research, provided it does not take time from work, and is not too uncomfortable.

"My mum says if it wasn't for people who helped earlier, you wouldn't be here today."

"I'd involve people with CF at every stage of research, from selecting projects onwards."

Researchers and counsellors should be more open and accountable. Nessa agreed to be in a trial but it did not get ethical approval. "It was quite invasive and controversial. But if they had

known more years ago, my two brothers might still be here."

Comments

The interviewees are likely to be unusually confident and positive to have agreed to talk to me. Some have severe health problems, but personality and attitudes seem to have a strong impact on quality of life. A larger study could follow this pilot, to see how typical these replies are. Yet, even if they are unusual, these views challenge the usual gloomy public images about CF. This group strongly feel that they cannot take full advantage of their better health from medical advances, because they are held back by negative social attitudes. They need social rather than medical progress to overcome prejudices which exclude them from worthwhile employment, reasonable income and more comfortable life-styles. They want to be able to say they have CF without strangers asking "so why are you still alive?" Knowing how much discrimination can hurt leads this group to be non-judgemental and tolerant, as they would like other people to be. So they generally respect other people's decisions to end a pregnancy if the fetus has CF. They all want prospective parents to be able to make choices, as long as these are properly informed, by more realistic knowledge about what it is like to live with CF.

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Living with thalassaemia

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Five men and five women who have thalassaemia and are aged 26-39 were interviewed about their daily life, and their views about screening and genetics. The research aims to inform people who plan, provide and use screening services.

Four of the interviewees have degrees and they are all employed except one, mainly in business. Six live with their parents, one is married and one is divorced. They mainly enjoy being with friends, social activities, travel, music and sports.

When asked if they would like to change anything in their life, only one mentioned their health or Thalassaemia. Four are happy as they are, "I've done all the things I want to do," but five want better housing, work, education or income. Asked what they would like to change in society, eight people want to change attitudes, fears, prejudice, and injustice, and to see more tolerance and equality.

In talking about their views on being or becoming a partner, only one women mentioned thalassaemia as very relevant. "I used to think about [marriage] a lot but thalassaemia does rule your life because of other people's attitudes."The others tend to think, "thalassaemia wouldn't create difficulties, if you're clear from the start and form a trust". Several hope to have a partner; one said, "I think about getting married sometimes, I get lonely" - like many people without thalassaemia.

They were asked about being or becoming a parent. The one parent said, "It's the best thing that's happened to me," but the others mainly expressed ambiguity, or reluctance; "It's too big

a responsibility." Only two discussed parenthood in relation to thalassaemia. One said, "Only under certain conditions will a Thalassaemia be born, so it doesn't worry me", and one woman said, "I'd have to be 100% certain that my partner will be able to look after the child."

Little interest was expressed in genetic research, which was seen as remote, complicated, belonging to the future, and of limited benefit. They said they knew little or nothing about it.

When asked about parental screening, one woman stated a strong view on not having a child with thalassaemia: "I wouldn't put anyone through what I'm going through, but I'd give people the advantages and disadvantages of everything, screening should be done". They all thought that screening is important, some said it should be compulsory. Yet they all stressed the importance of choice, and having proper information, which they do not feel always happens. "Often people only see the counsellor's point of view and that's not enough." They tend to feel that if couples decide to have affected children, it better for them to know and to choose during pregnancy than to feel that the baby had been "imposed" on them.

This group is probably unusually positive, to have agreed to be interviewed. Yet even if they are unusual, their positive views about their lives challenge general assumptions that life with Thalassaemia is better prevented. However, they believe that they could benefit more from the extra active years they have gained through medical advances, if they were less held back by negative social attitudes.

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