

# Chapter 13

## The Psychosocial Context of Cancer-Related Infertility

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### The Social Context

Fertility has always been associated with awe, curiosity, and magical thinking. Since the beginning of time, fertility has been deeply imbedded in the human experience and expressed throughout the ages by all cultures in symbolic art. In trying to decipher the atavistic meanings given to fertility, it is essential to consider the hostile world in which our progenitors struggled and eventually thrived. The population of the earth is an incredible success story. No species have ever so dominated the earth as have humans. Fertility has always been the central theme of our ancestors. In many ways, cancer, as a life-threatening disease, brings people back to their most basic and primitive selves.

Archeological findings in almost all ancient cultures establish the female (primarily in the form of goddesses) and particularly the womb and breast as the primary symbols for fertility. For the male, fertility is represented in the exaggerated erect phallus. The womb and phallus are universal symbols for fertility. Males and females fit together physically to create the miracle of new life – a life that is of them but not them. But the physical pieces are only part of the puzzle; the psychological, social, and spiritual interplay between men and women provides the synergies that truly make us human. “Mother” earth itself has been described as a womb from which all life springs. This is the magic of the ages. But fertility in men and women has always meant more than having genetic continuance and the dream of immortality. Wellness, health, strength, status, power, vitality, connection, commitment, love, family, social cohesiveness, and protection from the unknown forces in an uncontrollable future are all part of the essential fabric of trying to manage a harsh and challenging life. The promise of fertility has been the connective spiritual tissue and balm of the ages. The faces of young children reflexively move us at our very core.

Fertility mythology has had other significant implications beyond the reproductive functions. Every known culture has a creation myth explaining the existence of humankind within the context of their perceptions and level of development. For example, the ancient creation myth of Viet Nam is of the marriage of a dragon and a fairy, both having their own, but distinct, power and

magic. The theme of two alchemizing into three is universal. It is easy to see that the creation myth is an outgrowth of and deification of the cultural perceptions of fertility. For the connections between where we come from and where we go when we die is all part of the same story. This is our story. It is a story played out every day in every country in the world with little thought until something goes wrong.

Within this greater context of fertility, it is possible to understand that even for persons who have long decided not to have children, or are much too old to do so, being deprived of the option and having the decision made for them may involve a deep sense of loss, anger, confusion, and yearning that is beyond intellectual reasoning.

The recognition that having a child of your own is no longer possible always occurs within a social context. Society reinforces guilt, especially in women, when it comes to a threat to fertility. Delaying pregnancy due to personal choice, health concerns in self or partner, finances, lack of a partner, or career advancement is guilt provoking in women trying to balance the conflicting and all too often unrealistic expectations and realities of daily living. Regardless of the cause, infertility is usually assumed to be the problem of the woman. For men, the stressors are different and shame is common: financial concerns, job insecurity, and doubts about the ability to be a good father all may conspire to delay having a child, but ultimately the sense of shame that follows when the option to have children is at-risk can be very powerful and can result in disabling distress and avoidance. When a couple is unable to conceive, even if the man is fertile, his sense of self-esteem, respect, and power is undermined.

When it comes to something as instinctual and important as the ability to have children, both women and men have the unfortunate capacity for relentless self-blame, guilt, and shame, regardless of the cause or choice. When cancer is superimposed on the ability to have children, there can be great stress on the patient, partner, relationship, and family. When fertility is openly discussed and informed joint decision making is actively supported as it relates to cancer, this dreadful situation can have great potential for the deepening of commitment and love, with or without a biological child.

All cancers, to varying degrees, due to the illness itself, treatment side-effects, or related psychosocial distress, always have the potential to significantly undermine sexual health and the ability to have children [1]. Approximately 10.5 million Americans with a history of cancer are alive today, and over one million new cancer cases are estimated to be diagnosed in 2006 [2]. Given these statistics, it is not surprising that three out of four families have been affected by cancer [3]. These statistics make apparent the need for research to identify the impact of cancer on the women and men for whom fertility is a concern. Zanagnolo et al. reported that there is little information available regarding survivors' attitudes, emotions, and choices to have children; therefore, for treatment of young patients with malignant ovarian tumors who may be cured and lead normal lives, preservation of reproductive ability has become an important

issue [4]. In this cross-sectional study of 75 women under the age of 40 with Stage I ovarian cancer or any stage LMP tumors when at least one of the ovaries was not or was only minimally involved, malignant ovarian germ cell tumor, or Stage I sex cord-stromal tumor, 51% of patients feared that their ovarian disease could have damaged their reproductive potential. An additional 66% of these women felt anxiety about infertility. Significantly, the investigators found that infertility increased distress in this group of survivors, regardless of their current parental status. They also reported that counseling on infertility or pregnancy was rarely offered or available to these patients [4].

The face of cancer has significantly changed over the past 25 years. Cancer survivors are living longer, dying less often from the disease, and are increasingly concerned about quality of life. For many people, the ability to conceive and deliver a healthy baby of their own is of paramount importance. Unfortunately, in many circumstances, and for a variety of complex reasons, health care professionals fail to discuss fertility preservation and other options with cancer patients until it is too late. Prognosis, survival, and the timing of diseased-focused treatments seem to provide adequate rationale for the implicit delegation of fertility options as a second tier concern for health care professionals.

Our clinical experience consistently demonstrates that fertility is important to all people, regardless of age and situation, and marks a developmental milestone in their lives. Not surprisingly, women and men who were not informed about the option of preserving eggs and sperm manifest high levels of confusion, frustration, and anger toward their health care professionals that is not readily assuaged. At least in retrospect, very few women and men, if any, who wanted to have children report that hearing their physician say that “saving your life was of paramount importance” was an adequate reason not to discuss fertility preservation options when they were still viable. If the patient is lesbian or homosexual, there is even greater health care professional discomfort and the false assumption that having children is not relevant is the convenient default.

Clearly, with the recent dramatic progress in egg preservation options now available, open and timely communication followed by systematic referral processes are essential to ensure quality care and to avoid unnecessary psychosocial distress and litigation. Ultimately, any discussion of oncofertility must be integrated into the overall medical and psychosocial care of the patient and family. One way to introduce the conversation is through screening at the first visit. To open the conversation about fertility, we suggest that the treating physician say something like, “*You may be aware that cancer and or the treatments we provide frequently interfere with the ability to have children. Many people will not be able to have children after treatment. Can you please tell me what your thoughts are about this?*” Timing is essential here because the window of egg harvesting or sperm banking may be quite limited due to menstrual cycles and the urgency of cancer treatments. Therefore, it is essential that a triage system exists that prioritizes the needs of cancer patients in busy fertility clinics that may have long waiting lists that extend over weeks.

## **Psychosocial Screening for Infertility Concerns**

Cancer patients are confronted with many challenges to their sense of personal control and ability to integrate new and complex information. It is estimated that 30–50% of cancer patients are reported to have high levels of psychosocial distress at some point in the course of their diagnosis and treatment, yet only 5% ever access mental health services [5].

Psychological screening of cancer patients represents one of the solutions to the under-diagnosis of anxiety, depression, distress, and other cancer-related psychiatric morbidities [6]. However, screening is also helpful to anticipate potential non-psychiatric concerns and problems that may not be evident to the health care team. Screening is also helpful to open the conversation with frank and honest communication, normalize concerns, and to role model team work. Fertility preservation, sexuality, and intimacy are all subject areas that health care professionals tend to avoid, especially when the focus is on “survival”. In a longitudinal study of 17 women diagnosed with breast cancer before the age of 41, some of the psychosocial concerns related to reproduction were fertility, contraception, pregnancy (fear and anxiety concerning passing on a breast cancer gene to an unborn child), and breastfeeding (fear and anxiety that breastfeeding will not be possible or that they feel uncomfortable with breastfeeding their baby on the breast that was infected). This study found that fertility status can change over time for young women with breast cancer, as well as their perspectives on fertility. In other words, at baseline, women stated that fertility issues were not of concern; however, by the final interview, they stated that infertility became a concern for them. In addition, regrets of not utilizing fertility-preserving choices in early diagnosis were expressed [7]. Because survival fears can mask important life-long dreams and aspirations, it is incumbent on health care professionals to anticipate and to give voice to the longer term perspectives that may not be readily apparent to cancer patients in this context-sensitive situation.

### ***Biopsychosocial Screening Instrument: How Can We Help You and Your Family?***

As a part of the standard of clinical care at the Moores University of California - San Diego (UCSD) Cancer Center, an Institutional Review Board (IRB) – approved study is prospectively collecting data from patients using the only systematic universal program of biopsychosocial screening in the United States. New patients seen at the Moores UCSD Cancer Center outpatient clinic are asked to complete the self-administered biopsychosocial screening instrument, *How Can We Help You and Your Family?* (see Fig. 13.1). This screening instrument takes approximately 2–5 min to complete and consists of 36 cancer-related problems most commonly identified by cancer patients in the physical, social, spiritual, psychological, emotional, and practical domains. Patients are asked to rate the severity of the problems listed on a scale of 1

**How Can We Help You and Your Family?**  
By completing this form you will tell us how we can best work together with you as an effective team.

**Please take a few moments to:**  
1. Rate each and every problem by circling a number <sup>1 thru 5</sup>. [1 means this is *Not A Problem At All To Me*, 5 means this is the *Worst Problem I Could Have*.]  
2. Then, please circle Yes to indicate problems you would like to discuss with a member of our staff.  
*Ask at the Front Desk if you would like help completing this form.*

Problems	Rating [1-5]					Yes	Problems	Rating [1-5]					Yes
	Not a Problem	1	2	3	4			5	Worst Problem				
1. Transportation	1	2	3	4	5	Yes	19. Ability to have children	1	2	3	4	5	Yes
2. Finances	1	2	3	4	5	Yes	20. Being an anxious or nervous person	1	2	3	4	5	Yes
3. Needing someone to help coordinate my medical care	1	2	3	4	5	Yes	21. Losing control of things that matter to me	1	2	3	4	5	Yes
4. Sleeping	1	2	3	4	5	Yes	22. Feeling down, depressed or blue	1	2	3	4	5	Yes
5. Talking with the doctor	1	2	3	4	5	Yes	23. Thinking clearly	1	2	3	4	5	Yes
6. Understanding my treatment options	1	2	3	4	5	Yes	24. Me being dependent on others	1	2	3	4	5	Yes
7. Talking with the health care team	1	2	3	4	5	Yes	25. Someone else totally dependent on me for their care	1	2	3	4	5	Yes
8. Talking with family, children, friends	1	2	3	4	5	Yes	26. Fatigue (feeling tired)	1	2	3	4	5	Yes
9. Managing my emotions	1	2	3	4	5	Yes	27. Thoughts of ending my own life	1	2	3	4	5	Yes
10. Solving problems due to my illness	1	2	3	4	5	Yes	28. Pain	1	2	3	4	5	Yes
11. Managing work, school, home life	1	2	3	4	5	Yes	29. Sexual Function	1	2	3	4	5	Yes
12. Controlling my anger	1	2	3	4	5	Yes	30. Recent weight loss	1	2	3	4	5	Yes
13. Writing down my choices about medical care for the medical team and my family if I ever become too ill to speak for myself	1	2	3	4	5	Yes	31. Having people near by to help me or needing more practical help at home	1	2	3	4	5	Yes
14. Controlling my fear and worry about the future	1	2	3	4	5	Yes	32. Nausea and vomiting	1	2	3	4	5	Yes
15. Questions and concerns about end of life	1	2	3	4	5	Yes	33. Substance abuse (drugs, alcohol, nicotine, other)	1	2	3	4	5	Yes
16. Finding community resources near where I live	1	2	3	4	5	Yes	34. My ability to cope	1	2	3	4	5	Yes
17. Getting medicines	1	2	3	4	5	Yes	35. Abandonment by my family	1	2	3	4	5	Yes
18. Spiritual Concerns	1	2	3	4	5	Yes	36. Any other Problems you would like to tell us about (please specify):	1	2	3	4	5	Yes

**PLEASE CHECK ONE:**

Present Relationship:

Married       Single   
 Living with Partner       Widowed   
 Divorced

Language I prefer to Speak:    English     Spanish     Other

**PLEASE CHECK ONE:**

Race:

African American   
 Asian   
 Hispanic   
 Multi-racial

Native Hawaiian/Other Pacific Islander   
 Native American/Native Alaskan   
 Unknown   
 White   
 Other

[Stick-on Patient Info Label here]  
(For Office Use Only)

—Thankyou for taking the time to provide this information.11/16/2005

**Fig. 13.1** Biopsychosocial screening instrument – how can we help you and your family?  
Note: Item #19 Ability to Have Children

(Not a Problem) to 5 (Worst Problem) and indicate which problems they “*would like to discuss with a member of our staff?*” Significant to high levels of distress are defined as a rating  $\geq 3$ . Approximately 100 new patients are screened monthly. Completed copies of the screening form are distributed to the treating physician, nurse case manager, and social worker. A unique systematic triage system in real time is in place and assistance is provided to the patient in the problem areas where they have indicated they have difficulties. Every problem is pre-assigned to a specific health care professional(s) for intervention. Some problems such as “*Ability to Have Children*” will include more than one team member (see Fig. 13.2).

At the present time, year 2 of this 4-year study has already produced important information about infertility concerns. The population thus far is comprised of cancer center outpatients ( $N=2,063$ ) who were on average 55 years of age with 63.9% females and 36.1% males. The patient sample was composed of 70.8% Caucasian, 11.1% Hispanic, 7.5% Asian, 4.5% African American, and 1.9% other. Of the sample, 57.6% of the patients were married, 18.1% were single, 12.7% were divorced, 6.7% were widowed, and 4.9% were living with a partner, with the remainder being unknown or missing. Clearly, the large number of female patients (mostly breast cancer) is of particular importance to our interests in oncofertility and Gender Synergies (a strengths-based approach to maximizing the ability of women and men to work together in managing the challenges of cancer and its treatment, see below for further discussion).

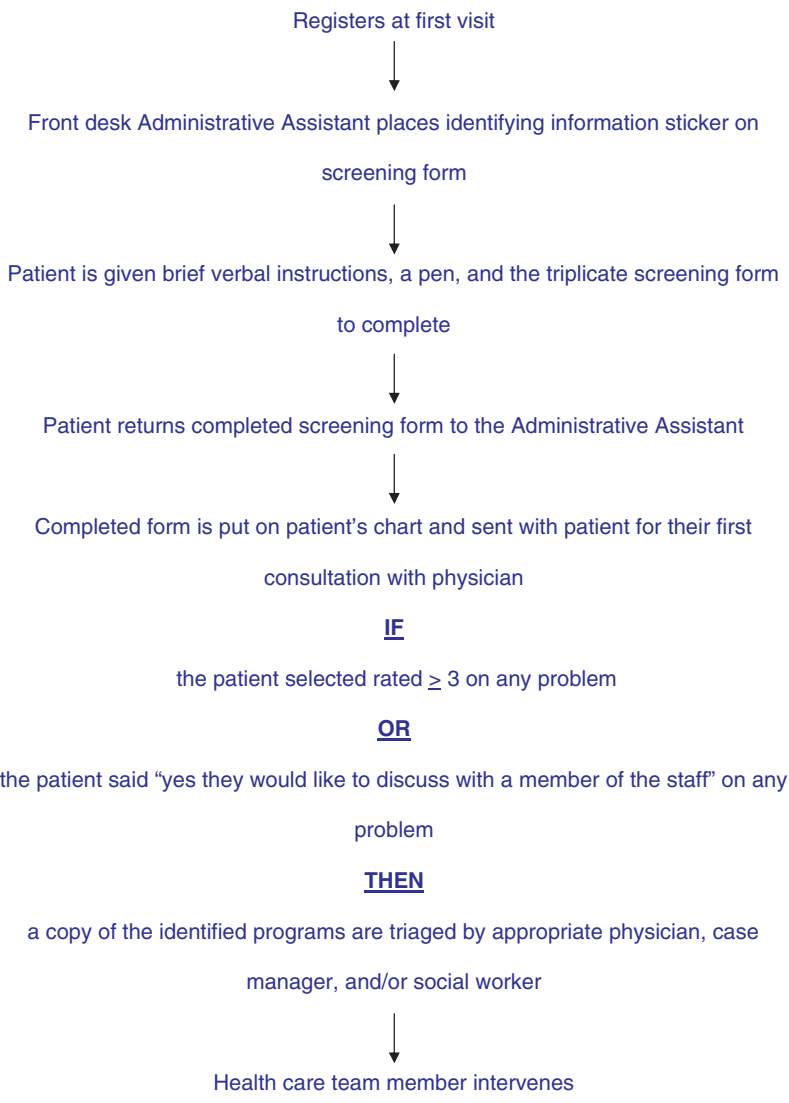


Fig. 13.2 Triage process

### Preliminary Results of Screening

To access psychosocial problems related to infertility, one of the items on the screening form is *Ability to Have Children*. Almost 9% of cancer patients reported that problems with *Ability to Have Children* rated  $\geq 3$ . The six most prevalent psychosocial problems reported that rated  $\geq 3$  were: *Fatigue; Finances; Pain; Feeling Down, Depressed, or Blue; Controlling My Fear and Worry About*

*the Future*; and *Being an Anxious or Nervous Person*. See Fig. 13.1 for average distress ratings in *Ability to Have Children* for the entire population compared with those who said they would like to discuss this problem with a member of our staff and those who would not. The average distress rating for the entire population was 1.30 and for those who asked for help the average rating was 3.69, which was almost triple the distress level rating of the overall population. However, a distress score of 3 out of 5 indicates a significant level of acute stress, which warrants therapeutic intervention. It should also be noted that for an individual to indicate that they need to speak to a member of our staff about any problem is an admission of vulnerability and distress and is a high threshold to reach on any scale.

As it relates with *Ability to Have Children*, 2% of cancer patients selected the statement *would like to discuss with a member of our staff*. Since cancer is primarily a disease of the elderly, 2% can be considered a robust unmet need. The six most prevalent psychosocial problems reported *would like to discuss with a member of our staff* by this subgroup were: *Understanding My Treatment Options*; *Controlling My Fear and Worry About the Future*; *Pain*; *Finances*; *Fatigue*; and *Feeling Down, Depressed, or Blue*. The implications for undermining quality of life of these specific problems are important to all areas of psychosocial functioning, especially for emotional regulation and problem solving.

Demographic differences in problems reported in *Ability to Have Children* were explored. Surprisingly, there were no significant differences between males and females on either the frequency of *Ability to Have Children* rated  $\geq 3$  or indicating they *would like to discuss with a member of our staff*. However, there were significantly more single (Divorced, Living with Partner, Single, and Widowed) cancer patients (10.3%) who rated *Ability to Have Children*  $\geq 3$  compared with married cancer patients (7.1%,  $p < 0.05$ ). Single cancer patients were also significantly younger than the married cancer patients ( $p < 0.05$ ). However, there were no significant differences in marital status and if they *would like to discuss with a member of our staff*. Cancer patients under the age of 40 (21.7%) were significantly more likely to experience psychosocial distress regarding *Ability to Have Children* than cancer patients 40 and older ( $p < 0.05$ ). In addition, younger cancer patients (younger than 40) were significantly more likely to report that they *would like to discuss with a member of our staff* problems with *Ability to have Children* than older cancer patients (40 and older,  $p < 0.05$ ). Ethnic differences were also found: 13.6% of minorities (African American, Asian, Hispanic, Multi-racial, Native Hawaiian/Other Pacific Islander, Native American/Native Alaskan, and other) rated *Ability to Have Children* at a distress level of  $\geq 3$ , which is significantly higher than reported by Caucasians (6.5%) ( $p < 0.05$ ). In addition, minorities also reported that they *would like to discuss with a member of our staff* this problem (3.4%) significantly more than did Caucasians (1.7%,  $p < 0.05$ ). See Table 13.1 for an overview of these demographic comparisons.

**Table 13.1** Demographic differences in distress regarding *ability to have children*

Demographic	High distress (rated $\geq 3$ )	Requested help
Gender	–	–
Marital status		
Single	↑↑	–
Married	↓↓	–
Age group (years)		
<40	↑↑	↑↑
$\geq 40$	↓↓	↓↓
–		
Ethnicity		
Caucasians	↓↓	↓↓
Minorities	↑↑	↑↑
–	No significant differences	
↑↑	Significantly higher distress	
↓↓	Significantly lower distress	

**Table 13.2** High distress in *ability to have children* also reported high distress in: ( $p < 0.01$ )

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*Abandonment by my family*

*Being dependent on others*

*Controlling my anger*

*Controlling my fear and worry about the future*

*Feeling down, depressed, or blue*

*Finances*

*Losing control of things that matter to me*

*Managing work, school, and home life*

*Nausea and vomiting*

*Needing someone to help coordinate my medical care*

*Recent weight loss*

*Solving problems*

*Spiritual concerns*

*Talking with family, children, friends*

*Understanding my treatment options*

*Writing down my choices about medical care for the medical team and my family if I ever become too ill to speak for myself*

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To explore other psychosocial problems, correlations were run between problems reported as distressing in relation to *Ability to Have Children*. The psychosocial problems that positively correlated with high distress (rated  $\geq 3$ ) with *Ability to Have Children* are displayed in Table 13.2.

A sum of all the problems rated  $\geq 3$  was calculated to determine an overall distress score, which ranged from 0 to 35. A score of 0 indicates that the patient did not have any problems that were rated  $\geq 3$ , while on the other end of the continuum, if a patient scored a 35, the patient would have rated 35 out of a possible 36 problems  $\geq 3$ . Thus, the higher the overall distress score, the more psychosocial distress



a patient is experiencing. Using this sum score, significant differences were found between those patients who reported problems in *Ability to Have Children* (rated  $\geq 3$ ) (mean=8.8) to those who did not (mean=5.5;  $p < 0.05$ ).

Consistent with other studies, women 40 years old and younger are more likely to report psychosocial concerns regarding fertility [8,9]; additional analyses to explore this subgroup were conducted. Two hundred and twenty-six women were included in this subanalysis. Of these 226 women, 21.6% rated *Ability to Have Children*  $\geq 3$  and 9.3% said they *would like to discuss with a member of our staff*. Women who reported high distress in *Ability to Have Children* were also significantly more likely to have reported high distress in the following problems: *Needing Someone to Help Coordinate My Medical Care*; *Understanding My Treatment Options*; *Managing Work, School, and Home Life*; and *Being Dependent on Others* ( $p < 0.01$ ). The data indicated a statistical trend where women who reported high levels of distress regarding *Ability to Have Children* reported a higher overall distress score (mean=7.0) than those women who did not report high levels of distress in *Ability to Have Children* ( $p < 0.07$ ). In contrast, of the 94 men in the same age range (40 and younger), 23.2% rated *Ability to Have Children*  $\geq 3$ , which, surprisingly, is slightly higher than the level of distress regarding *Ability to Have Children* that females within the same age range reported. It is important to note that women generally report distress and other problems at significantly higher levels than men. Therefore, it is important to recognize that the level of distress reported in this cohort requires additional exploration. On the other hand, 4.3% of the men age 40 and younger (as compared with 9.3% of women age 40 and younger) reported that they *would like to discuss with a member of our staff*. Therefore men age 40 and younger report higher levels of distress with *Ability to Have Children* but are less likely to ask for help with this problem.

## Discussion and Implications

In younger women with breast cancer, anxiety and depression peak at the time of diagnosis [10], which is also the time when women and male partners may have to make complex decisions about clarifying their intentions about having children, integrating complex medical information about their options of having children, and making choices that will have an impact on the rest of their lives. Decision making is made more difficult by the need to effectively manage the emotions endemic to a cancer diagnosis: fear of death, loss of dreams and aspirations, concerns about the stability of the relationship itself, and impact on the family and close friends. A diagnosis of cancer always influences families and friends and, in turn, their responses are important to how the patient copes, solves problems, and makes important treatment decisions. Social support, larger network size, and perceived support from partners has been shown to decrease depression, especially in younger adult women with cancer [11]. However, when in crisis overall and having children specifically, it is the committed couple who bear the onus of the most far-reaching decisions of their lives.

Overall, cancer patients and their spouses report a similar level of psychological distress [12]. As it relates to women and their male partners, both clinical experience and the limited research presently available support the importance of a supportive male partner [13]. Weihs et al. provides strong support for the unique contributions of the partner relationship and of the negative impact of a “distant” partner [14]. There is an emerging literature on the importance of how males and females provide and perceive support. Kim et al. reported that men found it easier and less challenging to their self-esteem to manage the many and complex practical aspects in supporting their partners with cancer than they did in communicating with women about their emotional needs [15]. The perceptual differences may be greatly increased during the cancer diagnosis and the emotional disynchrony exaggerated by the implications of decision making around having children during the crisis of a life-threatening illness. Stress always encourages rapid action, while emotional support and wisdom come much more slowly. When fertility is at risk in a couple for whom having children is at the core of their dreams and even the implicit basis of their relationship, it is essential for the health care team to help the couple to process the information and to communicate openly their priorities in relation to having children.

Clearly, the ability to tolerate and effectively use the energy generated by the emotion-laden context of cancer and making decisions about increasing the possibilities of having a child has important implications for individual coping and for the health of the relationship. For couples, the ability to make important decisions together will also impact how and even if anti-cancer therapies will be accessed. Thus, the implications for gaining an appreciation for how women and men can best support each other are crucial. In our program, we focus on Gender Synergies, a strengths-based approach to maximizing the ability of women and men to work together in managing the challenges of cancer and its treatment. Within this model, the differences and strengths of women and men are appreciated and actively embraced to maximize mutual respect and coordinated action to a clearly defined set of values and outcomes. This strengths-based approach focuses on the resiliency, perseverance, creativity, and commitment of women and men, regardless of their relationship, to work together as they have done since the beginning of time to transcend what seem to be insurmountable obstacles.

In this on-going study, we report on 2,063 consecutive cancer patients in an out-patient setting who completed the biopsychosocial screening instrument in which one set of questions provided the opportunity to indicate if they had concerns about having children related to treatment for cancer. As reported above, problems in *Ability to Have Children* rated  $\geq 3$  were reported by almost 9% of cancer patients. Because cancer patients report that there is inadequate attention to their concerns about fertility, it is important that standardized and systematic approaches for identifying those patients who could benefit from fertility-related information and education be implemented as essential part of overall medical care.

While we were impressed that 2% of cancer patients selected the statement *would like to discuss with a member of our staff* the problem *Ability to have Children*, it is clear that many more patients could benefit from early identification

of fertility-related concerns. This will only happen if health care professionals are able to comfortably address fertility concerns in an honest, open, and timely manner. The screening program described above, *Biopsychosocial Screening Instrument – How Can We Help You and Your Family?*, is a practical way to open the conversation, provide accurate and timely information, focus all energies on making informed treatment decisions, role modeling, team work, and creating a sense of direction and hope at a time when stress is high and it is difficult to manage the parallel processes of the present danger of cancer and the desire to achieve the dream of having children.

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