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Brief Report

Banking on Fatherhood: pilot studies of a computerized educational tool on sperm banking before cancer treatment

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Abstract

***Objectives*: We conducted pilot studies of the feasibility and efficacy of an interactive, computerized educational tool, *Banking on Fatherhood* (BOF).**

***Methods*: Two small randomized trials were conducted, with 20 male cancer patients eligible to bank sperm in Study 1 and 19 oncology fellows or residents in Study 2. In each trial, half of the subjects viewed BOF before completing questionnaires, and half viewed it afterward. Outcome measures included a knowledge test in both trials and a Decisional Conflict scale in the patient trial. All participants, plus a panel of 10 experts, ultimately viewed BOF and completed a form evaluating its usability and value.**

***Results*: Patients who completed questionnaires after viewing BOF had significantly less decisional conflict about banking sperm than those who had not viewed it ($P = 0.0065$), but knowledge scores were not significantly different between groups. Physicians who filled out questionnaires after viewing BOF scored significantly higher on the knowledge test ($P < 0.006$). Patients, physicians and experts rated BOF as easy to use, informative and addressing important psychosocial concerns, with videos and animations adding to the value of the educational tool.**

***Conclusion*: Pilot studies suggest that BOF is a feasible intervention that could enhance decisions about sperm banking. Research with larger groups is needed to validate its effectiveness.**

Keywords: cancer; oncology; sperm banking; infertility; education

Introduction

Banking semen before cancer treatment is an effective method of fertility preservation endorsed by professional societies in Europe [1] and the United States [2]. Nevertheless, surveys in the United Kingdom [3], Australia and New Zealand [4], Canada [5], and the United States [6,7] reveal that many patients do not receive adequate and timely information about sperm banking. Younger teens often fail to produce a semen sample because anxiety and embarrassment inhibit them at the sperm bank [8–10]. Programs for teens have begun in several academic medical centers [5,9,10], but are unavailable to adult patients.

Parenthood is an important issue to cancer survivors. Most men who are childless at the time of diagnosis would like to have future offspring [6,7]. Impaired fertility can cause emotional distress in young adults even 5 or 10 years after cancer treatment [11]. Oncologists and patients agree that better educational materials would facilitate decisions about sperm banking [7,8]. We have been developing a multimedia educational tool called *Banking on Fatherhood* (BOF). We describe BOF and pilot studies of its feasibility and efficacy.

Materials and methods

BOF educational tool

BOF is interactive and can be viewed over the internet or on a CD-Rom. The viewer selects a section for cancer patients or for health professionals. Both sections include search engines, a glossary and a national directory of sperm banks.

The section for professionals presents a medical update on cancer-related infertility and sperm

banking. Topics include damage from cancer therapies to sperm DNA and spermatogenesis, health of offspring, sperm banking procedures, assisted reproductive technology (ART) used with cryopreserved sperm and ethical issues such as advance directives for stored gametes, views of major religions on semen collection and ART and posthumous reproduction. BOF also includes a knowledge test with animated feedback called 'The Gamete Game', and a section on communication skills with video vignettes and a checklist of topics to discuss with patients.

The section for patients and families combines bulleted text; animations illustrating the anatomy of male reproduction, spermatogenesis and the impact of cancer treatments on sperm and; video vignettes depicting common issues with family or physicians. Topics include a cost–benefit analysis of ways to become a parent after cancer, making semen collection easier, testing for sexually transmissible infections, advance directives for stored semen and views of major religions. Special sections are tailored for teenagers, parents of teens and partners of cancer patients. Materials are sensitive to diverse cultures and ethnicities. A patient version of The Gamete Game is available, along with a 30-item questionnaire designed as a decision aid, The Sperm Banking Thermometer.

Pilot studies

Two small, randomized trials compared subjects who filled out questionnaires after viewing BOF with a group that completed them before seeing BOF. The hypotheses were: (1) Viewing BOF would increase knowledge about cancer-related infertility and sperm banking in physicians and patients. (2) Viewing BOF would reduce patients' conflict about making the decision whether or not to bank sperm. Studies were approved by our Institutional Review Board. Informed consent was elicited with each participant in Studies 1 and 2.

In Study 1, participants were male patients, aged 14–45, recently diagnosed with cancer and having had no more than one week of cancer treatment, although we do not recommend sperm banking after chemotherapy or radiation therapy has begun. Men were excluded if unable to read English adequately or to give informed consent.

Twenty male patients were randomized to fill out questionnaires either before or after viewing the patient and family section of BOF. If patients did not have access to a computer, a research assistant brought a laptop to a location with privacy. Questionnaires elicited demographic and medical information and included a 20-item true/false knowledge test based on the material in BOF. The score was the total number correct. The knowledge test was modified from a 15-item version used in a previous survey on sperm banking [6]. Patients also completed a 16-item multiple-choice Decisional Conflict scale measuring the difficulty of making a choice about medical treatments [12]. It has good internal consistency (0.92) and test–retest reliability (0.81). An introductory statement asked men to consider whether or not to bank sperm. They rated their agreement with each statement on a 5-point scale from 'strongly agree' to 'strongly disagree'.

Men who had not viewed BOF did so after these questionnaires. All patients then completed a 20-item evaluation form using a 4-point Likert scale response format from 'agree strongly' to 'disagree strongly'. Participants rated whether the material in BOF was easily understood, easy to navigate, would help in making a choice about banking, addressed emotional concerns, would be helpful to parents or significant others and was enjoyable or boring to view.

Study 2 used the same design but recruited oncology fellows and residents who viewed at least the professional section of BOF. Eligibility criteria included being a fulltime clinical oncology fellow or radiation oncology resident at our institution. Nineteen physicians entered the randomized trial, filling out a professional version of the true/false knowledge test, modified from our previous oncologist survey [7]. They also completed the evaluation form.

A panel of 10 experts also viewed both sections of BOF and completed the evaluation form. Members included nationally recognized experts in cancer and communication, cancer treatment and spermatogenesis, male infertility, sperm banking, psychosocial aspects of pediatric oncology, bioethics and four cancer survivors who were leaders in national advocacy organizations.

Statistical analyses

Analyses included descriptive statistics, such as mean, median and standard deviations. Fisher's Exact Test was used to compare the groups that viewed BOF before vs after completing questionnaires. Demographic variables were compared among the groups of interest using Fisher's Exact Test or the Pearson χ^2-test if more than two groups were involved. Continuous variables were compared between groups using Student's *t*-test. Statistical tests for *a priori* hypotheses were one-sided but all *post hoc* tests were two-sided. $P<0.05$ was used to indicate statistical significance.

Results

Study 1: oncology patients

The groups randomized to view BOF before vs after completing questionnaires did not differ significantly on any demographic or medical variables. Twenty percent had a high school degree or less and 50% had at least a college degree.

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Twenty percent were Catholic, 65% Protestant and 15% other religions. Twenty percent rated their religious observance as 'very active'. Thirty percent were ethnic minorities. Sixty percent had never been married. Mean age for men who filled out the questionnaires before viewing BOF and after was 32.4 ± 8.6 and 32.9 ± 10.4 years, respectively ($P = 0.91$). Twenty percent had testicular cancer, 40% had hematologic malignancies and 40% had other cancer sites. Fifty-five percent had been informed that their cancer treatment might impair fertility and 50% had been told about sperm banking.

Knowledge scores did not differ significantly between the two groups (13.7 ± 2.5 if viewed BOF vs 12.4 ± 2.6 if did not view BOF; $P = 0.13$). Decisional conflict was significantly less for men who viewed BOF, however (23.7 ± 8.4 vs 32.7 ± 6.0; $P = 0.0065$).

Study 2: oncology fellows and residents

The two groups in the physician trial did not differ significantly in age (84% 30–39 years old), gender (64% female), stage of training (95% fellows) or oncology specialty (5% surgical, 5% radiation oncology, 53% medical oncology and 37% other). Our hypothesis about knowledge was confirmed. Physicians who viewed BOF before filling out questionnaires scored significantly higher on the 20-item true/false knowledge test (mean score of 14.6 ± 3.5 compared with 10.8 ± 1.6 for those who had not viewed BOF; $P = 0.006$). Knowledge scores were not significantly associated with demographic factors.

Study 3: evaluation of BOF

Table 1 summarizes the evaluation form ratings of patients, trainee physicians and our panel of experts. The four original response categories are collapsed into 'agree' vs 'disagree'. Ratings were extremely positive within all groups. Only a minority felt that BOF was boring or had difficulty navigating within the program or absorbing information. The videos and animations were perceived as adding educational value.

Discussion

Despite the small sample sizes for both patients and physicians, we found significant differences between those who did and did not view BOF. Physicians exposed to BOF had greater knowledge about sperm banking and patients had less decisional conflict. The failure of BOF to increase patients' knowledge is difficult to interpret. Perhaps the difference between groups would be significant with a larger sample. Some items on the patient knowledge test may have been too difficult. However, only two items had incorrect answers from 50% or more of men who viewed BOF

Table 1. Evaluations of *Banking on Fatherhood*

Agree with the statement	Patients $N = 20$ (%)	Physicians $N = 19$ (%)	Experts $N = 10$ (%)
Easy to understand	100	95	100
Issues were new to me	95	95	38
Gave me enough information (for my patients)	90	89	100
Addressed emotional concerns	95	95	100
Found it boring	10	16	22
Time viewing was well spent	100	84	88
Allowed me to learn at my own pace	100	95	88
Easy to find information	100	89	100
Valuable to parents of teens facing decision	95	95	100
Would help patients understand their options	100	95	100
Personal stories were useful to me	80	74	100
Forms that can be printed/downloaded are useful	—[a]	84	83
It gave me reassurance	95	—	—
Felt overwhelmed by too much information	15	26	22
Would like to have patient section for use in clinic	—	72	80
Would be valuable for intimate partner	100	—	—
Confusing to get from section to section	5	21	12
Pictures/animations make it easier to understand	95	89	100
Counseling skills would make discussion easier	—	94	88
Will make it easier to decide to bank sperm or not	90	—	—
Information in BOF was relevant for my practice	—	79	100
Information in BOF was relevant	85	—	—
Decision aid helps patients clarify feelings	79	94	100
BOF will make professionals more likely to discuss sperm banking with patients	—	89	80
Valuable to all men facing infertility before cancer treatment	100	—	—

[a]Empty dashes indicate that a question was not asked in that version of the evaluation form.

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compared with four items for men who had not viewed BOF.

The positive evaluations suggest that BOF is ready for larger-scale validation trials. We plan to contact men two or three weeks after they view BOF and ascertain both their decision about banking sperm and their satisfaction with that choice [13]. We will then validate the Sperm Banking Thermometer, performing a factor analysis to see if we derive subscales with good internal consistency, predicting men's choices. Items that do not load on a subscale or are uncorrelated with sperm banking choice could be eliminated.

An advantage of BOF is that patients can access it directly by computer when they have to make a quick decision about sperm banking. BOF covers far more information than would typically be conveyed in an oncology clinic. If a patient spends 45–60 min viewing BOF, physicians and other health professionals can use their precious time to discuss his individual risk for infertility, provide psychological support and facilitate his decision-making.

Because BOF is interactive, with menus and search features, patients and family members can find the topics of highest interest. The videos and suggestions on reducing anxiety when providing a semen sample may help young adolescents who have difficulty ejaculating on demand at the sperm bank [8,14].

The main limitation of this study is the small sample size. Further validation will be necessary before BOF can be called an evidence-based intervention, and even then research may not be able to pinpoint the individual elements that are most effective. Still, BOF is already an attractive tool for educating health-care professionals and patients about banking sperm.

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