

Sexuality and Disability: The Role of Health Care Professionals in Providing Options and Alternatives for Couples

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Disability affects both the individual and his/her partner and, if health care professionals are to work with clients in a holistic manner, they will need to include the partner. A comprehensive review of the literature was completed to examine the impact of disability on sexuality as it relates to couple relationships and to explore strategies health care providers can utilize to help couples deal with these issues. The literature describes some common intervention strategies that have been shown to be effective in helping couples affected by disability or illness address the issue of sexuality. Specific concerns and difficulties faced by couples are also identified. Finally, the various intervention strategies will be incorporated into a framework known as the P-LI-SS-IT model. With this framework, health care providers will be able to determine the client's needs, as well as assess their own level of comfort and expertise in dealing with this very important task.

KEY WORDS: sexuality; disability; relationships; P-LI-SS-IT model.

Sexual Health is the integration of the somatic, emotional, intellectual, and social aspects of sexual being, in ways that are positively enriching and that enhance personality, communication and love (1, p. 6).

There has been a considerable increase in sexual health care curricula for health professionals of all disciplines, resulting in more effective sexual rehabilitation services and programs for clients (2–3). Despite these improvements

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and greater acceptance of professional health care involvement (4), surveys still show that most health professionals do not consider themselves competent to provide sexual health care. Many are unsure of their role in such services and many more neglect the area entirely (4–11). Clients report varying degrees of satisfaction with the sexual health services they received—many stating that they were not asked about their sexual concerns during rehabilitation (4,12). Within this larger topic of dealing with sexuality and disability, an area that is even further neglected is the issue of dealing with sexuality from a couple's perspective where one partner has a disability (13–15). A couple in this case is defined as two people in a committed relationship which may include but is not exclusive to heterosexual married and cohabitating couples. Disability can be defined “as a loss or deviation, in either a qualitative and quantitative way, the ability to perform an activity or behaviour, taking into consideration age, gender, and physical, social and cultural environment” (16, p. 16).

DEFINING SEXUALITY

Sexual behaviours and lifestyles vary greatly from culture to culture and on an individual basis; what is acceptable for some is unthinkable for others. Attitudes towards these matters are influenced by factors such as education, laws, ethnicity, family, peer groups, personal experience, and religion. Personal values will be most affected by whichever of these factors are most important to the individual (17).

It is important to establish at the outset of this discussion that sexuality will be addressed as a broad concept. Sexuality is a major component of who we are as individuals and not simply what we do sexually. We are all sexual beings from birth to death (18). Our needs and manner of expressing our sexuality are unique to each of us based on such factors as gender, age, personality, socialization and ethnicity. Sexuality includes behaviours, emotions, as well as an individual's knowledge and beliefs. Integration of these aspects of sexuality contributes to the overall health of individuals (1).

Dailey (19) describes sexuality as having five components: sensuality, intimacy, sexual identity, reproduction, and sexualization. *Sensuality* relates to our need to be aware of and acceptance of our own body through all of our five senses. *Intimacy* is described as our need and our ability to experience emotional closeness to another human being, and to have that emotional closeness predictably returned in kind. *Identity* is another part of being a sexual person and is a continual process of discovering who we are in terms of our sexuality. *Reproductive aspects* of sexuality deal with fertility and conception, and child rearing. *Sexualization* is the term used by Dailey (19) to describe our use of sexuality to influence, control and manipulate others. These five components—

sensuality, intimacy, identity, reproduction, and sexualization—are affected by an environment in which sociocultural influences such as family, ethnicity and religion influence the quality of their development. It is important to look at the five components as an integrated whole. Each component influences and is influenced by all other components. The greater the integration of the five aspects in an individual, the more positive his or her ‘sexual beingness’ (19).

IMPACT OF DISABILITY ON SEXUALITY ON COUPLE RELATIONSHIPS

A considerable amount of material has been written on the effects of disability on various aspects of one’s life. A major component of this will be the impact on an individual’s relationships and sexuality. Suffering a disability has a profound impact on overall quality of life and well being (20). In one study, sex was reported to be the most serious problem in marriages where one of the partners had a disability (21). People with disabilities are less likely to marry (22) and if they do marry or are already married, they have almost twice the risk of getting a divorce (23). Urey, Viar, and Henggeler (24) point out that divorce rates among individuals with spinal cord injuries have been estimated as high as 85%. The majority of individuals who have suffered a disability report a decline in frequency of sexual activity following disability (25). In the same study, greater than half of the subjects indicated they had to change their pattern of sexual activity following disability and experienced a decline in sexual satisfaction and interest following disability. Sadoughi, et al. (25) also found that 36% of individuals with disability surveyed indicated a desire for more sexual satisfaction in their present relationship and 42% believed that their spouse presently desired more satisfaction.

The literature also indicates several reasons as to why disability has the impact it does on a couple’s sexual relationship. The disability-related physical limitations were the most frequently cited reason for fear and feelings of discomfort in participating in sexual activities. (25–26). Other problems that have been reported to affect relationship development and enhancement include frequency of activity, perceived constraints on attraction and societal barriers (27). Generally, when a partner has a disability, problems have been reported in the frequency of sexual activity, who initiates (communication), amount of pleasure experienced and various other aspects of sexual activity (28).

Disability has also been shown to increase stress and affect the roles and personal boundaries experienced by couples (15,29,30). In their study, Kester et al. (30) reported significant findings in terms of the occurrence of adverse health consequences as a result of being married to, or living with a partner with a spinal cord injury. The non-disabled partner had significantly worse

scores on every health measure and the nature of the health problems appears to have been stress related.

PROBLEM STATEMENT/PURPOSE

There is a profound impact on an individual's sexuality and a couple's sexual relationship as a result of a disability. As indicated in much of the literature, health care providers often feel uncomfortable or ill prepared in dealing with the issues surrounding the changes in sexuality that occur as a result of a disability. Sexuality itself is a broad concept that incorporates both behaviours and emotions and the interplay of these with other elements of a relationship. The focus of this article will be to review the literature to examine the impact of disability on sexuality as it relates to couple relationships and to explore some of the intervention strategies front line health care providers can utilize to determine their own level of participation as well as assist couples to contend with these issues.

Limitations

This article will focus on sexuality only as it relates to couples where one partner has a disability. It will not focus on the specific effects that disability may have on an individual's sexuality nor on any of the various types of couples' relationships. The suggested interventions are those that are appropriate for use by frontline health care providers. For example, although couples counseling and intensive therapy may be effective or required they are beyond the expertise and skills of most general health care providers (3,8,31-34).

REVIEW OF LITERATURE

In rehabilitation service, a considerable amount of effort is spent on improving a client's physical, cognitive, and emotional status, as well as in dealing with vocational, leisure and self-care functioning (8,13,35). However, the areas of sex, love, intimacy, and relationship are often not addressed (13,15). When it comes to the perspective of the non-disabled partner the literature is "virtually silent" (14, p. 118). With a few exceptions, the issue of couples facing illness and disability remains a neglected topic in the literature (15,28,36). What follows is a review of literature addressing some of the key related topics that provide the basis for interventions/strategies suggested.

Pre/Post Disability Relationships

As already indicated, among disabled individuals as compared to non-disabled individuals, the frequency of forming a long-term committed relationship is lower and the likeliness of divorce is higher (22–23). It is important, however, to review the difference between pre-injury/illness relationships (relationships between couples that formed prior to the disability) and post-injury relationships (disability was already present when the relationship formed) (37). Crewe and Krause, (38) conducted a study that addressed the differences between pre-injury/illness and post-injury/illness. Their findings indicated that individuals in relationships formed post-injury/illness reported greater satisfaction with their sex lives, living arrangements, social lives, health, emotional adjustment and so forth. However, a study done by Kreuter et al. (28,39) did not find the same results. Their study found no significant difference in the level of satisfaction with current sex life, emotional attachment and satisfaction with the relationship as a whole when comparing pre-injury and post-injury relationships. They did reveal certain differences concerning sexual aspects of the relationship, all of which favoured post-injury relationships. Some of these differences included frequency of sexual activity and variety of sexual expression which were lower in the pre-injury group.

In general, Crewe (40) found pre-disability marriages that survived demonstrated “strength and commitment but also included noticeable areas of loss and regret” (40, p. 146). Spouses in these relationships were more likely to have an increased caregiver role (15,40). Individuals in post-disability relationships were more likely to be employed, socially active and have a higher level of education (38).

Changes in Roles and Expectations

Facing and accepting the disability should not be limited to the affected partner (13,15,37). A woman reported having difficulty becoming intimate and taking the role of a lover immediately following helping her husband with his bowel routine. These kinds of reports are common (14,41). Pre-injury expectations and role definitions may be impossible to meet in the presence of a disability (15,37). Miller (13) reported that the longer a non-disabled partner continues the caretaker role the more difficult it becomes to return to the pre-injury level of intimacy.

McNeff (37), reported gender socialization, may also affect how men and women cope with the disability of their partner. Men and women have different strengths and skills which affect how they deal with the issue of disability (37).

Couples also need assistance to clearly outline what self-care activities can be done independently, which activities require assistance from the partner and which require professional help (15). Early intervention to help couples identify and address all of these factors (e.g., renegotiate roles) may help avert a crisis (15,37).

Intimacy as a Key Ingredient for Developing and Maintaining Relationships

Sexuality involves an inter-play between physical and psychological elements (42). Sexual rehabilitation and research often focus on the mechanics of sex rather than on the process of regaining closeness and intimacy (13,41). However, the physical aspect is only a small component of a couple's sexuality (19). While sexual performance is important, it is intimacy in the relationship that provides the foundation for meaningful expression and experience of sexuality (13). When assessing the perspectives of non-disabled partners, it was found that feelings of emotional closeness, mutual concern and willingness to participate in a variety of sexual activities were reported to be more important for sexual fulfillment than the physiological aspects of sexuality (39,43).

In general, non-disabled partners report having greater difficulty dealing with the cognitive loss as opposed to physical impairment that affect sexual functioning (44–45). In disabilities that involve cognitive impairment as opposed to a physical impairment, the capacity for intimacy may be lost and cannot be salvaged: a new relationship must be developed (15). Couples who can redefine intimacy and nurturance in terms of valuing a mutually caring, companionate relationship with shared interests and pleasurable activities rather than purely sexual terms can successfully adapt to losses in the sexual components of their relationship (15). A good relationship is what is important, often even without the physical sex. If the individuals have the cognitive and emotional capacity there are other ways of establishing intimacy besides intercourse (13).

Couple Characteristics That Predict Successful Adjustment

Several factors have been noted in predicting how successful couples affected by disability will be in maintaining a healthy sexual relationship. Urey and Henggeler (24) found that with a few exceptions characteristics associated with successful marriages were the same for couples affected by disabilities and able-bodied couples. One of the major factors is the degree to which the indi-

viduals in a relationship associate with other people and activities. In a study conducted by Urey et al. (46), they found the strongest predictor of positive marital adjustment for couples was the number of recreational and social activities the couple participated in with others. Couples with the most problems were found to participate in fewer activities alone or as a couple (46). The same study suggests that education programs offered in rehabilitation settings should emphasize the participation of disabled individuals outside the home or institution (46). Another key predictor is the disabled individual's attitude and adjustment to his/her own condition. Those with a more positive attitude were likely to maintain or develop long-term relationships (14,47). Characteristics of partners of disabled individuals that predict greater marital adjustment have also been identified by Milligan, et al. (14). The degree to which the person is open to a relationship with someone with a disability, prior experience with disability, flexibility regarding role performance, acceptance of the disability and willingness to accept help were all factors affecting success. As well, an attitude aimed at fostering their partner's independence and resiliency in light of social disapproval also impacted on the couple's progress (14). In another study, Vargo (48) found six factors that were of primary importance for satisfactory adaptation to a partner's disability. These include: adequate support systems, commitment to the marital relationship, hope, health care staff attitude and advice, architectural/societal barriers and positive contribution of having children.

Current Interventions

Although the literature is very limited in the area of counseling and intervention for couples affected by disability, specifically on the topic of sexuality (15), there are consistent trends regarding strategies to enhance couples' sexual relations. General strategies that have been shown to be effective include mutual responsibility, education, facilitating communication between partners, facilitating attitude and behaviour change, and prescription/provision of aids, prosthesis and resources. It should be noted that counseling and therapy have been shown to be an effective tool for couples dealing with the changes and stress due to a disability (49). In a study conducted by Perlesz & O'Loughlan (33), it was found that the stress experienced by disabled individuals and their caregiver/family was reduced with counseling. Hoch (31) found that a mutually rewarding sexual relationship can be obtained and developed by individuals with a disability and their partner, through use of strategies which are similar to those used in therapy for couples not affected by disability. Each disability will have its own unique characteristics and effects, as such will require various forms of education and counseling (15).

Mutual Responsibility

The person most affected by the disability is most often the disabled person's partner (50). For this reason, the partner must be involved in the care and education of the disabled individual (5,46). By introducing the issues as "our" problem, the clinician is able ensure the couple is able to examine their own values, belief and attitudes (15). Optimal couple functioning depends largely on the willingness of both partners to take responsibility and the disability cannot be defined as exclusively the domain of the disabled partner (15,28,39,50). Both the disabled individual and his/her partner must share responsibility for sexual adjustment (15,51). For example, if both partners share in sexual pleasuring, increased satisfaction experienced by the partner will increase the satisfaction of the disabled individual (51).

Education and Information

Nothing is more helpful and reassuring to patients and their families than clear explanation and education regarding the disability (13). Williams (50) found that with increased information imparted to the spouse, the less negative the impact of the disability on marital satisfaction. The education component should include helping the couple understand the disability itself, the prognosis and any complications (13,15). Specific information on sexual anatomy physiology and function should also be covered (51). Other areas that should be addressed include fertility, pregnancy, contraception (4,49,52), and bowel and bladder management (34).

Facilitating Communication Between Partners

Communication is a crucial element for facilitating healthy couples' functioning (15,37,49). Assisting the disabled individual and the partner develop and maintain good verbal and non-verbal communication may be one of the most important challenges faced by a therapist (13). Both partners must be encouraged to discuss their sexual needs openly, including issues of intimacy (13). Without open communication, the sexual experience becomes a gamble and satisfaction cannot be guaranteed (51).

Attitudes and Behaviour Changes

Often societal myths and attitudes create inhibitions that interfere with a couple's ability to satisfy their own sexual needs (51). Sexuality must be re-

defined in broader terms as any activity that is mutually stimulating and pleasurable for the couple (15,51). Couples must be given options for activities that they may consider acceptable in order to learn about their new sexuality (8,13,34,51). Another area of attitude change is the establishment of healthy roles and boundaries (15). Couples have to accept the disability and establish new boundaries that may be different from societal norms or their personal expectations (15).

Prescription of Aids, Protheses, and Resources

Miller (13) suggests that when the disability is physical, one of the first options to consider is the use of orthotic and assistive devices that are acceptable to the couple. These assistive devices may help in positioning, overcoming functional limitations, as well as for enhancing sexual pleasure (13,35). Clinicians must also have available a list of resources in the form of literature and other professionals who are trained to deal with the specific needs of the couple (8,34,35).

Summary of Review of Literature

The literature in the area of disability and sexuality as it affects couples is quite limited. The few studies that address this issue of disability and its impact on couples from a sexuality perspective provide some key points including:

- Differences between impact of disability on pre and post injury/illness relationships.
- Importance of addressing changes in roles and expectations and the gender differences in ways of coping style and adaptation to the disability of a partner.
- Importance of meaningful expression and intimacy versus addressing only the physical component of sex.
- Importance of characteristics of both partners in the relationship such as participation in activities outside the relationship, attitude and acceptance of the disability.

The literature also shows that there are some common suggestions regarding intervention/strategies that have been shown to be effective in helping couples.

THE P-LI-SS-IT MODEL

Although somewhat dated, a useful model for determining both the client's needs and the professional's level of skills in regard to provision of sexual

Table 1. P-LI-SS-IT Model for Sexual Counseling (53–54)

Level	Description
<p><i>Permission</i> The practitioner brings up the topic of sexuality thereby validating sexuality as a legitimate health issue and giving the client permission to discuss sexual concerns now and later in their program.</p>	<p>Most clients need permission to raise their sexual concerns. Rehabilitation professionals may lack the confidence to discuss sexuality with their clients, however the majority of them have adequate skills and knowledge to provide this level of service.</p>
<p><i>Limited Information</i> The practitioner addresses specific sexual concerns and attempts to correct myths and misinformation.</p>	<p>Much of a health professional's knowledge and training can be applied to sexuality. At this level the practitioner's primary role is that of an educator and therefore should focus on basic sexual information applicable to their area of practice. Many clients would benefit from this level of intervention.</p>
<p><i>Specific Suggestions</i> The practitioner compiles a sexual history or profile of the client:</p> <ol style="list-style-type: none"> 1. Define the problem 2. Determine the course of the problem 3. Treat the problem 4. Formulate ideas about causes and develop appropriate goals and treatment plans. 	<p>Fewer clients require this level of intervention and fewer practitioners are qualified to provide this degree of service. The practitioner should possess counseling skills as well as appropriate information and treatment skills in order to provide treatment at this level.</p>
<p><i>Intensive Therapy</i> The practitioner completes a full history of the client and provides specialized treatment.</p>	<p>This level has the smallest clientele. Requires special skills of sex therapist or other appropriate professionals.</p>

health care was developed by Annon (53–54). The P-LI-SS-IT model (Table 1) is still one of the most commonly used frameworks when dealing with sexuality in the health care setting (2–3,8–10,34,55). This model has four levels, Permission, Limited Information, Specific Suggestions and Intensive Therapy (P-LI-SS-IT). The first three levels are appropriate levels of intervention for most health care professionals, while the final level, intensive therapy, should only be delivered by an expert in the area of need (3,8,34,55).

SUGGESTIONS FOR COUPLES INTERVENTION

As the literature indicates, a disability does not just affect the individual with the disability but also the partner. Using Dailey's definition of sexuality (19), intimacy, identity, sexualization, reproductive issues, and sensuality are all affected if the individual is in a relationship. There may be some hesitancy on

the part of the health care professional in dealing with a partner. It may raise questions and doubts regarding appropriateness, confidentiality and so forth. However, if the professional is to deal with the client in a holistic manner, he/she will have to address all aspects of the client's life and this will have to include the client's partner and the issue of sexuality. The health care professional should also assess the couple's characteristics in terms of when the relationship formed, their value systems, and expectations and so forth. The clinician should not lose sight of the goal; assisting clients to regain or develop intimacy with themselves and their partner.

Using the P-LI-SS-IT Model for Intervention

The P-LI-SS-IT model has been primarily used to deal with issues around sexuality and the individual (3,8,34,41,55). The model can also be used with couples in the same way. The framework can be used to address all the strategies outlined in the literature suggested for couples affected by disability when discussing sexuality. These include: mutual responsibility, education, facilitating communication between partners, facilitating attitude and behaviour change, and prescription/provision of aids, prosthesis and resources.

Permission

After working with the client, the clinician will have determined if the client is presently involved with a partner. They will also determine the type of relationship and so forth. The health care professional may ask permission from the client or give permission to the client that he/she is willing to discuss issues regarding sexuality with the partner. Permission can also be given indirectly, by involving the partner in all aspects of the care and education of the client (5,46). The clinician can facilitate the development of the attitude that it is "our" problem (15) and minimize any guilt or anxiety associated with resuming sexual activity (55). The permission stage may also be the best level at which to facilitate communication between the couple and decrease the myth that sexual expression is appropriate for only the young, healthy and physically-abled individual (34).

Limited Information

At this level of intervention, general information with regard to etiology, pathology and complications regarding the disability should be reviewed with

both partners. Special attention should be given regarding sexual function. By having the partner present, this allows the couple to ask questions addressing their special needs. It may also reduce any anxiety they may have regarding initiating sexual activity and possibly hurting the partner. This level may also be useful to further erase any myths the couple retains regarding the disability and sexual activity. By simply providing information, the clinician may be facilitating some attitudinal and behavioural changes.

Specific Suggestions

During this level of intervention, the clinician can discuss specific suggestions on how to cope with the disability. Before progressing to the next level, the clinician must decide if the couple requires more in-depth intervention in the form of specific suggestions. Before progressing to the specific suggestions level of intervention, the health professional must first conduct a full evaluation including completing a sexual history of the couple. By gaining all the pertinent information, the clinician ensures that the intervention prescribed is appropriate for the couple (8). Goals may be set regarding new strategies for sexual activity (8,34). Specific suggestions may come in various forms. These may include suggestions regarding various positions for sexual activity (34), adaptive devices and orthotics and so forth (13). This level is also the most appropriate time to discuss boundary setting as well as establishing roles that are acceptable to both partners. The final area that can be addressed in this level of intervention is facilitating attitudinal changes. If necessary, the clinician can assist the couple to redefine sexuality in broader terms as any activity that is mutually stimulating and pleasurable for them (15,51). Couples can also be given options for activities that they may consider acceptable (8,13,34,51). It is apparent that this level of the P-LI-SS-IT model requires much more from the clinician with regard to time, experience, and knowledge (8,34).

Intensive Therapy

This level is beyond the scope of most health care professionals. The clinician must assess the couple's need and his/her own level and area of expertise and then decide who would be best suited to deal with the issues. If the problems the couple is experiencing pre-dates the disability, it may require intensive counseling or more specific medical intervention. In this case, appropriate referrals should be made (8,34). For specific disorders such as problems with physiological response to arousal (erection and lubrication), a referral should be made to a Gynecologist or Urologist to deal with or rule out organic causes.

Individuals with psychosocial issues may be referred to a psychologist. If the issues are strictly sexual in nature, than a referral should be made to a certified sex therapist.

CONCLUSION

There is a general consensus on the fact that a disability can have a significant impact on an individual's life. What is often forgotten is that the disability will also greatly affect the lives of those around that person—especially the spouse or partner of the disabled person. The impact on the sexual relationship between the couple and how to address the issue is a neglected subject in the literature. Although, this article has highlighted some of the key findings, more research is required to determined:

- The effects, both immediate and long-term, a disability has on the sexual aspects of the relationship.
- The types of resources and interventions needed to effectively deal with the relationship issues raised by the disability.
- The effects of couple therapy and other specific programs.
- Reasons why high divorce rates, failure of relationships and other problems are more common among such couples.

The difficulties faced by health care providers in dealing with this issue may also be addressed through the inclusion of couples' issues in education curriculum. The literature clearly indicates that disability is a couples' issue when the person with the disability is involved in a relationship. By understanding the difficulties and issues faced by the couple and by incorporating the use of the P-LI-SS-IT model or similar strategies, health care providers will be able to determine the client's needs as well as assess their own level of expertise and experience in dealing with this very important task.

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