

Improving Access to Standardized Fertility Preservation Information for Older Adolescents and Young Adults with Cancer: Using a User-Centered Approach with Young Adult Patients, Survivors, and Partners to Refine Fertility Knowledge Transfer

Seline Tam¹ · Natasha Puri² · Derek Stephens³ · Laura Mitchell⁴ · Meredith Giuliani⁵ · Janet Papadakos⁶ · Abha A. Gupta^{7,8}

© American Association for Cancer Education 2016

Abstract Adolescent and young adult (AYA) cancer patients under 40 should be made aware of their fertility risks and preservation options throughout their care. However, discussions on fertility preservation (FP) do not routinely occur. With a dearth of FP resources, oncology providers may lack knowledge around FP. Thus, informational needs can be unmet, leading to anxiety and distress in patients. Provision of pertinent and timely information can help patients cope better with their diagnosis. FP pamphlets were developed for men and women with cancer. A cross-sectional in-house survey, using convenience sampling, evaluated the pamphlets' effectiveness and measured ease of understanding, acceptability, and perceived utility. Patients and partners were also asked to provide recommendations and complete the Short Test of Functional Health Literacy in Adults (S-TOFHLA) measuring health literacy level. This helps determine if health literacy influences perception of pamphlet effectiveness. All partici-

pants ($n = 56$) reviewed both pamphlets. Fifty-four participants (96 %) found the pamphlet for men useful, while 29 participants (52 %) improved their male fertility knowledge. The pamphlet for women was useful for 52 participants (93 %) and improved knowledge in 35 (63 %) of them. Although the majority of participants had adequate health literacy (98 %), there was insufficient sample diversity to determine if health literacy influenced the pamphlet's effectiveness. Participants indicated preference in receiving verbal (73 %) and written (66 %) information over watching videos or in-class education. They recommended including fertility clinics, financial resources, and statistics in the brochures. These FP pamphlets were concluded as effective in supporting patients in making FP decisions.

Keywords Adolescent and young adults · Fertility · Preservation · Patient education · Health literacy · Cancer ·

✉ Abha A. Gupta
abha.gupta@sickkids.ca

¹ Princess Margaret Cancer Centre, Adolescent and Young Adult Program, Schulich School of Medicine and Dentistry, University of Western Ontario, London, ON, Canada

² Princess Margaret Cancer Centre, Adolescent and Young Adult Program, College of Arts & Science, New York University, New York, NY, USA

³ Hospital for Sick Children, Biostatistics, Design & Analytics, Department of Public Health Sciences, University of Toronto, Toronto, ON, Canada

⁴ Princess Margaret Cancer Centre, Adolescent and Young Adult Program, Lawrence S Bloomberg Faculty of Nursing, University of Toronto, Toronto, ON, Canada

⁵ Radiation Medicine Program, Princess Margaret Cancer Centre, & Department of Radiation Oncology, University of Toronto, Toronto, ON, Canada

⁶ Princess Margaret Cancer Centre, Oncology Patient and Family Education, Toronto, ON, Canada

⁷ Princess Margaret Cancer Centre, Division of Medical Oncology, University of Toronto, Toronto, ON, Canada

⁸ Division of Hematology/Oncology, Department of Pediatrics, Hospital for Sick Children, 555 University Avenue, Toronto, ON M5G 1X8, Canada

Introduction

With more than 2000 adolescent and young adults (AYA) diagnosed with cancer within the reproductive age of 18 to 39 each year in Canada, the effects of cancer treatment on fertility has become an important consideration for both patients and oncology providers [1]. As such, it has become increasingly vital for providers to communicate with patients about fertility risks and preservation options [2]. The effect on an individual's fertility can vary from low to high risk based on numerous patient and treatment factors [3]. The American Society of Clinical Oncology (ASCO) developed fertility preservation (FP) guidelines to aid oncology providers in communicating with patients about potential threats to fertility as early as possible in the treatment process [4]. This guideline is meant to educate providers on all possible options for fertility preservation so they can best provide care for their patients based on each specific case. Despite that these guidelines were published in 2013, patients report that fertility discussions with providers are still lacking as the majority of physicians were unaware of the ASCO guidelines and were more likely to have conversations if they were educated around fertility or had favorable attitudes towards FP [5].

With increased cancer survival rates in AYA patients [6, 7], fertility has been highlighted as a significant cause of psychosocial distress and should be addressed [8]. If fertility risks and preservation options are not properly addressed by oncology providers, patients in their reproductive years can experience feelings of depression, anxiety, lowered self-esteem, and changes in self-identity [9, 10]. Published literature shows that men who banked their sperm prior to treatment felt more reassured and less worried about their fertility compared to their counterparts who did not sperm bank [11]. Fertility concerns can induce higher levels of distress, particularly in women with cancer due to their reproductive capabilities [12]. Fertility impairment among cancer survivors can also increase the pressure of finding a partner, while also affecting social relationships, dating prospects, and life-planning [13, 14].

There are many barriers that prevent oncology providers from discussing potential threats to fertility and fertility preservation options with patients [15]. Barriers include: feelings of discomfort about the topic, minimal knowledge and resources required to support discussions, urgency of treatment initiation, poor prognosis, and financial costs associated with fertility preservation procedures [15]. This is unfortunate because in light of cancer type, cancer treatment, and prognosis, AYA have expressed interest in knowing their fertility risks and preservation options [8, 16]. Most patients, including those who have not received gonadotoxic treatments that

directly threaten their fertility, indicate that they still want their reproductive health included in conversations with oncology providers [12, 17].

The provision of pamphlets around the risk of infertility and fertility preservation options can facilitate information sharing between young adult cancer patients and oncology providers. Pamphlets can act as a tool to minimize discomfort in providers through supplementing and initiating conversations around fertility. Additionally, these pamphlets can address fertility-specific concerns that patients may encounter, as well as provide a general understanding of the potential effects of cancer and treatment on fertility. This will help ensure that there are beneficial resources available to sufficiently reduce the knowledge gap existing among patients and providers. In addition, the provision of written information is important as patients only retain 40–80 % [18] of the information provided to them at diagnosis, while only recalling half of that information correctly. Pamphlets can also serve as useful reference material to equip patients in making well-informed decisions [19].

It is important to consider health literacy when developing patient education resources because a significant number of Canadians have limited health literacy [20]. Health literacy is defined as the skills and competencies necessary to find, comprehend, evaluate, and use health information to make decisions and improve quality of life [21]. Although limited health literacy in Canada is primarily found among older adults, members of the Aboriginal population, recent immigrants, and people with lower levels of education and/or low English or French proficiency, limited health literacy can also be found among AYA [22]. The reason for this is that many AYA are still in the process of developing their competency with functional literacy and may have less experience with the healthcare system compared with their adult counterparts [23]. As such, AYA may have greater difficulty applying health information to themselves than those with more experience with the healthcare system. Patient education resources that are directed at AYA must consider strategies to mitigate the potential that AYA patients have limited health literacy. These strategies include writing in plain language, underpinning the educational content with appropriate adult learning theories, and making sure that resources are accessible [23].

Study Purpose

The purpose of this study was to (1) co-create fertility pamphlets that provide high-quality information to help AYA patients know their fertility risks and preservation options, (2) evaluate the effectiveness of the pamphlets, and (3) determine whether patient perception of pamphlet effectiveness is influenced by health literacy level.

Study Design and Methods

Part 1. User-Centered Resource Development

A user-centered design approach was employed to develop the fertility preservation pamphlets. This approach included three stages of development. The first stage was an environmental scan of existing reproductive health information and an analysis of the applicability of existing resources to AYA diagnosed with cancer. The second stage was to adapt existing content and tailor for AYA cancer patients through a review process that involved an interdisciplinary team of healthcare professionals, patients, and partners. The third stage was to conduct a plain language review of the draft pamphlets and to underpin the content with adult learning theory.

An environmental scan of available FP resources currently distributed across Canada was conducted. The scan yielded seven resources related to FP, where six mentioned risks from treatment, two mentioned more than one preservation option, and all were cancer-specific. Approximately five of these pamphlets were distributed in healthcare institutions and were either tailored to a specific fertility clinic in the area or provided only a brief description of the fertility risks and options available. However, they did not address psychosocial concerns (i.e. when a decision has to be made, what to expect at the clinic) that could help guide patients through the decision-making process of FP. Thus, a dearth of resources providing information that can help guide patients and their partners around their fertility preservation options exists.

Next, permission was obtained to have appropriate content collected from an existing pediatric resource, expanded, and tailored to AYA cancer patients. A pamphlet on sperm banking, developed at an affiliating pediatric hospital, was reviewed by several young men with cancer and their partners, who provided feedback through a qualitative interview focused on (1) ease of understanding, (2) appropriateness, and (3) perceived utility of the brochures to determine if the content needed to be expanded for their particular age group. Main concerns with this pamphlet include the age appropriateness of the wording and graphics, and a lack of detail necessary to support the patient in their decision-making and understanding of FP. Changes were then made to create pamphlets that are better suited to this population by increasing the maturity and depth of the content provided (Fig. 1). The female fertility pamphlet was then developed by the Adolescent and Young Adult (AYA) Program at the Princess Margaret Cancer Centre with the support of an oncologist, reproductive endocrinologist, clinical nurse specialist, young adults (not patients), and a graphic design team (Fig. 2). Once the subject matter experts and patients completed the content, a plain language review of each resource was conducted to develop user-friendly resources for patient and family use. The recommendations for plain language improvements included

improving flow of content, limiting the number of words per sentence to ten, avoiding the use of words with more than three syllables, chunking content into a logical order, and using bullets to break up chunks of text to increase readability. The final version was reviewed again by healthcare experts to ensure that the pamphlets maintained informational integrity.

Part 2. Pamphlet Evaluation

Study Design

A cross-sectional survey using convenience sampling was conducted to evaluate the fertility preservation pamphlets. The survey consisted of an in-house developed evaluation that assessed patient perception of pamphlet effectiveness and the Short Test of Functional Health Literacy in Adults instrument (S-TOFHLA) to measure health literacy [24].

Setting and Sampling Procedure/Recruitment

Participants from the Princess Margaret Cancer Centre were recruited to participate in the evaluation if they were under 40 and had completed at least 2 months of cancer treatment, or if they were a partner of a young adult cancer patient.

Data Collection

Patients were first asked to complete a demographic form to provide information on their cancer type, treatment type, and educational background. Additionally, it contained several questions regarding their ability to read English and interests in fertility. A survey was developed in-house to evaluate the FP pamphlets. The survey included 27 questions about the pamphlets and used 5-point Likert scales to ask patients to rate their agreement with statements about the pamphlet from “strongly disagree” to “strongly agree.” The survey questions were adapted with permission from another study that evaluated patient education materials developed for elderly lung cancer patients [25]. This survey evaluated the pamphlets in terms of their (1) ease of understanding, (2) acceptability, and (3) perceived utility. Participants were also asked to compare their knowledge of FP before and after reading the pamphlets.

To assess health literacy level, the S-TOFHLA was completed by participants. The S-TOFHLA score is a validated reading comprehension exercise that tests the ability of participants in reading passages using real materials from a healthcare setting. It contains two passages where each participant is given a 7-min time frame to complete all passages. The test involves 36 items and uses a modified Cloze Procedure [24].

Fertility Preservation

For Men Starting Cancer Treatment



The ability to have children is often a concern for many men starting cancer treatment.

This pamphlet provides information on sperm banking, the most commonly used fertility preservation method for men.



What happens at the fertility clinic?



What if I have more questions or concerns?

Please ask any member of your healthcare team. If you feel more comfortable talking to a male staff member, this can be arranged.

Fig. 1 Section of the fertility preservation pamphlet developed for men with cancer

Data Analysis

The S-TOFHLLA was scored according to the developer's recommendations to determine the functional health literacy for each participant. Demographic data, descriptive statistics, and pamphlet effectiveness scores were reported

with means and standard deviations, medians, and inter-quartile ranges and proportions, where appropriate. The questionnaire scores were used to determine the effectiveness of the FP pamphlets. Pamphlet "effectiveness" is determined from a participant if an "agree" or "strongly agree" is assigned to at least 17 of 20 assessment items.

Fertility Preservation

For Women Starting Cancer Treatment



The ability to have children is often a concern for many women starting cancer treatment.

This pamphlet provides information on egg and embryo freezing, and how it may increase your chances of having a child one day.



What happens at the fertility clinic for egg and embryo preservation?

→ Egg Preservation → Embryo Preservation

PREPARATION
Go through blood tests and transvaginal ultrasound (probe inserted into vagina to look at ovaries)

STIMULATION
Hormone medications are given through a needle to stimulate your ovaries to produce eggs

IN VITRO FERTILIZATION (IVF)
Eggs are fertilized with sperm in a test tube to form an embryo

SURGERY
Eggs will be collected through day surgery. Pain medications will be given as you will be awake during it

IN VITRO FERTILIZATION (IVF)
Eggs are fertilized with sperm in a test tube to form an embryo

EXAMINATION
Eggs will be examined to make sure they are healthy

IN VITRO FERTILIZATION (IVF)
Eggs are fertilized with sperm in a test tube to form an embryo

STORAGE
Eggs and embryos will be safely kept frozen using liquid nitrogen

RECOVERY
When you are ready to conceive, your eggs or embryos will be thawed

IMPLANTATION
An embryo will be placed inside your uterus (womb)

What if I have more questions or concerns?

Please ask any member of your healthcare team. If you feel more comfortable talking to a female staff member, this can be arranged.

Figure 2 Section of the fertility preservation pamphlet developed for women with cancer

The pamphlets are therefore effective if 75 % of all participants find it effective. To determine if health literacy impacts the perception of infographics effectiveness, the mean score on the S-TOFHLLA was compared on a two-sided *t* test for those who found the pamphlets effective (at least 17 out of 20 items scored as agree or strongly agree) versus those who did not find the pamphlets effective.

Results

Between July and August 2015, 70 participants were approached to participate in the study and 56 (80 %) of those approached participated. All 56 participants completed the demographic form, read and evaluated both of the fertility preservation pamphlets (for men and women), and completed the S-TOFHLLA.

Table 1 Patient and partner demographic information

	Patient/partner <i>n</i> = 56 (%)
Gender	
Male	26 (46)
Female	30 (54)
Age (years)	
15–19	5 (9)
20–24	6 (10)
25–29	14 (25)
30–34	20 (36)
35–39	10 (18)
40–44	0 (0)
45–49	1 (2)
Ethnicity ^a	
White	35 (63)
Asian	14 (25)
Hispanic	1 (2)
Other	11 (20)
Sex orientation	
Opposite	55 (98)
Other	1 (2)
Cancer type	
Leukemia	16 (28)
Lymphoma	20 (36)
Breast	11 (20)
Genitourinary	1 (2)
Gastrointestinal	2 (3)
Sarcoma	4 (7)
Head and neck	1 (2)
Gynecological	1 (2)
Treatment type	
Chemotherapy only	23 (41)
Radiation only	0 (0)
Surgery only	1 (2)
Two of three	18 (32)
All three	14 (25)
Educational background	
Some high school	1 (2)
High school	8 (14)
Technical school	0 (0)
Post-secondary	38 (68)
Post-graduate	9 (16)

^a Some participants indicated multiple ethnicities; *n* > 56

Table 2 Method and importance of fertility conversations

	All participants <i>n</i> = 56 (%)
Preferred method of receiving FP info ^a	
Verbal	41 (73)
Written	37 (66)
Video	12 (21)
Website	32 (57)
Education	6 (11)
Importance of FP conversation	
Very important	43 (77)
Important	8 (14)
Somewhat important	3 (5)
Not important	2 (4)

^a Participants were asked to choose their preferred methods; *n* > 56

Table 3 Overall comments and thematic feedback from participants

	Pamphlet for men <i>n</i> = 56 (%)	Pamphlet for women <i>n</i> = 56 (%)
Patients with fertility concerns would find the pamphlet useful	54 (96)	52 (93)
The pamphlet provided helpful information	53 (95)	53 (95)
Overall impression of pamphlet was excellent or above average	45 (80)	46 (82)
The pamphlet changed what I know about fertility preservation	29 (52)	35 (63)
Feedback		Comments from participants
Information on fertility Clinics		“Possibly list clinics that are available to go to...”
Statistics		“More statistics – makes it easier to understand the importance of preserving eggs, etc.”
Financial resources		“You can add some financial resource options.”
Color scheme		“Maybe change the colour scheme. Blue is a more peaceful colour when presenting information in relation to red.”

Demographics

Demographic and treatment information are listed in Table 1. Forty-eight (86 %) of the participants were patients, while the other 8 (14 %) were partners of patients. Twenty-six (46 %) participants identified as men while 30 (54 %) identified as women. Disease sites associated with the participants were leukemia, 16 (28 %); lymphoma, 20 (36 %); breast, 11 (20 %), and others, 9 (16 %), which included sarcoma, genitourinary, gastrointestinal, head and neck and gynecological. The median age of participants was between ages 25 and 29. All participants indicated that they spoke English at home, and 47 (84 %) participants indicated that their ability to read English was “excellent.”

FP Pamphlet Evaluation

Both the pamphlets developed for men and women were rated as effective with the majority of participants (46, 82 %; 44, 79 %, respectively) rating “agree” or “strongly agree” for at least 17 of the 20 items. Twenty-nine (52 %) participants indicated having improved knowledge after reading the pamphlet for men while 35 (63 %) participants had improved knowledge after reading the pamphlet for women. No

significant differences were found between groups when comparing sex, age, ethnicity, and cancer type with the usefulness, ability to provide helpful information, ability to improve knowledge, and ability to create a good overall impression of the pamphlet. Finally, health literacy scores from S-TOFHLA indicate that 98 % of participants had adequate health literacy, while the health literacy of the remaining 2 % was marginal. The study team was unable to conclude if the pamphlets would be effective for patients with low health literacy. As such, there was insufficient diversity among the sample to determine whether the effectiveness of the pamphlet is influenced by health literacy.

Most participants (91 %) believed it was either “important” or “very important” to have conversations with their oncology providers about FP. Participants preferred receiving information on FP verbally (73 %), in written form (66 %), and online through a website (57 %) (Table 2).

Participants provided comments within the open-ended section of the survey. Comments were not negative, but primarily consisted of suggestions—the most common ones being to include a list of nearby fertility clinics, appropriate fertility statistics such as *in vitro* fertilization and preservation success rates, and financial resources to support these procedures (Table 3). They included positive feedback, such as “this should be in every oncologist’s office and should be part of a package given to every cancer patient.”

Discussion

This study used a user-centered design where participants were able to contribute to the development of FP educational materials, while considering health literacy in the young adult cancer population. The majority of study participants indicated that they would prefer to have FP information provided to them verbally and/or reinforced through written information.

The data from this study shows that having discussions around fertility with oncology providers is of great importance. These pamphlets were found effective for patients with fertility concerns and provided helpful information capable of increasing their knowledge around FP options. This study highlighted key items that patients and their partners suggested to be included in the fertility preservation pamphlets, including a list of fertility clinics, resources that can relieve financial burden, and statistics that can help patients better understand the importance of the FP process. To complement the use of these pamphlets, oncology providers need to be educated on fertility risks and preservation options so they can understand the importance of initiating these conversations with their patients. If healthcare providers do not have the time to facilitate these conversations, they can still provide these pamphlets to patients and their families to review as an

initial means of introducing the topic. The pamphlets can also support clinicians who may be experiencing discomfort with addressing the topic of fertility [15]. Furthermore, having FP information available in pamphlet format will help supplement physician-explained information, as patients may forget up to 80 % of the information provided to them at diagnosis [18]. As most FP pamphlets do not use the “plain-language” approach to produce more “user-friendly” pamphlets for patients, the development of these reviewed FP pamphlets play an important role in informing patients about FP risks and may help open dialogue between patients and oncology providers since FP conversations do not routinely occur.

However, the sample size is small and includes both patients and partners. We were unable to determine whether the FP pamphlets would have been effective for patients with limited health literacy. This may be due to volunteer bias from study participants, as individuals with limited health literacy are less likely to participate in studies that require reading and writing skills.

Partners may have different informational needs. The influence of health literacy could not be determined in part due to small sample size and bias of a convenience sample. Although only a small number of partners participated in the study, this was in part due to fewer of them being present in clinic at the time of recruitment. Future work is needed to obtain feedback from the partners of patients since many AYA may rely on their partners to help them navigate FP-related decision-making. Additionally, an important next step is the development of a different format for user-friendly knowledge transfer for AYA with limited health literacy.

Based on the feedback of study participants, the pamphlets have been revised and are now widely circulated throughout the hospital. Revisions included adding a list of fertility clinics in the region, re-organizing pamphlet sections so that important questions around fertility would be addressed first (i.e., costs and reimbursement programs), and explaining preservation options in greater detail with statistics. These pamphlets are being distributed by the Clinical Nurse Specialist working with the AYA Program at the Princess Margaret Cancer Centre and can be found at the Patient and Family Library at the hospital, as well as the hospital website. Emails were sent to patients enrolled in the AYA Program and to hospital staff notifying them of the fertility resource. Additionally, the pamphlets were presented to oncology nurses at a national nursing oncology conference, where nurses expressed interest in using this resource. Moving forward, the AYA Program at Princess Margaret will continue to inform other nationwide clinics and hospitals of this resource to help reduce barriers that prevent discussion around fertility risks and preservation options.

Compliance with Ethical Standards This study was conducted with approval from the University Health Network Research Ethics Board (REB).

References

1. Canadian Cancer Society's Advisory Committee on Cancer Statistics (2015) Canadian cancer statistics 2015. Canadian Cancer Society, Toronto, ON
2. Benedict C, Shuk E, Ford JS (2015) Fertility issues in adolescent and young adult cancer survivors. *J Adolesc Young Adult Oncol*. doi:10.1089/jayao.2015.0024
3. Rodriguez-Wallberg KA, Oktay K (2014) Fertility preservation during cancer treatment: clinical guidelines. *Cancer Manag Res* 6: 105–117
4. Loren et al. (2013) Fertility preservation for patients with cancer: American Society of Clinical Oncology Clinical Practice Guideline Update. *J Clin Oncol* 31(19):2500–2510
5. Quinn G et al. (2009) National survey of physicians practice patterns: fertility preservation and cancer patients. *J Clin Oncol* 27: CRA9508
6. Johnson MD, Cooper AR, Jungheim ES, Lanzendorf SR, Odem RR, Ratts VS Sperm banking for fertility preservation: a 20-year experience. *Eur J Obstet Gynecol Reprod Biol* 170(1):177–182
7. Rodriguez-Wallberg KA (2012) Principles of cancer treatment: impact on reproduction. *Adv Exp Med Biol* 732:1–8
8. Rosen A, Rodriguez-Wallberg KA, Rosenweig L (2009) Psychosocial distress in young cancer survivors. *Semin Oncol Nurse* 25(4):268–277
9. Halliday LE, Boughton MA (2011) Exploring the concept of uncertain fertility, reproduction, and motherhood after cancer in young adult women. *Nurs Inq* 18(2):135–142
10. Crawshaw MA, Sloper P (2010) 'Swimming against the tide'—the influence of fertility matters on the transition to adulthood or survivorship following adolescent cancer. *Eur J Cancer Care (Engl)* 19(5):610–620
11. Saito K, Suzuki K, Iwasaki A, et al. (2005) Sperm cryopreservation before cancer chemotherapy helps in the emotional battle against cancer. *Cancer* 104(3):521–524
12. Gorman, JR, Su HI, Roberts SC et al. 2014. Experiencing reproductive concerns as a female cancer survivor is associated with depression. *Cancer*
13. Carpentier MY, Fortenberry JD (2010) Romantic and sexual relationships, body image, and fertility in adolescent and young adult testicular cancer survivors: a review of the literature. *J Adolesc Health* 47(2):115–125
14. Tschudin S, Bitzer J (2009) Psychological aspects of fertility preservation in men and women affected by cancer and other life-threatening diseases. *Hum Reprod Update* 15(5):587–597
15. Medicine, A. S. f. R (2013a) Fertility preservation and reproduction in patients facing gonadotoxic therapies: a committee opinion. *Fertil Steril* 100(5):1224–1231
16. Crawshaw M (2013) Psychosocial oncofertility issues faced by adolescents and young adults over their lifetime: a review of the research. *Hum Fertil (Camb)* 16(1):59–63
17. Wright CI, Coad J, Morgan S, et al. (2013) 'Just in case': the fertility information needs of teenagers and young adults with cancer. *Eur J Cancer Care (Engl)* 23(2):189–198
18. Kessels R (2003) Patients' memory for medical information. *J R Soc Med* 96:217–222
19. Nagel K, Wizowski L, Duckworth J, Cassano J, Hahn SA, Neal M (2008) Using plain language skills to create an educational pamphlet about sperm banking for adolescent and young adult males with cancer. *J Pediatr Oncol Nurs* 25(4):220–226
20. Manganello JA (2008) Health literacy and adolescents: a framework and agenda for future research. *Health Educ Res* 23:840–847
21. Zarcadoolas C, Pleasant A, Greer DS (2003) Elaborating a definition of health literacy: a commentary. *J Health Commun* 8(Suppl 1): 119–120
22. Davis T et al. (2002) Health literacy and cancer communication. *CA Cancer J Clin* 52(3):134–149
23. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K (2011) Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med* 155:97–107
24. Parker RM, Baker DW, Williams MV, Nurss JR (1995) The test of functional health literacy in adults: a new instrument for measuring patients' literacy levels. *J Gen Intern Med* 10:537–541
25. Jewitt N, Hope AJ, Milne R, Le LW, Papadakos J, Abdelmutti N, Catton P, Giuliani ME (2015) Development and evaluation of patient education materials for elderly lung cancer patients. *J Canc Educ*. doi:10.1007/s13187-014-0780-1