

Article 67

Self-Compassion and Sexuality: A New Model for Women With Disabilities

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Abstract

Sexuality and self-compassion are two concepts which have not been previously considered or combined when discussing the needs of women with disabilities. Sexuality, by itself, is a challenging topic for many counselors to address, let alone in combination with the needs of women with disabilities. Additionally, self-compassion is an emerging area which has rarely been applied to the needs of women with disabilities. In an effort to bridge this gap and to improve the sexual adjustment counseling services offered to women with disabilities, barriers which affect sexual adjustment, sexual concerns, and an illustration of ways to infuse sexuality into the adjustment to disability process are discussed followed by a new model of sexuality and disability.

Sexuality and self-compassion are two concepts not typically perceived as being related to one another, nor have they been conceptualized as a means of creating a healthy paradigm for improving sexual adjustment following disability. Sexuality is often referred to throughout the literature as issues or concerns related to a person's sexual self-concept and identity such as attractiveness, dating, and parenting, as well as more complicated sexual functioning concerns. Self-compassion, as discussed in the professional literature, refers to a person's ability to be kind, loving, tolerant, forgiving, and generous toward oneself, especially when life events do not turn out well or as desired (Neff, 2003, 2011). Self-compassion is a way of being which helps people be less self-critical and more self-accepting, particularly during difficult times (Neff, 2011). Both concepts have applicability to the needs of women with disabilities and can serve as means to help them achieve healthy sexual adjustment following disability.

Counselors may be called upon to assist women with disabilities with their sexual adjustment needs following disability. Yet few models currently exist that help counselors teach women essential skills such as self-compassion, which can be used to enhance their sexual adjustment process. For this reason, counselors are presented with

information pertaining to (a) barriers known to impede the exploration of sexuality and disability, (b) integration of sexuality into the sexual adjustment process, (c) limitations and rationale for new models of sexuality, (d) a sexuality model which infuses self-compassion, and (e) professional recommendations.

Barriers Affecting Sexuality and Disability

Several barriers prevent or inhibit the discussion and exploration of sexuality and disability. Some of these barriers are promoted through societal myths (Neufeldt, Klingbeil, Bryen, Silverman, & Thomas, 2002; Rousso, 1981), while others are related to the attitudes or discomfort of family members and helping professionals (Dotson, Stinson, & Christian 2003). Regardless of the source, women with disabilities are the recipients of many negative messages pertaining to their sexuality. As a result, some may choose not to explore or inquire about needed information and support.

Myths About Sexuality and Disability

Societal myths and beliefs about sexuality and disability are powerful. They have the ability to influence societal, personal, and professional attitudes which in turn can affect policy, and agency practices, as well as professional and personal behaviors. Several sexuality and disability scholars have discussed sexuality and disability myths related to the needs of women with disabilities, including:

- perceived as asexual or not interested in sexual relationships (Addlakha, 2007; DeLoach, 1994; Hassouneh-Phillips & McNeff, 2005);
- viewed as inadequate mothers or as not having the ability to bear children (Addlakha, 2007);
- thankful they are in a relationship, regardless of the quality or safety of it (Pitrowski & Snell, 2007);
- viewed as people who cannot perform sexual acts (Esmail, Darry, Walter, & Knupp 2010; Milligan & Neufeldt, 2001; Rousso, 1981);
- discouraged from exploring the issues of sexuality, as they are often viewed as shameful topics within some contexts and cultures (Hadoubi & Lincoln, 2003; Ide, 2004);
- seen as someone who is “damaged” or “less than” by society (Hahn, 1981);
- too personal to discuss outside of romantic or sexual relationships (Hadoubi & Lincoln, 2003; Ide, 2004);
- viewed as unattractive or undesired due to society’s emphasis on youth, beauty, and fertility (Hassouneh-Phillips & McNeff, 2005; Neufeldt et al., 2002; Parker & Yau, 2012; Rintala et al., 1997); and
- seen as people who ought to worry about other life concerns such as employment, functioning, or independence rather than sexuality.

Identification of Personal Versus Professional Barriers

Societal myths are not the only barrier inhibiting the exploration and acceptance of sexuality as an essential component of successful adaptation to disability. It is also important to consider the obstacles created by women, their families, or by helping professionals. Some women may be hesitant to approach the topic of sexuality based on

the existence of prior negative experiences or messages conveyed. Women may have been told they do not need to worry about such issues or should focus on some other area such as employment and independence (Addlakha, 2007). Women with disabilities may directly ask for assistance from “helping” professionals only to have their questions and concerns side-stepped or minimized (Stuntzner, 2012). Additionally, women with disabilities may receive negative feedback or experience personal rejection if their male counterparts with disabilities don’t want to date them or prefer women without disabilities (Rintala et al., 1997).

Families are not necessarily helpful in a woman’s exploration of sexuality and disability as they may have their own concerns and attitudes (McCabe, Cummins, & Deeks, 2000). For instance, parents of children with disabilities may be concerned for their child’s safety and may want to prevent them from being taken advantage of or abused. Families may not receive adequate information about the needs of persons with disabilities in relation to sexuality (Gordon, Tschopp, & Feldman, 2004). As a result, many are likely to feel unprepared to address such a topic. Families may also hold beliefs, similar to society or other professionals, that sexuality is not the most important issue to address, as others are deemed more essential.

A final area of concern is the attitudes held by counselors in relation to sexuality and disability. Counselors may have their own beliefs about sexuality and disability, whether overt or covert. For example, some may feel it is someone else’s responsibility to discuss sexual issues and as a result, they overlook or neglect the needs of women with disabilities. Counselors may hold attitudes similar to those held by society and families, some of which can encourage or hinder the exploration and discussion of sexuality and disability. Others may simply feel they lack the training or are uncomfortable which contributes to their unwillingness to delve into women’s personal issues (Juergens & Miller-Smedema, 2009; Pitrowski & Snell, 2007). For these reasons, it is important for counselors to examine their own beliefs and expectations, as well as the messages promoted within their work environment. Counselors who are aware of their personal and professional attitudes can greatly enhance the professional relationship and the exploration of sexuality issues, particularly when they are willing to identify areas they need to improve and change.

Integrating Sexuality Into Adjustment to Disability

Sexuality is as an area which can be integrated into the process of adjustment to disability. Knowing *how* and *when* to introduce sexuality issues into the adjustment to disability process is relevant to the overall coping and adaptation needs of women with disabilities. For example, a woman’s body-image following disability may affect her self-concept and perception of self-worth (Parker & Yau, 2012; Rousso, 1981). Of particular concern is when women internalize negative messages and stigma pertaining to their sexuality (De Loach, 1994), self-worth, and attractiveness. Women who understand their disability and the unattractive image it may represent to others have an opportunity to increase self-awareness and to understand the potential impact their disability may have on others (Rousso, 1981). Furthermore, they are empowered to make decisions about what constitutes appropriate treatment from a partner and to develop healthy relationships. Counselors who address sexuality and disability need to be aware of some

concerns and associated issues sometimes encountered. One approach counselors can use is to conceptualize the needs of women according to a number of topics rather than one large issue. An illustration of this is provided in the following sections.

Sexual Concerns of Women With Disabilities

Sexual concerns of women with disabilities includes more than the discussion of sexual functioning and disability or sexual satisfaction following disability. Women may be interested in issues pertaining to motherhood, co-parenting, dating (Di Giulio, 2003), divorce, or acquiring parental custody when they decide to leave a relationship where the partner does not have a disability (Caruso et al., 1997). Women may want to discuss relationship concerns such as how and where to find a suitable, caring, and open-minded partner (Rintala et al., 1997). Similarly, women may want help to develop or enhance social skills so they can meet new people or feel more comfortable when disclosing information about their disability.

Earlier in the coping and adaptation to disability process, women may wish to explore feelings of insecurity as they relate to (a) disability and relationships, (b) attractiveness and beauty (DiGiulio, 2003; Esmail et al., 2010), (c) body-image (Hassouneh-Phillips & McNeff, 2005; Ide, 2004; Moin, Duvdevany, & Mazor, 2009; Parker & Yau, 2012; Rousso, 1981), (d) self-esteem and self-confidence (Esmail et al., 2010), and (e) negative societal messages and barriers (Rintala et al., 1997). Women with disabilities may desire support and assistance to help them navigate poor attitudes conveyed about their request for information on sexual or healthcare concerns (i.e., effects of medication, women's issues, birth control; Ballan, 2008; Caruso et al., 1997), or with learning how to express oneself sexually (Parker & Yau, 2012). If sexual abuse and exploitation (Hassouneh-Phillips & McNeff, 2005) has occurred, some women may want support and guidance to move past these issues and to help them prevent it from happening again.

Conceptualizing the Sexual Needs of Women With Disabilities

Counselors can provide the positive support needed if they are willing to explore and consider the sexual issues of women with disabilities. Those who are not may negatively impact women's mental, emotional, and psychological adjustment (Milligan & Neufeldt, 2001). Compounding the situation is the fact that the needs of women with disabilities and sexuality have often been overlooked by many helping professionals as is evident by the professional discomfort discussed throughout the literature. Also relevant is the reality that counselors may be the only professionals willing to have such a conversation.

Counselors who work with this population may find it helpful to assess and consider the reported issues of concern (see figure 1). Sexuality and disability concerns can be viewed according to nine areas: (a) life roles or changes in familial relationships; (b) disability impact; (c) emotions or feelings as they relate to sexuality and adjustment; (d) information about one's disability; (e) skills needed to cope better (i.e., personal boundaries, coping with others invasive questions; Stuntzner, 2012); (f) barriers encountered or lack of access to necessary services as they relate to sexuality concerns; (g) relationship and personal problems (i.e., dating, finding a suitable partner; Rintala et al., 1997); and (h) sexuality and intimacy issues. Viewing sexual concerns in this way can

assist counselors by focusing on the presented issue rather than the magnanimous topic of sexuality and disability.

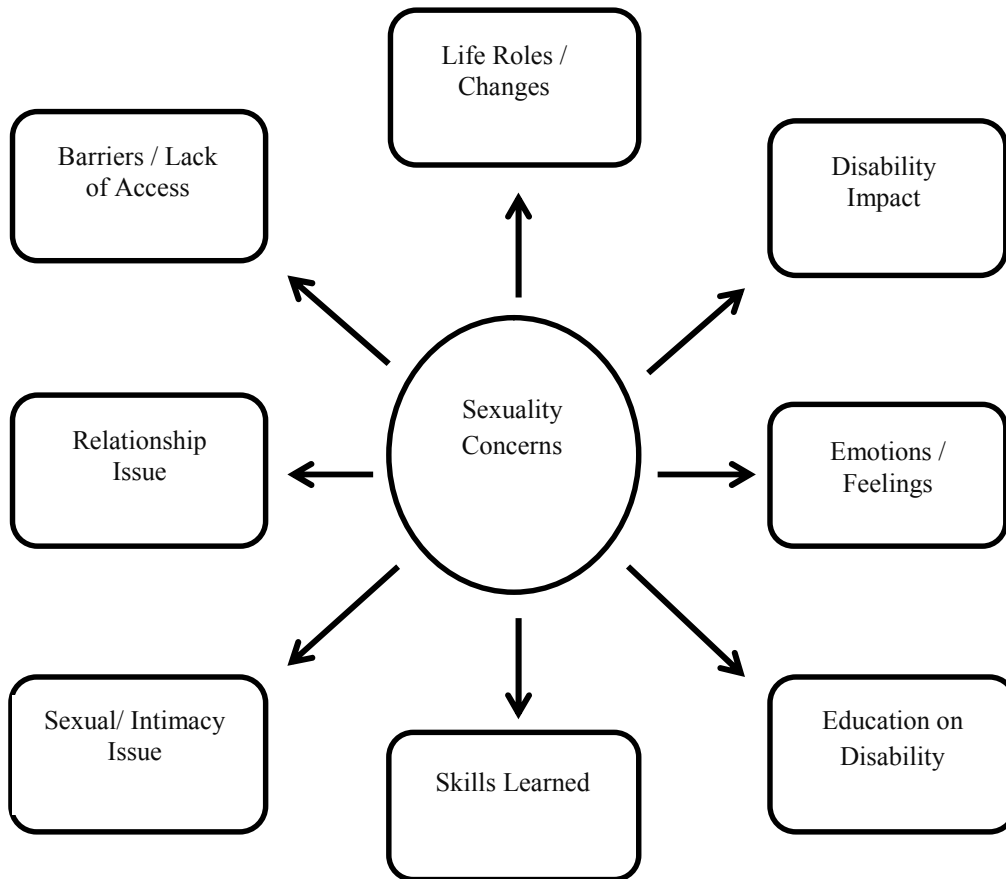


Figure 1. Integrating Sexuality into Adjustment to Disability.

Many of these concerns are also related to the adjustment to disability needs of persons with disabilities or are factors known to enhance the functioning of persons with disabilities. For instance, it is well-known throughout the literature that the amount of education and information a person has about the disability, the better he or she will adjust (Trieshmann, 1988). People who have access to support and the disability-related services they need are likely to cope better than those who do not. Related to this is the reality that persons with disabilities often discover they need to learn new skills such as self-advocacy, assertiveness, and redefining of one's self-concept and self-image due to life changes following disability (Wright, 1983).

Counselors who are able to apply the same logic and understanding to the sexuality and disability needs of women with disabilities are well-positioned to understand clients' concerns. Using the same categories as previously mentioned, counselors can easily comprehend this rationale. In regards to education on disability, women with disabilities may need education, information, or support from others who have gone through similar experiences to help them understand their experiences. Counselors can be a strong source of support for women, directly or indirectly. Those who do not know this information can assist women by connecting them to agencies that do or to peers with disabilities with whom they can converse. Counselors can help

women explore their own understanding of disability and the ways it may affect them or others in their lives. Additionally, women with disabilities may discover they need to develop new skills to enhance their ability to cope with the changes or issues that arise within their sexual life because of disability. Similar to the aforementioned, women may need help in learning how to self-advocate with medical professionals in acquiring more information about sexuality as it relates to their disability (Taylor & Epstein, 1999). They may want assistance in developing a new self-concept and identity (Wright, 1983), one that is positive and honors their desire for intimacy and respect as a viable relationship partner.

Sexuality and Disability: A New Approach for Women With Disabilities

Models pertaining to sexuality and sexual concerns have been useful to counselors in attempting to approach the topic of sexuality and disability. The PLISSIT Model is well-known and has historically been used to assist counselors in their own understanding of sexual matters (Annon, 1976). The PLISSIT Model provides a format for counselors to approach sexual issues and concerns within their comfort level and knowledge. Such an approach allows them to address the sexual concerns of many people, on some level, without being a sexual therapist. For example, the model provides four levels from which to address sexual concerns: Permission, Limited Information, Specific Suggestions, and Intensive Therapy (Annon, 1976). Each of these levels or layers of understanding requires more in-depth skill and knowledge than the previous ones with the final level (Intensive Therapy) viewed as the most involved and complex (Annon, 1976; Taylor & Davis, 2007). However, it is not a model that specifically addresses the needs of persons with disabilities or those of women with disabilities. In addition, it is a model that perceives giving people permission once is sufficient for them to want to discuss this rather personal topic (Taylor & Davis, 2007) and that may not necessarily be the case for women with disabilities.

More recently, this model has been expanded and is referred to as the EX-PLISSIT Model (Taylor & Davis, 2007). The EX-PLISSIT Model stresses that giving people permission to approach the topic of sexuality once is not sufficient; therefore, this model encourages counselors to give and explore the possibility of giving permission at each of the other stages and that intensive therapy may be provided at any time (Taylor & Davis, 2007).

While both of these models are important and of some relevance toward the exploration and discussion of sexuality and disability, they appear to have limitations in regards to helping women with disabilities develop the skills they may need. Some of these limitations are mentioned in the next section followed by the introduction of self-compassion as an essential component of treatment and a new model for sexual adjustment.

Limitations of Existing Models

Both of the aforementioned models may be perceived as being geared towards the needs of helping professionals more than the people they serve or the specific needs of women with disabilities. While these models are important to help counselors approach this delicate and sensitive topic, other models are needed to help them determine

identified issues and to assist women with disabilities in learning skills which can aid them in addressing their own concerns and emotional hurts.

Existing sexuality models appear to have some limitations which can support the need for a new model or approach. Some of these limitations include the following:

1. The needs of women with disabilities are not necessarily addressed adequately (Thierry, 1998) nor are any of their needs considered separately from men with disabilities.
2. Previous models are not constructed to encourage the development of specific skills and abilities which may be learned and later applied by women with disabilities to address their sexual concerns.
3. Sexuality models often focus on the counselor's comfort level rather than the relationship between psychological adjustment, self-concept, and sexual identity (Taleporos & McCabe, 2001).
4. Existing models do not address the fact that coming to terms with a person's sexual needs and identity is a process that often unfolds. Each person is likely to have varying sexual needs and to desire different amounts of information based on the type of disability, the adjustment concerns at that given time, and the mental and cognitive capacity for processing such information (i.e., physical versus cognitive disability).
5. Sexuality models do not typically stress the importance of being comfortable with one's own sexuality as this issue may affect the counselor's ability to be effective (Boyle, 1994).

Self-Compassion: An Essential Treatment Component

Self-compassion was previously defined and is a construct which has emerged in the past decade throughout the professional literature as a skill which can be used and taught to reduce negative thoughts and feelings as well as improve overall functioning (Neff, 2011). Self-compassion as an essential skill for persons with disabilities has historically been overlooked; however, it is in the process of being introduced and applied to the needs and specific concerns of persons with disabilities (see Stuntzner, 2014a; 2014b).

To date, research shows many benefits for those who learn and practice self-compassion. More specifically, self-compassion helps reduce (a) self-blame and defensiveness (Terry & Leary, 2011), (b) self-critical thoughts (Neff, 2003), and (c) negative emotions such as anxiety and depression (Leary, Tate, Adams, Allen, & Hancock, 2007; Neff, 2003) and manage (d) stressful and unpleasant thoughts such as being embarrassed or rejected by another person (Leary et al., 2007).

Self-compassion has also been found to have many positive effects which may influence how well people cope with unpleasant situations. Some of these positive indicators include (a) helping people forgive (Neff & Pommier, 2012), (b) learning to view situations differently (Feldman & Kuyken, 2011), (c) experiencing personal growth (Pauley & McPherson, 2010), (d) coping with situations which do not turn out as desired (Neff, Hsieh, & Djitterat, 2005), and (e) having a better outlook on life (Neff, Rude, & Kirkpatrick, 2007) - all of which can assist women with disabilities in learning to cope and adapt better with their disability and their disability-related sexual concerns.

Infusion of Self-compassion Into Sexual Adjustment: A New Approach

Counselors interested in learning how to infuse self-compassion into the process of sexual adjustment following disability are encouraged to refer to the illustration provided in Figure 2. This model has been modified and expanded from a previous one developed by Stuntzner (2014a) which applied the concept of self-compassion to the adjustment to disability process. Many of initial categories are the same; yet, the context and information covered in counseling may differ – one application refers to the adjustment to disability process and the other focuses more specifically on issues and concerns related to sexuality issues and disability. Furthermore, this expanded model addresses important concerns such as counselors’ comfort, knowledge, and attitudes, as well as personal and professional assessment of counselors’ skills and barriers.

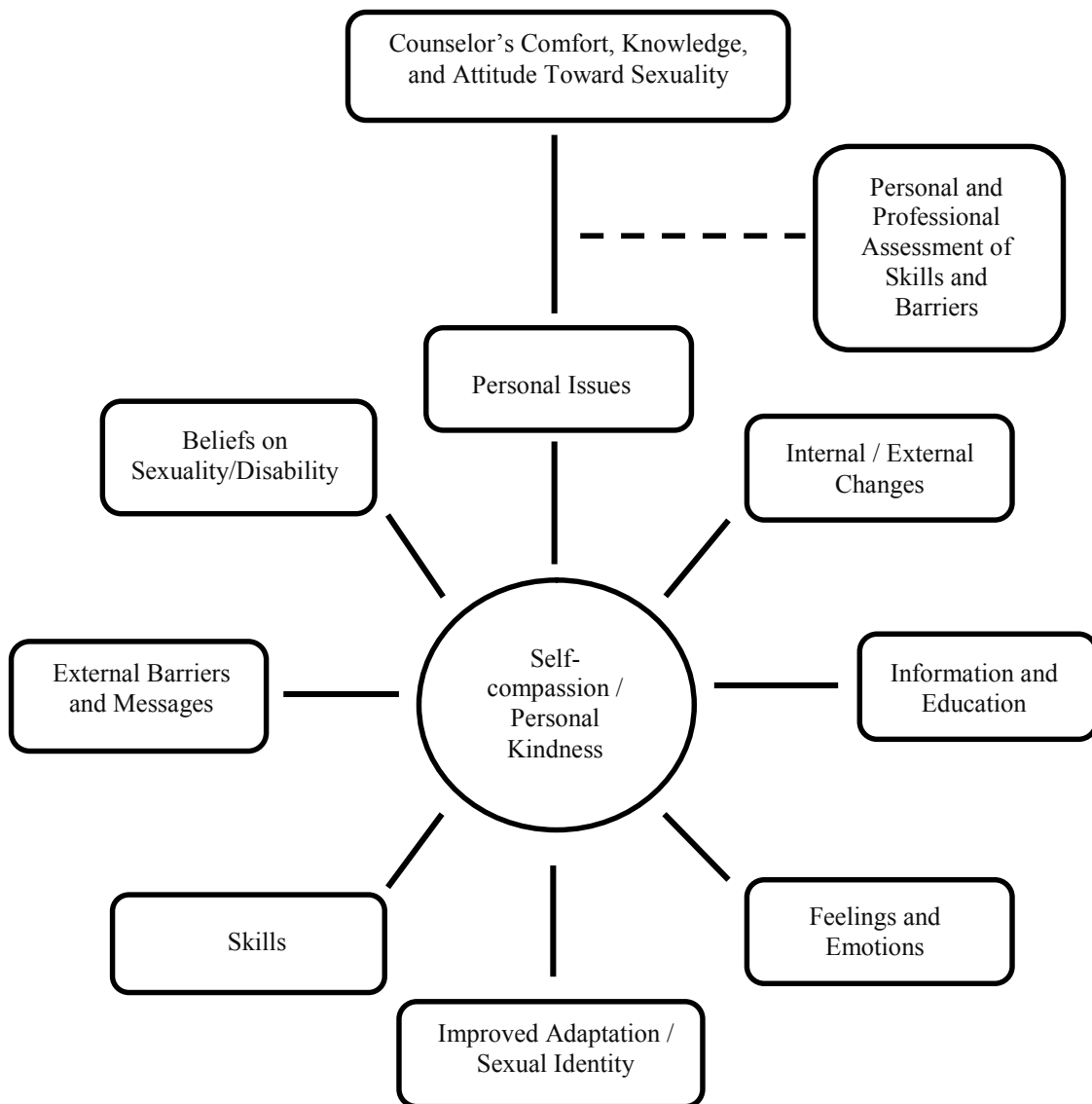


Figure 2. Self-Compassion and Sexuality: A New Model. Adapted from Stuntzner, S. (2014a). Compassion and self-compassion: Application to the adjustment to disability process following disability. Manuscript submitted for publication.

Counselors using this model are expected to first check their own level of comfort, knowledge, and attitudes about sexuality and disability. According to this model, counselors are not expected to be experts about sexuality and disability because there are many areas they are qualified to explore as outlined in Figure 2 (i.e., learning new skills, exploring feelings). However, personal exploration of potential biases or negative attitudes is encouraged and essential for counselors prior to agreeing to work with women with disabilities, as these may negatively impact the relationship and the exploration of sexual concerns. During this phase of the model, counselors are asked to informally assess their ability to extend compassion to themselves and others, as this trait may positively or negatively influence the counseling relationship. Counselors who discover they either exhibit negative attitudes toward oneself or others, particularly in regards to sexuality, may first want to address their own beliefs so they can be more compassionate throughout the counseling relationship.

Counselors who are ready to proceed and work with women on the identified sexuality concerns may conceptualize the reported issues based on the following nine categories: (a) personal issues, (b) changes following disability, (c) information (Livneh & Antonak, 1997), (d) emotions (Lane, 1999), (e) skills needed for adaptation, (f) negative messages or societal barriers (Smart, 2009; Stuntzner, 2012), and (g) personal beliefs about disability. These nine areas were chosen because they are also factors known to influence peoples' adjustment to the disability process, regardless of disability type.

According to this model, counselors can informally assess and quantify the concerns reported by women with disabilities so they can be addressed. For example, women who report difficulties with building relationships, intimacy with their partner following disability, or with developing a healthy body image can be perceived as having problems with *personal issues*. Similarly, women who report problems in dealing with societal or environmental barriers or negative societal messages about wanting to be in a relationship may be observed as a person striving to cope with *external barriers and messages*.

Throughout this process, women with disabilities may experience difficult or hard-to-face emotions or even critical thoughts. For this reason, counselors are encouraged to teach women how to approach, face, and work through their emotional and mental hurts and potential injustices with self-compassion and personal kindness – all the while respecting that what they feel and experience may be hard and painful. From this perspective, the goal is to teach women how to be self-compassionate as they learn to cope with their sexual issues and changes and improve their overall adaptation, functioning, and sexual identity.

Implications for Counselors

Professionals who counsel women with disabilities can learn to view change and adaptation as a process. Issues and concerns may surface as women are able to consider and address them. For example, in the case of an acquired disability such as spinal cord

injury, women may first find themselves concerned about personal care, physical functioning, and learning skills to maneuver their environment. As personal functioning and mobility become more natural, some may discover particular thoughts and feelings beginning to surface. Some of these may be related to how their injury impacts interactions with others or their personal relationships. Others may begin to question if others will find them attractive or if they can have children (Stuntzner, 2012). Still some may try to accept their new reality before thinking about personal or sexual concerns. The possibilities are vast and change following disability does not necessarily occur quickly or in a linear way (Livneh & Antonak, 1997). Therefore, counselors may need to learn to adequately address sexuality concerns as they arise in the lives of the women they serve.

Before engaging in a counseling relationship with this population, counselors are encouraged to consider their own personal and professional attitudes regarding sexuality and disability (Taylor & Davis, 2007). Counselors' understanding of their own thoughts and feelings is pertinent to the counseling process, especially due to the fact that their own biases may influence the therapeutic relationship in the event women disclose a need to explore and discuss sexual issues.

Second, counselors may find it helpful to consider which disability types they are most familiar with versus those they are not. During the initial exploration of sexuality and disability within the counseling relationship, counselors are likely to be more comfortable with disabilities or diagnoses they know well. As their comfort with the topic increases, counselors may become more willing to address sexual concerns among women living with less familiar disability diagnoses. Over time and with experience, counselors are provided with the opportunity to understand how many of the reported concerns tend to overlap without feeling as if they need to be sexual experts.

Third, before approaching this topic, counselors should consider which disabilities are most relevant to the model(s) presented, as well as those which require a modified teaching approach. For instance, are the experiences of women with physical, medical, or progressive conditions the most applicable to the sexuality and disability model (i.e., spinal cord injury, cancer, breast cancer, multiple sclerosis)? In what ways, can you alter the delivery of the model or the content covered to meet the individual needs of women with cognitive disabilities (i.e., teach self-compassion skills in a manner that is understood and meaningful)? Are some domains more relevant, at this time, to the women you serve? Which sexual issues are causing the most problems in a woman's life?

Fourth, sexual adjustment is a challenging topic for many, even without the added context of disability. To help alleviate some of the discomfort experienced, counselors may find it useful to refer back to Figure 1 and consider methods they can use to approach the topic of sexuality according to specific areas such as those presented and to view sexuality in a more holistic manner – one that influences a woman's overall adjustment process. Related to this point is the fact that women's needs are often different than men's, so it is important for counselors to listen to their perspective.

Next, counselors are encouraged to look for multiple ways they can encourage and approach the topic of sexuality and changes following disability. While many may view it as a topic covered in a traditional counseling setting, there are other options. For instance, counselors may have brochures or advertisements in their office. They may opt to develop a women's counseling group or community psycho-educational classes, or co-facilitate training with another interested professional in the area.

Finally, because self-compassion continues to be an emerging area within the research and our society, counselors may feel the need to enhance and further develop their understanding of it. Counselors who want to know more about this important and therapeutic topic are encouraged to seek additional training and information so they can apply it in their personal and professional lives with greater ease (Stuntzner, 2014b). A solid starting basis is to research Web sites that are devoted to the topic of self-compassion such as the one developed by Dr. Kristen Neff (www.self-compassion.org). Neff's (2009) Web site is very thorough and advertises trainings and workshops on self-compassion. The Web site also has meditation products, exercises, links to other websites about compassion and self-compassion, and several research articles on self-compassion.

Conclusion

Sexuality and disability is a difficult topic for many counselors to address. Many counselors do not receive training on this topic or how it affects women with disabilities. Sexuality models, typically, do not address sexual concerns in relation to disabilities, nor do they discuss ways to enhance counselors' comfort. To change this trend, information pertaining to potential barriers, myths, and methods for integrating sexuality into the process of adjustment to disability were discussed, as well as a new model for women with disabilities. The model provided infused self-compassion as an essential component women can learn to use when addressing sexual adjustment concerns.

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