An Integrated Model of Sexual Health Module

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Learning Themes

- Introduction to an integrated model of sexual health
- Domains of sexual health

Introduction

The physical effect of a chronic disease such as cancer is often quite specific. Damage to one organ or a subtle change in body chemistry. The psychosocial impact of an illness is broad however altering many aspects of a person's lifestyle. As healthcare professionals we tend to focus on pathology and sexual dysfunction but we also need to have a concept of what encompasses sexual health (Schover & Jensen, 1988). A model that encompasses all facets of a person's life provides a goal for our interventions and reminds us to assess individuals or couples strengths and resources even in the midst of a crisis such as cancer (Robinson & Lounsberry, 2010). It is our intent to introduce and explore a conceptual model of sexual health that encompasses not only a person's physical experience of sexuality but also their psychological, relational, social and spiritual dimensions.

The World Health Organization (WHO) defines sexual health as "the integration of somatic, emotional, intellectual and social aspects of sexual being in ways that are positively enriching, and that enhances personality, communication and love" (WHO, 2004, p. 7). This definition of sexual health expands beyond the physical and reminds us as healthcare professionals that "the notion of sexual health implies a positive approach to human sexuality, and the purposes of sexual health care should be the enhancement of life and personal relationships, and not merely the counselling and care related to procreation or sexually transmitted diseases" (WHO, 1975, p. 2).

Sexual health is a multidimensional construct that has physiologic, psychological, relational and social and spiritual dimensions and dynamic interactions between these dimensions. Gender identity and roles, what it means to be a man or a woman, are integral components of sexuality. Sexuality includes our concept of ourselves as sexual beings (Hyde, Delamater & Byers, 2009). Sexuality is an integration of mind, body and spirit and is a vehicle for experiencing and expressing emotions. Body image, reproductive capabilities, and sexual functioning are considered three distinct and yet interrelated components of sexuality (Schover, & Jensen, 1988).

The developmental stage of an individual, their cultural norms, and past experiences will all shape and influence sexual expression. Cultural norms define what is considered normal sexual expression. Values, attitudes, relationships, and style of dress are also expressions of sexuality. An individual's sexuality is often expressed in the context of a bond formed with another individual. Sexuality includes various aspects of sexual activity such as fantasy, hugging, touching, kissing, masturbation, oral genital stimulation, and intercourse. In the hierarchy of human needs, the theorist Abraham Maslow recognized sexual activity as a basic need and placed love and connection to others on a higher tier (Hyde et al, 2009). All individuals have a lifelong need for emotional connection to others and are sexual beings regardless of age, sexual orientation, state of health, or current relationship status. To fully appreciate the effects of cancer and the treatment of cancer on sexuality, one must consider the broader understanding of sexuality and not simply physical sexual activity (Schover & Jensen, 1988).

Historically research into the sexual health of those experiencing cancer was focused solely on those cancers of the reproductive or sexual organs such as breast, testicular, prostate, or gynecologic cancers. In recent years this focus has shifted to an understanding that sexual health is affected and impacted no matter the type or location of the cancer (Tierney, 2008). A high number of persons experiencing cancer report alterations in their sexual health and that these changes often persist for many years following treatment (Baker, Denniston, & Smith, 2005; McKee & Schover, 2001; Meyerowitz et al., 1999, Schulz & Van De Wiel, 2003). Just as in other critical transition points of distress, shifts in sexual health happen regardless of age, relationship status, gender, or type of cancer; with the incidence and types of alterations varying across diagnoses and treatment therapy (Hordern & Street, 2007).

Changes in sexual health have been found to negatively affect the quality of life for persons experiencing cancer (Hughes, 2000; Ferrell & Dow, 1997; McKee & Schover, 2001; Pricto et al., 1996). Carelle et al. (2002) uncovered that in a group of cancer survivors, across a variety of diagnoses, the loss of sexual desire ranked sixth out of ten on a list of the most severe side effect of chemotherapy. In conjunction, changes to sexuality and family distress posed the most negative effect to their own social wellbeing. These findings fit with another study that revealed 41% of persons with cancer experienced sexual dysfunction and again ranked it sixth out of ten overall problems (Baker et al., 2005)

Toward an Integrated Model of Sexual Health

Sexual health care can then be viewed as a “process of facilitating sexual health through prevention and through intervention when problems occur” (Schover & Jensen, 1988, p. 3). It is imperative that we as healthcare professionals maintain a wholistic person-centred perspective when dealing with sexuality. The arguments of organic versus psychological causation need to make room for an

integration of the psychological, physiological, informational, relationship, societal and spiritual threads that weave together to create the pattern we finally observe (Schover & Jensen, 1988).

An integrative model, such as the one outlined by Schover and Jensen (1988) and on whose work we base our own model, views an illness such as cancer as situated within multiple systemic interactions. This system is made up of macroscopic components such as family and society and microscopic elements such as cells and molecules. In contrast the medical model assumes that a specific disease agent acts in a linear cause and effect fashion to produce a diseased person.

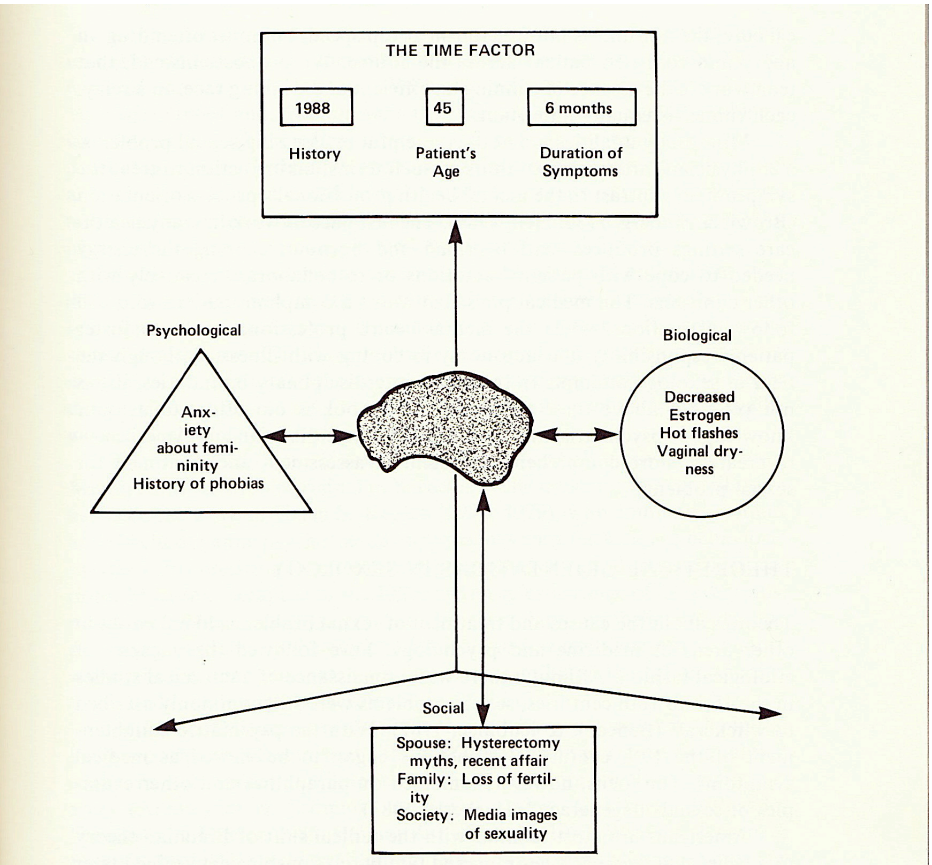

Figure 1-1. The integrative model applied to a problem of inorgasmia.

(Schover & Jensen, 1988)

Each factor is important in its own right, yet all interact to create the symptom picture. To create a treatment plan for the problem we must also consider the influence of time. That is to say we must consider a person's individual time. How their individual history intersects with historical perspec-

tives including society's sexual attitudes and the types of help currently available for a sexual dysfunction.

Domains of an Integrated Model of Sexual Health

Persons with cancer have been shown to experience an array of psychosocial and supportive care needs. These domains of needs have been identified in several systematic reviews (Richardson et al., 2007), population based surveys (Boberg et al., 2003; Fitch, 2008; Gustafson et al., 1993; Sanson-Fisher et al., 2000; Vachon 2006; Vachon, 1998), and in two major reports (IOM, 2008; The Ontario Cancer Treatment and Research Foundation, Supportive Care Program Committee, 1994). Fitch (1994), among others, has identified seven elements or dimensions of health as part of a patient's experience of cancer and treatment; physical, informational, emotional, psychological, social, spiritual, and practical (Ashbury, Findlay, Reynolds, & McKerracher, 1998; Boberg et al., 2003; Fitch, 1994; Gustafson, Taylor, Thompson, & Chesney, 1993; Richardson, Sitzia, Brown, Medina, & Richardson, 2005; Richardson, Medina, Brown, & Sitzia, 2007; Sanson-Fisher et al., 2000).

These seven domains of need are common across the cancer continuum. However, certain phases of the cancer continuum appear to bring to the foreground specific needs (Fitch, 2000). Critical transition periods have been identified as the time prior to diagnosis for at- risk populations or those with a suspicion of cancer, as well as at time of diagnosis, during treatment, post-treatment or survivorship, recurrence, palliative care, end-of- life, and family bereavement (IOM, 2008; Richardson et al., 2005; Veach, Nicholas, & Barton, 2002).

Cancer Continuum (CAPO, 2010)

Critical transition points reflect times when patients and their families may be most vulnerable to unmet psychosocial needs and emotional distress. These needs vary with type of cancer and treatment, life- stage of individuals and their families, and according to socio-demographic, environmental, and living circumstances (Fitch, 2008; Veach et al., 2002).

Issues of sexuality and sexual health following diagnosis and treatment of cancer are multifaceted. Persons and their partners may experience alterations in sexuality and sexual health as a result of changes in multiple dimensions of health. Alterations to sexual health may be caused by: 1) the cancer; 2) distress associated with a diagnosis and living with cancer; 3) treatment; 4) side effects associated with treatment; 5) distress following treatment; and 6) alterations in relationships during and following treatment, especially the relationship with the intimate partner. It is also important to remember that cancer treatments, more often than the cancer itself, have the potential to disrupt one or more phases of the sexual response cycle (Tierney, 2008).

In their work on screening for distress in cancer care Morck and McLeod (2010) came upon the metaphor or image of a labyrinth to pictorially capture the integrated and fluid nature of these domains of need. For over four thousand years, humans have used the labyrinth as a focus for meditation that integrates mind, body, and spirit. It has always been a symbol of the path of life, a reminder that although that path seems very confusing and the centre sometimes very far away, it can always be found. The labyrinth is a pattern whose meaning is expressed on both conscious and unconscious levels. Its shape, the circle, is a universal symbol of wholeness (which is the root meaning of the word health) and unity. Its meandering path is a metaphor for the path of life. According to the psychologist Carl Jung, the labyrinth pattern is an archetypal image of the psyche (Labyrinth Society, 2010). This image of a labyrinth and the dimensions of health in cancer care are pertinent to an examination of sexuality and sexual health given a diagnosis of cancer and provide the framework for our integrated model of care.

These needs or dimensions of health reflect that people are multidimensional and complex and that health is a dynamic, ever-changing process. This leads us to the reminder that healthcare professionals working in cancer care must respond and view the whole person and their whole experience. While these domains have been identified as “categories” of need, it is important to remember that they are integrative, fluid, influence and affect one another. A concern or challenge in one domain affects and influences all the other domains and vice versa. Needs under seemingly distinct domains in actuality merge, blend, and are fluid states.

A labyrinth adapted from the Screening for Distress Education Resource (Morck & McLeod for CAPO, 2010)

Physical Dimension

This dimension includes physical comfort and freedom from pain, optimum nutrition, and the ability to carry on activities of daily living (Fitch, 1994). Physical changes that can contribute to altered sexual health may be a consequence of the cancer treatment or due to the cancer itself. Although not an exhaustive list, many common symptoms arising during and after cancer therapies such as pain, nausea, vomiting, diarrhea, fatigue, skin changes, cognitive impairment, incontinence, decreased physical stamina, sleep disturbances, and peripheral neuropathies may result in altered sexuality. Fatigue is a common symptom at the time of diagnosis and following treatment. The distress associated with persistent fatigue can result in disruptions in the sexual response cycle, particularly diminished sexual desire. Many medications have the potential to disrupt the sexual response cycle leading to altered sexual health (Hughes, 2008, Robinson & Lounsberry, 2010, Schover & Jensen, 1988, Tierney, 2008).

Chemotherapy, in particular, affects nutritional status because of changes in functioning of the gastrointestinal tract. These can include weight changes (loss or gain), changes in taste and smell, and anorexia, and can leave a person feeling asexual. Weight changes can also affect body image. Any of the changes in the mouth, including dry mouth, mucositis, nausea and vomiting, and taste changes can greatly hinder kissing and other forms of oral intimacy. With diarrhea or constipation there can be discomfort in the pelvic area that can hinder genital activity (Katz, 2007; Krebs, 2006).

Sexual dysfunctions associated with disruption of the neurovasculature of the genitalia or hormonal changes include diminished desire and arousal, erectile dysfunction (ED), and dyspareunia (Tierney, 2008). Direct injury to gonads from chemotherapy and radiation to the pelvis may result in infertility in both genders and premature ovarian failure (POF) in women. Chemotherapy and radiation damage the germinal epithelium of the testicles, resulting in temporary or permanent oligospermia or azoospermia. Ovarian toxicity following chemotherapy or radiation may lead to temporary or permanent cessation of menses. Women who retain normal menstrual cycles following treatment remain at risk for POF. Vascular changes, hardening of the arteries or fibrosis, can occur years following radiation treatment, resulting in ED. Nerve damage secondary to chemotherapy or radiation may diminish the intensity of orgasm in some men. ED caused by cavernosal arterial insufficiency has been documented in some men, particularly those receiving total body irradiation. In women, pelvic radiation may result in vaginal stenosis and fibrosis (Hughes, 2008; Tierney, 2008).

Practical/Informational Dimension

The practical dimension is associated with the need for direct assistance or resources to accomplish tasks or activities (Fitch, 1994). Practical issues can include financial or employment worries related to loss of income associated with the cancer experience. These may include financial burdens related to having either reduce or stop work during treatment. It can also include however the additional cost of cancer treatment, prostheses, aids, or transportation.

Cancer symptoms and treatment side effects can sometimes make it very difficult to keep up with normal daily routine, especially with children. This may include problems or disruptions associated with the completion of day-to-day tasks such as picking children up from school or doing the shopping. Additionally, it may mean having to rely on friends and family for assistance with activities of daily living. When practical issues create distress, diminish energy and create conflict leading to decreased interest in sexual activity (Hughes, 2008).

The Informational component refers to information to reduce confusion, anxiety and fear, to inform personal and family decision-making, and to assist in skill acquisition. This would include information regarding cancer, treatment, treatment side effects and management. It would also include communication with healthcare professionals and other care providers' care processes and system navigation needs. It may also include assistance help with decision-making (Fitch, 1994). As we outlined in the previous module on interprofessional healthcare and sexuality this also includes the need for specific information and open non-judgmental communication regarding the impacts of cancer on sexuality and sexual health.

Psychological/Emotional Dimension

Refers to a sense of comfort, safety, understanding and reassurance. This includes an understanding and assistance with the emotions that may arise in the cancer experience. It is also associated with coping with the illness experience and its consequences, personal control, self-esteem (Fitch, 1994).

The diagnosis and treatment of cancer are associated with significant psychological distress that can result in altered sexuality. Psychological distress includes anxiety, depression, anger, an emotional response to infertility, fear of relapse, sense of vulnerability, changes in body image, decreased self-confidence, worry about loved ones, and concerns about the reaction of the sexual partner (Baker, et al, 2005; Holland, & Reznick, 2005; Krebs, 2006; Soothill et al., 2001; Stanton & Ganz, 2005). Psychological distress in persons experiencing cancer is quite common with recent study of cancer survivors reporting numbers approached 45% (Zabora et al., 2001). Decreased desire and arousal are common in individuals suffering from depression. Emotional distress, especially anxiety, negatively influences sexual desire (Baker, et al, 2005; Krebs, 2006; Tierney, 2008).

A key component of sexuality is body image. This encompasses a person's attitudes and feelings of attractiveness with regards to their body. Cancer, treatment, and sequelae can result in numerous changes that negatively impact body image. These changes may be permanent or temporary, visible (scars, amputations, prosthesis) or invisible (beliefs, attitudes, feelings) to self or others. Changes in body image may include alopecia, weight gain or loss, scarring caused by surgeries and biopsies, and placement of venous access devices. Changes in one's body associated with surgical amputation, mastectomy or creation of ostomies for colorectal or bladder cancer can be devastating. Research has shown that changes in body image may persist for years following treatment and negatively impact sexuality (McKee & Schover, 2001; Wright et al., 2002; DeFrank et al., 2007). Fifty-two percent of cancer survivors indicated needing help in dealing with changes in body image (Soothill et al, 2001).

Mood can affect sexual functioning in a negative or positive way. Clinical depression is the main psychological cause of deceased libido in patients with cancer, but it often goes undiagnosed and untreated (Hughes, 2008). Other psychological issues that may affect sexual health include frustration, stigma and embarrassment, anxiety, anger and irritability, loneliness and despair, sadness, grief at the numerous losses experienced as a result of the cancer, misinformation, guilt and shame, disappointment, and fear. Fears of death, rejection, or loss of control affect libido and ability to enjoy sex. Persons with cancer may also have a lowered self- esteem as well as performance anxiety and changes in personality. Age-appropriate developmental goals (education, marriage, pregnancy, child rearing, career, retirement) may be affected by treatment. Persons may

be unable to continue working, which may affect self-esteem or increase financial burdens (Hughes, 2008; Katz, 2007, Tierney, 2008).

Social and Relational Dimension

The social and relational dimension is related to family relationships, community acceptance and involvement in relationships. This may include adjustments in social roles, coping with interpersonal problems and changes in sexuality, starting new social or intimate relationships, reintegration and return to work, and the availability of social support (Fitch, 1994).

Alterations in sexual health after cancer affect not only the life of the person with cancer but also their sexual and or life partner. Following the diagnosis and treatment of cancer, couples face a number of issues that may alter sexuality. As part of reintegrating into day-to-day life, couples may struggle with resuming sexual activity. Not only dies the distress of the person with cancer need to be addressed but also the psychological distress of the sexual partner needs to be attended to. A renegotiation of roles and responsibilities that may have were shifted during treatment and recovery will need to be explored (Tierney, 2008).

The resumption of sexual activity may be a difficult task that requires a willingness to be vulnerable, exposed, and open with their partner. If one's self-confidence has been disrupted and shaken by the diagnosis and treatment of cancer this can be particularly the case. There may be uncertainty related to decreased desire or how they will respond to sexual stimulation and heightened anxiety about sexual performance. Men may be concerned about ability to obtain or sustain an erection and women may worry about adequate lubrication and discomfort. These may be present in the sexual partner as well as the person with cancer. Several research studies have identified factors that predict for healthy sexual adjustments following treatment. One factor is a good relationship, and a second factor is having a satisfying sexual relationship before the diagnosis of cancer. Other factors include support from the sexual partner and the partner's sexual health. The stress of cancer and its treatments can exacerbate underlying marital tension and likewise affect the sexual relationship. The partner may also be experiencing distress and struggling with fatigue, anxiety, depression, or uncertainty about the future. In a recent study of couples, nearly half of the sexual partners experienced changes in sexual functioning (Tierney et al., 2007). The sexual partner may find changes in the appearance of the cancer survivor unattractive, resulting in rejection, withdrawal, or loss of sexual desire (Tierney, 2008).

It is also important to remember that the culture and society in which a person grew up as well as in which they currently live will affect how they cope with cancer, and in turn how it influences their sexual health. If a person lives in an isolated, rural area, they may feel a lack of support and

may not have accessible resources. Lack of privacy may hinder discussions of sexual issues during clinic visits or while hospitalized (Hughes, 2008).

Spiritual Dimension

The spiritual dimension includes the search for hope, belonging, meaning, and purpose of life (Fitch, 1994). Spirituality both transcends and permeates the physiological, psychological/emotional, practical/informational, social and relational dimensions of life. Spirituality is a global construct encompassing traditional religion as well as more abstract concepts such as one's view of 'the ultimate meaning and value of life' and the search for peace and harmony. Concepts such as faith, worship, love, hope, and forgiveness form a link between spirituality and religion. While the terms spirituality and religion are often used interchangeably for many people they hold different meanings. Religion may be defined as a specific set of beliefs and practices, usually within an organized group. Spirituality may be defined as an individual's sense of peace, purpose, and connection to others, and beliefs about the meaning of life. Spirituality may be found and expressed through an organized religion or in other ways. In this way persons may think of themselves as spiritual or religious or both (Koenig, McCullough, & Larson, 2001; Koenig, 2002).

A life-threatening disease, such as cancer, confronts persons with realities and questions that prompt reflection on the meaning and implications of the illness. Perspectives on these realities and questions are often filtered in large measure through spiritual or religious understandings and beliefs (Murray et al., 2004). They influence how the illness is experienced, what meaning is attributed to not only to cancer itself, but also to the suffering and turmoil that cancer may evoke. These are questions of meaning--the meaning of life and what is important, the meaning behind ones personal affliction with cancer and finding meaning in suffering.

Spiritual understandings of suffering are important to help us understand how people cope with pain, anguish, infirmity, death, losses, humiliation and hardships (Tarakeshwar et al., 2006). Spirituality and religion are the main resources used to make sense of suffering. All the major religious traditions reserve a central role for the idea of suffering and all of them try to explain or give meaning to suffering. The major religions traditions offer principles to alleviate suffering by giving it meaning, by reframing fatalism within the context of ways of looking at life and perceptions across the cancer continuum and by highlighting how God, Allah or a spiritual other guides one's life in a positive rather than a fatalistic way. Cancer is a great equalizer. It is diagnosed in people regardless of age, race, class or ethnic group. All who are diagnosed will suffer in some way from this disease. How they make sense of these suffering and the value or meaning they attribute to it is often closely tied to their spiritual beliefs (Riley et al., 1998)

Because spirituality has been shown to influence multiple domains of health it follows that spiritu-

ality also plays a major role in influencing how persons with cancer understand their sexual health and quality of life. Riley et al. (1998) and Peterman et al. (2002) found that among patients with chronic diseases, those who were non-spiritual, reported significantly worse quality of life. These relationships extend into the oncologic realm as well. Evidence in women with breast cancer suggests that spirituality correlates positively with better functional and physical wellbeing (Targ & Levine, 2002).

Research examining spirituality in relation to chronic illness is in its infancy. Only a handful of studies have attempted to link spirituality to specific physiologic pathways. However, these initial explorations have revealed that the association between greater spirituality/religiosity and longer survival in HIV/AIDS patients appears to be mediated by cortisol (Ironson et al., 2002). Spirituality and the immune system have been implicated as in women with metastatic breast cancer as well. Women who reported greater spirituality had higher numbers of circulating helper and cytotoxic T cells (Sephton et al., 2001).

Regardless of the state of current state of research in physiologic connections of spirituality and cancer states other research has shown that many patients with cancer rely on spiritual or religious beliefs and practices to help them cope with their disease. This is called spiritual coping. Serious illnesses like cancer may cause persons with cancer or family members to have doubts about their beliefs or religious values and cause much spiritual distress. Some studies show that patients with cancer may feel that they are being punished by God or may have a loss of faith after being diagnosed; while others may have mild feelings of spiritual distress when coping with cancer (Blockner et al, 2006; King & Bushwick, 1994). It is however important to be mindful and assess how these issues may be influencing and tied into a person's sexual health and identity.

Research has shown that spiritual values are important to the majority of North Americans (Ben-Arye et al., 2006). Most American adults say that they believe in God and that their religious beliefs affect how they live their lives. However, people have different ideas about life after death, belief in miracles, and other religious beliefs. Such beliefs may be based on gender, education, and ethnic background (Peterman et al., 2002).

Return to an Integrated Model

There is a dynamic relationship between the physical, psychological/emotional, social and relational, informational/practical, and spiritual dimensions of sexuality and the impact of cancer on these dimensions. Changes in sexuality and sexual health will rarely be isolated to a single variable or dimension, which complicates the diagnosis and treatment of changes to sexual health. The complexity of the interrelationships between these dimensions of sexuality can be highlighted in the following scenarios outlined by Tierney (2008). A man experiencing ED may quickly loose his desire for sexual activity rather than place himself in the position of being unable to satisfy his partner or

experience personal frustration. ED and loss of desire may in turn affect the image he has of himself as a man. Similarly, if a women experiences dyspareunia, she may also quickly loose her desire for sex to avoid a painful sexual encounter. Avoiding sexual activity may change her perception of herself as a sexual being and alter her sense of femininity and in turn her relationship with her partner, friends, family, and co-workers may shift.

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