Chapter 11
Shared Decision Making: Fertility and Pediatric Cancers

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We live our lives like chips in a kaleidoscope, always part of patterns that are larger than ourselves and somehow more than the sum of their parts.

— Salvador Minuchin

Childhood cancer is a familial disease; no family member escapes unscathed from the impact of a young person’s cancer diagnosis, treatment, and follow-up procedures. As new treatment options unfold and more children survive, families are faced with multiple critical decisions at the time of diagnosis. This chapter will address one of the goals of oncofertility research – to improve the decision making competencies of family members confronting the news of a child’s cancer diagnosis plus the additional information that the treatment may or will affect the child’s future fertility. We will bring together key constructs and research from family systems theory and the shared decision making model in order to understand better how families whose children are newly diagnosed with cancer can make informed choices about the future fertility of their children while immediately confronting a potentially life-threatening illness.

To accomplish this purpose, the chapter will unfold in the following manner: first, we will briefly articulate the current state of childhood cancer and fertility preservation. Second, we will explicate a systems approach to family communication and decision making. Third, we will summarize the recent evolving work on shared decision making in health care. Fourth, the current state of childhood cancer and fertility preservation options will be described as a highly stressful context into which a family systems approach and shared decision making models must be integrated for immediate and long-range successful health care outcomes. In doing so, we will review the recent research that has investigated how families and health care professionals do and want to make decisions about fertility preservation when children are diagnosed with cancer. We will conclude by summarizing what we now know about shared decision making by families and health care professionals concerning fertility preservation for children with cancer and what we still need to know.

As family members and health professionals confront this situation together, the desired outcome is a shared decision-making process that involves parent(s),
potentially the child, and relevant medical personnel. Few family members are
prepared for such stressful experiences; even fewer are prepared to engage in
decision making that is both informed and takes personal values into account about
such critical topics in such limited time frames. Therefore, there is a growing need
to prepare medical professionals with the knowledge and tools for managing these
stressful circumstances and to develop information and strategies to empower
family members faced with such a life crisis.

The Current State of Pediatric Oncofertility

In 2006, an estimated 9,500 new cases of pediatric cancer were diagnosed in the
United States [1]. Over the last several decades, survival rates for children with
cancer have increased tremendously, and most children who develop cancer can
be expected to survive [1]. Concurrent with these advances in cancer treatment,
interest in cancer survivorship for childhood and adult cancer survivors has
grown in both the academic and lay communities. Although the survival rate for
those with childhood cancer has risen to almost 80%, such a diagnosis sends
families into a crisis mode that alters life as they know it. Parents must come to
terms with the reality that their child has cancer, a life-threatening disease, at
the same time they are confronted by numerous related decisions regarding
treatment and clinical trials. This period after diagnosis involves a steep learn-
ing curve [2]. Such revelations are accompanied by an expectation on the part
of the treatment team that treatment decisions will be made quickly. During this
time, some parents learn that side effects of the recommended treatments will,
or may, render the patients infertile.

Therefore, these parents, and perhaps the patients, are faced with consider-
ing fertility preservation options at the same time they are struggling with
understanding the cancer diagnosis and immediate treatment possibilities. In
general practice, only parents of pubescent males learn of fertility preservation
options because highly developed techniques for partnerless patients exist only
for post-pubescent males [3]. The fertility options for females, however, are
more limited, as egg harvesting and preservation have low success rates with
unfertilized mature oocytes and are not options for girls with immature oocytes
[4,5]. Further, many pediatric oncology providers are not adequately informed
about current standards in fertility preservation and may have difficulty finding
and contacting fertility specialists in a timely manner [6]. Experimental options
for women and young girls include harvesting and freezing immature ovarian
tissue for later auto-transplantation (i.e., restoring the tissue to her body) when
the patient is ready to have children or maturation of the ovarian tissue in vitro
and then fertilizing the mature egg [5]. In other words, parents of girls and
young women are likely to learn that the options for preserving fertility are few
and unpredictable (see Agarwal and Chang, this volume, for further discussion
of fertility preservation options).