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Fertility Preservation in Sub-Sahara Africa: Myth or Reality

Abayomi B Ajayi[1]*, Bamgboye M Afolabi[1] and Victor D Ajayi[2]

[1]Health, Environment and Development Foundation, 18, Ogunfunmi Street, Surulere, Lagos, Nigeria

[2]Nordica Fertility Center, 106/108 Norman-Williams Street, Southwest Ikoyi, Lagos, Nigeria

ABSTRACT

Due to current developments in cancer therapy, there has been an increase in the number of enduring cancer survivors. Nevertheless, cancer patients or those with other intractable diseases may be confronted with fertility challenges. Though the option of fertility preservation (FP) techniques are on the increase, yet it is not certain if this is a myth or a reality in sub-Sahara Africa.

Methods: The objective of this study was to assess the opinions, knowledge and attitude of gynecologists from different parts of Nigeria on fertility preservation among women in child-bearing age with cancer. A Focus Group Discussion (FGD) was conducted including gynecologists who were asked about their opinions on the possibility of FP in the country and about factors that could support or degrade it.

Findings: Gynecologists agreed that awareness and cost are important as people have to know the availability of such facility before accessing it. Socio-cultural aspects of FP were deliberated upon positively. There is always suspicion about how "the doctors can take out my eggs, freeze them for a long time and these eggs still survive." Certain participant held the view "a lot of people have issued with mixing up gametes" while another wanted the subsidy of FP by the government.

Interpretation: The positive opinions of the gynecologists towards fertility preservation far out-weight negative opinions. Public awareness, cost and socio-cultural were deliberated upon by participants in the FGD. Greater emphasis should be placed on counselling opportunities, the provision of adequate information and supporting material. A better understanding of these issues will hopefully enhance patients' decision-making about FP options and assist the development of strategies to improve quality of care.

***Corresponding author**

Bamgboye M. Afolabi, Health, Environment and Development Foundation, 18 Ogunfunmi Street, off Akobi Crescent, Surulere, Lagos, E-mail: bmafolabi@gmail.com

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Introduction

Fertility preservation (FP) has been defined as "the process of saving or protecting eggs, sperm, or reproductive tissue so that a person can use them to have biological children in the future. Certain group of people, among who are those with diseases such as uterine myomas, endometriosis, cancers, hematological disorders, those whose occupation or day-to-day life that could disrupt their fertility profile, among others may benefit from fertility preservation. In developed countries, options for FP such as embryo cryopreservation, oocyte preservation, gonadal shielding and ovarian transposition are accessible for female patients while sperm cryopreservation, gonadal shielding and testicular tissue freezing are available male patients. In sub-Sahara Africa (SSA), communicable diseases such as HIV/AIDS, Tuberculosis and Malaria exert a huge burden on the health sector [1-7]. With the emergence of non-communicable diseases such as hypertension, diabetes, pulmonary disease and chronic renal diseases, little attention has, hitherto being paid to cancer. The non-communicable diseases, such as cancers, are emerging health problems that need to be dealt with appropriately to sustain public health advances that have already been achieved. It was earlier though that cancer is rare in Africa, but it is now known that that it is not rare on the continent. Though the chances that a sub-Sahara Africa woman will develop a cancer about the age of 60 years is just approximately 20% lesser than that of a European woman, however, services for healthcare of cancer patients in sub-Sahara Africa are negligible. Most frequent pediatric cancers in SSA are (i) Leukemia (ii) Kaposi sarcoma (ii) Burkitt lymphoma, (iii) Non-Hodgkin (iv) Nephroblastoma (v) Sarcomas (vi) Retinoblastoma all of which require chemo and/or radiotherapy. There is little information about pediatric cancer and childhood cancer register in African children is almost unknown except in South African Children's Cancer Study Group in Tygerberg, South Africa, though cancer is 4.8% of all childhood malignancies in Africa [8-10]. In SSA, the top six cancers among adult males are (i) Kaposi's sarcoma (15.9%) (ii) Cancer of the liver (13.3%) (iii) Cancer of the prostate (10.7%) (iv) Cancer of the esophagus (6.0%) (v) non-Hodgkin's lymphoma (5.8%) and (vi) stomach cancer (4.5%); in adult females, leading cancers are (i) cervical cancer (25.4%) (ii)

Breast cancer (17.4%) (iii) Kaposi's sarcoma (6.2%), (iv) cancer of the liver (5.5%) (v) Cancer of the stomach (3.8%) and (vi) non-Hodgkin's lymphoma (3.8%) [9]. But many cancer management plans have momentary or lasting deleterious effects on human fertility for bearing a child, especially for those at child-bearing age. Cancer treatment in males can damage the reproductive organs by (i) causing damage to the endocrine glands or endocrine-related organs such as the testicles, thyroid gland, and adrenal glands (ii) causing alterations in the pituitary-hypothalamus axis which controls the endocrine system (iii) causing direct damage to the Sertoli cell, DNA structures of the sperm cells or other systems relating to sperm production. In females, both radiotherapy (dose-dependent, part of the body being irradiated and age at time of irradiation) can aggravate the risk of injury to the reproductive organs, most especially the ovaries, the endometrium and uterine vascular system. Surgical oncology treatment can be added to the management of cancer and the risk of infertility also arises in such modality of treatment. However, despite the fact that the incidence of cancer is rising and despite the fact that there is some level of awareness about cancer among government officials, public and health workers than before, still little attention is paid to the consequences of cancer management among survivors who wish to start their own family. A recent study indicates that adequate information or access to fertility preservation is not provided for female cancer patients in child-bearing age and most health workers who see cancer patients in reproductive age do not discuss fertility preservation with their patients. Furthermore, awareness about fertility preservation among the general public appears to be exceptionally low. Data on fertility preservation in sub-Sahara Africa is very scarce. Cursory discussions show that fertility planning may not be real, it will be associated with legal issues or it may not be approved by regulatory body. The objective of this study was to document the views and opinions of clinicians who see female cancer patients which would contribute to knowledge about fertility preservation in sub-Sahara Africa [11-13].

Method

The Society of Obstetricians and Gynecologists of Nigeria (SOGON) had a mini conference in 2017 at Mainland Lagos Nigeria which provided an opportunity for a Focus Group Discussion (FGD) to be planned and implemented. Prior to the meeting, a three-man committee at Nordica Fertility Center, Lagos Island, was convened to deliberated upon possible questions to ask a group of 8 gynecologists who would participate in an FGD. The committee also planned on time, venue, duration, refreshments, and instrumentation for a successful and smooth-flowing FGD. Participants in the FGD were not predetermined by the committee, though the committee sent email message to the president and executive committee of SOGON about its intention to carry out FGD on Fertility Planning which was responded to favorably. A consensus was reached that the FGD will take place after the SOGON meeting, the meeting will take place in a separate comfortable room in the hotel, refreshments would be provided for participants and that the participants will be both male and female gynecologists who have been practicing for a minimum of ten (10) years and the maximum time for the FGD would be two hours to allow for those who would be travelling back to their respective states outside Lagos. Also, it was agreed that the participants would have been working in different parts of the country so as to capture, as much as possible geo-special views of fertility preservation. Participants were Nigerians in the field of gynecology who had been practicing for 10 years or longer, were working either in public or private health facilities, were members of SOGON. Gynecologists practicing for less than ten years or expatriates working in Nigeria were excluded from the study. For ice-breaker, it was also agreed among the participants that (i) names will not be used but participants will be coded as MP1, MP2 etc for male participant 1, 2 etc and FP1, FP2 for female participant 1 and female participant 2,(ii) The study was approved by a local Ethics Committee. Participants in the FGD were asked direct or leading questions about their opinions on FP in Nigeria and about factors that could sustain and those that could not deplete it.

After explaining the purpose of the FDG to the participants, the moderator opened discussion with a question on fertility preservation and allowed to discussion to continue for a while, guiding proceedings where necessary and prompting participants. In all, the moderator asked a total of 10 questions and all participants responded one after the other. There was a recorder who took notes verbatim, especially key responses. Where a response was unclear, the moderator asked for clarification from the responder or from any other participant. Responses of each of the participants were recorded on a hand-held recorder. Data was collated and cross-checked immediately after the meeting. Key terminologies were noted and expatiated in the notes. Thematic content analysis was used to extract the main themes from each participant. These main themes were gathered and compared with the views rendered by each of the participants to clarify which themes were common in the discussion.

Results

There were seven key themes that stood out in the FGD were (i) need for FP among cancer patients (i.e. cancer) (ii) need for FP among women in reproductive age not yet married (i.e. late marriage) (iii) Cost and affordability (iv) awareness of FP (v) socio-cultural issues (vi) legal issues and (vii) regulation authorities.

On the first thematic area, participants presented different views of cancer patients that need fertility preservation. The first participant was a male gynecologist who mentioned one such group as "young women and young men developing cancers and they are yet to exercise their fertility potential. For such group of people, his opinion is that FP is "realistic and is an opportunity for these young people with cancer to keep their fertility potential. The first speaker claimed that his response to few patients who inquired about FP was "fertility preservation not a thing we can do for now but if you have access to developed countries and you have the fund. You have to think about the cost implication." His view is "Fertility preservation is something that is new to us here." The next speaker, another male gynecologist, spoke on the first thematic area about another group of people for whom FP is especially important. He said "the other group are women that have conditions which warrant the removal or destruction of the ovaries (a) at surgery that removes the ovaries i.e. malignant conditions of the genital tract ovariectomy (b) those undergoing chemotherapy or radiotherapy (c) those with fulminating infections. His opinion was "Fertility preservation is not really new in this environment" which counters what the first male participant said. One of the two female gynecologists in the FGD said "It might not even be the woman this time around. Maybe the man or the woman's partner has cancer or a terminal disease. They can find a way of preserving their fertility for an issue that will combine the two of them." The third male gynecologist to speak briefly supports the opinion of the first male speaker by saying "in childhood malignancy like leukemia, you can preserve the ovaries" referring to childhood leukemia in the female. A male gynecologist who had been quiet since the discussion began finally said "Cancer can now be managed well, and the patient lives longer. There is

preservation of not only oocytes but of ovarian tissue, even sperm for those who have cancer of the testis. FP is an aspect that has to be given a lot of prominence in this part of the world."

A somewhat older gynecologist, the fourth male speaker, said "FP is one of the advances in fertility management. It is particularly important that it is coming at this time because there is so much interest and expectation in it." The moderator then asked this older gynecologist of his view of FP relative to cancer. His response was "In treatment and cure of cancer generally, young female cancer patients can now live longer and when they are on medication or treatment, their ovaries may suffer some consequences as a result of the chemotherapy, radiotherapy medication or other treatment which may actually jeopardize their chances of having babies. It is expected that they will live long after the cancer management and want to have babies. If they have not frozen or preserved their fertility, maybe the ovaries could have been knocked off by chemotherapy or radiotherapy." He concluded by saying "This (FP) is a positive development for cancer patients which is important and very necessary at this time". The second female gynecologist in the group said "Women are getting married late now. Women who are above 40 years and it's now dawning on them that they are getting older and marriage is not coming on come for the program called "Social prison." One of them said that she got to know some few weeks back that she can actually freeze her eggs, otherwise she would have done so and not come for the Social Prison program". She recounted that she had two male clients presently who sperms have been frozen because they were going for surgery – one for testicular cancer and the other for prostate cancer – and they still want to achieve pregnancy. The first female speaker said "The eggs of a woman is older than the woman (because oogenesis starts before a woman is born) and there is decline in both the function and quantity of the oocytes as the woman advances in age. So, as a husband is not coming, a woman can retrieve her eggs and freeze it when she is 22 years old and leave it there. If she now gets married at 45 years, she can now retrieve the eggs she froze at age 22 years which will still be as viable as the egg of a 22-year-old and use it for IVF. The success (of IVF) will be better because the eggs are younger and that is still her genetics than at 45 years when she has to use a donor egg." The response of the third male speaker was "A lot of women are now getting married at later age and by the time they are getting married, their ovarian reserve is almost zero. If you have a career woman who is so driven to be a very successful person in life, she may not even have time for marriage. She wants to get to the top of her career before talking about marriage. If at the end of the day she has nobody to marry, she might go for an anonymous sperm to fertilize her eggs that have been frozen if she is so desperate to have a child instead of adoption." The moderator then asked if participants were willing to discuss FP with their patients. When the first male participant responded, "Certainly, Certainly. This is something that is beneficial to them, something that will give them the opportunity to fulfil their dreams of having their own children. It is very important", every other participant agreed with him. The last male speaker said ": "A lot of women are now getting married at later age and by the time they are getting married, their ovarian reserve is almost zero. If you have a career woman who is so driven to be a very successful person in life, she may not even have time for marriage. She wants to get to the top of her career before talking about marriage. If at the end of the day she has nobody to marry, she might go for an anonymous sperm to fertilize her eggs that have been frozen if she is so desperate to have a child instead of adoption."

Another thematic area was cost, availability and affordability which all participants agreed are major issues that can downgrade the importance of FP in Nigeria. Among the reasons given were importation of materials and instruments needed for FP, maintenance of liquid nitrogen tank, constant electric power supply and other infrastructures. Preservation is a long-term process, not just for one or two months and the person comes back to use it. It can be there for 10 years and it is a running cost that client has to pay for which amounts to a lot of money. Some of the clients will have to weigh it against waiting and maybe consider using donor eggs. If these are not considered, the facility risks losing gametes. Part of the cost is the out-of-pocket cost to be incurred by the client for travelling long distance to the facility for FP, for hotel and accommodation, for communication with the facility to check on client's gametes and other additional issues. All participants believed that awareness and cost are important as people have to know the availability of such facility before accessing it. The first female said, "Cost of FP should be subsidized by the Federal Government to make it bearable for some of our patients. I will discuss this certainly with my patients."

On the fourth thematic area, the second female gynecologist reiterated that early awareness and enlightenment on FP could prevent many women aged about 40 years and above from partaking in Social Prison program. She said, "I think, basically, awareness is what we need. Most of them do not know that they can actually freeze their (eggs and sperms) for as long as long as they want to make use of them. Even this embryo, a lot of people don't know that they could make use of frozen embryos for future use. I think awareness is the way to go and we can achieve so much." Another participant responded to the moderator by answering "Not much public awareness or public enlightenment on FP. It (FP) is something the society has to be abreast of." The fifth male speaker also contributed saying, "Awareness is important because people have to know. If you know you will be educated on it and you can indulge in it. The other aspect is availability and cost. You must know where it (the services of FP) is offered and you must have the resources to be able to pay for the services. These will strongly affect FP.

Socio-cultural thematic area mentioned by the participants included the suspicion about "how the doctor can take out my eggs, freeze them for a long time and these eggs still survive", "a lot of people will have issued with mixing up gametes", "if the gametes will still be effective or alive after such a long time being frozen". One item under socio-cultural thematic area was Religion. One participant remarked, "…Moslems do not believe in taking gametes, freezing etc. Some of them believe that it is a sin and so many things." The participant also mentioned the issue of Trust saying, "A client said she wanted to see her embryo discarded before her very eyes." Under this socio-cultural thematic area was fear of the unknown. As stated by sixth male participant, "The issue of getting something (human tissue) from somebody's body, they want to know what you will be doing with the remaining after you have used some for analysis. Is it for rituals or for something diabolical. You now say you want to preserve it (the egg or sperm) for so long. How am I sure that you are going to preserve it for that purpose only and not going to give it to somebody else or share (with others)? The fear of the unknown too is there. We need more enlightenment."

Then there was thematic area concerning legal issue to which all participants agreed is necessary for health workers to be legally protected as much as possible because, as the second female

participant state "the doctor and/or the health facility conducting FP can be sued by a client if she/he thinks that her/his gamete has been tampered with. Health facilities should endeavor to be transparent and communicate with clients and regularly to avoid such instances."

Lastly, the third male advised that the issue of setting up FP in the country should be approved by regulatory bodies. The first female gynecologists then said that facilities that aspire to set up FP should get registered with regulation authorities to avoid legal issues.

Discussion

In developed countries, fertility preservation is evolving as protecting future reproductive potentials of male or female patients with cancer, other debilitating illnesses, and infections or of career females who wish to postpone having their own family till future with cancer or other serious illnesses [13]. Fertility Preservation appears relevant among women in child-bearing age group and may not be relevant to post-menopausal women. It is also relevant for males who would undergo radiotherapy chemotherapy or surgery or reproductive organs such as orchidectomy. In the developing part of the world such as sub-Sahara Africa (SSA), fertility preservation is uncommon, though various cancers and their management are common among both sexes and in all ages. This paper has some salient points about fertility preservation in SSA that needs discussion. First is that young people with cancer may wish to exercise their fertility potential after cancer treatment. This agrees with the findings of Burns et al, that 81% of female adolescents with cancer were enthusiastic about preserving their fertility. In line with the 2006 guideline of American Society of Clinical Oncology, participants in the study admitted that discussing the negative side effect of cancer treatment, such as infertility, with patients is a necessity prior to radiotherapy, chemotherapy, or surgery for cancer. Jensen et al suggested that counselling on fertility preservation should highlight latent outcome of cancer management on future fertility, choices accessible to patients among other and legal framework for disposal of biological tissues that are no more viable. Fertility preservation is not common in sub-Sahara Africa. It is surprising that one of the participants stated that fertility preservation is not really new in this environment. However, another participant countered by saying that fertility preservation is actually new in this environment. The only facility conducting fertility preservation is Vitalab in South Africa. Cost and affordability of fertility preservation may be a limiting factor for accessing this procedure in sub-Sahara Africa. Fertility preservation options such as egg freezing, embryo freezing, ovarian tissue freezing, or ovarian transposition may cost up to US$15,000 service charge while storage cost could range from US$300-500 annually. In SSA, socio-cultural issues such as religion, tradition, and disposal of the dead play important parts in the daily life. Certain religious affiliations may not take kindly to fertility preservation while others are suspicious of what happens to their gametes when they are not there and even if their gametes could be exchanged for others. These are valid considerations because the wish and ability to start a family with one's offspring(s) is a key quality of life [14-18].

A previous study reported high level of awareness about fertility preservation among gynecologists [12]. But expected to be low in the general public as indicated by the response in this study. This is not surprising because fertility preservation is a new concept, is expensive and as such not many facilities can set up such a procedure and is costly for many sub-Saharan Africans. This might be one of the reasons why a participant in the FGD requested that the Federal Government should subsidize fertility preservation. Another option is for health insurance companies to look into funding fertility preservation. Before starting treatment, it may be worthwhile for cancer patients to discuss the following points with their clinicians, even though their clinicians may not remember to talk about fertility preservation with them: (i) threat of infertility from the treatment decision (ii) effective treatment with lower risk of infertility (iii) other options for fertility preservation (iv) support available for coping with infertility (v) legal issues that can arise.

Conclusion

It is obvious from this study that fertility preservation in sub-Sahara Africa is more than a myth, it is a reality, though there are limiting factors. Data is scarce to indicate that most cancer patients in child-bearing age in sub-Sahara Africa are aware of possible harm to their fertility with cancer management. Therefore, clinicians need to be abreast of fertility preservation to adequately guide, counsel and refer their patients with such needs to fertility experts. Seven thematic areas were arrived at in the Focus Group Discussion on Fertility Preservation in sub-Sahara Africa which included need for fertility preservation among young cancer patients and among women in child-bearing age not yet married or who are delaying having a family because of career or professionalism, cost and affordability of fertility preservation, awareness, socio-cultural issue, legal issue and regulation authorities for fertility preservation. Massive information, education and communication should be provided through print and electronic media to raise the level of awareness of people in SSA on the possibility of FP. There should also be a way to subsidize the cost so that it is available and accessible to as many cancer and non-cancer patients who desire it. Clinicians should always discuss the possibility of FP with cancer patients and possibly include this discussion when referring patient to or from an oncologist [19-21].

Study limitation

The data in this study was from a Focus Group Discussion which included only gynecologists. Other cadre of health providers in the cancer management, such as oncologists, pharmacist, nurses, and embryologists were not involved, and the views reported are thus limited. Future studies, whether qualitative, quantitative or mixed, should take into consideration these other cadres to have a holistic assessment of fertility preservation in SSA.

Authors' contribution

Dr. Abayomi B. Ajayi - Original idea, study design, literature search, data interpretation

Dr. Bamgboye M. Afolabi - Study design, literature search, data collection, data analysis, data interpretation, writing

Dr. Victor D. Ajayi - Study design, literature search, data collection, data analysis, data interpretation, writing.

Conflict of interest: No

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