Chapter 8
Communicating Oncofertility to Children: A Developmental Perspective for Teaching Health Messages

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Introduction

Oncofertility is a new discipline that focuses on the intersection of oncology and fertility [1]. People often think about cancer as a disease that occurs in aging populations. While this is true, there are a number of cancers that affect children and younger adults, resulting in a population of cancer patients and survivors whose cancer treatment may impact their future fertility. With young cancer patients, especially children, communicating about cancer is undeniably an arduous task, which makes communication about the impact that cancer and its treatment may have on their future fertility even more complex.

Communicating health information generally, and information about sexuality and health more specifically, requires an understanding of what is developmentally appropriate for children to comprehend. Research shows that children under age 7 struggle with abstract concepts and hypothetical reasoning [2]. Further, American children know very little about their bodies or their reproductive system [3]. Given that children have a poor understanding of their own bodies, explaining health- and fertility-related issues of cancer often requires education about their bodies in general and then education about oncofertility-related issues, or they may be left to rely on largely abstract ideas and concepts.

For children with cancer, communicating about oncofertility is a new concept and one that has not yet been well researched. In this chapter, we provide a

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developmental perspective about what children already know about their bodies and reproductive systems. Next, we discuss the use of various types of media to communicate health messages to children in a general audience as well as to specific populations of children, particularly patients in hospital settings. We conclude with recommendations for how oncofertility experts can use media to educate young audiences.

Developmental Progression of Health Concepts and Body Knowledge

Research indicates that there is a developmental progression in children's sexual knowledge and that there are cultural differences in children's understanding of procreation, birth, and sexual activity [3–5]. Investigations of very young children's sexual knowledge focused on their understanding of gender identity and genital differences [3]. Volbert found that by age 2 or 3, children can identify themselves as either boys or girls and by age 4 or 5, they are able to identify gender-appropriate genitalia [3]. According to Gordon, Schroeder, and Abrams, before middle childhood (approximately age 7), children have very little understanding of the sexual functions of genitalia; children typically only understand that they are involved in making babies [6]. Up to age 7, children have a rudimentary understanding of pregnancy and gestation in the mother's "stomach," but little understanding of birth or adult sexual behavior [3]. In cross-cultural research with 6-year-old children in the USA, England, the Netherlands, and Sweden, Caron and Ahlgrim found that American children lagged behind those of the other countries in understanding conception and birth [4]. Moreover, children from the Netherlands and Sweden (both countries with progressive attitudes toward sexual education) showed greater understanding of sexuality, procreation, and birth than children in the other countries [4].

More recent research on sixth-grade middle school students found that, when allowed to ask questions anonymously, children asked about sexual activity (e.g., "If you have anal sex, is it still sex?"), the female anatomy (e.g., "How big is the vagina?"), reproduction (e.g., "Does reproduction hurt?"), and puberty (e.g., "What is the latest age a person can get puberty?") [7]. These findings suggest that, even with middle school students, there is some confusion and uncertainty about reproduction and sexual activity. This is consistent with the American Academy of Pediatrics Committee on Public Education [8], which has pointed out that much of children and adolescents' knowledge about sexuality comes from popular television and movies, which provide little information about birth control and how to protect against HIV or other sexually transmitted diseases [8]. By the time children reach adolescence, puberty and sexual development lead them to a much better understanding of their bodies, sexual behavior, and reproduction. Along with hormonal changes associated with puberty and increased interest in sexuality comes increased risk-taking and increased influence of peers as adolescents explore their own sexuality and identity, often via media portrayals [9].

Just as children's understanding of sexuality and reproduction improve as they grow older, so too does children's understanding of health and illness. Bibace and Walsh conducted the most complete age-related systematic studies of children's understanding of illness and its causes [10, 11]; their study has become the classic reference for how children's understanding of health concepts and illness is related to their development of logical reasoning and their ability to differentiate between themselves and others. Bibace and Walsh [10, 11] identify six stages in children's development of an understanding of illness and its causes between ages 4 and 12: (1) phenomenism explanations—whereby illness is understood as an external phenomenon separate from the person; (2) contagion type explanations offered by 4-year-olds who understand illness can be caused by objects or people around the child; (3) contamination type explanations in which illness is understood to be related to physical contact with people who are sick; (4) internalization explanations whereby illness is understood as a process of internalizing elements such as breathing in bacteria; (5) physiologic explanations whereby illness is understood as a process such as people getting colds from a virus that gets into the body; and (6) psychophysiologic explanations in which the child (typically by age 11 or 12) understands that psychological factors can also influence health status. Doctors generally are cognizant of this developmental progression and use language consistent with children's understanding about health when discussing illness with young patients.

Overall, as children develop, they learn and understand more about health, illness, and their bodies, but again, Americans know less than children in other countries. This disparity may exist due to aspects of American culture in which we avoid communication and conversation with young children about their bodies or sexuality. When children have a lack of understanding of basic bodily functions, it makes communicating about complex health and illness issues even more challenging, especially for parents who are uncomfortable talking to their children about health and sexuality.

Communicating with General Audiences Through Mass Media

Forty years of research has demonstrated that children can learn from educational, curriculum-based television programs [12, 13], but they can also learn from entertainment-based media [14]. Research on learning from mass media has focused primarily on social-emotional and academic skill learning for younger children [15] and less on specific health issues and outcomes. However, there is considerable research about how teens learn health information from mass media [16], specifically information about sexual health [14, 17], and there are a few examples of programs created specifically to teach younger children health information.

There are fewer educational curriculum-based programs dedicated to teaching young children about health. *Fizzy's Lunch Lab*, a PBS online website, provides an opportunity for children to learn more about healthy eating through online videos,

games, and activities. *Doc McStuffins* is a Disney preschool program about a child who pretends to be a doctor to her stuffed animals to help them feel better. Neither program has been assessed for its effectiveness in teaching young children health information. *Sesame Street* recently began its Healthy Habits for Life initiative, which includes videos, books, PSAs, and outreach materials to promote health and healthy practices, both in the USA and around the world [18]. Abroad, *Sesame Street* co-productions have had success in educating mass audiences about health concepts like HIV/AIDS and malaria. Specifically, *Takalani Sesame* in South Africa, *Kilimani Sesame* in Tanzania, and *Jalan Sesam* in Indonesia focus on teaching and educating young children and families about specific area-related health messages.

In South Africa in 2001, there was a very high rate of HIV infection: nearly 11 % of the population was affected [19], and a considerable stigma was associated with the disease. *Takalani Sesame* was created to communicate both academic and health messages to preschool children. One of the primary aspects of this project was the creation of an HIV-positive character, named Kari, who taught young children basic health and social information about HIV/AIDS [20]. Multiple studies have demonstrated the vast success that *Takalani Sesame* has had on educating young children about HIV/AIDS in South Africa [21]; specifically, there was improvement in children's basic knowledge of HIV/AIDS, blood safety, destigmatization, and coping with the illness [21].

Mass media, and television specifically in the USA, has been a successful tool used to educate teens about certain health-related behaviors, primarily sexual health. While entertainment television in the USA often depicts sexual content [22], it can occasionally provide positive information about sexuality. Recent data suggest that online media currently outranks parents and health professionals as the primary source of information about sex for teenagers [23]. Teens also report that they rely on television as a source of information about birth control, menstruation, pregnancy, and sexually transmitted diseases [23]. One study found that 67 % of teens who watched the *Friends* episode about condom failure recalled that the condom failure resulted in pregnancy and 10 % of viewers spoke with an adult about condom efficacy as a result of the show [14]. Also, social network sites like Twitter have been used by the World Health Organization to provide updates to mass audiences about diseases such as the H1N1 influenza [24]. For teens, social networking sites may be a particularly appropriate and comfortable environment for youth to receive and learn about health information [25].

Some television shows work with organizations like the National Campaign to Prevent Teen Pregnancy and the Media Project to incorporate health messages into their television shows. In the past, *Dawson's Creek*, *Felicity*, *ER*, and *Beverly Hills 90210* developed episodes in which the characters dealt with teen sexual health to provide information for viewers [26]. While there are few studies on the effectiveness of these episodes, viewer's knowledge of emergency contraception increased by 17 % after an *ER* show depicted a date rape victim taking an emergency contraceptive [27]. More recently, a study of a particular episode of *Grey's Anatomy* found that viewers learned that with proper treatment an HIV+ mother can give birth to a

healthy baby; the study also found that this information was retained for 6 weeks after viewing the episode [28]. These studies provide some evidence that even through traditional media, such as entertainment television, health messages can be communicated and positively influence adolescent health knowledge.

For some health issues, information needs to be presented to both the parent and child simultaneously. Oncofertility is a new concept for parents and children alike, and both audiences are learning about the consequences of cancer and its treatment on fertility together. An example of how to successfully communicate to the adults and children simultaneously comes from Sesame Workshop. As a result of the long wars in Iraq and Afghanistan, the Workshop created a toolkit of videos and information for military families to help them cope with military transitions that included deployment, homecoming, and changes [29]. Sesame Workshop uses friendly, child-like characters, and child-appropriate language in their videos to educate children about issues related to such transitions, and also provides activities and information that can help educate parents about best practices and ways for them to continue the conversation with their children. This method of addressing both the child and parent together can increase parent–child interaction and communication around sensitive topics, and can also help the parent provide the child with concrete examples to enhance their understanding of what is going on. For example, a parent could say, "Remember in the video how Rosita's father was in a wheelchair? Well when we see Daddy at the hospital, he will be in a wheelchair like Rosita's daddy." For young children, these explicit, concrete examples can help them understand and process the messages being presented.

Media to Communicate with Special Audiences

To communicate health information in hospital settings, medical practitioners have used, created, and advocated for a variety of media- and non-media-based tools/interventions, including printed leaflets, hospital tours, medical play sessions, puppet shows, instructional videos, and computer-based multimedia demonstrations [30–32]. Large numbers of health researchers first began advocating for the use of educational puppet shows and videos in the mid-1970s [31, 33]. Staff have used these tools with children who are preparing for surgery [31], with children about to undergo dental procedures [34, 35], and with healthy children who may be unfamiliar with or frightened by the hospital or various illnesses [36]. Many health practitioners and researchers believe that children can learn about illness, hospitalization, and medical procedures [30, 32, 37], and have developed child-friendly educational tools to encourage the acquisition of health knowledge and ease anxiety about health issues.

Educational interventions involving puppets and dolls have been used to target preschool- and school-aged children [38]. Puppetry "is active and immediate, and it engages a child at once verbally and physically" [36], p. 129. Puppets are "likeable, trustworthy, and interesting enough to command attention" [39], p. 33, for many

children. To ensure that puppet-based interventions are effective, it is important that the puppets are used in ways that are as realistic as possible [39]. These interventions have effectively taught children health-related information [38]. Additionally, by talking to a puppet or about a puppet show, children can work through tough emotions—such as fear and anger—about health issues [36].

To communicate health-related information to children, many practitioners alternatively opt for instructional videos, including filmed puppet shows [36] and filmed enactments of various medical procedures with child actors serving as model patients [34, 35]. Media-based interventions offer several distinct advantages for medical staff over live demonstrations with puppets and dolls. First, healthcare providers can show a filmed puppet show if they themselves lack facility with puppets or the time to enact a long show in front of children [36, 39]. Second, the use of media-based tools can standardize the transmission of educational information in hospitals, ensuring that every family is given the same information [40]. Finally, these tools can be dispersed widely, potentially reaching multiple hospitals and children in need of learning health-related information outside the hospital setting [32].

Indeed, films have successfully imparted topical information about health and reduced children's anxiety in health settings [34, 35]. Through the use of imagery, films help make health-related ideas and concepts more concrete for young children [30]. In particular, tapes that star child actors have been demonstrated to be more educationally efficacious than tapes that simply feature doctors describing medical procedures [35]. When appropriate, children who have been encouraged to act out behavior modeled in health videos (e.g., practicing breathing while sitting in a dental chair prior to a procedure), have demonstrated less fear and greater gains in knowledge compared to children who viewed similar videos that did not prompt their participation [34].

More recently, practitioners have advocated for the use of computer-based educational tools with children; these tools can simultaneously display written and pictorial information to enhance learning [35, 40]. Nelson and Allen [32] demonstrated that children learned and became less fearful after exploring a hospital-created computer demonstration, and children who engaged with these demonstrations were more satisfied with their learning experience than children who viewed static slideshows. Many scholars are particularly enthusiastic about computer-based interventions because they can easily be shared across the Internet [30, 32]. Nevertheless, experts have identified a need for further evaluation of the efficacy of such computer-based tools [30].

In a survey of healthcare providers at a children's hospital in the UK, respondents identified a lack of age-appropriate educational resources as a major barrier in serving adolescents, a finding those researchers believe reflects an international problem [41]. Further, only a limited number of studies have examined media-based health interventions/tools designed for adolescents [42]. Nonetheless, the existing research indicates that health media targeted to adolescents can be educationally efficacious. For instance, in a review of sexual health interventions with adolescents and young adults, a panel of experts identified 30 interventions they deemed particularly promising for implementation across the nation, 17 of which included educational video

components [43]. Prior published evaluations of all of these programs demonstrated that participants adopted healthy sexual behaviors, such as increased condom use, in response to each intervention. Similarly, in a study with adolescents and young adults, youth who played a video game specifically created to teach about cancer and its treatment improved their knowledge about these areas, perhaps in part because the video game stimulated participants' topical interest [42].

Although ground-level health practitioners are sometimes unfamiliar with research demonstrating the efficacy of various educational tools such as instructional videos, increasingly, hospitals are relying on media-based educational aids [33]. For example, the GetWellNetwork provides on-demand, health-themed educational television programming to 28 children's hospitals nationally [44].

The Potential for Media to Convey Challenging Messages: Recommendations

Children's developmental needs are sometimes an afterthought in the planning and execution of hospital-based educational interventions [30]:

> In a sociocultural climate where detailed medical information provision is a legal requirement, information is generally provided to parents and children but often without much consideration as to how children of different ages will understand and respond to the information (p. 137).

That said, experts have offered suggestions on choosing and tailoring the aforementioned techniques depending on the ages of the children being targeted.

Aspects of the information need to be simplified for very young audiences. Jaaniste and colleagues [30] recommend "using [age-appropriate] terminology consistent with the child's own spontaneous language production" (p. 134). They also propose using displays and demonstrations that are fairly concrete, straightforward, and focused on external and sensory descriptions for preschool-age children. Creators should select out a few topics to teach the child, rather than providing them with too much complicated material to process all at once. For example, since children know very little about reproduction and the human body [3], initial media presentations should focus on these key aspects of the body before bringing in details about the effects of treatment on future fertility.

Additionally, Morrison and researchers [38] advocate incorporating tactile components if possible when designing interventions for very young children. Therefore, a simple video that focuses on one aspect of oncofertility (e.g., sadness an adult may feel when learning about cancer-related fertility issues) that comes with a related physical display or dolls for the child to play may work well with preschool-age children. Further, if possible, interactive technologies, like computers or touch screens, in which the child can interact and help the characters on the screen express or display their emotions may be an effective way for young children to strongly engage and learn about oncofertility.

Older children may be receptive to more complex interventions. Elementary school-age children, who have greater symbolic processing abilities, may learn more from puppet shows or videos featuring models than younger children [30, 39]. Accordingly, video demonstrations of puppets or children interacting with cancer patients may be well received by school-aged children and may be sufficient to teach them about the basic concepts of oncofertility. As elementary school-aged children know more about their bodies [3] and have a better understanding of abstract ideas and concepts as they get older [2], videos and media that communicate the range of issues that may arise as a result of cancer treatment may still be informative and helpful for these children. However, for all young audiences, creators of educational media and experts who communicate with young children should understand Bibace and Walsh's six stages of children's understanding of illness [10, 11].

Keller and Brown [26] make recommendations that mass media be used to teach responsible sexual behavior to teens as it is successfully done in other countries. If teens have already received information about sexual behavior and reproduction via mass media, oncofertility communication can delve into the more complex aspects of how cancer and treatment can influence fertility now and in the future. Adolescents are capable of processing multifaceted informational interventions describing internal bodily functions and future states [30]. Likewise, more so than younger children, adolescents may have an "appreciation of situations in which there are competing plausible explanations or approaches" [30], p. 131, which is important for understanding health and illness information. Therefore, adolescents may be capable of understanding thorough and complex explanations about oncofertility—or other health issues—that feature unanswered questions and various potential outcomes associated with cancer treatment.

It is also important to note that parents often participate in hospital-based, multimedia educational interventions with their children [33, 36]. Both adults and children can learn from media-based educational offerings. For instance, parents who participated in a multimedia consent process demonstrated a stronger understanding of the procedure their children were about to undergo compared to parents who participated in a traditional consent process without media aids [40]. In some cases, parents who participated in these interventions felt less anxious prior to their children's procedures [31].

Conclusions

Oncofertility is a new interdisciplinary approach to understanding and preparing patients and their families for potential fertility issues during and after cancer treatment. When these patients are children and adolescents, special communication practices are necessary. To provide an understanding of promising strategies for educating youth about oncofertility, this chapter has examined broadly how children and adolescents develop an understanding of sexuality, health, and illness. In particular,

previous research indicates that cognitive developmental changes in children's abilities to comprehend abstract concepts and causality can impact children's understanding of their own sexuality, procreation, and childbirth. Medical practitioners should take into account the differences among preschoolers, elementary school children, and adolescents in the ways in which they explain oncofertility to pediatric patients. Media-based tools may aid these conversations. Indeed, research on how media productions are used in conveying health information to youth demonstrates the potential of media outlets (especially videos and online website information) for educating children and adolescents about health-related topics, such as oncofertility, in ways that are sensitive to young people's needs and sensibilities.

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