
TRADITION, HERITAGE AND SPIRITUALITY

My Illness, Myself: On the Secrecy of Shame

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Abstract

Research has shown that the experience of being diagnosed with cancer has a negative psychosocial impact on patients and their families, often resulting in distress, and numerous practical and relationship challenges. Men with prostate cancer and their partners face special challenges. A range of symptoms that result from monitoring patients and side effects of treatment may reverse the quality of life and intimate relations between patient and partner. However, patients often are reluctant to bring up their distress about the symptoms, leading to an underestimation and reduction in optimal symptom control. As a result of their illness, chronically-ill male patients often experience elevated levels of stress, daily activities are often limited, they are frustrated about the unpredictable course of the illness and its symptoms, and are immersed in fears about their present and future social identity. Most of them avoid disclosure about their illness – when and where possible - and place great importance on sustaining a normal life. Factors related to limiting disclosure include men's low perceived need for support, fear of stigmatization, the need to minimize the threat of illness to aid coping, practical necessities in the workplace, and the desire to avoid burdening others. This paper contributes to an understanding of the complex issues of disclosure related to prostate cancer patients and raises issues about how best to be helpful, within their cultural and social framework. It also deals with feelings of shame, guilt and inadequacy as the cause – or consequence – of concealing the illness. The oral presentation will use a clinical example of secrecy and the subsequent conflicts and quandaries of a religious person diagnosed with advanced prostate cancer. Dilemmas of shame, disclosure and guilt will be the focus of the discussion.

Keywords: Prostate cancer - stigma - family - secrecy - disclosure - shame

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Introduction

Cancer: a burdensome reality “*One person's truth is another's conundrum.*” P. Marshall, 1994.

Cancer is a broad and complex subject interrelated with biological, sociological and cultural constructs. A number of studies involving patients diagnosed with cancer have been published that focused on qualitative and psychosocial aspects, thereby describing the patients' emotions, perceptions and functioning within the ecological system. Critical research has examined the reactions of patients - particularly of men diagnosed with prostate cancer- their perceived quality of life, and their family's responses. Nevertheless, there is less knowledge about patients' subjective appraisals and subsequent coping with the possible impact on their partners - specifically about the various side effects of cancer treatment (Boehmer and Clark, 2001; Spanish, 2004).

An understanding of coping strategies is particularly warranted in the case of advanced prostate cancer patients receiving hormonal therapy due to the unique nature and special severity of the psychosocial problems they may face (Terris and Rhee, 2005). The difficulties entailed in their disease are compounded by those stemming from its

treatment, which is aimed at halting the tumor's growth via androgen deprivation.

Male patients are particularly vulnerable due to the age-related stressors and the uncertainties associated with the detection and treatment of prostate carcinoma (see Table 1 for statistical rates of incidence of prostate cancer in Israel). Profound effects occur on mood, with increased depression, irritability and anxiety. Side effects of treatment, such as hormonal therapy, steroids and pain medications, add to the reasons for high psychological distress, loss of libido, erectile dysfunction, gynecomastia, weight gain, female distribution of fat, loss of bodily hair, hot flashes and sweats, nausea, osteoporosis, decreased vitality and mood disturbances (Waldron, 2002).

The paper will describe the process that men diagnosed with prostate cancer go through in determining whether to disclose or conceal the illness from their family, friends and social network. There is perhaps a greater potential for stigma for these men than for men diagnosed with any other cancers. The association of prostate morbidity with symptoms such as sexual dysfunction, diminished testosterone and fatigue may be perceived by an outsider with disdain and negative judgments. While various studies have considered the impact of prostate

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Table 1. Prostate Cancer: Incidence Rates in Israel, 2000-2007 (Barchana and Lifschitz, 2007)

Diagnosis year	Jews		Arabs	
	Average	SD	Average	SD
2000	72.0	9.39	72.7	9.18
2001	72.4	9.34	70.5	10.32
2002	72.0	9.06	72.1	9.18
2003	71.5	9.40	72.3	10.05
2004	71.2	9.26	68.8	9.55
2005	71.0	9.56	70.8	10.57
2006	70.5	9.61	70.0	9.65
2007	69.6	9.38	70.2	10.15

Σ Prostate cancer is the most common cancer among Jewish men, and the rate of diagnosis has been affected mainly, since the end of the 1980s, by early detection through the use of PSA. More than 2100 men are diagnosed annually. The incidence rate increased steadily until 2004, at which point there began an apparent decrease in the incidence rate; even though it is not possible to predict if this trend will continue. Σ A similar picture of increasing morbidity rate and somewhat of a decrease from 2004 was demonstrated among Arab men. This decrease can be real or a result of changes in the reporting and testing methods.

cancer on men and their spouses, only a handful have focused specifically on issues of stigmatization and disclosure (Gray et al., 2000).

Most research about disclosure is based primarily on stigma theory and, thus, is steeped in the assumption that ill or disabled persons are motivated to avoid being stigmatized by others by avoiding disclosure whenever possible (Okano, 1999). Although self-disclosure is an understudied area of investigation, especially with respect to cancer, the scarce research that has been done is suggestive of important implications for how men and their partners respond to illness. Especially concerning prostate cancer, with the double label of life-threatening illness and sexual dysfunction, relevance of disclosure and secrecy issues seems highly germane (Helgason et al., 2001).

The Circle of Life: Individual or Family Illness?

“Two voices is the minimum for life, the minimum for existence...” M. Bakhtin, 1984

It is becoming an accepted fact that models of stress and coping need to incorporate a relational perspective. Major life stressors affect not only individuals but the lives of their intimate partners, spouses, friends and others in their social-cultural networks. Systemic-transactional theory proposes that coping is a stress management process where partners either ignore or react to each other's stress signals to maintain a level of stability in the relationship on the individual and the dyadic levels (Bodenmann, 2005). Each partner's well-being mutually

Table 2. Relational Qualities (Kayser et al., 2007)

Characteristic: Definition
Relationship awareness: Thinking about one's relationship in context of the illness and the impact on the partner and the relationship
Authenticity: Not hiding feelings from partner
Mutuality: Empathic responding in a shared experience

depends upon the other's well-being, as well as upon the couple's ability to use resources in the social environment during the stress process (Fekete et al., 2007).

Coping is typically thought of in terms of individual-level strategies, such as active coping, planning, positive reframing, acceptance and behavioral disengagement, but it also has fantasied or real dyadic-level implications. Relationship-focused coping strategies are designed to maintain, preserve and protect social relationships during times of stress. Studies on how couples face cancer center on how the strategies used by one partner affect the other partner's adjustment to the stress of the illness. Moreover, individuals' perceptions of their partners' emotional responsiveness may be more important in maintaining the relationship than their partners' actual behaviors (see Table 2).

Langer et al. (2009) emphasize a particular relationship-coping strategy of protective buffering (PB) as applied to cancer and defined as “hiding one's concerns, denying one's worries, concealing discouraging information, preventing the patient from thinking about the cancer, and yielding in order to avoid disagreement.” A patient might be experiencing certain symptoms, but so as not to worry the partner or out of fear of the partner's reaction, hesitates to disclose any of these symptoms.

Patients in need of protecting their family may either pretend not to know the real meaning of the symptoms or forbid the physician to discuss their medical condition with family members. These façades can be distracting, debilitating and harmful. Sometimes, tragically, while the patient and family are attempting to protect the other by pretended or imposed denial, in reality both sides are desperate to escape from their self-imposed seclusion. Such denial obstructs both communication and the completion of the normal pattern of life's routines. The isolation may induce premature conflicts, depression and fear, and result in a more difficult interactional process for each family member (Vangelisti et al., 2004).

Cancer: Shadow of Secrecy and Shame

Family life is a dynamic, intricately patterned kaleidoscope of feelings and emotions, ranging from intense hues of anger, hate and love to the mildest shades of irritation, hurt and forgiveness. There are times when the family provides an emotional refuge, a “haven in a heartless world.” At other times, the family is a crucible of dark emotions that may fracture and destroy family relationships (Caughlin et al., 2004).

The theory of family communication argues that people want to control private information by granting or denying access to confidential information. They feel they own it (and therefore have the right to control it) and because revealing the information has the potential to make them vulnerable and ostracized from social boundaries (Petronio, 2002). Secrecy is a metaphorical marker of who controls, regulates and shares ownership of private information (Petronio et al., 2003).

Data describing the deterioration of patients' relationships with their partners relate to the belief that they are no longer capable of fulfilling their role as

Table 3. Case History

General: The following clinical case describes a Rabbi who is defined not only by his religious commandments and responsibilities, but also by the socio-cultural environment and family system in which he lives and is expected to be a role model.

Sociodemographic data: David F. was born in France in 1956 and immigrated to Israel with his parents in 1958. Parents were born in Algeria. He grew up in a religious family and studied in a religious school. He graduated and became a teacher and rabbi. David has 6 brothers and 4 sisters, all religious and living in Israel. David is married to Yaffa, 39 years old, and they have 4 daughters: a married daughter of 18 and 3 aged 16, 12, and 7. Besides being a full-time homemaker, Yaffa runs a private day care group for babies in their home. She was born in Tunis and came to Israel as a child with her extended family.

Medical history: In March 2009, David was diagnosed with metastatic prostate cancer. Treated with radiation and hormone therapy (LHRH). Despite clear, persistent symptoms, patient refused to see a physician for more than one year. Because of intense pain and urinary difficulties, he finally consulted with his family doctor who sent him to the Institute of Oncology. There he received medical care from a senior oncologist.

Psychological referral: Patient was referred by the oncologist with symptomatology of high psychological distress. He thought that his wife could become pregnant again, if he discontinued all medical treatment. He refused to communicate with wife or any of his close family about the illness. Only his older brother knows about the present situation.

Problems that patient presented: Absolute privacy and confidentiality about disclosure; secrecy; shame of being ill; guilt that he cannot fulfill the commandment of giving his wife more children that she desires and expects; fear of being rejected socially and abandoned by his family.

husbands (see Table 3). Moreover, feelings of inferiority derive from the dual stigmatization of cancer and impotence, and the impairment of their psychological quality of life due to fatigue, low self-concept, anger and shame (Navon and Morag, 2008).

Whereas certain patients reportedly benefit from sharing their disease-related concerns with their spouses, others restrict communication to avoid upsetting conversations. Such concealment has also been found to be adopted for preventing social degradation (Gray et al., 2000; Jakobsson et al., 2000).

In Navon and Morag’s study (2008), an initial analysis of the patients’ psychosocial difficulties generated five topic areas related to their body image, sexual life, ties with spouses, social relationships and self-perception (see Table 4). As the statistical analysis progressed, only three topics emerged, because low self-concept and strained social interactions stemmed, in fact, from bodily feminization, sexual dysfunction and spousal tensions.

Patients live in constant tension between withholding personal anguish about their disease and sharing private struggles to sustain emotional closeness by hiding their asexuality (Okano, 1999).

Shame may be one of the most hidden human feelings. Patients are reluctant to talk about their own shameful experiences and often do not even want to admit having this feeling. It is the nature of shame that patients hide feelings of inadequacy or inferiority either from themselves or from others. Shame “generates concealment

out of a fear of rendering the self unacceptable,” in contrast to guilt which “invites confession and forgiveness.” It is often experienced as the inner, critical voice that judges whatever we do as wrong, inferior or worthless. Shame and humiliation are closely connected to social exclusion, making the individual feel deviant and an outsider. They contribute to the understanding of the psychological and cultural aspects of being pegged as a cancer patient (Oravec et al., 2005).

Heller (1996) points out the difference between the “physical manifestation of shame” –blushing - and “social shame” in cultures in which the intensity of the shame depends on the nature of the violated rule. In contemporary societies, the intensity is also determined by the social environment of the person who has violated the rule.

There are three different psychological aspects of shame:

A particular type of anxiety in a situation of threatened exposure or humiliation.

An emotion or a cognitive/emotional reaction.

A reactive formation (character trait).

Shame comes with consciousness - particularly self-consciousness – that is the awareness of our inadequacy and worthlessness. It comes with the sense of being cut off from an essential source of family support, community, God or other in the sense of splitting off or repressing the shameful part (Nathanson, 1992).

One source of shame is associated with the expression

Table 4. Coping Strategies (Navon and Morag, 2008)

Individual level	Feminized body	Extinguished sexuality	Constrained intimacy
Self-redefining	Self-perception with neither sex	Being asexual	Self-identifying as spouse’s brother or friend
Self-distancing	Refraining from looking at oneself	Relegating sex to a past stage of life	Changing familial roles
Self-solacing	Reframing bodily changes		Changing intimacy
Interpersonal level	Feminized body	Extinguished sexuality	Constrained intimacy
Disguising	Camouflaging the bodily changes	Concealing the sexual losses	Masking the lack of libido
Diverting	Exhibiting masculine behavioral traits	Acting as if nothing happened	Emphasizing commitment to family and society
Avoiding	Refraining from public body exposure	Withdrawing from social events	Restricting any closeness

of impulsive emotions such as anger, fear, sadness and vulnerability. Often admonitions are internalized so that when we get in touch with any of these “shameful feelings,” we will automatically feel shame and try to control or hide the feelings or, at the very least, to apologize profusely for not fulfilling what – under normal circumstances - is expected of us.

Shame may often be at the root of marital discord. If one member of the couple wants more intimacy, and/or communication than the other, both feel shame as a result. The one wanting more intimacy may feel rejected and shamed for wanting too much, and the other may feel shame for either not being comfortable with more closeness or for wanting more distance than the other. Shame is often bypassed and may produce coping styles by avoidance, withdrawal and isolation (Baider, 2008).

Quandary: Possible Resolution?

“Man is only wise during the time that he searches for wisdom; when he imagines he has completely attained it, he is a fool.” **Solomon Ibn Gabirol**, circa 1040

What is shame and what is guilt, and when and how do these emotions occur and develop? Since the surrounding norms and conventions affect people’s actions, thoughts and feelings, it is necessary to take a closer look at the specific society’s cultural norms, family interactions and rules regarding private and public disclosure (Pattison, 2000).

It is the meaning patients attach to the experience of shame that is profoundly dependent on the socio-cultural and religious beliefs. Different meanings given to shame may reflect different behavioral secretiveness within each social group.

Adaptive individual and family functioning involves the open exchange of reactions, the frequent expression of positive and negative emotions and the ability to effectively regulate the range of these emotions concerning the fate of cancer. Psychosocially adaptive families may be those in which family members validate and embrace different notions of shame, guilt and secrecy within a culture that allows mutual acceptance, flexibility and compassionate regard for being different.

Patients may be able to learn the overt language of dialogue. Families may be able to readjust to their systems of beliefs and convert the silence of shame into a new language of trust, mutual care and spiritual hope.

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