Decision making about reproduction and pregnancy by women with cystic fibrosis

With significant improvements in longevity, women with cystic fibrosis are increasingly likely to consider pregnancy and parenthood. This article reviews the literature relating to medical and psychosocial research that informs the decision-making process these women undertake.

Women with chronic illnesses considering pregnancy have many physical and psychosocial issues to consider including the impact of a pregnancy on their health, the effect of their condition on the child, the effect of having a child on their lifestyles, their ability to balance child-care with their condition, and the impact on their families who may have to provide much of the care either for the child, the mother or both. Cystic fibrosis teams need to ensure that women with cystic fibrosis have enough information to make informed choices and to facilitate, without being seen to intrude, discussion around personal and non-medical decisions.

Cystic fibrosis

Advances in the management of cystic fibrosis have resulted in major improvements in longevity and quality of life. Cystic fibrosis is now considered a life-limiting disease of adulthood rather than a lethal disease of childhood, and those born after 2000 are expected to live into their fifties, even in the absence of effective therapies to correct the underlying genetic defect (Dodge et al, 2007). However, improved longevity is accompanied by increasingly challenging and time-consuming treatment regimens, including oral and inhaled medications and physical therapies to prevent decline, and aggressive and often invasive treatments for acute deterioration.

Over half the patients registered on the UK cystic fibrosis database are over 16 years of age (Cystic Fibrosis Trust, 2007). Unlike their healthy peers, they are continually faced with the reality of an advancing disease, its complications and treatment, including recurrent infections and their complications, diabetes, liver disease and osteoporosis. Perhaps surprisingly, psychological and psychosocial functioning of patients with cystic fibrosis cannot be distinguished from that of healthy controls until the disease becomes severe (Pfeffer et al, 2003).

Although cystic fibrosis remains a life-limiting condition, the desire for a 'normal life' can be balanced with managing chronic ill health. People with cystic fibrosis are as likely as their healthy peers to be considering starting a family, with identical numbers in sexual relationships (Fair et al, 2000). They do not differ from their healthy peers in sexual knowledge, attitudes and behaviour (Cromer et al, 1990). The literature highlights several concerns women with cystic fibrosis may have about sexual intimacy and establishing long-term relationships, including body image, physical obstacles to intercourse (breathlessness, coughing up sputum, urinary incontinence), concerns about heredity, and fear of dying before any children grow older (Pfeffer et al, 2003). Despite some women feeling a responsibility to raise these issues early with partners, many do form lasting relationships and go on to consider childbearing. However, it cannot be assumed that all women plan for pregnancy by weighing up medical information and making active reproductive decisions.

Sexual and reproductive behaviour

In the general population, 40–50% of pregnancies are unintended, often occurring without prior consultation with a health professional, planning, consideration of pertinent social issues or practical support (Adams et al, 1993). The sexual behaviour of adolescents with chronic disease may be no different to that of their healthy peers. Although sexual behaviour may vary according to disease type, girls with chronic conditions may be more sexually active as they try to 'fit in'. Janz et al (1995) reported that that in their sample of women with established diabetes, only 24% sought preconception care, and those that did were more likely to be married, living with partners, employed and have a higher level of education and income compared to those whose pregnancies were unplanned. It is likely that women with cystic fibrosis do

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not differ significantly from this pattern and, for reasons not yet understood, may be less likely to use contraception than matched controls (Sawyer et al, 1995).

Conception and fertility

The literature on female reproduction in cystic fibrosis has steadily increased since the first recorded successful pregnancy in 1960 (Siegel and Siegel, 1960). Initially it was generally accepted that fertility may be diminished by up to 80% (Kopito et al, 1973). However, more recent reviews indicate that fertility approaches that of women who do not have cystic fibrosis (Tonelli and Aitken, 2007) so contraception is as important for women with cystic fibrosis as for any other woman. Women who became pregnant were less likely to have poor respiratory health or be homozygous for the DF508 genotype and had a significantly earlier median age at diagnosis (Boyd et al, 2004).

A spontaneous pregnancy rate of 85% in Norway and Sweden has been reported in women with cystic fibrosis who wanted to become pregnant and it is estimated that this is in keeping with cystic fibrosis populations in other developed countries (Odegaard et al, 1999). In 2004, nearly 6% of women with cystic fibrosis in the UK became pregnant, with good outcomes in approximately three-quarters of cases (Boyd et al, 2004). Despite potential health issues, many women with cystic fibrosis see motherhood as a natural outcome. One third stated that they would be ‘angry’ if a health professional challenged whether they should have a child or not (Fair et al, 2000).

Once the decision to attempt to conceive has been taken, healthy women report being excited and happy, but also anxious, at the prospect of pregnancy and child-rearing. Fears of abnormality and miscarriage are common (Chalmers and Meyer, 1992). In cases of unplanned pregnancy, the issues centre upon feelings of commitment, responsibility and whether or not the woman is in a relationship (Lydon et al, 1996). However, most psychological studies of pregnancy have excluded women with chronic illness to avoid confounding factors, so little information on their experience is available.

Knowledge about reproductive and pregnancy issues

Decisions about conception and childbearing by women with cystic fibrosis and their partners are often based upon incomplete or misunderstood information (Yankaskas and Fernald, 1999). Sawyer et al (1995) assessed the reproductive health knowledge of 55 women with cystic fibrosis. Many planned to become pregnant in the near future and 22% had tried to conceive with a success rate of 67%. Only 15% correctly estimated the risk of having a child with cystic fibrosis. Poor knowledge of potentially deleterious effects of pregnancy was demonstrated. Two per cent thought pregnancy might improve lung function, while 34% did not know whether lung function would be affected.

Women with cystic fibrosis also acknowledge feelings of denial, anger and grief about pregnancy (Johannesson et al, 1998). Many lack information about the implications of pregnancy, while some may actively avoid acquiring knowledge as a coping strategy, for fear of being dissuaded from conception and parenthood (Conway et al, 1994) or as a way of normalizing the experience of pregnancy (Simcox et al, 2009).

Reproductive decision-making

Extensive reviews show that the main factors for women considering pregnancy are health risks, genetic risks to offspring, the psychosocial wellbeing of their unaffected partner, and the financial and child-care responsibilities associated with impaired health and shortened life expectancy (Gotz and Gotz, 2001). Interestingly, the death of a sibling from cystic fibrosis did not adversely affect attitudes to reproduction (Conway et al, 1994).

A recent qualitative study supports these findings (Simcox et al, 2009), highlighting four variables in the decision-making process for women with cystic fibrosis: the impact of the decision, preparation for making and living with the decision, owning the decision, and intrapersonal dilemmas (when people make choices that are in the best interest of themselves at the moment of choice, but not in the best interest of themselves in the long run; Read and Roelofsma, 1999). The main influences on decision making were the impact of pregnancy on the participants’ health and on their ability to care for the child, the pregnancy experiences of other women with cystic fibrosis, the moral implications of having a child, and the support and beliefs of family members.

These results concur with findings from studies of women with other diseases (Smeltzer, 2002). Referral to an obstetric medicine specialist to further discuss aspects of pregnancy, the effects of medications and potential obstetric management may be useful at this point in the decision-making process. This would only add to women receiving as much information as possible that will inform their decisions.

The genetics of motherhood

All infants born to mothers with cystic fibrosis will be carriers of a cystic fibrosis transmembrane conductance regulator abnormality but the risk of the child having cystic fibrosis depends on her partner. If the partner’s genetics are unknown the risk is 1:50, if he is found to be a carrier the risk is 1:2 but if he tests negative the risk is reduced to ~1:500 (based on UK prevalence and testing protocols). This raises another major issue for women with cystic fibrosis who potentially may be faced with the decision whether or not to terminate a fetus with cystic fibrosis (abort a life perhaps like their own) or let the pregnancy continue knowing the child will have cystic fibrosis. The advantage of knowing the partner’s genetics in advance is that this can be discussed, and also pre-implantation genetic diagnosis can allow a healthy embryo to be implanted. Studies of these aspects of decision making are almost non-existent, being beset with ethical and moral methodological complications. It has been recommended that women are seen in the pre-conceptual phase to fully discuss the issues, with full involvement of the partner and provision of paternal screening and counselling (Sueblinvong and Whittaker, 2007). The emphasis needs to be on helping women and their partners to make an informed choice, although currently this ideal is often not achieved.

Medical issues

Women with cystic fibrosis attempting to become pregnant are advised to optimize their health and have their medication reviewed before trying to conceive. They are forewarned of the likelihood that they may need more treatment, have more complications with their cystic fibrosis and that this may impact on their pregnancy (Tonelli and Aitken, 2007). Furthermore, they are alerted to the possibility that physiological changes during pregnancy may exacerbate symptoms, e.g. hormonally-driven breathlessness in the first trimester, mechanical breathlessness later in pregnancy, or exaggerated problems with maintaining or gaining weight.

Being underweight can affect fertility (Goldberg, 2002) and the additional stress factors associated with cystic fibrosis attach importance to achieving good pre-conceptual nutritional status. Healthy eating recommendations aimed at the general population may be inappropriate for women with cystic fibrosis, with a high fat diet and pancreatic enzyme replacement usually being advised together with education on the use of oral nutritional supplements or enteral tube-feeding.

Near normal pre-pregnancy lung function (i.e. forced expiratory volume in 1 second (FEV_1) >80%) is associated with a favourable outcome but maternal survival may be poor when pre-pregnancy FEV_1 is <60% predicted (Edenborough et al, 2000). Gillet et al (2002) found that three women who died within a year post-partum had an FEV_1 <50% before pregnancy, a level widely regarded as a contraindication to pregnancy, confirming the findings of Edenborough et al (2000). Women who delivered at full-term began their pregnancy with a higher FEV_1 than those who delivered pre-term (Edenborough et al, 2000; Gillet et al, 2002).

Some studies have suggested that pregnancy may not adversely affect the mother when compared to a non-pregnant woman with cystic fibrosis of similar disease severity, even in advanced disease (Goss et al, 2003). Experience from other studies suggests that some women may do unexpectedly badly during pregnancy and this is more likely if the mother has more advanced disease (Edenborough et al, 2000). The Gillet study compared 90 pregnancies in women with cystic fibrosis matched for age and genotype with non-pregnant cystic fibrosis female controls, and found no significant difference in pulmonary function during pregnancy. However, the pregnant group appeared to lose more lung function and weight than the control group in the year following pregnancy.

There are few absolute contraindications to pregnancy in cystic fibrosis (pulmonary hypertension and cor pulmonale) but relative contraindications associated with poor prognosis for both mother and baby include FEV_1 <60%, body mass index <18 kg/m^2, unstable disease and infection with *Burkholderia cenocepacia* (genomovar III).

It is outwith the scope of this review to discuss the management of pregnancy in detail (Edenborough et al, 2008). However, great attention to the detail of care is needed, requiring flexibility of the cystic fibrosis team and patient without inducing anxiety. It is also important that care should be managed by both the cystic fibrosis team and an obstetric medicine specialist. Drug and inhaled therapy regimens will need to be reviewed, physiotherapy techniques modified as pregnancy advances and pelvic floor exercises introduced. Dietary intake must be maximized while being watchful for hyperglycaemia, reflux and constipation. Complications of cystic fibrosis must be treated aggressively, remembering that the unborn child is much more likely to come to harm from the mother's ill health than from, for example, antibiotics used to treat infection.

It is particularly important that the cystic fibrosis team liaise with the midwives, obstetrician and an obstetric anaesthetist used to high-risk pregnancies at an early stage to optimize outcomes for mother and baby. The risk of prematurity and with it the risk to the baby increases as lung function and maternal health decreases, and decisions around early delivery are usually made for the mother's sake rather than for the baby per se. In addition to answering questions and alleviating anxiety, close liaison between cystic fibrosis and obstetric colleagues reduces the risk of misinformation or contradiction and may reduce duplication of tests and numbers of outpatient visits. If possible, one or two obstetricians could be identified to whom all referrals are initially made.

Specific medical problems encountered in pregnancy include gestational diabetes, increased risk of vulvovaginal candidiasis, hyperemesis, reflux and constipation, urinary incontinence, and ligamental laxity and pain. Unsurprisingly outpatient clinic attendances are 33% more frequent during pregnancy (McMullen et al, 2006). Pregnant women with cystic fibrosis who are also diabetic will need yet further involvement from relevant obstetric and diabetes specialists. Here dietetic management is of supreme importance, with further consideration of the nutritional intervention required to maintain adequate maternal weight.

The timing and method of delivery must also be discussed. The risk of prematurity for the baby and the risk of instrumental or caesarean delivery, either planned or as an emergency, increases in women with more advanced disease or who are less well, and the decisions are usually necessitated by concerns for the mother's safety rather than that of the child. They may need to discuss obstetric risks including early or assisted delivery. It may even be beneficial to 'plan' for an emergency delivery with an obstetrician and consider analgesia and anaesthesia according to the state of her chest.

Breast-feeding is encouraged in cystic fibrosis as in all pregnancies, but mothers should be individually assessed and advised, taking into consideration their preferences, and in particular their ability to maintain the nutritional demand. A compromise with some breast-feeding and some bottle-feeding may need to be reached and may be the ideal for mother and baby. Counselling should be ongoing throughout pregnancy, with an emphasis on helping make informed choices.

Post-partum care

Post-partum and beyond, the physical and emotional demands of caring for a child may have adverse effects on the ability of the mother to care for herself leading to potentially negative consequences for her health. Certainly, the perceptions of women with cystic fibrosis about raising a child are clouded by worries that their participation in this may be limited (Lemke, 1992). However, a survey of the experiences of both female and male parents with cystic fibrosis reports that they do not see themselves as differing from healthy parents, expressing little worry that their illness affects their child or their parenting ability (Frankl and Hjelte, 2004).

While there may be negative social, emotional and behavioural consequences for the child of a chronically ill mother as a result of the effect of the mother's ill-health and possible early death, these issues have yet to be adequately explored in cystic fibrosis populations. Evidence from non-cystic fibrosis samples suggests children can be unaffected and may even benefit from increased emotional 'closeness' within the family (Mukherjee et al, 2002).

Practical psychotherapeutic implications

There is a firm suggestion that women with cystic fibrosis have wide-ranging concerns about the effect of pregnancy on their health, the effect of their health on the baby, relationships and self-care, in addition to possible moral dilemmas about what is best for their child and ideals about how they want to live their lives. As such, although at times this may be unsolicited or even unwanted, there is an obligation for cystic fibrosis teams to at least attempt to provide education and support.

Enabling informed decision making

Medical teams need to carefully consider the way this issue is handled to avoid lack of clarity. Information should be provided at puberty with cystic fibrosis doctors taking the initiative while being sensitive towards the needs of each patient. Women with cystic fibrosis place significant emphasis on the experiences of others when considering pregnancy (Simcox et al, 2009). It may be helpful for health professionals to collaborate on internet discussion forums for girls and young women with cystic fibrosis to share experiences. Psycho-education needs to begin in adolescence and continue throughout adulthood to assist, encourage and support proactive decision making as the epidemiology of the disease changes. Cystic fibrosis centres should develop policies to ensure this is dealt with appropriately and sensitively and that information is upgraded regularly.

Avoiding staff–patient conflict

Sometimes cystic fibrosis teams and patients come into conflict over decisions about conception and pregnancy; the team acting in the physical best interest of their patient, and women exercising their rights to fulfil their personal goals. It remains difficult to determine prospectively which women will tolerate pregnancy well but problems are likely and cystic fibrosis teams may be faced with strongly advising women against pregnancy for medical reasons and find themselves in potential conflict with a woman who desperately wants a child. Steps can be taken to prevent this by defining a therapeutic alliance early, exchanging information and maintaining open dialogue and deliberation. Discussion of alternative options is important if there are strong medical contra-indicators (Wexler et al, 2007).

Decision-making aids

Health-decision aids are designed to facilitate shared decision making by helping patients and their health carers choose between reasonable clinical options. Systematic review of the impact of such tools in health settings indicates that their use makes no difference to outcome but can aid the process of decision making by ensuring informed choice and minimizing conflict (O'Conner et al, 2003). Patients making decisions under uncertainty base their beliefs upon accumulated facts and emotions, which may be subject to individual bias and distortion. Fear and recent loss or gain also play a powerful role. Good decisions need to be well informed, compatible with patient values, practical and not reached by the patient in isolation. A strategy to ensure these conditions are met currently seems elusive.

Conclusions

Women with cystic fibrosis are increasingly viewing conception, pregnancy and parenting as desirable and realistic goals. Their decision making, while based in the deepest personal ethos and social circumstances, also needs to be influenced by their ongoing health-care needs. In trying to maximize health and minimize intrusion, complex dilemmas arise for cystic fibrosis teams attempting to provide psycho-education and support for women with cystic fibrosis, and their partners and families. While considered assumptions about their reproductive psychosocial concerns are made, health carers need to respect patients' right to choose and to be diplomatic in their role while simultaneously helping individuals maximize their quality of life.

Future endeavour needs to focus on aspects of making and living with decisions, using larger samples across ages and levels of functioning. Current information about pregnancy can lead to confusion and alienation so methods of information giving should be assessed, including the best time and way to begin the process. As concerns about the future are particularly salient to women with cystic fibrosis, prospective studies are required focussing on the impact of motherhood on self-care and the potential psychological and developmental implications for the child of parents with cystic fibrosis. **BJHM**

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KEY POINTS

- Women with cystic fibrosis are increasingly likely to consider pregnancy and parenthood.
- Their views on sexual intimacy and reproduction do not differ from their health peers and it is likely that only a small percentage will consider pre-conception care and discuss medical management with their health carers.
- Main influences on decision-making are the impact of the pregnancy on their health, their ability to care for the child, the pregnancy experiences of other women with cystic fibrosis, the moral implications of having a child and the support and views of their family.
- Whilst near-normal lung functioning is associated with favourable outcomes, there are a range of risk factors and contra-indicators that necessitate comprehensive medical management by the cystic fibrosis team and close liaison with obstetricians.
- Cystic fibrosis teams need to balance the need to be respectful of individuals' rights to choose with diplomatically helping women maximize their health outcomes and quality of life.