

Utilising the experience of consumers in consultation to develop the Australasian Oncofertility Consortium Charter

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Abstract

In Australia and New Zealand, there has been no national systematic development of oncofertility services for cancer patients of reproductive age although many cancer and fertility centres have independently developed services. A number of barriers exist to the development of these services, including a lack of clear referral pathways, a lack of communication between clinicians and patients about fertility preservation, differences in the knowledge base of clinicians about the risk of cancer treatment causing infertility and fertility preservation options, a lack of national health insurance funding covering all aspects of fertility preservation and storage costs and cultural, religious and ethical barriers. The development of strategies to overcome these barriers is a high priority for oncofertility care to ensure that equitable access to the best standard of care is available for all patients.

The Future Fertility Research Team (FFRT) led a collaborative consultation process with the Australasian Oncofertility Consumer group and oncofertility specialists to explore consumers' experiences of oncofertility care. Consumers participated in qualitative focus group meetings with oncofertility specialists to define and develop a model of consumers driven or informed 'gold standard care' with the aim of putting together a Charter which specifically described this.

The finalised Australasian Oncofertility Consortium Charter documents eight key elements of gold standard oncofertility care that will be used to monitor the implementation of Oncofertility services nationally to ensure that these key elements are incorporated into standard practice over time.

Background

The subspecialty of oncofertility is very new and encompasses both the science needed to develop new fertility preservation options for cancer patients, and the development of clinical care to provide fertility preservation, psychosocial support, and reproductive

advice and follow up.^[1] Despite promising advances in oncofertility in the past decade, and an increasing number of patients seeking fertility preservation, there is currently no national standardized approach to the provision of oncofertility care.

There is still a paucity of robust data on the short, term, and particularly the long term, fertility effects of various chemotherapy regimens (with the exception of alkylating agents), especially for the more novel chemotherapy agents, combinations regimens, or multimodality treatment^[2] Data regarding the approach and efficacy of fertility interventions is limited to small trials with relatively short follow-up especially for pre-pubertal children and AYA patients.^[3-7] The optimal timing for use, duration of storage, success of assisted reproductive techniques following fertility preservation, and outcomes of pregnancy are also unknown.

Although not all patients wish to have children following treatment, most patients would like to have the option to discuss the risk of infertility.^[8-10] Studies suggest that not all cancer doctors inform patients about the potential risks for infertility^[4, 11, 12] although they acknowledge the importance of having discussions around topics relating to sexual and reproductive health. Research also suggests that there is inadequate communication between cancer specialists and fertility specialists.^[13] Given the complexity of providing detailed information about both cancer treatment and infertility risk to young people and their families traumatised by the diagnosis of a potentially life-threatening condition, and having to do so within a very brief time-frame, an efficient and robust strategy for collaboration is required between cancer and reproductive specialists and their respective teams. This will achieve the best outcome for patient care.

With substantial improvements in survival, cancer patients can expect to lead long and healthy lives, with the expectation of having their own biological family in the future. At present the economic impact of fertility preservation consultations and procedures and future artificial reproductive technologies are unknown. Without Medicare and comprehensive insurance coverage for oncofertility care, these guidelines are not a practicable recommendation for many patients to benefit from. The cost of psychological distress due to infertility and treatment related costs are also not known.

The guidelines from the National Comprehensive Cancer Network ^[16], American Society of Clinical Oncology ^[22] and Clinical Oncological Society of Australasia^[17] confer that potential fertility side effects of treatment must be discussed, and fertility preservation should be offered. In 2005, the ethics committee of the American Society for Reproductive Medicine extended physicians' duty to 'inform patients about options for fertility preservation and future reproduction, prior to starting cancer treatment.'^[18, 19] In Australia, the Royal College of Physicians and the Royal Australian and New Zealand College of Obstetricians and Gynaecologists have not made similar statements about fertility preservation, however the Clinical Oncology Society of Australia, Fertility Society of Australia and the Fertility Preservation Special Interest group have both supported recommendations for Oncofertility care.

When patients are first informed that they have cancer, it may be difficult to think beyond the cancer diagnosis due to psychological distress or high levels of anxiety. Discussion about the distant future may overwhelm a young patient and they may not yet have the breadth of understanding and or cognitive maturity to appreciate the multiple demands of an illness and the late effects consequences of cancer treatment. Young patients may have no imminent wish for children and may have not yet considered their future fertility.^[13] The significance of potential future infertility may not be recognised by patients until some years into survivorship and young patients may not remember or were never informed themselves nor their parents informed by their treating cancer clinician about the potential or actual fertility risks associated with their cancer treatment.

Conflict also arises over parents' ability to allow autonomous decision making about their child's future fertility.^[13] Studies have shown that although most AYA positively acknowledged their parent's involvement in the decision making process, some preferred to either have discussions without their parents being present or to make an autonomous decision. ^[4, 20-23]

Aims

The aim of the study was to explore the experiences of consumers of oncofertility care and to identify areas of oncofertility care needing development or implementation. The

second aim was to develop a 'Charter' of the value and goals of consumer and health care professionals regarding gold standard oncofertility care.

Methods

Consultation process and engagement

Since 2013, the FFRT have conducted national consumer consultation and engagement, for all the studies in our research portfolio which started with the development of the Australasian Oncofertility Registry Study^[24] in accordance with the consumers' health forum of Australia and the National Health and Medical Research Council model framework for consumer and community participation in health and medical research.^[25]

From April 2014 the Australasian Oncofertility Consumer group was formed and consumers were invited to actively contribute to the development of the brand name 'FUTuRE Fertility, logo design, development of the research proposal and the development of the research governance structure and the development of resources and advocacy strategy.

We invited consumers from the Australasian Oncofertility Consumer group to participate in focus group consultations. Focus group participants from this original consumer group represented paediatric, adolescent and young adult and adult cancer patients as well as being parents or partners of cancer patients. Patients represented metropolitan, regional and rural cancer centre and we had presentations from three states in Australia. The Australasian oncofertility consumer group now has involved members from each state and territory in Australia.

We held four focus group meetings from October 6th 2014 to January 7th 2015 at the Kids Cancer Centre, Sydney Children's Hospital to explore the consumers experiences of oncofertility care and discuss what the consumers felt would be 'gold standard oncofertility care' in the future with the aim of putting together Charter illustrating consumers' needs of oncofertility care.

All the consumer members were contacted by a researcher, who explained the aims and methods of the focus group discussions. Forty three consumers agreed to participate in the focus groups comprising of four groups: 10 childhood cancer survivors, 10 adolescent and young adult current cancer patients, 12 adult cancer patients of a reproductive age, and a fourth group of 6 parents and 5 partners. The thirty -two patient's age ranged between 15 - 46 years of age, 14 were male and 18 female. All the consumers had completed treatment and all were in remission. All the consumers were English speaking and no translation was required. The 32 patient consumers had a number of different tumour types (7 Hodgkin's Lymphoma, 5 Testicular Cancer, 5 Acute Lymphoblastic Leukemia, 3 Acute Myeloid Leukemia, 3 Osteosarcoma, 3 Ewing's Sarcoma, 2 Breast Cancer, 2 Medulloblastoma , Nasopharyngeal Carcinoma, 1 Colorectal Cancer).

Table 1 – Consumer focus group characteristics

	Characteristics	Number	Percentage %
Consumer Patient Number		32	74.41%
	Childhood Cancer Survivors	10	31.25%
	AYA Cancer Patients	10	31.25%
	Adult Cancer Patients	12	37.5%
Consumer Patient Age	Total Group 15-46 year old	32	Median 22 Range 15-46
• AYA Consumer Patients	15-25 years old	19	Median 18 Range 15-24
• Adult Consumer Patients	26-46 years old	13	Median 35 Range 26-46
Consumer Number		11	25.58%
	Parents	6	54.5%

	Partners	5	45.5%
Sex of Patients	Male	14	43.75%
	Female	18	56.25%
Tumour Type	Hodgkin's Lymphoma,	7	21.87%
	Testicular Cancer	5	15.62%
	Acute Lymphoblastic	5	15.62%
	Acute Myeloid Leukemia	3	9.37%
	Osteosarcoma	3	9.37%
	Ewing's Sarcoma	3	9.37%
	Breast Cancer	2	6.25%
	Medulloblastoma	2	6.25%
	Nasopharyngeal Carcinoma	1	3.12%
	Colorectal Cancer	1	3.12%

The consumer groups were not given any information about current oncofertility care but were provided with a summary of the definitions of the two terms, fertility preservation and oncofertility. The consumers were all asked to complete three written questions about demographics (age and sex); and were asked if they had had a referral to see a fertility or andrology specialist for fertility preservation care. This information was not shared with other consumer participants.

On the day of the focus group the consumers were provided with seven moderator posed questions.

1. How important is fertility preservation for you, your partner or your child?
2. At what stage of your treatment did you hear about fertility preservation or the effects of cancer on your fertility?
3. What information did you receive about fertility risks of treatment or fertility preservation?

4. Did you experience any barriers in accessing fertility care for yourself, your child or your partner?
5. What Oncofertility services/support did you receive that you would recommend?
6. What Oncofertility services/support would you have like to receive during treatment or in the survivorship period?
7. What Oncofertility services/support would you like to receive in the survivorship period?

The questions were prompts for discussion with consumer participants to provide responses that provided good insights into oncofertility care. The researcher was the moderator and was present during each focus group. The focus groups were audio taped and transcribed verbatim. The consumers also made notes on a white board, which were photographed and included in the analysis.

The chief investigator analysed the transcribed data for thematic comparisons of key issues and concepts before using the framework approach to allocate themes. Several themes emerged from the focus group discussions and these were mirrored in each focus group irrespective of the age of the patients. Similar themes were grouped together under six headings (communication, availability of data, referral pathways and Oncofertility care, training and education, psychosocial support and equitable access), which have been used to develop the eight principles of gold standard oncofertility within our Charter (Table 2).

Following the data analysis the Charter concepts were circulated to researchers of the FFRT and consumers refining the wording of each principle to be clear for patients and health care professionals.

Results

Nineteen (19/32, 59%) patient consumers had been referred for fertility preservation. Proportionately more male patients (10/14, 71%) than female patients (9/18, 50%) participated in the focus group. Patient ages ranged from 15 years to 46 years old with a median age of 22 years old.

Analysis of the data highlighted six different themes:

1. Communication

Cancer patients, parents and partners reported that any risk of infertility should be discussed prior to the start of a patient's cancer journey irrespective of the age of a patient, the possibilities for survival and the available options for fertility preservation. *'I am pleased that my doctor discussed fertility preservation at diagnosis even though I was too sick to have fertility treatment. I had an opportunity to discuss my options with my fertility doctors and now I have finished my treatment I am considering my option of having eggs collected.'*

The consumers reported that it was equally important to be informed also in situations where their cancer treatment had a low risk of causing future infertility and to be involved in the decision that fertility preservation was not needed. Patients who had received fertility preservation information but had not gone on to have fertility preservation, valued how important this information was and described feeling hopeful when given the opportunity to consider aspects of life after cancer treatment at a very difficult time.

The consumer's reported that although it was very important for cancer specialists to discuss the risk of treatment on patient's fertility, consultation with a fertility specialist gave them additional benefits, such as providing an opportunity to hear about different types of fertility preservation methods, and learning more about individual fertility preservation procedures and the success rates and complications of different fertility preservation procedures.

'The fertility consultation was useful to discuss my fertility choices and it also allowed me to have an opportunity to talk about how my sexual health and relationships may have been affected during cancer treatment.'

Consumers also reported that if the fertility doctor asked specific questions about their medical, gynaecological and/or obstetric history this influenced their decisions to undertake fertility preservation. Additionally, fertility consultations provided an avenue

to also be able to receive advice about follow up and general sexual health and sexual dysfunction concerns that patients experienced.

2. Referral pathways and oncofertility care

Many consumers reported experiencing delays in seeing a fertility specialist. Some centres did not have a designated fertility centre to refer patients to, while others had a number of potential providers at different fertility centres and yet did not have a referral pathway for sending patients. Patients therefore experienced delays waiting for appointments. Patients being treated in rural cancer centres believed that the distance to travel to metropolitan fertility centres was a significant barrier for seeking a consultation and treatment; and therefore delayed treatment as the work up prior to cancer treatment and fertility preservation had to be done consecutively rather than at the same time.

'When I asked my cancer doctor to refer me to see a fertility doctor I was surprised that he was not sure who to refer me to. The referral took a long time to organise and by the time I saw the doctor I felt I had no time to undergo treatment. It still makes me angry to think that I might have had time to collect eggs before I started my chemo if I was referred at the time I was diagnose rather than days before starting treatment.'

The fertility preservation consultation at diagnosis and in the survivorship period was seen as an opportunity to not only discuss fertility risk and fertility preservation options but as also an opportunity to talk about sexual health, safe sex practices, and symptoms of sexual dysfunction. The fertility consultation also provided an opportunity for patients to receive advice and support about fertility related psychosocial distress.

3. Availability of data

The consumer's agreed that additional oncofertility data was an important factor in the development and uptake of oncofertility services. Many patients described the lack of data on the risks for infertility after treatment, and a lack of oncofertility resources as impeding their fertility related decision making.

'I was shocked that my doctors could not tell me the risk of my cancer treatment on my fertility. I found it very difficult to make decisions without having all the information I needed.'

Many patients wanted to learn about any available data on the success of both fertility preservation and assisted reproductive treatment for cancer patients, as well as specific information about success and complication rates of fertility preservation in cancer patients.

4 Training and education

The consumers agreed that consultation about fertility preservation came at a very difficult time and not surprisingly was difficult for patients to process. Communication about fertility preservation and sexual health was an area that consumers described as needing to be improved, as these consultations often felt rushed, and used medical jargon that patients were not familiar with. They reported that often clinicians made assumptions that patients had an understanding about fertility treatments. Many patients also stated that they were not offered a choice about who attended these meetings and related that they would rather not have discussed fertility preservation with their parents or friends present.

Some patients believed that the knowledge base of their cancer doctor about fertility preservation options, or the fertility doctor's knowledge about the risk of infertility as a result of cancer treatment, was limited and that they did not receive the oncofertility information and support that they needed from either specialist.

The consumers commented that some of the consultation styles were based on clinician's assumptions that patients wanted to be parents and often included assumptions about the sexuality of patients, without asking patients about what future parenthood or having a meant to them.

Many of the consumers described the conversations with cancer health professionals as 'embarrassing,' however some patients reported that the health professionals were more embarrassed than they were, which stopped them from asking questions.

'My cancer doctor was so nervous and embarrassed talking about fertility preservation and sexual health that I could not ask any questions and I regret that now!'

5 Equitable Access

The cost of fertility preservation and storage was a significant barrier for accessing such services for many of the consumers. Consumers discussed how distressing it was to be in a situation at diagnosis where they had a limited time to make decisions about fertility preservation, which was further compromised by a decision for many of the consumers to either borrow money, rely on family support or miss an opportunity for fertility preservation. Other consumers discussed the relief of being referred to centres who provided reduced or no cost for fertility preservation and storage.

'I could afford fertility preservation before I started treatment. Sadly I now know my fertility has been affected by cancer treatment so I am now trying to save up enough money before it's too late.'

Our consumers who knew about their sub-optimal fertility or infertility felt that the financial aspect of fertility preservation or assisted reproductive treatment was a significant burden on them and had led to additional stresses in their relationships and quality of life as well as causing psychological distress.

6 Psychosocial Support

The consumer's reported receiving a varying amount of fertility related support during and after fertility preservation, with most describing that they felt the support received was very general, rather than focused on the experience of fertility preservation or the psychosocial effects surrounding infertility in a cancer patient. Many consumers also reported feeling more anxious about their fertility potential after cancer treatment than at the time of diagnosis and fertility preservation. Some described their fear of being infertile as 'terrifying' and as having a negative impact on starting intimate relationships. Others also reported that their fear of being infertile had a negative impact on their self-confidence and self-esteem.

Discussion

There are no nationally agreed guidelines for fertility preservation in Australia. Instead informal state and or national referral pathways occur on an adhoc basis. This results in many cancer patients not having the opportunity or option to discuss fertility preservation options with a reproductive specialist.^[26-28] Referral pathways between cancer and reproductive clinics exist but referrals occur intermittently between certain clinicians. Guidelines from the National Comprehensive Cancer Network^[16], American Society of Clinical Oncology, American Society of Clinical Oncology^[19] and Clinical Oncological Society of Australasia^[17] agree that fertility-related side effects of cancer treatment must be discussed, and fertility preservation should be offered wherever possible.

The themes emerging this study have driven the development of a 'Charter' with the value and goals of consumer and health care professionals regarding gold standard oncofertility care. It demonstrates the value of a collaborative consultation process between the Future Fertility consumer and health professional research groups in order to define and develop essential elements of universal oncofertility care. The six themes have been synthesized into the Australasian Oncofertility Consortium Charter as a method of defining best clinical care.

The Charter will also be useful in benchmarking the development of oncofertility services^[24], as well as being able to focus on important outcomes associated with uptake of fertility preservation services and opportunities at diagnosis. These changes will provide cancer patients with the opportunity to have the choice for a biological family in the future, although it does not guarantee the success of assisted reproductive treatment. Additionally, it will encourage clinicians to consider, and better address, patients' physical and psychological health complications of cancer treatment. The Charter will also be a powerful tool for education of cancer and fertility health professionals in Australia and New Zealand. In the future we will be able to compare both short and long-term oncofertility outcomes from cancer and fertility centres participating on the Australasian Oncofertility Registry, benchmarked against the

Charter, in order to develop sustainable evidence-based clinical practice guidelines to improve quality and continuity of care offered to all cancer patients.

The Charter, in conjunction with the Australasian Oncofertility Registry,^[24] will enable local and national cancer services to focus on the development and incorporation of oncofertility services, which will encourage collaborative efforts on the part of both cancer and fertility clinicians, the development of referral pathways, an improvement in communication and improved knowledge about the risk of infertility. It is vital that oncofertility services are developed and implemented to ensure equitable access of oncofertility care to all patients, and to identify and address barriers surrounding oncofertility care; such as a lack of resources, decision aids and clinician education which will need to be developed.

One of the biggest barriers of oncofertility care remains the cost and the Charter recognises how important it will be to implement services, which provide equitable access and care. The FFRT in collaboration with CanTeen Australia have begun the consultation process with the Federal Health Department in Australia, and a Protocol Advisory Subcommittee (PSAC) application will be submitted in 2016, outlining recommendations for ten new oncofertility Medicare Item numbers to be added into onto the Medicare Benefits Schedule in Australia.

This is the first Charter developed internationally, and the principles of care are not only applicable to the Australian context but globally to all cancer patients of reproductive age. We advocate that it is timely to establish as an 'International Oncofertility Charter,' in order to reflect the global significance and need for oncofertility clinical services and research.

Table 2 – Australasian Oncofertility Consortium Charter

<p style="text-align: center;"><u>Australasian Oncofertility Consortium Charter</u></p> <p>Cancer clinicians should discuss the possible effects of cancer treatment on a</p>

patient's fertility before the start of treatment, irrespective of age, diagnosis and prognosis of the patient.

Cancer clinicians should give patients an opportunity to discuss a patient's future fertility by offering a referral to a fertility specialist (reproductive endocrinologist, andrologist, paediatric gynecologist or paediatric endocrinologist) who can discuss fertility preservation strategies and their fertility and reproductive health follow-up following cancer treatment.

Cancer centres should have a clear referral pathway between cancer and fertility and/or andrology services to ensure that a fertility preservation consultation and appropriate treatment can be organised in a timely manner when it is deemed appropriate to do so before the start of cancer treatment.

National Oncofertility data should be collected to enable the development and implementation of national standardised guidelines and governance structure, which takes into consideration the age of patients.

Oncofertility care should be incorporated into the training curriculum for cancer and fertility multi-disciplinary health professionals at both graduate and postgraduate levels to ensure that oncofertility care become standard practice in Australasia.

Fertility preservation strategies and storage of gonadal tissue and embryos should be affordable and equitable for all cancer patients irrespective of age, ethnicity, sexual orientation or socioeconomic factors.

Fertility related psychosocial support should be available to all cancer patients during and after cancer therapy, irrespective of whether they choose to pursue fertility preservation strategies.

Health care professionals should offer all patients reproductive health

information and support. This will enable patients to initiate or maintain personal relationships following a cancer diagnosis and to maintain safe sexual health practices.

List of abbreviations

1. *AOFR*-Australasian Oncofertility Registry
2. *ART*-Assisted Reproductive Treatment
3. *AYA*- Adolescent and Young Adult (15-25 year olds)
4. *FP*- Fertility Preservation
5. *FPS*-Fertility Preservation Services
6. Fertility Specialist- reproductive endocrinologist, andrologist, paediatric gynaecologist or paediatric endocrinologist.

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Competing interests

The authors declare that there are no conflicts of interest.

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CJS over sees a clinical FPS with a research focus and the program has received non-directed grants from MSD and Merck Serono to assist with database creation and FPS laboratory research. CJS has not received any funding for her involvement, nor any

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Authors' contributions

All authors contributed to the development of the Australasian Oncofertility Consortium Charter and have approved the final manuscript.

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