



Experiences of cancer-related fertility concerns among people of South Asian and White origin: Summary for professionals

Introduction

This is a summary of a qualitative research project that explored the personal impact of cancer treatment on fertility, within the context of a **multi-cultural society**.

Survival rates are improving, leaving increasing numbers living with the long term consequences of cancer treatments. Actual or potential fertility impairment can be one of those consequences and can, for some, affect recovery and well-being. Professionals, however, struggle to offer appropriate support.

We interviewed 47 men and women from White (n=26) and South Asian (n=21) backgrounds, aged between 18 and 40 years old, who had lymphoma, sarcoma, testicular or breast cancers. We were especially interested in how participants made decisions about their treatment in the light of its potential impact on their fertility, what kind of information and support they received over time from health and social care professionals and the role played by family and friends.

By recruiting a culturally diverse sample, we hoped to explore when **ethnicity** made a difference to people's experience and when it did not.

We also conducted focus group discussions and interviews with professionals involved in cancer and fertility services. These included doctors,

nurses, social workers, scientists, psychologists, counsellors, youth workers, commissioners and representatives from third sector organisations (n=33).

Our discussions with professionals helped us explore their views on taking care of people affected by cancer and, more specifically, their responses and experiences of offering care to patients from minority ethnic backgrounds. These conversations also enabled us to understand how different services and sectors work in relation to each other.

Diagnosis, treatment and follow-up

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 patients found it difficult to understand why they were not given more definite information and were troubled. Others on the other hand found that the uncertainty afforded them hope.

Some professionals did not engage with the long term social and emotional consequences of infertility, seeing it instead as a physical state with little meaning beyond the capacity to reproduce. This led to missed opportunities for revisiting information,

discussing coping strategies and/or offering psycho-social interventions.

Referrals to generic rather than specialist therapeutic or other psycho-social services could on occasion prove counter productive. One of our participants who was struggling with the prospect of not being able to have children felt her concerns were not addressed, as the counsellor chose instead to focus on her experiences of having cancer.

What did the professionals see as key influences?

Overall, professionals saw **gender, age or life course** as having more influence on people's experiences than **ethnicity, culture or religion**. Those at the younger end, for example, were perceived to be less affected unless in 'serious' relationships or actively considering parenthood. Women undergoing treatment when close to menopause were seen as especially vulnerable to distress.

Women, in general, were thought to face a greater emotional burden when dealing with potential threats to fertility. Professionals explained this in three ways: motherhood was seen as an intrinsic part of their identity; the limited options for women to store gametes/embryos; and the potential for premature menopause. Some had known women (but no men) refusing cancer treatment as a result.

Oncologists emphasised the need to prioritise and start treatment. While appreciating professionals' concerns, some women we spoke to felt that they had not been given enough time or information at this stage. They would also have valued the opportunity to discuss their options of preservation with a specialist, even knowing their choices might be limited.

This would, they believe, have enhanced their present and future abilities to cope.

Professionals only called on **ethnicity-based explanations** when talking about South Asian or other minority groups, often assuming their homogeneity *and* conflating ethnicity, culture and religion. Inappropriate stereotypes could therefore emerge, leading to some professionals interpreting similar responses very differently according to the ethnic background of the patient.

While acknowledging that some professionals took a more nuanced view - engaging with the complexity of individuals' experiences in which religion, culture or ethnic origin *may* play their part - we provide a summary of the most common stereotypes.

Some professionals perceived 'South Asian' men as having particular difficulties with masturbation when banking sperm, because of assumed religious prohibitions within Islam. None of the Muslim men we interviewed supported this view. It was seen by them as a medical procedure related to a serious condition. Like other men interviewed - irrespective of ethnicity - it nevertheless generated unease and embarrassment.

While professionals recognised parents' desires to accompany their adult children to consultations, the involvement of South Asian parents/fathers was, at times, seen as controlling, intrusive and driven by concerns about 'arranged marriages', whereas that of 'white' parents was more often seen as reflecting their struggle to detach from the intensity of the shared cancer experience.

Similarly, some professionals associated South Asian cultures with a 'pronatalist bias' and strong patriarchal values and saw this as explaining relationship breakdown for couples facing fertility problems. In contrast, breakdown of 'white' couple relationships was seen to result from emotional strain.

Another tension occurred around the supposed 'culture of silence' which professionals identified exclusively with South Asian patients. Among our participants – again irrespective of ethnicity - not sharing fertility-related information beyond a close circle of friends and family reflected a wish for privacy.

This is not to deny that for some patients of South Asian origin, the relationship between self, close/extended family and wider community might operate differently. However, our research highlights more shared experiences of a serious illness and its repercussions than differences across ethnic groups.

What did patients see as key influences?
Not surprisingly, patients talked of the biographical disruption caused by cancer permeating many aspects of their lives and recovery. Uncertainty as to whether fertility had been damaged was a major issue for some and could add to, or supersede, uncertainties attached to the cancer experience alone. For others, it carried relatively little significance.

Gender influenced the emotional and physical consequences of potential infertility, especially within the context of options for preservation and its long term ramifications. However it was also clear that self worth, personal relationships and life planning of both women *and* men could be significantly affected.

Effects could be invisible to others and could differ across time and place, often related to changing life circumstances. This results in a need for different kinds of information and support at different times.

Culture and religion – irrespective of ethnic background – can provide shared frameworks for engaging with illness, treatment and its aftermath. For some who followed a religion, illness assumed meaning and purpose and religious teachings offered guidance. However, where guidance ran counter to personal inclinations – for example, in relation to assisted conception treatments – some patients accepted it, while others sought their own religious interpretation, sometimes in discussion with those close to them.

Religious values usually had enough flexibility to enable this. Professional generalisations about religious 'communities', therefore, need to be used with insight.

Finding a way forward for individuals also extended to negotiating 'cultural expectations' around fertility and reproduction according to gender, age, class and so on rather than ethnicity and religion alone.

Religion and culture are not the preserve of 'Asian' communities either. Professional accounts could also rely on cultural assumptions too. This is why some professionals found it hard to disentangle their personal value judgements (as part of their wider cultural frameworks) from professional assessments in addressing ethical dilemmas (also see below).

Consequently, the complexity of reflecting on the meaning of cancer, while coming to terms with the risk of being childless implicated a need for highly reflective and specialised trained health and social care professionals who can provide appropriate support to people in different cultural (and religious) settings.

Professional encounters with ethical dilemmas

Professionals in the field of oncology and reproductive medicine encounter various ethical issues. These include whether people receiving palliative care should be helped to become parents; posthumous use of stored gametes; and the use of gamete donation across the ethnic divide.

Professionals did not appear to draw much on research evidence or formal ethical decision-making frameworks. Instead, they tended to be influenced by personal beliefs and what they thought they might do if faced with a similar situation.

Sometimes professionals' moral or emotional uncertainties were lowered when specialist counsellors had been involved. They felt counselling 'wheeded out' 'unsuitable' people or otherwise led them to feel less morally responsible for the outcome of their own part in the intervention.

What needs to get better?

On the whole, professionals thought that they had got better at dealing with fertility matters at diagnosis and during treatment but believed they had a long way to go to match this standard when offering longer term follow-up.

Even so, some professionals guarded their right to exercise discretion in talking about

fertility *prior* to cancer treatment. Sometimes this was prompted by protectiveness about 'troubling' patients with such matters or by moral beliefs as to whether someone with a poor prognosis had a 'right' to parenthood. Following treatment, some considered it better to avoid offering fertility tests until a person was actively planning for parenthood, believing an earlier negative result could pose too great an emotional 'burden'.

Most patients felt that they had received efficient and timely care during diagnosis and treatment but felt that, unless raised by them, fertility had not been adequately discussed during follow-up contact.

Professionals, in turn, felt cautious about raising fertility matters during follow-up appointments for fear of causing distress, appearing intrusive, or in the words of one, opening a 'can of worms'. Some felt that time constraints within busy clinics made it difficult to deal properly with the matter; others feared 'getting it wrong', especially when the patient was younger or of a different ethnicity or gender from them.

Patients wanted professionals to use plainer language concerning risk to fertility without being blunt and to make clear what information and services might be available in the future. Women in particular did not always understand that questions about their menstrual cycle related to their reproductive capacity.

Patients and professionals alike recognised the need for improvements to psycho-social support, both through specialist therapeutic counselling and through specialist social work and related services.

Patients would have also liked more support and advice about benefits, education and employment and greater challenges to discrimination against cancer 'survivors'. Often the long-term physical and psychological side effects of treatment - including those to do with fertility - are exacerbated by loss of work or educational and training opportunities.

Facilitating culturally competent practice
Our research offered many examples of assumptions about 'Asian' families being governed by prescriptive norms laid down by religion and culture. These views remind us, yet again, of the challenges of achieving 'culturally competent care' alongside 'patient centred care' within a multi-ethnic society.

Understanding and engaging with ethnic diversity should be seen as integral to the general training of health and social care professionals, rather than as an *ad hoc* 'competence' to be achieved through brief training sessions. Nor is reliance on 'fact-files' about cultural practices of minority ethnic groups an appropriate response.

This study indicates the need for reflective practitioners able to consider what is 'familiar in the unique and unique in the familiar' when working with diverse ranges of patients and families.

Greater sensitivity to the subtleties with which individuals use cultural values and norms to give meaning to their experience is called for - not denying the importance of paying attention to social and cultural context but doing so *as patients see it*.

Professionals need support and training to extend such reflective processes into reflexivity – to understand how they themselves impact on their patient/client

and vice versa and to use that 'knowledge' to inform their interventions. Such processes will facilitate improved confidence when working in multi-cultural settings, without assuming there is one 'right' approach.

Engaging with cultural, religious and ethnic diversity and challenging stereotypes is an important step forward in enabling professionals to raise meaningful questions within the context of providing care in a multi-cultural society.

Recommendations

1. 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.
2. 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.
3. It is important to incorporate discussions of fertility routinely in long term follow-up, taking care to use plain language and to involve specialist therapeutic/psycho-social support services as necessary.
4. 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.

5. Better coordination and communication between primary and secondary/tertiary care during and following treatment, including in relation to fertility, would improve continuity of care.
6. Professionals need to have greater confidence in responding to situations without relying on 'fact-files' or generalisations about cultural practices of minority ethnic groups. Incorporating attention to reflective/reflexive processes in professional training and support is called for.

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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 a more general summary reflecting the patient point of view) 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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