



Experiences of cancer-related fertility concerns among people of South Asian and White origin

Introduction

This is a summary of our research exploring the personal impact of cancer treatment on fertility, within the context of a **multi-cultural society**. We talked to 47 men and women from White (n=26) and South Asian (n=21) backgrounds, aged between 18 and 40 years old, who had different types of cancer. We also spoke to a few partners who were keen to be involved.

We asked about their experiences of the long term (social and emotional) impacts of treatment and any specific issues related to fertility that they might have encountered. We were especially interested in how people made decisions about their treatment and how they felt these decisions might impact on their fertility. We also asked them about the kind of information and support they received from health and social care professionals and the role played by family and friends.

In addition, we spoke to various professionals involved in cancer and fertility services, in groups and individually. This helped us explore their views on taking care of younger people affected by cancer and how they respond to patients from minority ethnic backgrounds. It also enabled us to understand how different services and sectors work in relation to each other

The main aims of our research were to compare the experiences of younger men and women from different ethnic backgrounds; identify gaps in service provision; and make

some recommendations to address these gaps. This summary offers highlights from our findings. To help illustrate some points, we have used quotations from the people we spoke to. These are in italics. If you would like more information, the full report can be downloaded from the web address listed at the end.

Being diagnosed and having treatment

Most participants felt that they had received efficient and timely medical care. However, a few believed their GPs had not taken the severity of their complaints seriously. This might have been due to their young age. One of our participants said that getting her GP to refer her for investigations was like 'squeezing blood out of a stone':

I went four times with such excruciating pain and I begged them, and they forwarded me. So I'd urge GPs to try and listen to their patients. I mean, we're not just saying it for the hell of it.

The potential risk to fertility caused by a particular cancer treatment is usually discussed during initial consultations about diagnosis. Doctors, however, cannot be certain about risks and are not able to give definite answers to individual patients. Some participants found it difficult to understand why they were not given more definite information. Others on the other hand found the uncertainty comforting, allowing 'a window of hope to remain open' and the possibility that 'things might turn out all right'.

Professionals relied on ethnicity-based explanations when talking about South Asian or other minority groups. Inappropriate stereotypes could therefore emerge, leading to some professionals interpreting similar responses very differently according to the ethnic background of the patient.

Facing a risk to fertility is different for men and women. Most men were able to preserve a sample of sperm, irrespective of their ethnic or religious background; contrary to the assumptions of some professionals about religious proscriptions for certain groups, especially Muslims.

Most men were aware of the possibility of a 'fertility test' but did not necessarily want to have one until they were in a stable relationship or thinking of settling down and having children. Professionals working within oncology often supported this decision, recognising the importance of hope in helping people move on and deal with their illness.

Many women did not have a choice to preserve eggs, embryos or ovarian tissue. This was due to the technical difficulties of the procedures and the time involved (four to six weeks), which could potentially delay a start of treatment.

Retrospectively, women who faced problems in conceiving naturally felt that they had not been given enough information or opportunity to discuss the matter with a specialist. As observed by one of the participants:

I do understand that my fertility wasn't the priority of a single doctor in the hospital. Their priority obviously is getting me better. But I just always felt that as a young woman, someone maybe should have recognised that and been able to talk me through at least over a longer period of day, rather than being dropped on me like a bombshell.

Preservation of gametes (sperm, eggs, embryos) throws up many personal and ethical issues. Younger people in particular are forced to reckon with profound issues such as the meaning of procreation, kinship and death.

The process of consent for preservation involves a redefinition of what might have been up until now, a transitory relationship to one with a commitment to raising children together.

Professionals are aware of the dynamics of the changing nature of interpersonal relationships. They, however, struggle to resolve various ethical issues about preserving and using gametes when someone is terminally ill, or not likely to survive and be able to use their own stored gametes.

Long term care and psychosocial support

Most men and women felt that, unless raised by them, fertility had not been discussed during follow-up consultations. Even when women were asked whether their periods had resumed, they often did not make the link with fertility, seeing it more as a general question about the temporary side effects of the treatment. Some would have liked health care professionals to be more explicit about the issue of fertility, following treatment.

Further, clinicians advise their patients to use contraception and avoid having children or conceiving for three to five years following treatment; a mile stone for achieving remission or cure. Such advice often sends conflicting messages to individuals about their fertility.

One woman who was prescribed hormonal treatment for premature menopause was still advised to use a contraceptive by the chemist, resulting in anxieties about getting pregnant,

mixed with a ray of hope that she might still be able to have children.

In addition, waiting for three to five years following treatment may not fit easily with the life plan of many who wish to have a child.

Individuals often negotiate a 'safe period' for having children, with or without the approval of clinicians. Most couples, for example, wait for a year to let the effects of chemotherapy 'flush out' of their system. One couple had planned on having their second child around the time the husband was diagnosed. His wife remarked:

I've waited the year, in that sense, if his cancer did come back, there's nothing I can do about it. But we can't stop living our lives... And I said, well, I am not going to live my life thinking what if. If it does happen we will deal with it, if it doesn't we get on with it.

Even though the husband in the above case took recourse to his Muslim faith to help him deal with the dilemma, his belief in 'what will be will be' (fate) did not preclude him from preserving a sperm sample before starting treatment or undergoing a fertility test to find out whether or not he was fertile.

Participants across different ethnic groups who had a faith, took recourse to religion in helping them make a right moral choice, and seek meaning in hardship. Religious teachings did not necessarily predefine their actions related to treatment. As observed by a man of Catholic faith who was contemplating using a sperm donor and was upset by the Pope's views:

It's just wound me up, about the Pope and what he's been saying about assisted conception, and the people who do that are sort of completely wrong and immoral. And I think that has sort of shook my faith quite a lot.

Participants from different ethnic backgrounds faced different social and cultural pressures. These can be broadly defined as 'pronatalist', reinforcing a need to have children; for example, the idealised view of a large Irish family, or the traditional values held by some South Asian families about having sons.

However, the association of womanhood with motherhood cut across cultural backgrounds. And many men – irrespective of their ethnic origin – found the prospect of infertility threatening to their manhood. Similarly grandparents' desire to have grandchildren is found in all ethnic and cultural groupings.

Despite these wider pressures, the threat to fertility was interpreted and experienced differently, when considered alongside a serious illness such as cancer. The complexity of reflecting on the meaning of cancer, while coming to terms with the risk of being childless implicated a need for highly specialised and trained health and social care professionals who can provide appropriate support to people in different cultural (and religious) settings.

Referrals to a generic professional, such as a counsellor or clinical psychologist, can at times be counter-productive. One of our participants who visited a counsellor because she was struggling with the prospect of not being able to have children said:

I started to get a bit tearful and said, 'I'm really concerned that I won't be able to have children.' And she didn't address it at all, just kind of skipped it and finished the session, and I just thought, 'Well, actually if we're not going to address the one issue I'm struggling with, I'm not going to (go back).'

We found that support and advice about education and employment need to be a part of support for long term care. Often the long-

term physical and psychological side effects of treatment are exacerbated by loss of work or educational opportunities. Employers and educational institutions may not recognise the non-visible signs of illness beyond treatment.

Participants whose education or employment had been disrupted following treatment, often struggled to find advice regarding benefits and financial help. It is important to offer financial advice regarding benefits irrespective of prognosis.

Recommendations

Patients of all ethnicities should be offered an opportunity to consult a specialist in reproductive medicine before starting cancer treatment. It is especially important to avoid partial or rushed advice when discussing options for preservation of gametes with women, given the additional complexity of such processes and potential outcomes. More openness about the possible options and their likely outcomes would also be appreciated by patients.

All patients, including those where the need for treatment is too urgent to allow cryopreservation options to be considered, should be offered an early opportunity to discuss fertility matters again once cancer treatment is underway.

It is important to incorporate discussions of fertility routinely in long term follow up care, taking care to use plain language and to involve specialist therapeutic/psycho-social support services as necessary.

Another useful strategy would be to incorporate advice on financial assistance/benefits into the discharge and

follow up routine, irrespective of the prognosis or severity of illness.

Better coordination and communication between primary and secondary/tertiary care during and following treatment, including in relation to fertility, would improve continuity of care and offer better signposting for a range of support and advice not included in routine care.

Professionals need to have greater confidence in responding to situations without relying on 'fact-files' or generalisations about the cultural practices of minority ethnic groups. Incorporating attention to reflective/reflexive processes in professional training and support is called for. Engaging with cultural, religious and ethnic diversity and challenging stereotypes is an important step forward and helps empower professionals to raise meaningful questions within the context of providing care to an ethnically diverse population.

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This is a summary of a CRUK funded research project, 'The experience of cancer-related fertility impairment among people of South Asian and White Origin' (C8351/A9005). Other summaries (including one aimed at professionals) and information about the research, along with details from a conference organised to disseminate our findings can be found at <http://www.york.ac.uk/healthsciences/research-information/conference-cancer-survivorship/>.

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