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The Psychosocial Impact of Cancer-Related Infertility on Women: A Review and Comparison

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The objective of the current article was to assess the psychosocial impact of treatment-related infertility or the possibility of infertility on young women with cancer in contrast to the general population. Literature on the subject of female infertility among the general population and treatment-related female infertility among young women with cancer was identified and examined in the context of what is known about the psychosocial impact of infertility among the general population. Women whose fertility was affected by cancer treatment were likely to experience negative emotional reactions, which can strain their relationships. Additional concerns included receiving inadequate information about infertility, enduring distress, and feeling uncertainty regarding fertility status.

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Cancer can affect fertility directly by involving reproductive organs and indirectly by suppressing reproductive function or delaying reproduction because of time spent receiving cancer treatment (Carter et al., 2005; Dellapasqua, Colleoni, Gelber, & Goldhirsch, 2005; Elit, Esplen, Butler, & Narod, 2001; Friedlander & Thewes, 2003; Meirrow & Nugent, 2001). In the past 25 years, pregnancies occurring in women older than 35 years have increased (Botting & Dunnell, 2003). Therefore, more patients with cancer are diagnosed and treated when their reproduction is not complete, making fertility issues more relevant. Fertility loss is important to cancer survivors (Canada & Schover, 2012; Carter, Chi, et al., 2010) and, often, their concerns about fertility are poorly addressed (Duffy, Allen, & Clark, 2005; Partridge et al., 2004; Thewes et al., 2005). To highlight issues with fertility faced by young women with cancer, researchers summarized and considered the fertility needs of cancer survivors in light of what is known about the experience of infertility among the general population. The objectives of the literature review were to examine the nature of fertility concerns, compare them to the concerns of women

suffering from infertility in a noncancer setting, and identify those who are at risk for experiencing a particularly negative response to fertility concerns.

Methods

Relevant studies were identified from electronic searches of PubMed, PsycINFO, Highwire, and Ovid databases and from manual searches of scientific journals all from 1982–2012. The following key words were used for electronic searches: *cancer, cancer treatment, oncology, survivor, psychological impact, distress, fertility, infertility, reproduction, and in vitro fertilization (IVF)*. Citations from publications identified by the electronic search were used to identify additional relevant studies. All identified articles were assessed for applicability. Included studies featured the psychological effect of infertility; were subject to peer review; published in academic journals; and used qualitative, quantitative, or mixed-methods design. Instead of systematic or meta-analytic review procedures, a narrative synthesis of identified studies was used because of the substantial heterogeneity in study design, population, and outcomes.

Results

Forty studies met criteria and were included in the review. Twenty-two focused on infertility among the general population and 18 on infertility among cancer survivors. Twenty-five studies used quantitative methods, 12 used qualitative methods, 2 were literature reviews, and 1 used a mixed-methods design. Research data suggested that the impact of infertility could be considered from the perspective of its effect on women and their relationships with significant others.

Impact of Infertility on Individuals

Impact on the general population: Literature suggested that the psychological impact of infertility would not lead a woman to experience a psychological disorder (Connolly, Edelmann, Cooke, & Robson, 1992; Domar, Broome, Zuttermeister, Seibel, & Friedman, 1992; Edelmann & Connolly, 1998; Freeman, Garcia, & Rickels, 1983; Hynes, Callan, Terry, & Gallois, 1992; Leiblum, Aviv, & Hamer, 1998; Paulson, Haarmann, Salerno, & Asmar, 1988; Wright et al., 1990). However, evidence was mixed as to whether infertility could lead to psychological distress.

Hynes et al. (1992) reported that a sample of infertile women experienced elevated levels of depressive symptoms and lower self-esteem when compared to fertile controls. Similarly, Lechner, Bolman, and van Dalen (2007) reported elevated levels of depression, anxiety, and complicated grief among infertile women compared with the general population. Leiblum et al. (1998) found that women whose IVF treatment resulted in pregnancy had lower anxiety than women whose IVF treatment was unsuccessful. In contrast, when comparing infertile women with fertile control participants, four studies did not find significant differences in self-esteem, symptoms of depression, or self-concept (Connolly et al., 1992; Edelmann & Connolly, 1998; Freeman et al., 1983; Paulson et al., 1988). Those studies drew their samples from specialist infertility clinics that provided either fertility investigations or infertility treatments (Connolly et al., 1992; Edelmann & Connolly, 1998; Freeman et al., 1983; Paulson et al., 1988). People who are undergoing fertility investigations or treatments usually are hopeful about the outcome (Lechner et al., 2007; Woollett, 1985); therefore, those four studies may have underestimated distress. Women who are most at risk for experiencing psychological distress as a result of infertility are women who have a strong desire for a biologic child (Kraaij, Garnefski, & Schroevers, 2009; Wischmann, Scherg, Strowitzki, & Verres, 2009) and those who engage in self-blame (Kraaij et al., 2009).

Qualitative research has consistently indicated that infertile women experience emotional distress. Some studies report that women who experience infertility develop new infertile self-identities; for a period of time, that identity becomes central to their overall self-concept (Becker, 1994; Greil, Leitko, & Porter, 1988; Olshansky, 1987; Woollett, 1985). Changes in identity occur because the ability to reproduce is a basic human expectation (Becker, 1994; Berg, Wilson, & Weingartner, 1991). Becker (1994) reported that many women in his study viewed their body as defective and unproductive. In addition, some stated that infertility disrupted their plans for the future (Becker, 1994; Woollett, 1985) and redefined their purpose in life (Greil et al., 1988; Woollett, 1985). Women also sensed a loss of control over their lives and

bodies, which contributed to psychological distress (Greil et al., 1988; Woollett, 1985).

Few studies, whether quantitative or qualitative, accounted for time since diagnosis of infertility, which likely influenced the degree of distress or adaptation. Lechner et al. (2007) assessed the anxiety, depression, and complicated grief reactions of women who were informed that they were infertile and found a negative relationship between those variables and time since infertility diagnosis. In addition, Salmela-Aro and Suikkari (2008) assessed depression while participants underwent IVF treatment and six months after the end of treatment. Participants whose treatments were not successful had adjusted their childbearing goals by the six-month follow-up assessment and depression had decreased. If studies do not consider the effect of time, changes in amount of psychological distress and adjustment to infertility over time will go undiscovered.

Impact on cancer survivors: Similar to infertile women in the general population, cancer survivors with fertility concerns may experience periods of emotional distress and adjustment (Canada & Schover, 2012; Carter, Chi, et al., 2010; Carter et al., 2005; Carter, Raviv, et al., 2010; Ganz, Greendale, Peterson, Kahn, & Bower, 2003; Knopf, 2002, 2006). The loss of menstrual function because of treatment could lead to psychological distress, which also may affect women who do not have plans for children in the future (Knopf, 2002, 2006; Penrose, Beatty, Mattiske, & Koczwar, 2012). Ganz et al. (2003) reported that the poor quality-of-life scores of young women breast cancer survivors (aged 24–34 years) who were treated primarily with chemotherapy were associated with undergoing menopause. In Carter et al.'s (2005) sample of 20 women with gynecologic cancer, the majority ($n = 15$) felt a sense of meaninglessness in their lives without biologic children, and 25% reported this to be marked or overwhelming. Forty percent felt that their future lacked purpose without the ability to have a biologic child, and 30% reported a lost sense of safety and security as a result of infertility. Forty percent also met the clinical criteria for depression. Longitudinal research indicated that women who are at least one year post-treatment and infertile experience symptoms of depression, distress, and grief (Carter, Chi, et al., 2010; Carter et al., 2005; Gorman, Malcarne, Roesch, Madlensky, & Pierce, 2010).

Impact of Infertility on Relationships

Impact on the general population: Many couples reported that their relationships were stronger because of stressful infertility experiences (Golombok, 1992). That was true for 50% of the 22 couples studied by Greil et al. (1988). In Sabatelli, Meth, and Gavazzi's (1998) study, 68% of participants ($n = 81$) reported that the emotional support of their spouses had increased after learning about the infertility. Bradbury, Fincham, and Beach (2000) documented that although stressful life events could cause strain

Exploration on the Go



Learn more about how cancer treatment affects fertility and what options are available in *After You Ring the Bell . . . 10 Challenges for the Cancer Survivor* by Anne Katz, RN, PhD. To access, open a barcode scanner on your smartphone, take a photo of the code, and your phone will link automatically. Or, visit bit.ly/13U5yjj.

in relationships, they also could strengthen those relationships by eliciting greater emotional support from partners.

Downey et al. (1989) used marital satisfaction scales to assess relationship functioning and found that differences did not exist between infertile and fertile couples and that they had similar expectations for future relationship satisfaction. For couples who were infertile because of cancer treatment, marital satisfaction scores were in the expected range compared to the general population (Bayley, Slade, & Lashen, 2009; Berg et al., 1991; Connolly et al., 1992; Wright et al., 1990) and remained stable throughout the infertility experience (Connolly et al., 1992; Leiblum et al., 1998).

The impact of infertility on relationships was more negative when couples assigned blame for infertility on someone or something (Wilkes, Hall, Crosland, Murdoch, & Rubin, 2009). Wilkes et al. (2009) found that couples in that situation often blamed the relationship or each other for infertility, which resulted in emotional isolation, communication problems, and arguments. Couples commonly reported a lack of communication and feelings of frustration with each other (Greil et al., 1988). Sabatelli et al. (1988) found that 41% (n = 21) of their female sample experienced an increase in conflicts with their partner.

Impact on cancer survivors: Similar to the general population, infertility can place strain on the intimate relationships of cancer survivors (Zebrack, Casillas, Nohr, Adams, & Zeltzer, 2004). Single women may have difficulty beginning new relationships as demonstrated by Zebrack et al. (2004), who found that young adult survivors of various childhood cancers reported being rejected by potential partners because of their fertility status or fearing that it would happen in the future. Canada and Schover (2012) reported that women who were an average of 10 years post-cancer and identified as infertile post-treatment experienced lower relationship satisfaction compared to women who identified as fertile. However, although most women and couples reported some relationship difficulties, they generally were satisfied in those relationships (Carter et al., 2005; Karaöz, Aksu, & Küçük, 2010).

Fertility Concerns of Cancer Survivors

Lack of information: One of the main fertility concerns for cancer survivors was a lack of information about the effects of

cancer treatment on fertility (Duffy et al., 2005; Partridge et al., 2004; Thewes et al., 2005). About 70% of young women diagnosed with cancer recalled having a discussion with a physician about fertility-related issues (Duffy et al., 2005; Partridge et al., 2004; Thewes et al., 2005). The fact that 30% of patients did not is concerning given that 56% of young women diagnosed with breast cancer reported wanting to have a child or more children at the time of diagnosis (Partridge et al., 2004). Women who already had children were less likely to recall having a discussion about early menopause with a health professional (Duffy et al., 2005), which may imply that fertility is given lower priority for patients with children. In Thewes et al.'s (2005) sample (N = 228), 45% recalled initiating the conversation regarding fertility issues with their physician. In Partridge et al.'s (2004) study, 51% of women felt that their concerns were addressed appropriately; however, 26% did not. Knobf (2006) found that women who did not feel adequately prepared for chemotherapy-induced menopause reported more uncertainty and psychological distress; however, that finding was not supported by other studies (Duffy et al., 2005).

Potential for infertility: Numerous factors impact fertility status after treatment and infertility cannot be predicted reliably; therefore, patients need to consider a potential for infertility without knowing for sure. Similar to confirmed infertility, potential infertility can be a source of distress (Avis, Crawford, & Manuel, 2004; Dunn & Steginga, 2000; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997; Knobf, 2006; Partridge et al., 2004; Penrose et al., 2012). Women concerned with potential infertility typically were younger, wanted more children, had fewer pregnancies prior to diagnosis, and had a history of difficulty conceiving (Partridge et al., 2004). Knobf (2002) found that among breast cancer survivors, the degree of uncertainty was dependent on information received from healthcare providers, providers' inability to predict the experience for individual patients, and lack of discussion among healthcare providers and patients. Uncertainty regarding fertility status may be emotionally difficult for individuals and cause tension in their relationships (Zebrack et al., 2004).

In Partridge et al.'s (2005) sample of breast cancer survivors (N = 667), 29% indicated that fertility concerns influenced their treatment decisions and 45% slightly questioned those decisions after treatment was complete. Of those who questioned their treatment decisions, 33% reported that their questioning related to fertility issues. Patients are presented with more aggressive treatments that will maximize survival but, in the process, may cause infertility. Therefore, young women with cancer may have conflicting priorities to consider.

Enduring distress: Women who have undergone cancer treatment may have enduring fertility distress. Canada and Schover (2012) reported findings from a sample of women with cervical cancer (n = 20), breast cancer (n = 130), or a lymphoma (n = 89) who were treated with surgery (94%), chemotherapy (77%), and radiation therapy (61%) and were an average of 10 years post-cancer. Twenty percent of Canada and Schover's (2012) sample experienced clinical levels of distress. Women who reported that their reproduction was affected by cancer or treatment experienced significantly more distress and intrusive thoughts, and employed avoidance strategies for managing their distress (Canada & Schover, 2012). Those effects remained

- ▶ Breast Cancer Network of Australia Fertility Decision Aid
www.bcna.org.au/store/products/fertility-related-choices-decision-aid
- ▶ Fertile Hope
www.fertilehope.org
- ▶ Fertility Preservation for Adolescents and Young Adults Diagnosed With Cancer: Guidance for Health Professionals
http://wiki.cancer.org.au/australia/COSA:AYA_cancer_fertility_preservation/Information_for_patients_and_families
- ▶ My Oncofertility
<http://myoncofertility.org>
- ▶ Save My Fertility
<http://savemyfertility.org>

FIGURE 1. Resources for Patients and Health Professionals Relating to Fertility and Cancer

Implications for Practice

- ▶ Oncology nurses are critical in identifying patient concerns and discussing survivorship issues such as infertility.
- ▶ A greater understanding of the psychosocial impact of treatment-related infertility would assist nurses in identifying patients who are particularly vulnerable to infertility-related distress.
- ▶ Nurses can better support patients with fertility-related concerns, particularly those at risk of enduring distress.

even after controlling for medical and demographic variables (Canada & Schover, 2012). Wenzel et al. (2005) assessed psychological distress and quality of life in relation to infertility in 231 women with gynecologic malignancies or lymphoma who were at least five years post-treatment. Women who reported that they were infertile as a result of treatment were significantly more likely to report poorer mental health ($p < 0.001$) and more cancer-specific distress ($p < 0.001$) than women who did not have fertility difficulties after treatment (Wenzel et al., 2005). They also were significantly more likely to have lower overall physical and psychological well-being than patients who did not report fertility difficulties (Wenzel et al., 2005). However, only 8% of participants stated they were less satisfied with life and 6% felt like less of a woman because of their fertility difficulties (Wenzel et al., 2005).

Implications for Research and Practice

Despite the evidence outlined, gaps in research remain. Much of the research is based on breast cancer survivors; however, responses to infertility may differ by diagnosis. Also, a distinct lack of longitudinal research exists, which would note how distress changes over time and what factors aid adjustment to changed or uncertain fertility status. Studies that assessed specific interventions and aimed to predict who are most vulnerable to fertility-related distress also would be helpful. Although assistive reproductive technologies are available that support young women survivors, few studies examine how the availability and use of those technologies impact survivors' psychosocial experience with infertility.

Oncology nurses could play important roles in screening for concerns, identifying patients at risk, providing information, and supporting and delivering interventions. Research indicated that patients see nurses as their preferred providers of information (Koutsopoulou, Papatthanassoglou, Katapodi, & Patiraki, 2010). A nursing model of care that focuses on holistic care and wellness was suited appropriately to supporting patients with cancer (Gilbert et al., 2011). The hierarchal model indicates that at the most basic level, patients are able to self-navigate through the diagnostic process with appropriate information and may not require additional support. Other patients require more information and support but assistance from a layperson may be adequate. Those patients who require greater clinical intervention for physical or psychological symptoms may require a healthcare professional. As nurses increasingly

deliver services to cancer survivors, they must be provided with strategies to effectively manage those patients' fertility needs (Irwin, Klemp, Glennon, & Frazier, 2011). Nursing strategies effectively employed in fertility are similar to skills employed in other cancer settings, for example, identification of needs as part of a comprehensive nursing assessment that includes care planning, appropriate specialist referral, facilitation of the multidisciplinary care, and delivery of ongoing support. However, those generic strategies are best supported by resources unique to fertility (see Figure 1). Because clinical practice informs research needs, nurses play key roles in developing a body of evidence to support practice in the area of infertility's impact on cancer survivors.

Conclusions

Fertility concerns may have a significant impact on young women who are cancer survivors. Consistent with the general population, women whose fertility was affected by cancer treatment could experience negative emotional reactions and go through a period of difficulty in their relationships. Cancer survivors may face additional difficulties, which impose emotional burdens including concerns about lack of information regarding infertility, feeling forced to compromise fertility in favor of more aggressive anticancer treatments, uncertainty regarding their fertility status, and enduring distress. Future research on how distress changes over time, strategies to improve information provision, interventions to promote adjustment, and the identification of those at greater risk of distress is warranted.

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