

Chapter 2

Communicating Across Diverse and Differently Literate Audiences

Jennifer E. Mersereau and Anna R. Brandon

Barriers to Communication: The Scope of the Problem

The majority of health information is delivered in English [1]. Yet, according to the US Census Bureau, about 20.3 % of the population speaks a language other than English in the home, a number that increased by 140 % between 1980 and 2007 [2, 3]. More than 400 languages are spoken in the United States [2]; more than 50 million people residing in the United States (16 %) are of Hispanic or Latino origin alone, an increase of 15.2 million just in the last decade, and growing at 4 times (43 %) the growth of the total population (10 %). Practically illustrating the disparities, one cross-sectional study revealed that while whites received 57 % of all eligible health services, only 35 % of Hispanics with limited English proficiency received the health services for which they were eligible [4]. Although inequities in health care result from multiple factors, research suggests that those minorities with limited English proficiency are among the groups treated most unfairly [1].

Communication, however, is more than speaking the same “language.” Attitudes, beliefs, and values passed down through generations in families and societies have a significant impact on both the clinician and the patient regarding expectations for care and outcomes. A sample of 74 Russian-speaking cancer patients in San Francisco, California highlighted that cultural taboos about the word “cancer” and other dynamics of care benefit from interpreters trained to understand the interaction of language and culture [5]. Cultural “mismatches,” occurring when provider and

J.E. Mersereau, M.D., M.S.C.I. (✉)

Department of Obstetrics and Gynecology, University of North Carolina,
Chapel Hill, 4001 Old Clinic Building, Chapel Hill, NC 27599, USA
e-mail: jmerse@med.unc.edu

A.R. Brandon, Ph.D., M.S.C.S.

Department of Psychiatry, University of North Carolina, Chapel Hill, NC, USA
e-mail: anna_brandon@med.unc.edu

patient have disparate attitudes, beliefs, and values about disease and treatment, have been found to negatively impact not just patient satisfaction but the actual quality and effectiveness of health care [6].

Low Health Literacy: A National and International Epidemic

In the United States, approximately half of the adult population has been found to have low health literacy, or the ability to successfully obtain, process, and appropriately act on health information [7]. Census reports indicate that 15 % of adults have not completed high school education, and estimates are that approximately 43 % of American adults had “basic” or “below basic” prose literary skill (the lowest of four levels) [3, 8, 9]. Particularly concerning in the health arena, 20 % of adult Americans read at a fifth grade level or lower, and the resulting low health literacy has been associated with increased cancer disparities [7, 10]. Further support for this association is found in a study of men in the US Veteran’s Administration system suggesting that, compared to men with better reading abilities, men with a reading level below the sixth grade had a were 69 % more likely to be diagnosed with late-stage prostate cancer, despite equal access to screening tools [11].

Discussion cancer, reproductive function, and technology utilized for fertility preservation (FP) require the use of language often unfamiliar even to individuals with high school and above educational levels, further disadvantaging those with limited proficiency in English and those in lower socioeconomic groups.

Internet-Based Information

In the United States in 2012, over 81 % of adults reported routinely accessing the Internet, and 80 % of these individuals endorsed gathering health-related information on the web [12]. The US National Cancer Institute’s “Health Information Trends Survey” (HINTS) found that 28 % of Americans specifically searched for cancer information on the Internet in 2005, and that a significant majority went to the Internet first, before seeking care with a health professional [13]. Potential explanations for this trend have not been fully studied, but may include limited accessibility to their healthcare provider, hesitancy to ask providers sensitive issues about reproduction, or limited ability for the healthcare professionals to answer questions outside their area of expertise.

The term “e-health” has been coined to describe the use of the Internet (or related technologies) to gather health information and locate services. Such technology affords user flexibility for access, and provider tailoring of content and language to unique user needs. Online tools can be adjusted based on user’s culture or language, using interactive tools to enhance learning. E-health programs potentially could provide substantial opportunities in low-health literate populations by providing

pictures, and consistency in navigation [14]. In addition, E-health strategies have other potential benefits, such as broad reach, 24-h availability, anonymity or a social interaction (whichever is preferred), multimedia options, and the potential to tailor to the needs of groups or individuals [15].

However, despite these advantages, e-health has not been demonstrated to be universally beneficial in providing information in a way that improves health outcomes. There are several potential reasons why internet-based information may fail to provide adequate information to high-literacy or low-literacy populations. For example, the overall readability for many cancer-focused websites is at a high-school level or beyond [16]. In a study of a sample of Spanish-language health-related websites, 86 % were written at a college-level readability [17]. Other HINTS research has shown that people who have lower subjective health literacy are more likely find online material frustrating and “took a lot of effort” to understand [18].

The Unequal Burden of Cancer

Current advances in the field of oncology have great potential to improve survival and quality of life after cancer treatments. However, the above-discussed barriers to communication and low health literacy mean vulnerable populations of patients often have limited access and comprehension of new options and strategies to prevent and treat cancer. More than a decade ago, the US Institute of Medicine document “The Unequal Burden of Cancer,” described and prioritized addressing the disparities of cancer incidence and mortality among the US populations [19]. Unfortunately, in certain minority groups, cancer continues to be often poorly understood, with significant misperception about screening techniques. For example, in a 2005 cross-sectional US study, more than 25 % of Hispanics and about 18 % of African Americans, compared to 14 % of whites, believed that there was nothing they could do to reduce their risk of cancer [20]. In another study, 75 % of Vietnamese-American women, a group with high rates of cervical cancer, did not know the purpose of Pap smears [21]. Finally, nonwhite cancer survivors report a higher number of information needs, including more health promotion, interpersonal and emotional, side effects and symptoms, and insurance needs [22].

Unmet Needs About Information Regarding Fertility and Cancer

Research in young adults with cancer consistently supports that these patients have an interest in their fertility and that they believe they should have, at the very least, the opportunity to understand that the treatment they undergo for cancer may end fertility potential. In the area of breast cancer, 57 % of women reported substantial concern at diagnosis about losing fertility, and 29 %

admitted that those concerns influenced treatment decisions [23]. However, while young survivors express an interest in fertility, many women felt that they had inadequate exposure to information about fertility before and after cancer treatments [24]. Unfortunately, a recent study suggested that only 28 % of patients reporting fertility concerns actually reported meeting with a fertility specialist [25]. On the other hand, healthcare providers are challenged by the lack of consensus about what characteristics identify patients as “appropriate” to refer for a fertility preservation consultation (FPC).

Recent evidence suggests that there are racial, social, and demographic disparities that distinguish which young women with cancer receive FP information and treatment vs. those who do not [26]. For example, nonwhite racial groups have greater unmet information needs regarding fertility and cancer, compared to Caucasians [27]. In a retrospective chart review of 199 medical records of women with a new cancer diagnosis, Caucasian women were referred twice as often for fertility preservation consultation (FPC) than women of other ethnicities, and patients with insurance coverage were 40 % more likely to be referred for FPC [28]. According to the study, only 22 % (9/51) of eligible African American women received FPC, and no Hispanic women (0/19) received FPC. A survey study from the California Cancer Registry found that Latina women were 80 % less likely to pursue FP treatments than Caucasians [26]. They also reported that of 31 African American women, none pursued FP strategies. Beyond racial and ethnic factors, the level of education also predicts a woman’s access to information about FP. In a survey-based study of 918 young women receiving cancer treatment, women were significantly more likely to have fertility addressed by their oncologist if they were educated at the Bachelor’s level or beyond (Adjusted OR [95 % CI] 1.4 [1.0–2.1], $p=0.005$) [26]. Only one study to date has addressed sexual orientation and FP access; the investigators reported that, compared to 32/813 heterosexual women, none of the 29 women who self-identified as non-heterosexual pursued FP treatment [26]. Potential explanations for these differences have not been adequately explored but are likely to include language barriers, health literacy, and cultural beliefs about the issues of cancer and reproduction [26, 29, 30].

What Are Unique Communication Challenges with Fertility Preservation?

Fertility Preservation Topics Are Complex

In all young men and women with a new cancer diagnosis, discussion about fertility and cancer treatments can be challenging. Advances in assisted reproductive technology provide ways to preserve fertility in young women, with four clear options: (1) oocyte cryopreservation, (2) embryo cryopreservation, (3) ovarian suppression by administration of a GnRH agonist, a medication that puts the ovaries “at rest” during cancer treatment, or (4) ovarian tissue cryopreservation.

A final option is to elect to “wait and see” if fertility is compromised after treatment. Each of these FP options carries unique risk factors as well as varying probabilities for later pregnancy. It is difficult to discuss these risk factors with patients because outcomes are dependent upon the dose and duration of cancer treatment, the age of the patient, and the patient’s baseline ovarian reserve when treatment begins, all alongside other risk factors for infertility that women face independent of cancer or cancer treatment [31]. Perhaps in part because of this complexity, less than half of the female cancer patients of reproductive age receive sufficient information about these options or an appropriate referral for FPC before cancer treatment begins [26, 31–34].

Because the FPC covers such complex topics, women who have a higher level of education are at an advantage to understand and integrate the concepts quickly enough to pursue intervention. In addition, women with a higher education background may be more assertive and proactive with their providers, bringing up the topic of FP themselves, important since many oncologists are NOT routinely discussing FP unless their patients bring it up [35]. The complexity of FP options has led to research elucidating what patients know, need to know, and what they retain after receiving an FP consultation. Using objective measures of FP knowledge, investigators consistently find poor FP knowledge in patients prior to the FPC [36, 37]. After the FPC, findings suggest that the objective measures of overall FP knowledge remain poor, with an average score on a validated FP knowledge scale of about 50 % correct [38]. Specifically focusing on those questionnaire items addressing patient comprehension about the risks associated with FP (e.g., cancer recurrence risk, birth defects in future children), approximately half of the sample responded with inaccurate assessments of these risks. Such misperceptions of risk may prevent women from making informed decisions not just about immediate FP, but also about any future pursuit of biological reproduction. On the other hand, those women in the sample who demonstrated higher pre-visit and post-visit knowledge also had higher levels of education or had actively sought out information prior to a FPC. These data suggest that significant numbers of young women need basic preparation for the information they will receive at the FPC and the decision-making processes involved in choosing an option (or not choosing FP at all).

Time Limitations Exist to Absorb Complex FP Information

Understandably, most oncology providers themselves do not have the time or expertise to take responsibility for the essential communications about FP [39, 40]. Even more than other medical fields, the language used during an FPC is highly specialized, filled with interrelated medical, embryological, and statistical concepts about processes and probabilities for achieving later pregnancy. When FP is discussed with patients, methods vary from simply providing printed information from organizations such as Fertile Hope or LiveSTRONG, to counseling by the oncology provider and to formal consultation with a fertility specialist. Surveys of breast

cancer survivors identify limitations to these methods, suggesting that at least 25–50 % do not receive adequate or appropriate education, counseling, or resources about reproductive decisions prior to their cancer treatments [25, 41]. Unlike an infertile woman who may have been attempting pregnancy for years and is already familiar with basic concepts of assisted reproduction, young women newly diagnosed with cancer have to assimilate unfamiliar information regarding their FP alternatives simultaneously with the details of cancer treatment.

Beyond the time and expertise required for conveying this complex set of alternatives to patients are the serious concerns oncologists may have about delaying cancer treatment long enough for FP to occur [42, 43]. One cycle of ovarian hyperstimulation may take several weeks; physician and patient alike may believe that this delay could have adverse survival consequences that outweigh the benefits of consideration of fertility options. However, at least one qualitative investigation suggests that women benefit from at least being informed that there are ways for preserving fertility even if the oncologist believes the risks of FP are too great [24, 32].

Appropriately Translated FP Material Does Not Exist

Language has been considered the “lowest common denominator of cultural sensitivity,” and language barriers are an obvious problem in populations who may have difficulties maneuvering through health information. In the United States in 2007, 20 % of the population over the age of five spoke a language other than English at home [44]. However, it is estimated that only 2 % of websites use a language other than English [15]. Literal translation alone does not always allow for effective communication of complex health topics and regional and cultural nuances may add extra challenges. Ideally, complex medical topics, such as FP, would be linguistically and culturally adapted, rather than literally translated, to meet the needs of the intended audience. However, this type of adaptation can be expensive and resource-intensive.

Cultural Sensitivities

Cultural variation adds an extra level of difficulty beyond language and literacy in the effective communication of complex medical topics such as FP. Intangible concepts such as values, risk perceptions, and family/community/religious relationships may affect the comprehension of and satisfaction with communication about fertility and cancer. Healthcare providers, with their own medical culture, may not be fully aware of their own communication skill level, assumptions about cultural values, or personal biases [6]. Cultural beliefs and norms affect views about screening and early detection, compliance with treatment, and even the disease of cancer [45]. To demonstrate this complexity, one team identified at least seven domains impacting the view of aging Chinese women toward cancer screening and treatment: fatalism, the use of herbs, self-care, hot-cold balance, lifestyle, medical

examination, and Western medicine [46]. Although at least one group has piloted a counseling intervention for female breast cancer survivors at risk for reproductive health problems, outside of documenting ethnic and social predictors of care little is known about the cultural beliefs and values of specific populations of women surrounding cancer and FP [47].

Because both the diagnosis of cancer and of the possibility of future motherhood are emotionally charged topics, discussion by health professionals necessitates sensitivity to the cultural standards influencing patient expression of emotion. Unfortunately, behavioral science research suggesting how clinicians might better accommodate and regulate emotion specifically during FP conversations is lacking [40]. Social psychologists, on the other hand, have published extensive research on communication processes. The so-called difficult conversations generally have three core elements: Establishing what has/is happened/happening, exploring feelings, and establishing what the impact is upon an individual's self image [48]. There are cultural and individual variations of how these three features are negotiated between speakers, but they are always in play. Most clinicians have little difficulty establishing a diagnosis or a recommended treatment plan, but often exploring a patient's feelings may be more of a challenge. Yet most research suggests that patient-centered care requires a working alliance, that is, a physician–patient relationship that moves beyond fact sharing and treatment planning to discussions that include psychosocial and experiential issues the patient may be facing [49]. Unexpressed feelings make it hard for patient and clinician to hear each other, and could be one reason why women may hear an oncologist mention a referral for an FPC, but not attend to the details regarding the options or probabilities for later conception success. The simple question, “What are your feelings about having a child at some later point in your life?” not only opens the conversation but assures the patient that these feelings are normal, valid, and important to the clinician as treatment recommendations are being formed. Following that question up with “How important is it to you to have your own biological child?” moves the conversation then toward how important natural conception is to the identity of the patient to a mental health professional. If a patient appears to be at risk for depression or anxiety, an appropriate referral can be made, normalizing the distress by pointing out many women seek out additional support when considering important decisions like this one.

Strategies to Improve Communication: Addressing the Challenges

There are potential strategies that exist to improve communication about complex topics such as FP and cancer in all populations, especially vulnerable populations who may have racial, educational, and language barriers. For example, prior research has shown that cancer survivors of lower socioeconomic status may need assistance and training in how to gain access to information and may benefit the most from training [50].

Table 2.1 Strategies to improve communication in clinical care

Pay close attention to patient cues
Repeat your message
Slow down your speech
Avoid colloquial expressions
Present information in more than one way (diagrams, pictures, notes)
Verify the patient’s response
Provide hand-outs in simple English for the patient to bring home
Use a formal translator when possible, rather than a family member or friend

Practical Advice for Clinical Care

Strategies for enhancing communication with patients are not specific to FP or cancer. However, these topics are emotionally and technically difficult for patients. The following section includes some evidence-based recommendations. First, paying close attention to patient cues is imperative for assessing comprehension and understanding [51, 52]. Patients that do little more than nod and smile, demonstrate self-conscious mannerisms, or use vague responses may be revealing a lack of understanding. If a clinician suspects that a patient does not fully comprehend the discussion or understand the terms, he or she should find a graceful way to repeat the message. Slowing down one’s own speech in a relaxed manner and speaking clearly and without colloquial expressions, jargon, or slang will minimize confusion and reduce stress for a listener. This is useful when discussing topics that are difficult emotionally, technically complicated for a layperson, or when the patient is processing a nonnative language. Also, ensuring that the patient is given enough time to complete his or her own thoughts will increase comprehension and encourage him or her to ask for clarity when needed.

Second, clinicians should be as complete and explicit as possible, presenting information in more than one way (i.e., diagrams, pictures, notes). The clinician should verify the patient’s response, taking a moment to restate concretely what he or she heard and concluded, perhaps saying, “As I understand, you are concerned about...Is that correct?” Clinicians need to be aware that certain words and phrases have multiple meanings in English—beyond making sure that the patient understands you, clinician’s need to make sure they understand what their patient is trying to say (Table 2.1).

Although there are definite cultural norms, clinicians need to beware of stereotyping patients. They should ask questions, make observations, and gather history, setting assumptions aside until they have a better assessment of what their patients may need or desire in the consultation. Inaccurate physician assumptions, may act to reduce the number of referrals for consultation [53].

Table 2.2 Recommendations for study personnel approaching minority and disadvantaged women for research participation [55, 56]

Be alert, clear spoken, and a good listener
Be positive and assertive, but not aggressive
Be responsive to the patient’s reasons for reluctance
Be respectful and culturally sensitive
Be confident, sincere, and spontaneous in introducing self and the study
Be credible, by knowing the objectives of the proposed study and what is involved in participation
May be helpful for a senior doctor to initiate the invitation to participate
Utilization of staff representing the population being recruited
Tailor consent forms to the population
Consider audio consent aids where language fluency is low
Engage community leaders to publicize research benefits
Highlight the role of Ethics Committees or Institutional Review Boards (IRB) in safeguarding patients

Often reading a nonnative language (passive fluency) is less difficult than using the language in real time (active fluency). If translated materials are unavailable, writing down (or providing brochures) in simple English allows the patient to take the information home, read in a less stressful environment, and offers the opportunity to consult English-speaking family or friends to help. If the clinician cannot understand the patient, it is sometimes helpful to ask the patient if he or she could write out his or her questions for improved communication.

The Conduct of Research

Mirroring the disparities in treatment and survivorship are the disparities in minority representation in clinical research. Racial and ethnic diversity have been documented in the access to FP (referral and treatment), but no similar investigations have been conducted surrounding access to research trials [26, 28, 54]. Potential explanations for our lack of empirical research in this area likely go beyond socio-economic status to include overarching recruitment challenges such as mistrust of the medical system, lack of understanding about the benefits and risks of research participation, and communication barriers. For example, investigators involved with stroke-prevention in African-Americans described a “recruitment triangle” that predicted a patient’s probability of participation in a clinical trial. The patient, key family members or others in the patient’s support system, and medical personnel form this triangular relationship, and each must be considered in establishing strategies to recruit and retain minority research participants. Other work has provided recommendations for study personnel approaching African American and Latina women for research participation (Table 2.2) [55, 56].

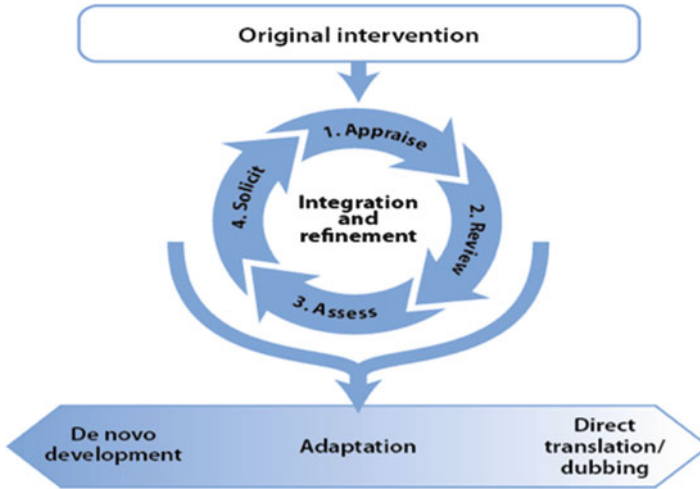


Fig. 2.1 Cultural adaptation of educational materials [57]

Developing Culturally Relevant Patient Literature and Decision Aids

Specific techniques have been developed to facilitate the cultural and linguistic adaptation of existing educational materials. For example, to modify educational and/or decision aid materials for Spanish speakers, researchers have conceptualized the adaptation process as one of locating an optimal point along a spectrum between complete de novo development of an intervention at one extreme, and simple, literal translation of the existing English decision aid (or the simple addition of dubbing or subtitles, in the case of a video) at the other extreme [57, 58]. Utilizing a cyclical framework and an iterative process, culturally relevant decision aids for FP can be developed through the following process:

1. Appraising the current FP educational material to identify essential concepts and information that must be retained in the new version.
2. Reviewing previously identified recurring themes in published literature relevant to FP and the patient population (e.g., cultural norms regarding family size) to enable development of appropriate materials [59–61].
3. Assessing the regional context of the population and engaging the patient stakeholders.
4. Soliciting direct input through interview and focus group processes regarding stakeholder perspectives on fertility potential post-cancer treatment, collecting specific suggestions for making the adapted version both linguistically and culturally relevant.
5. Integrating the feedback and refining the educational materials, such as worksheets or decision aids (Fig. 2.1) [57].

The aim is thus to neither abandon the useful and applicable knowledge already gained from development and refining the original English language version nor merely translate the text of the existing decision aid, but to consider the broader cultural considerations critical to making decision aids and patient literature relevant, appealing, and accessible to the target population.

Improving Online Communication

Several studies and guidelines provide strategies to improve the quality of online educational material. In a study designed to guide the development of E-health tools, focus group members identified several critiques of the use of current E-health resources [62]. For example, one theme that emerged was the distrust of websites with and “.edu” or “.gov” address, with concerns that .edu websites would not be constructed with layman’s terms and .gov websites could not be trusted to provide unbiased information. Another theme that was exposed involved websites being too simple, with videos that moved too slowly or animations that were too basic. Take-home messages from this study include considering “layering content” to allow users at various literacy levels to utilize the site in methods and a pace that is appropriate for them, as well as the suggestion to develop simple E-health content that is intended for families (parents and young children) to explore together [62].

Several institutions provide guidance about how to make one’s website content more accessible to a low literacy population. For example, the US National Cancer Institute and the Department of Health and Human Services furnish general information and instruction about developing accessible online content at www.usability.gov and a PDF handbook called the “Research-based Web Design and Usability Guidelines” at www.usability.gov/guide-lines/guidelines_book.pdf. They provide a step-by-step guide to produce a “user-centered” website that will allow for appropriate content and easy navigation (Fig. 2.2) [63].

Conclusion

As we become more successful in treating cancer, the numbers of survivors will only continue to increase. We echo the call to close the divide in regard to the stark inequalities and disparities that exist in the access to treatment and the subsequent survival rates of nonwhite patients [64]. For female survivors, this can only begin with the dissemination of FP information that reflects an understanding of the culturally influenced beliefs and boundaries that motivate women’s responses to cancer, treatment, and survivorship.

Acknowledgments This work was supported by the Oncofertility Consortium NIH 5UL1DE019587.

References

1. Saha S, Fernandez A, Perez-Stable E. Reducing language barriers and racial/ethnic disparities in health care: an investment in our future. *J Gen Intern Med.* 2007;22 Suppl 2:371–2.
2. Shin HB, Kominski RA. Language use in the united states: 2007: U.S. Department of Commerce, U.S. Census Bureau; April 2010.
3. United States Census Bureau. U.S. Census Bureau: state and County QuickFacts. 2012. <http://quickfacts.census.gov/qfd/states/00000.html>
4. Cheng EM, Chen A, Cunningham W. Primary language and receipt of recommended health care among Hispanics in the United States. *J Gen Intern Med.* 2007;22 Suppl 2:283–8.
5. Dohan D, Levintova M. Barriers beyond words: cancer, culture, and translation in a community of russian speakers. *J Gen Intern Med.* 2007;22:300–5.
6. Quinn GP, Jimenez J, Meade CD, et al. Enhancing oncology health care provider's sensitivity to cultural communication to reduce cancer disparities: a pilot study. *J Cancer Educ.* 2011;26(2):322–5.
7. Nielsen-Bohlman LPA, Kindig D. Health literacy: a prescription to end confusion. Washington, DC: National Academy of Science; 2004.
8. OECD and Statistics Canada. Literacy in the information age: final report of the International Adult Literacy Survey. Paris and Ottawa; 2000.
9. Kutner M, Greenberg E, Baer J, National Assessment of Adult Literacy (NAAL). A first look at the literacy of America's adults in the 21st century. Washington, DC: US Department of Education, Institute of Education Sciences; 2005.
10. Doak LG, Doak CC, Meade CD. Strategies to improve cancer education materials. *Oncol Nurs Forum.* 1996;23(8):1305–12.
11. Bennett CL, Ferreira MR, Davis TC, et al. Relation between literacy, race, and stage of presentation among low-income patients with prostate cancer. *J Clin Oncol.* 1998;16(9):3101–4.
12. <http://www.pewinternet.org/Static-Pages/Data-Tools/Get-the-Latest-Statistics.aspx>. Accessed Dec 2012.
13. Hesse BW, Nelson DE, Kreps GL, et al. Trust and sources of health information: the impact of the internet and its implications for health care providers: findings from the first health information national trends survey. *Arch Intern Med.* 2005;165(22):2618–24.
14. Campbell MK, Honess-Morreale L, Farrell D, Carbone E, Brasure M. A tailored multimedia nutrition education pilot program for low-income women receiving food assistance. *Health Educ Res.* 1999;14(2):257–67.
15. Neuhauser L, Kreps GL. Online cancer communication: meeting the literacy, cultural and linguistic needs of diverse audiences. *Patient Educ Couns.* 2008;71(3):365–77.
16. Wilson FL, Baker LM, Brown-Syed C, Gollop C. An analysis of the readability and cultural sensitivity of information on the national cancer Institute's Web site: CancerNet. *Oncol Nurs Forum.* 2000;27(9):1403–9.
17. Berland GK, Elliott MN, Morales LS, et al. Health information on the Internet: accessibility, quality, and readability in English and Spanish. *JAMA.* 2001;285(20):2612–21.
18. Manganello JA, Clayman ML. The association of understanding of medical statistics with health information seeking and health provider interaction in a national sample of young adults. *J Health Commun.* 2011;16 Suppl 3:163–76.
19. Institute of Medicine. The unequal burden of cancer: an assessment of NIH research and programs for the ethnic minorities and the medically underserved. Washington, DC: National Academies Press; 1999.
20. Rutten LF, Beckjord EB, Hess BW, Croyle RT. Cancer communication: Health Information National Trends Survey. Washington, DC: National Cancer Institute. NIH Pub. No. 07-6214.
21. Schulmeister L, Lifsey DS. Cervical cancer screening knowledge, behaviors, and beliefs of Vietnamese women. *Oncol Nurs Forum.* 1999;26(5):879–87.
22. Kent EE, Arora NK, Rowland JH, et al. Health information needs and health-related quality of life in a diverse population of long-term cancer survivors. *Patient Educ Couns.* 2012; 89(2):345–52.

23. Partridge AH, Gelber S, Peppercorn J, et al. Web-based survey of fertility issues in young women with breast cancer. *J Clin Oncol*. 2004;22(20):4174–83.
24. Gorman JR, Bailey S, Pierce JP, Su HI. How do you feel about fertility and parenthood? The voices of young female cancer survivors. *J Cancer Surviv*. 2012;6(2):200–9.
25. Thewes B, Meiser B, Taylor A, et al. Fertility- and menopause-related information needs of younger women with a diagnosis of early breast cancer. *J Clin Oncol*. 2005;23(22):5155–65.
26. Letourneau JM, Smith JF, Ebbel EE, et al. Racial, socioeconomic, and demographic disparities in access to fertility preservation in young women diagnosed with cancer. *Cancer*. 2012;118(18):4579–88.
27. Hammond CT, Beckjord EB, Arora NK, Bellizzi KM, Jeffery DD, Aziz NM. Non-Hodgkin's lymphoma survivors' fertility and sexual function-related information needs. *Fertil Steril*. 2008;90(4):1256–8.
28. Goodman LR, Balthazar U, Kim J, Mersereau JE. Trends of socioeconomic disparities in referral patterns for fertility preservation consultation. *Hum Reprod*. 2012;27(7):2076–81.
29. Richardson LD, Norris M. Access to health and health care: how race and ethnicity matter. *Mt Sinai J Med*. 2010;77(2):166–77.
30. Fedewa SA, Lerro C, Chase D, Ward EM. Insurance status and racial differences in uterine cancer survival: a study of patients in the National Cancer Database. *Gynecol Oncol*. 2011;122(1):63–8.
31. Matthews ML, Hurst BS, Marshburn PB, Usadi RS, Papadakis MA, Sarantou T. Cancer, fertility preservation, and future pregnancy: a comprehensive review. *Obstet Gynecol Int*. 2012;2012:953937.
32. Niemasik EE, Letourneau J, Dohan D, et al. Patient perceptions of reproductive health counseling at the time of cancer diagnosis: a qualitative study of female California cancer survivors. *J Cancer Surviv*. 2012;6(3):324–32.
33. Schover LR, Rybicki LA, Martin BA, Bringelsen KA. Having children after cancer. A pilot survey of survivors' attitudes and experiences. *Cancer*. 1999;86(4):697–709.
34. Forman EJ, Anders CK, Behera MA. A nationwide survey of oncologists regarding treatment-related infertility and fertility preservation in female cancer patients. *Fertil Steril*. 2010;94(5):1652–6.
35. Duffy CM, Allen SM, Clark MA. Discussions regarding reproductive health for young women with breast cancer undergoing chemotherapy. *J Clin Oncol*. 2005;23(4):766–73.
36. Balthazar U, Fritz MA, Mersereau JE. Fertility preservation: a pilot study to assess previsit patient knowledge quantitatively. *Fertil Steril*. 2011;95(6):1913–6.
37. Peate M, Meiser B, Friedlander M, et al. It's now or never: fertility-related knowledge, decision-making preferences, and treatment intentions in young women with breast cancer—an Australian fertility decision aid collaborative group study. *J Clin Oncol*. 2011;29(13):1670–7.
38. Balthazar U, Deal AM, Fritz MA, Kondapalli LA, Kim JY, Mersereau JE. The current fertility preservation consultation model: are we adequately informing cancer patients of their options? *Hum Reprod*. 2012;27(8):2413–9.
39. Lee SJ, Schover LR, Partridge AH, et al. American society of clinical oncology recommendations on fertility preservation in cancer patients. *J Clin Oncol*. 2006;24:2917–31.
40. Quinn GP, Vadapampil ST, Bell-Ellison BA, Gwede CK, Albrecht TL. Patient-physician communication barriers regarding fertility preservation among newly diagnosed cancer patients. *Soc Sci Med*. 2008;66(3):784–9.
41. Meneses K, McNeess P, Azuero A, Jukkala A. Development of the fertility and cancer project: an internet approach to help young cancer survivors. *Oncol Nurs Forum*. 2010;37(2):191–7.
42. Peddie VL, van Teijlingen E, Bhattacharya S. A qualitative study of women's decision-making at the end of IVF treatment. *Hum Reprod*. 2005;20(7):1944–51.
43. Peddie V, Porter M, Barbour R, et al. Factors affecting decision making about fertility preservation after cancer diagnosis: a qualitative study. *BJOG*. 2012;119(9):1049–57.
44. <https://www.census.gov/hhes/socdemo/language/data/acs/index.html>. Accessed Dec 2012.

45. Navon L. Cultural views of cancer around the world. *Cancer Nurs.* 1999;22(1):39–45.
46. Wenchi L, Wang JH, Chen MY, et al. Developing and validating a measure of chinese cultural views of health and cancer. *Health Educ Behav.* 2008;35(3):361–75.
47. Schover LR, Rhodes MM, Baum G, et al. Sisters Peer Counseling in Reproductive Issues After Treatment (SPIRIT): a peer counseling program to improve reproductive health among African American breast cancer survivors. *Cancer.* 2011;117(21):4983–92.
48. Stone D, Patton B, Heen S. *Difficult conversations.* New York, NY: Penguin; 1999.
49. Meystre C, Bourquin C, Despland JN, Stiefel F, de Roten Y. Working alliance in communication skills training for oncology clinicians: a controlled trial. *Patient Educ Couns.* 2013;90(2):233–8.
50. McInnes DK, Cleary PD, Stein KD, Ding L, Mehta CC, Ayanian JZ. Perceptions of cancer-related information among cancer survivors: a report from the American cancer Society's studies of cancer survivors. *Cancer.* 2008;113(6):1471–9.
51. Mast MS. On the importance of nonverbal communication in the physician-patient interaction. *Patient Educ Couns.* 2007;67(3):315–8.
52. Schouten BC, Meeuwesen L. Cultural differences in medical communication: a review of the literature. *Patient Educ Couns.* 2006;64(1–3):21–34.
53. Quinn GP, Vadaparampil ST, King L, et al. Impact of physicians' personal discomfort and patient prognosis on discussion of fertility preservation with young cancer patients. *Patient Educ Couns.* 2009;77(3):338–43.
54. Lee S, Heytens E, Moy F, Ozkavukcu S, Oktay K. Determinants of access to fertility preservation in women with breast cancer. *Fertil Steril.* 2011;95(6):1932–6.
55. Symonds RP, Lord K, Mitchell AJ, Raghavan D. Recruitment of ethnic minorities into cancer clinical trials: experience from the front lines. *Br J Cancer.* 2012;107(7):1017–21.
56. El-Khorazaty MN, Johnson AA, Kiely M, et al. Recruitment and retention of low-income minority women in a behavioral intervention to reduce smoking, depression, and intimate partner violence during pregnancy. *BMC Public Health.* 2007;7:233.
57. Ko L, Reuland D, Jolles M, Clay R, Pignone M. Cultural and linguistic adaptation of a multi-media colorectal cancer screening decision aid for Spanish speaking latinos. *J Health Commun.* (in press).
58. Reuland DS, Ko LK, Fernandez A, Braswell LC, Pignone M. Testing a Spanish-language colorectal cancer screening decision aid in Latinos with limited English proficiency: results from a pre-post trial and four month follow-up survey. *BMC Med Inform Decis Mak.* 2012;12:53.
59. Quinn GP, Hauser K, Bell-Ellison BA, Rodriguez NY, Frias JL. Promoting pre-conceptional use of folic acid to Hispanic women: a social marketing approach. *Matern Child Health J.* 2006;10(5):403–12.
60. Sawyer L, Regev H, Proctor S, et al. Matching versus cultural competence in research: methodological considerations. *Res Nurs Health.* 1995;18(6):557–67.
61. Simmons VN, Cruz LM, Brandon TH, Quinn GP. Translation and adaptation of smoking relapse-prevention materials for pregnant and postpartum Hispanic women. *J Health Commun.* 2011;16(1):90–107.
62. Mackert M, Kahlor L, Tyler D, Gustafson J. Designing e-health interventions for low-health-literate culturally diverse parents: addressing the obesity epidemic. *Telemed J E Health.* 2009;15(7):672–7.
63. <http://usability.gov/about/index.html>. Accessed March 2013.
64. Guidry JJ, Torrence W, Herbelin S. Closing the divide: diverse populations and cancer survivorship. *Cancer.* 2005;104(11 Suppl):2577–83.

Oncofertility Communication

Sharing Information and Building Relationships across
Disciplines

Woodruff, T.K.; Clayman, M.L.; Waimey, K.E. (Eds.)

2014, XIX, 237 p. 26 illus., 21 illus. in color., Hardcover

ISBN: 978-1-4614-8234-5