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A QUALITATIVE STUDY OF THE EXPERIENCES OF TEENAGERS AND YOUNG ADULTS WHEN FACED WITH POSSIBLE OR ACTUAL FERTILITY IMPAIRMENT FOLLOWING CANCER TREATMENT

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Research Report
Executive Summary

In depth interviews were conducted with thirty eight individuals diagnosed with cancer between ages 13 and 21 and aware of a risk, no matter how small, that their fertility may have been affected. Age at interview ranged from 16 to 30. Twenty one females (nine teenagers and twelve adults) and seventeen males (seven teenagers and ten adults) were drawn from a range of backgrounds regarding educational achievement, employment, family situation and ethnicity. While none had a prior major impairment, several were left with impairments following treatment.

Recruitment was primarily through three regional paediatric oncology centres in the North of England.

At diagnosis

- There was strong support across both genders for being told at diagnosis about the potential impact of treatment on their reproductive system.
- There was strong support for sperm banking to be offered to all males regardless of their physical or emotional state.
- Those males who tried and failed to bank their sperm were nevertheless very positive about being afforded the opportunity to try.
- There were good levels of understanding and recall about fertility related information received at around diagnosis. A range of reactions were experienced ranging from lack of concern to significant distress for both the individuals affected and their parents.
- Some females would have preferred greater clarity to be offered by doctors about the link between possible interruptions to their menstrual cycle and their reproductive system. Some wanted an explanation at this stage about why egg freezing was not on offer.
- There was a range of interpretations about the level of likely risk to fertility arising from what was said (and not said) by professionals at this stage and later.
- Many respondents spoke positively about professionals who appeared to take a genuine interest in fertility matters both at this stage and later.

Sperm banking

- Decision making about, and preparation for, fertility preservation was largely straightforward and aided by clarity of information sharing, the manner and context within which it was shared, being spoken to directly and having parents involved (provided that the young person wanted their parents present).
- There was satisfaction with decision making and preparation for banking taking place predominantly within the paediatric oncology setting with the consent and semen collection process taking place within the sperm bank.
- Some would have preferred consent to be taken in the paediatric oncology setting.
- Age and stress of coping with diagnosis did not appear to be significant to the ability to decide about sperm banking and act on that decision. Although some respondents *said* that their age

and life stage made a difference, this appeared to affect what they *thought* about undertaking this task rather than their *ability* to do it.

- Paediatric oncology professionals were rated consistently highly by respondents; the picture was more variable amongst those encountered in the sperm banks. Where there were difficulties, these centred on the professionals being too formal, using too complex language, not smiling enough and not employing appropriate humour.
- The young men welcomed having a choice about whether to be accompanied to the sperm bank and by whom. Many chose to have family members present and this helped; others were accompanied by professionals or went alone.
- The journey to the sperm bank (whether on site or off site and whether accompanied or not) was experienced as stressful. Some would have preferred to produce a sample either at home or away from the sperm bank (though not on the ward).
- There was considerable confusion about the consent conditions, including about 'consent to disclosure' and whether or not other couples would be able to use the stored sperm. There was also very limited awareness that these can be revisited. Some were distressed by questions about posthumous arrangements for semen disposal.
- The need to improve the facilities in the semen collection room was identified – making it more homely, more private, ensuring that pornographic magazines were clean and unambiguously available for all ages, providing written instructions and a clear procedure for handing in the sample.
- Many took a 'matter of fact' approach to semen collection and saw it as a required part of the process towards treatment though a few found it made them feel 'smutty'. All found it embarrassing.
- There were variations in getting the results of the semen analysis; getting them quickly seemed to be particularly well received. There were good levels of knowledge about storage matters.

From diagnosis to present day

- There was a more varied picture of information sharing and opportunities for discussions about fertility with professionals following diagnosis with only about half of the respondents feeling that it was sufficient.
- There was strong support from both genders and age groups for professionals to raise the subject sooner, more frequently, in a low key way and without ambiguity. This would enable those concerned to either acquire more information or to discuss concerns as and when they felt ready.
- Although most preferred their consultant to raise the subject initially, there was also support for other professionals to do so, especially psycho-social professionals.
- Some would have liked named staff on the wards to deal with sex and fertility matters or a wholly independent service delivered from elsewhere.
- The lack of relevant psycho-social services, the need for them to be offered proactively and to be home- as well as centre- based was identified at different stages and was not necessarily related to any imminent desire to become a parent.
- Preferred professional attributes included being honest, clear and unambiguous in dialogues, friendly, approachable, compassionate, competent and not embarrassed with the subject. Respondents valued professionals who were interested in fertility matters and who engendered hope in their ability to come through.
- Respondents wanted to be treated by professionals as partners and hence prioritised over their parents.
- Although there were gender differences in understanding, recall seemed broadly similar across genders.
- Males of all ages expressed no knowledge or interest in the sperm production process; females were interested in their menstrual cycle but reported poor understanding of it despite discussing it regularly with professionals and parents. This was a source of confusion and/or distress.

- Understanding of hormone replacement therapy appeared to be particularly problematic.
- Some reported increasing concerns about the impact of uncertainty about their fertility status as the uncertainty around cancer diminished.
- While both genders were faced with possible temporary fertility impairment, females were facing a possible shortening of their reproductive lifespan through a premature menopause (which was also uncertain) while males would retain lifetime fertility if function were to return. The implications were therefore very different.
- The presence of stored sperm was an important source of reassurance to males, providing that they were confident in its quality.
- The retention of hope of reproductive function or of successful fertility treatments - even where there appeared to be a strong likelihood of damage - was an important boost to coping. Those told that their fertility was permanently and irreversibly damaged were typically badly affected.
- Information levels about contraception across gender and age were limited. When combined with attitudes towards its use, sometimes influenced by possible fertility impairment, a worrying picture of risky behaviour emerged.
- Some had sought fertility related information from other sources. Several wanted more age-appropriate written and/or internet based information to be made readily and discreetly available.
- Gender differences emerged over fertility analysis. Some females became aware unexpectedly of fertility damage through gynaecological investigations; none were expecting to be called routinely for fertility testing. Most males who had banked sperm anticipated being recalled routinely and did not express any particular anxiety about this.
- The complexity of decision making about fertility was especially apparent among older respondents and those who did not have stored gametes.
- Some reported little impact after testing (including some found to be affected) though others did. Several would have welcomed access to psycho-social services but none were offered.
- Few had sufficient knowledge about fertility treatment options. Females were far more likely than males to know others in their family or social networks that had been through fertility treatments. None had yet accessed fertility treatments themselves though some anticipated needing to.
- Some in all four groups cited media coverage as a prompt for them to think about their own situation.

Involvement of families

- Families were much less likely to talk about cancer-related fertility matters than cancer matters at any stage. Sometimes the lack of discussion was because the respondent had not felt troubled; sometimes it was because the respondent feared upsetting others, or being upset themselves, by such a discussion.
- Some respondents talked to siblings and extended family members more than to parents.
- Where the respondent felt in control of the level at which their parents and family members were involved in their lives (including treatment and contact with professionals) both in the past and in the present, this was experienced positively. While a number were saddened by the strain that their cancer experience had already imposed on the whole family, some worried that they may add to this by not being able to provide grandchildren.

Involvement of friends

- Respondents across all four groups were more likely to discuss cancer-related fertility matters with friends than with family members but nevertheless reported different reactions towards, and from, friends around this area than to cancer matters.
- Discussions were often restricted to a small number of close friends and proved helpful. A small number did *not* talk with friends; that worked well when it was because the subject was of little concern but distressing when it was.

- Some found fertility matters particularly difficult to manage in their re-entry into the education-based context.
- The stigma attached to (in)fertility and the desire to appear ‘normal’ influenced the decision of some not to tell friends either in the early stages or over time. This appeared more difficult to sustain over time.
- Females were particularly likely to find themselves managing conversations about parenthood plans (and actual pregnancies).
- Some of both genders used humour to diffuse the awkward nature of some conversations but males reported particular difficulty in coping with ‘laddish’ jokes about virility and sexual prowess. This was made more stressful where friends were not aware of their possible fertility impairment.
- A small number discussed it with opposite gender friends though the majority restricted it to same gender friendships. A few females had used discussions with male friends as a ‘rehearsal’ for anticipated discussions with boyfriends
- Some reported changes over time with friends either becoming less interested or becoming more involved and supportive. Some females had been involved by friends in bringing up their children.
- There was mixed evidence of respondents talking about fertility within friendships made through cancer – sometimes it had not come up at all whereas for a small number, it was an important site of shared experience.
- None had yet got friends facing fertility difficulties for non cancer related reasons.

Involvement of romantic relationships

- Some were in permanent romantic relationships but many were not; some had no experience in this area at all.
- Most of those closer to treatment were more concerned with the impact of body changes than of the impact of possible fertility impairment.
- Although many said that the possibility of fertility impairment did not influence their approach to relationships, including sex, there were many examples of how it had done.
- Some were anxious about finding a partner willing to enter a potentially childless relationship while others were concerned about finding a permanent partner who later came to experience distress. A few were concerned that they themselves might not feel attracted to a partner willing to contemplate a childless relationship.
- The possibility of not being able to have a child together had contributed to the ending of a small number of relationships but was never the sole cause.
- Anticipated and actual concerns about when and how to tell a romantic partner were dominant and often present from very early on in relationships.
- Many respondents feared rejection following disclosure fuelled in part by the stigma that was perceived to attach to fertility impairment and hence the feeling that they were ‘damaged goods’. This was reinforced by the subject rarely being raised in other contexts.
- Respondents across all four groups were far more likely to talk to partners about their cancer experience than about cancer-related fertility matters, mirroring communication patterns with family and friends.
- Those where complete honesty was a strongly preferred feature of relationships in general were more likely to disclose early in permanent and non permanent relationships and to feel less anxious about the process.
- Some had not disclosed in order to hide their probable infertility; some felt disclosure should be restricted to ‘serious’ relationships and/or that it might give the wrong message if done too early.
- Those who had told a romantic partner typically found the outcome to be more positive than anticipated and led to them feeling relieved and reassured. In other words, the anticipation of disclosure appeared worse than the reality.

- However there was variance in the extent to which fertility matters had been discussed following disclosure. Some did not discuss it very often even though (or perhaps because) they found it deeply distressing.
- Uncertainty about fertility status also affected romantic relationships. Some reported the need for more information or better coping strategies in order to help a partner when the time came to disclose. Some of the older ones had wondered whether to undergo fertility analysis as part of this preparation and strategy building process.
- Some of the older group had enjoyed a number of post treatment relationships (mainly casual) but this had changed more recently and they reported a drop off in this aspect of their lives. Some had only ever had casual relationships.
- There were varying reports of the comfort and reassurance that came from being in a permanent relationship; while there were accounts of feeling that fertility impairment was now a shared 'problem' there was also evidence of ongoing loneliness surrounding it.
- Reactions were not static but changed over time and across different situations and within different romantic relationships.

Becoming and being a parent

- Females were more articulate about alternatives; had thought about it more frequently and in greater depth than had males; had the subject raised with them more often than did males. Only females had received offers of surrogacy or donated gametes from family members.
- Both genders and age groups held reservations about non biological parenthood, especially through gamete donation.
- The response of romantic partners to alternative routes was seen as important though few had actual experience of this.
- For those trying to get pregnant, the strain was clear; the extent to which the emotional impact was shared by partners varied as did responses to the styles of medical intervention.
- Some parents had planned pregnancies and others not; several had believed previously that they were infertile.
- Increased levels of monitoring of the pregnancies of affected females were welcomed; most were fearful of the pregnancy triggering a recurrence of cancer.
- Others, including non-affected females, were concerned about the risk of transmission of cancer to the unborn child; this was made worse where relevant information was not provided until after the birth.
- One parent reported that the fear of his child getting cancer had grown over time.
- Several felt better able to cope than their parents if their child were to get cancer because of their own experience and resulting strengths.
- On the whole, all appeared to have adjusted well to being parents.

Overall

- Coping with the impact of cancer-related fertility concerns was a dynamic process with different aspects arising at different times, in different contexts and in different life stages.
- One key aspect was the relative invisibility of fertility matters compared to cancer matters in dialogues between the individual affected and those around them – be they professionals, family members, friends or romantic partners. Survivors were coping alone with their thoughts and feelings for much of the time.
- Some respondents felt little or no associated concern but for others it was stressful and this had grown over time.
- Lack of attention from others also limited opportunities to correct misinformation, provide new or repeated information or to help build strategies for longer term coping. It also appeared to reflect

and reinforce the perceived stigma that attached to (in)fertility and thus the potential for hopelessness that comes with holding a ‘spoiled identity’.

- A few reported fertility concerns arising from diagnosis onwards but they more typically strengthened once treatment ended, especially where there was uncertainty about damage or definite information to indicate damage was done.
- For some, the threat to wellbeing from fertility concerns had overtaken cancer-related concerns. This did not appear to relate to gender although age and life stage did appear to be an influence.
- Threats to wellbeing from fertility concerns were formed and maintained by, among other things a strong and conscious desire to become a biological parent one day; the way that individuals (and sometimes their parents) interpreted information received from their doctors about the likely risk of damage; the presence of an ‘impaired’ or ‘uncertain’ fertile identity
- Prior to diagnosis, all appeared to have held a ‘fertile’ fertile identity though some had shifted to an ‘impaired’ or ‘uncertain’ fertile identity through treatment. It seemed to prove particularly difficult to shift back to a ‘fertile’ identity.
- Those who had given parenthood little thought had nevertheless assumed they would become parents one day so also experienced some degree of threat.
- The priority following treatment was re-entry into the social and educational trajectory being navigated prior to diagnosis and ‘active recovery through striving for normality’. For those focussed on this, fertility concerns were either consciously put to one side or ‘forgotten’, reinforced by their potential to make survivors appear or feel ‘different’.
- Normality is contextual and is variously located in gender, ethnicity, culture, sexual orientation and so on. There was evidence of this influencing some attitudes to contraception and social friendships.
- Those less focussed on ‘normality’ in their recovery appeared less likely to be striving for conformity to fertility related expectations and could therefore accommodate the possibility of remaining childless for the foreseeable future.
- Those who remained fearful of relapse or who were coping with significant physical impairments or health difficulties (some with associated stigma) were preoccupied with those and less affected by potential fertility impairment.
- However there were some who felt near to, or beyond, the active recovery phase and others for whom this approach was working less well who reported that fertility concerns were not resolving.
- Where recovery was starting to be affected by fertility concerns, many nevertheless spoke positively of being a cancer survivor. They felt good about themselves and their achievements and pointed to positive role models and images among cancer survivors, including some who had become parents.
- However there were many reports of more negative associations with (in)fertility and none identified positive role models or images.
- The opportunity to exercise reproductive choice about whether or not to enter the social state of parenthood is one that most young people expect to acquire as they move towards adulthood. For those being diagnosed with cancer in their teens, that opportunity is threatened and is often an unexpected consequence of cancer treatment. When placed alongside the threat to life, it may appear as of secondary concern and become invisible. However, if life is for living, then it is of little surprise that many in this study reported that it did not stay invisible to them. Perhaps it is time that those around them to also make it more visible.

The full research report is available in pdf format at no cost. It is also available in hard copy (ISBN 1 872159 36 2) at a cost of £10 inc p&p (UK)(cheque payable to University of York) from Marilyn Crawshaw, Dept of Social Policy & Social Work, University of York, Heslington, York YO10 5DD. Email: mac7@york.ac.uk. The research study was funded by Candlelighters.