

My home, your workplace: people with physical disability negotiate their sexual health without crossing professional boundaries

Jan Browne^{a*} and Sarah Russell^b

^a*Deakin University, Burwood, Australia;* ^b*Research Matters, Victoria, Australia*

This paper aims to describe research that examined the views of people with physical disability, living in Australia, of their sexual well-being needs from their own perspective. We explored the impact their sexual well-being needs had on their relationships with professional carers. A social model of disability was used to understand how sexual well-being is facilitated or denied in community care. We also explored whether clients' sexual well-being needs could be met without carers or clients 'crossing the line'. Our findings indicate the multiple ways that 'professional boundaries' were negotiated between clients and professional carers. The data show that the location of the 'line' changed, depending on a range of personal, social, economic and environmental factors. The data also show a gap between the sexual well-being needs of people living with a physical disability and the level of support provided at the social and organisational levels. Suggestions are made for research and practice directions.

Keywords: In-home services; People living with physical disability; Professional carers; Sex and disability; Sexual well-being.

Introduction

People living with a physical disability are sexual beings, and sexual wellness is important for overall health. However, sexual wellness is not widely regarded as integral to the overall health of people living with a physical disability (Pfeiffer, 1994; Shakespeare, 1998). People living with disability are widely presumed to be 'asexual' (Sant Angelo, 2000), and are often labelled as 'deviant' when expressing sexual

* Corresponding author. C/-PO Box 1235, North Fitzroy, VIC 3068, Australia. Email: janbrowne@comcen.com.au

behaviours or desires (Earle, 2001). It is difficult for people with disability to be sexually healthy when their attempts at sexual expression are met by misunderstanding, fear and prejudice.

In this research project we explored the sexual well-being needs of people living with a disability in Australia, *from their own perspective*. Rather than emphasise the physical aspects of sex (erection, ejaculation, vaginal lubrication etc.), we aimed to explore a range of sexual experiences for people living with disability. The focus of this research was on 'sexual well-being' because 'well-being' encompasses a broad range of issues. Given the complex mix of values, norms, interaction and the cultural arrangements in which we live, 'sexual well-being' does not conform to a single definition or social standard. In this paper 'sexual well-being' is conceptualised broadly as the capacity to enjoy and control sexual behaviour in line with a personal and social ethic. As such, a person has the freedom to express themselves sexually without shame, guilt, fear, oppression, abuse or prejudice (WHO, 1986; Bolton, 1995; Few, 1997; Weeks, 1985). In addition, focusing on sexual well-being also enabled us to avoid confusion about the meaning of terms such as 'sexual health' (often used to refer to the presence or absence of disease) and 'sexuality' (used in everyday conversation to refer to sexual preference).

The aim of this research was to gain an understanding of how people living with physical disability perceived their own sexual well-being needs and the impact these sexual well-being needs had on relationships with carers. We used a social model of disability to understand how the sexual well-being of people living with physical disability was facilitated or denied in community care.

The findings indicate that sex and sexual relationships were important to participants. Participants affirmed that sex was not simply about the physical aspects of sex but was often more about intimacy, desire and love. However, the data also showed a gap between participants' sexual well-being needs and the level of support they received at the organisational and social levels to meet those needs.

Literature review

Physical disability can impact on sexual self-sufficiency. As a result, people with a physical disability may require assistance to meet their sexual well-being needs. This may create a conundrum for clients and professional carers. Although professional carers assist with intimate activities such as showering and dressing, and social activities such as shopping, banking and recreational pursuits, they are generally unsure of how to work with a patient's sexuality and sexual behaviour (Whyte, 2000).

Ways in which the sexual well-being of people living with disability can be achieved are rarely examined in academic or professional literature (Earle, 2001). Professional understandings of living with physical disability often exclude the complex sexual well-being needs and desires of people living with a disability. Rather than conceptualise sexual well-being for people with disability as something that embodies fun, pleasure, desire, attraction, love and fantasy (Earle, 2001), the literature emphasises the mechanics of sex. Most of this literature focuses on men (erection, ejaculation),

and occasionally women (lubrication, arousal). Furthermore, issues are constructed as sexual 'needs' and 'problems' such as the use of sex workers, facilitated sex and protecting vulnerable clients from abuse, thus denying the full range of sexual experiences that are possible for people living with disability (Garden, 1991; Hulter & Lundberg, 1995; Earle, 2001).

In an Australian study of sexual behaviour and relationships, Richters *et al.* (2003a) found that sexual difficulties are quite common among people, including people living with a disability. They found that masturbation is a common practice—about half the men and a quarter of the women surveyed had masturbated during the past 4 weeks (Richters *et al.*, 2003b). However, masturbation is often associated with fears and taboos that stem from religious or cultural beliefs. In addition, the study by Richters and colleagues showed that 17 per cent of men and 2 per cent of women had visited Internet sex sites within the previous 12 months.

Helping clients to achieve sexual well-being can create tensions for professional carers between understandings about what is 'work' and what is 'personal'. The difference in understandings between work and personal also challenges organisational notions of 'professional boundaries'. Briant (1997) observed that crossing professional boundaries changed the service provider–client relationship. He described conflicts of interest and unrealistic expectations of work relations.

It is generally acknowledged that responsibility for maintaining professional boundaries rests with the professional (Neal, 1999). In the current study, however, most participants described themselves, not their carer, as maintaining the professional boundary. Participants' stories showed that they often controlled where the line was drawn.

In Australia, there have been changes in the community service workforce. Anecdotal evidence shows that attendant carers, rather than registered nurses, are increasingly providing care for people at home. Attendant carers are not registered, and control over practice occurs through specific organisations rather than professional bodies. Although this change was intended to empower clients, the deregulation of the workforce has implications for the delivery of care. In particular, use of an unskilled workforce may have implications for people's sexual well-being.

Method

People living with physical disability volunteered to participate in an in-depth interview, during which they shared experiences of how they met their sexual well-being needs and ways in which organisational guidelines were transgressed. After these preliminary interviews, two teleconference focus groups were conducted. During the teleconferences, participants discussed the specific themes that were identified during analysis of preliminary interviews. Together, participants explored these issues in more depth. During the teleconferences, there was also a discussion about future directions for professional training and possible research directions. Each person was invited to participate in one personal interview and one teleconference group interview.

There was comment made by a participant that the interviewer was a female, and did not have a (visible) disability. However, the advertisement had been placed in disability organisational newsletters and daily media, but no person with a disability applied. The interviews were, nevertheless, very frank and open discussions. Numerous people with a physical disability also responded online to this comment and said that they were grateful for the opportunity to discuss sexual well-being despite the interviewer not having a physical disability. There was no reason to suggest that the interviewer's abilities or gender impacted strongly on the information obtained.

Ethics

The research process was conducted in an ethical and reflective manner. The research project received ethical approval from Deakin University's Human Research and Ethics Committee. To ensure confidentiality, pseudonyms were chosen by participants. In addition, participants were assured that any information provided regarding a carer would be treated confidentially. When a participant reported unprofessional behaviour exhibited by a carer, the interviewer encouraged the participant to report the behaviour to the relevant authority. However, whether or not to report the behaviour was the participant's choice and the interviewer respected that choice.

Recruitment

To be included in the study, participants had to be living with physical disability, over 18 years of age, receiving professional care services from a professional carer and English-speaking. It was not possible to recruit people from non-English speaking backgrounds because the research budget was insufficient to employ interpreters. In addition, research with culturally and linguistically diverse communities is most successful with researchers from their own communities.

Specific organisations working in the area of physical disability agreed to circulate a flyer entitled 'Here's your chance to talk about sex' to clients living in Melbourne, Australia. As a result, 12 participants (6 men and 6 women) were recruited. The ages ranged from 21 to 75 years (2 people were in their 20s, 3 were in their 30s, 1 was in his/her 40s, 5 were in their 50s; and 1 was over 70). Of the participants, 7 people had an acquired disability and 5 people experienced congenital disorders.

Interviews were conducted at times and places that were agreed to by the participant and the interviewer. The purpose of the interviews was to explore experiences that made participants feel sexually well and the types of relationships that participants shared with carers. Participants were also asked how they managed the relationship between 'carer as worker' and 'carer as friend/lover'. They were asked whether they had ever 'crossed the line', and how they responded to that situation. The teleconference focus group was also asked to identify future directions for research

from the findings from the preliminary interview. The interview questions were open-ended.

Data analysis

All but one participant agreed to have the interview tape recorded. The eleven tape recorded interviews were professionally transcribed verbatim while the remaining interview was recorded in written notes. From this interview data, two preliminary themes are discussed in this paper. These themes were explored in more depth with participants during the teleconference focus groups.

Teleconference focus groups were incorporated as part of the research design because attendance at face-to-face focus groups for people living with disability is often difficult. Two separate teleconferences were held, each with six participants. The teleconference data, together with the data from in-depth interviews, inform the findings of this study.

Findings

The data showed that people with physical disability have diverse sexual desires, fantasies and needs—just like people without physical disability. As Suzie said: ‘you don’t stop being a sexual being because you are disabled’. However, the data demonstrated that people with a physical disability may have special needs in terms of fulfilling their sexual desires. In addition, the data demonstrated that relationships with carers impacted on participants’ sexual wellness, particularly in terms of privacy, sensitivity and support.

While some participants described situations in which carers provided valuable support for, and understanding of their sexual well-being needs... most participants felt that their sexual well-being needs were unsupported. Two main themes identified in the data were:

- finding new ways to achieve sexual well-being with an altered body; and
- crossing the line.

Finding new ways to achieve sexual well-being with an altered body

In the past, research about sex and physical disability has focused on the physiological changes that occur when people acquire a disability, such as a loss of physical sensation or a loss of ability to have an erection. The findings show that the physical reality of having an altered body was a major hurdle to participants achieving, and maintaining, sexual well-being without assistance.

For participants, finding new ways to be sexually well was not as simple as buying a sexy outfit or wearing a new brand of aftershave. Finding new ways to be sexually well was often a complex process for people with physical disability. The practical implications of a physical disability were sometimes so overwhelming that some

participants negotiated new relationships with their partner. These relationships were intimate and loving, but were not necessarily 'sexual relationships' in the conventional sense.

Negotiating a new relationship with partner

All participants with an acquired disability indicated that they were no longer able to be sexually well in the same ways that they had been prior to having a disability. Many participants found new ways to share intimacy. This may, or may not, have involved sexual intercourse. For some, sexual intercourse was replaced with other activities. Participants described their relationships with lovers as intimate, loving and providing companionship.

Those participants who were not partnered said that they would need to negotiate a different type of relationship with any future partner. One participant, Melanie, said that she would need a relationship in which her partner had intimacy with her but 'sex' with someone else as she was unable to participate in sexual intercourse. Melanie recognised that this would make the relationship very complicated. Like several other participants, she said it was unlikely that she would ever have a partner.

Several participants said they were unaware of the different ways to have an intimate, loving relationship. This demonstrated the importance of ensuring access to knowledge about the diverse sexual possibilities available to people with an acquired physical disability. Although participants described many different ways to have an enjoyable sex life with a physical disability, they indicated that they often gained this knowledge by trial and error. This learning involved some enjoyable times, but also much emotional pain for some participants. The participants agreed that it would be very helpful for information, advice and support for sexual well-being to be readily available to people with a disability. Participants said that they would like to learn from the life experiences of others. They said that it was also important for partners of people with physical disability to also have access to this information. Accounts from others, including partners of those who had experienced similar difficulties, were considered extremely valuable. Participants also suggested that people with a newly acquired physical disability would benefit from knowing that it takes time to adjust to an altered body.

Taking time to adjust to an altered body

Participants noted that it often took time to find new ways of having a sexual relationship. Suzie, for example, described a couple of years of emotional struggle before she and her husband became sexually comfortable with each other again after her injuries. Suzie talked about bodily constraints such as pain and limited movement. She also had to remove her limbs before getting into bed.

We just couldn't make love in the way we used to. Every time we made love, I would be reminded of how it used to be. I would just end in tears. Gradually, naturally, it got a bit

better. We figured out ways and different positions that we could make love in that were either comfortable or not too uncomfortable.

In the early days, Suzie said she found it particularly difficult that her husband was emptying the commode chair and assisting her to change sanitary pads. Although her husband said that these things were not a 'turn off' for him, they were for Suzie.

John found sexual activity harder as he faced the problem of decreased physical flexibility. He found it increasingly difficult to manoeuvre himself around the bed. According to John, his wife adapted well to his physical disability and together they found other ways to have sex.

Participants' stories also highlight the lack of professional support that they received while trialling new ways to establish intimate connections with their altered body. Participants described a powerful sense of aloneness in this journey. The data indicated that much of the pain could have been avoided if participants had had access to professional information about sexual well-being, informed conversations with carers, and the benefit of learning from other people living with a physical disability. One of the issues rarely discussed by professionals with people with physical disability was masturbation.

Masturbation

As noted in the literature review, masturbation is a common practice among the Australian population. For people with a physical disability, however, there were sometimes limitations in addition to religious or cultural beliefs. Some participants said they felt the need to masturbate but could not for physical reasons. Petah, for example, described not having 'normal release like a normal person'.

To maintain their sexual well-being, many participants were reliant on other people to achieve sexual well-being. Cathie, for example, needed to be 'set up' to masturbate. Cathie said she believed that helping clients to masturbate was a valid role for carers. However, in her experience, most carers were too embarrassed to assist.

To masturbate I have to be set up. I have to have someone willing to do it and that brings the whole thing of carers into it ... I think it is a valid part of their role as a carer to fit a vibrator and then walk out of the room ... But they're too embarrassed to set it up.

It was not only carers who were 'too embarrassed'. Participants described being 'too shy to ask'. Some participants indicated that it would be a great relief if they could feel comfortable enough to ask carers to help them to masturbate. Will, for example, sometimes asked subtle questions to ascertain whether or not his carers were open to assisting him to masturbate. If he received negative responses, he did not pursue the issue. If, on the other hand, the carer indicated a willingness to help, he continued discussions to find out how much the carer was willing to do to help him. Cathie described technical inventions that would soon enable people with a physical disability to masturbate more easily and independently. These involved using the Internet and virtual sex.

Internet and virtual sex

The literature review indicates the usage of Internet sites among Australians. Data from the study indicated that having access to the Internet was also a very important sexual health resource for people with physical disability. The Internet served as a resource for people with physical disability that enabled them to access sexual health information and to purchase sexual aids privately online.

The Internet can also be a source of companionship as it facilitates communication with people who share similar experiences. Several participants indicated that they used the Internet to make connections with people, and some said they used their personal computer to assist their sexual well-being. Will, for example, described the benefit of being able to communicate with people without showing your physical self.

To use the Internet as a sexual resource, participants required privacy to search the Internet and view information on a screen. In some instances, participants worried that their carers might see the screen and find the sexual material offensive. Although participants indicated they should be able to view such explicit material on their own home computer, they were aware that their home was also their professional carers' workplace. As a result, Internet sexual activity was often hidden from carers. In addition, Internet sex is only available to those who have the skills, financial resources and physical ability to access a computer and the Internet.

Cathie described the possibilities of technological advances such as virtual sex in a virtual body suit. The virtual body suit would provide sexual sensations without the need for another person to be physically present. Nonetheless, someone would be required to dress people in the suit, which once again would limit privacy. Another option for those who can afford it is to buy sex.

Paying for sex

Although commercial sex was an option for several male participants, the data indicated that most female participants did not consider it to be an option. Female participants described the lack of opportunities for them to engage in commercial sex. Some female participants suggested that service providers should employ people specifically to service sexual needs. However, these female participants said that it was unlikely that many women would want to take up this option. Although some women liked the idea of a 'fuck buddy', they indicated they would not feel safe having a stranger in their homes. The single women considered the financial costs of using a sex worker as another barrier. In addition to issues of safety and cost, the women said that the impersonal nature of paid sex made female participants reluctant to engage the services of sex workers.

Although commercial sex was more accessible for male participants, the male participants also described some of the problems inherent in using sex workers. Whilst able-bodied men could visit sex workers discreetly, this was not possible for men with a physical disability. Engaging in paid sex required assistance and support from another person. In some cases, male participants said that a professional carer

would take them to a brothel. One participant, Will, said that he had an ongoing, regular relationship with a 'surrogate partner'. This was a paid, sexual relationship with a woman on a regular basis. According to Will, his surrogate partner understood the sexual and intimate needs of a man with a physical disability. Will said that the relationship helped him to feel more 'normal'.

Although commercial sex is a viable option in the sexual well-being of people with a physical disability, it often requires a carer's assistance. By helping clients to access commercial sex, professional carers were in breach of organisational guidelines.

Crossing the line

All participants acknowledged the importance of a 'line' between 'carer as worker' and 'carer as friend/lover'. However, the data showed that the participants' 'line' was not always consistent with organisational understandings of 'professional boundaries'. For participants, the 'line' was dynamic. It shifted according to specific circumstances. Nonetheless, several participants described how they were in control of maintaining the boundary between themselves and their professional carers.

Most participants described circumstances in which their relationships with professional carers had 'crossed the line'. Examples of crossing the line included participants giving money to carers, providing carers with emotional support and, for some participants, engaging in a sexual relationship with a carer.

The most common examples of crossing the line occurred when participants developed genuine friendships with their professional carers. Although some participants were clear that a carer was a worker/helper, not a friend, several others socialised with their professional carers out of hours. This included attending carers' family birthday parties, going to movies and shows, and talking on the phone for hours. Petah said that he felt that socialising with carers outside work (paid) hours was important. He said he did not want to feel that people were being paid to be his friend.

David did not separate work and personal relationships. He described reciprocal relationships in which he cared about his carers and *vice versa*. This challenged the commonly held stereotype of carers providing support to the client. It is rarely acknowledged in the literature that clients also provide support for professional carers. David said that he felt that many organisations would consider the mutual support in his relationships with carers to be 'crossing the line'.

It's really a job that's based on relationships and on people supporting each other. I know that I provide a lot of emotional support for my carers, which is probably completely inappropriate in terms of the way that the industry would see the role.

While several male participants described experiencing a sexual relationship with a professional carer, only one female participant said she had experienced a sexual relationship with a carer. This female participant later married her carer. Most women in this study had not, and said they believed they most likely would not, have sex with a professional carer (male or female). Female participants all agree that men with a physical disability had more opportunities to have sex with carers because 'most

carers were women'. This hetero-normative view was based on the assumption that both carers and clients were heterosexual.

A few male participants described having a sexual relationship with a female carer but most indicated it was preferable to keep carers 'at arm's length' to avoid being reported. Bryan, for example, described his sexual relationships with two carers. He described how it was easier to get involved with carers than to meet new people outside the home. According to Bryan, 'carers understand'. However, he indicated that the organisations in which the carers work were less understanding. Bryan described the mediation processes that occurred when his relationships with carers 'crossed the line'. He reported that the mediation processes were 'ugly stuff'. Not surprisingly, participants chose to withhold information about their sexual relationships with professional carers from service providers. They said they feared the situation would result in 'mediation' or various forms of punishment, such as carers losing their jobs.

Some participants said that they would terminate a carer's contract if they became sexually attracted to a carer. Will, however, suggested that it was 'not right' to fire or remove a carer just because a client was attracted to the carer. David said it was 'natural to have feelings' for people with whom he spent a lot of time. In his case, carers were often the only people he saw. He specifically hired carers around his own age, making attraction 'more likely'. David said that when he experienced feelings of desire for a carer, he chose not to act on this desire. He crossed the line only in his mind. Similarly, when Alice felt attraction to a carer, she had sex with him 'in her head' because she said that expressing her sexual desire would be 'wrong and immoral'. Both Alice and David said they fantasised about having sex with carers they found attractive. However, they did not act on their fantasies, nor tell the carer about them.

Although most participants said that it was unlikely that they would ever have a sexual relationship with a carer, many said they would consider gaining assistance from carers to meet their sexual needs. Given that most participants were unable to meet their own sexual well-being needs without various forms of support from another person, they said that carers needed to be appropriately trained to assist clients to meet their sexual needs.

In most cases, clients were not comfortable discussing their sexual needs with their carers. However, there were several instances in which carers supported clients' sexual needs. For example, one carer assisted a participant to get in and out of his girlfriend's bed. Another carer attached a device so that a client could masturbate. In addition, it was also common for carers to escort male participants to brothels.

Professional organisations in Australia provide guidelines to discourage carers from assisting clients with their sexual needs. However, when participants felt a situation was 'getting out of hand', a few participants had clearly defined strategies. Others felt uncertain about what to do in such situations. In general, participants were concerned about causing hurt to carers or disruption to their care. Participants indicated that they were not sure whether helping them to masturbate or taking them to a brothel was against organisational rules. They were, however, clear that the organisational

guidelines needed to explicitly acknowledge the importance of sexual well-being. Participants said that these guidelines should allow carers to support the sexual well-being needs of people with physical disability without anyone 'crossing the line'.

All participants agreed that training professional carers to be more aware of clients' sexual well-being needs would help to ease participants' tension about carers' responses. Suzie, for example, said she would like to be able to have sex without worrying about carers' reactions when they discover lubricants on the bedside table or see/smell other evidence of sex. Others said they would like to be able to enjoy pornography without offending carers who were working in the house.

Future research directions

The participants all agreed that further research is required into how service providers can support clients' sexual well-being. In addition, they agree that research is needed to explore gender issues, particularly in relation to the needs of women, including lesbians living with a disability. Given that many male participants regarded carers as potential sexual partners, studies examining how sexual well-being needs impact on occupational health and safety issues for professional carers would also be instructive. In addition, research to explore sexual well-being for people with disabilities from culturally and linguistically diverse groups is indicated.

There are many tensions in the conduct of care in the home, some of which are inherent to all home care. The home will, for instance, always be both home and workplace. Clients, carers and organisations may continue to have different views on the meaning and implementation of professional boundaries. Further research is required to keep professional boundaries on the agenda. Researchers could also explore how service organisations can ensure codes of conduct, ethical guidelines and training remain relevant to both clients and carers. This is especially the case when particularly complex situations need to be managed. Another focus for future research might be the options for carers and clients who become attracted to each other. Researchers could also investigate how ambiguities in the meaning of professional boundaries can be reduced and clearer guidelines for practice and clients established. Investigating ways in which clients and carers could have input into the development of such guidelines would be particularly useful.

Conclusion

Consistent with other research, participants in this study affirmed that people with physical disability are sexual. By not recognising the importance of sexual well-being needs, health and community-care organisations may be failing many people with physical disability. This study indicated that there was a need for increased professional awareness of the *diversity* of people's needs and desires and the *ongoing* importance of sexual well-being for people living with physical disability.

This research indicated that people living with disability and service providers may have different understandings of what is 'work' and what is 'personal'. There were

many variations on what constituted 'work' and what constituted 'friendship'. This blurring of boundaries can have 'benefits' for carers, as demonstrated in this study with cases of participants providing extra shifts. It can also have 'benefits' for clients, if, for example, carers provide assistance with masturbation.

Although people living with physical disability can find new ways to be sexually well, this is often a complex process. It requires both open negotiations with partners and the assistance of others. Time, support, information and advice, including the experiences of others, are all needed to ease the process of becoming adjusted to sexual well-being with an altered body.

Participants suggested that masturbation, virtual sex and Internet viewing were ways to be sexually well, but intruded on the carers' workplace. Participants said that there were also barriers associated with using paid sex, especially for women. Helping clients achieve sexual well-being by enabling them to put into practice whatever resources they can, requires that carers and clients work together with organisations to find answers to solve the dilemmas involved, especially in relation to privacy.

In this research we identified instances in which, in a home, residents tend to do what they like; in a workplace, occupational health and safety rules apply. However, home as the workplace often created an environment in which 'crossing the line' was difficult to avoid.

Participants described the need for privacy as being crucial to their sexual well-being. The data indicated that professional carers needed to more aware of clients' need for privacy. Although it was crucial for participants to have professional help to take the pressure off partners and children, this often meant the loss of privacy. Working as they do in clients' homes, carers often have access to the most intimate areas of people's lives. It is inevitable that carers will encounter situations that may be embarrassing for both clients and themselves. Professional carers require training to ensure that clients' sexual lives do not create uncomfortable working environments.

An organisational directive to 'be friendly, not friends' does not necessarily support clients and carers to be clear about when friendliness is becoming friendship. It would be helpful to have training that includes clear directions and strategies to use when a person feels that situations are becoming uncontrollable. This would ease the burden of causing potential hurt or causing a disruption to services.

Gender relationships between clients and carers (male/female) were highlighted by participants as an issue needing more attention. In particular, some male clients saw carers as potential sexual partners. This may have limited their willingness to seek new sexual partners outside the home. It may also have increased tensions between clients and carers.

Our data show that clients often provide mutual support to carers, but usually remain in control of whether boundaries are crossed. Nonetheless, it is particularly difficult for clients and carers to identify the subtle situations in which kindness can shift the boundary towards friendship. In non-sexual situations, such as when money had been lent or given to a carer, the boundaries for participants in this study often shifted. However, many organisations advise against such transactions, believing that clients and carers may become vulnerable to exploitation. Participants need

strategies to determine when their acts of kindness and responses to carers telling clients about their personal troubles are 'crossing the line' and how to act in these situations.

Participants were clear about when relationships with carers were becoming sexual in nature. Some men, and one woman, in this study described having had sexual relationships with carers. The woman married the carer, as did one of the men. This indicates that loving, long-term relationships can develop between clients and carers. The men said that their carers were the initiators. Although men were aware of sexual harassment claims, such sexual relationships with carers were, in the words of one participant, 'always a possibility'. All the single women, however, said they thought there was much less possibility for them to have a sexual relationship with a professional carer, and that they did not wish to.

The participants agree that people living with physical disability want their diverse sexual well-being needs acknowledged in organisational guidelines. People living with physical disability also wanted carers to assist them to be sexually well, without anyone being required to cross the line.

Acknowledgements

This research was funded by ParaQuad, Victoria and the Faculty of Health and Behavioural Sciences, Deakin University. We would like to thank all the participants for sharing their intimate stories with us. We also wish to acknowledge Susan Peake for undertaking the interviews; Sarah L'Estrange for taking notes during the teleconference groups; and Marlene Bailey for transcribing the interviews. We especially thank Helen Bryant for her ongoing support of research activities, and her advice throughout the project. Our thanks also go to Damien Ridge and Mari Botti for their willingness to be on the Advisory Committee. Philomena Horsley and Tania van Megchelen made important contributions by reviewing and editing the original draft report, and we greatly appreciate their assistance.

References

- Bolton, R. (1995) Rethinking anthropology: the study of AIDS, in: H. T. Brummelhuis & G. Herdt (Eds), *Culture and sexual risk: anthropological perspectives on AIDS* (Australia, Gordon and Breach), 285–313.
- Briant, S. (1997) Too close for comfort, *Nursing Times*, 93(6), 22–24.
- Earle, S. (2001) Disability, facilitated sex and the role of the nurse, *Journal of Advanced Nursing*, 36(3), 433–440.
- Few, C. (1997) The politics of sex research and constructions of female sexuality: what relevance to sexual health work with young women? *Journal of Advanced Nursing*, 25(3), 615–625.
- Garden, F. H. (1991) Incidence of sexual dysfunction in neurologic disability, *Sexuality and Disability*, 9, 34–47.
- Hulter, B. M. & Lundberg, P. O. (1995) Sexual function in women with advanced multiple sclerosis, *Journal of Neurology, Neurosurgery, and Psychiatry*, 59, 83–86.
- Neal, K. (1999) When power corrupts, *Nursing Times*, 95, 8–29.
- Pfeiffer, D. (1994) Eugenics and disability discrimination, *Disability & Society*, 9, 481–500.

- Richters, J., Grulich, A. E., de Visser, R. O., Smith, A. M. & Riseel, C. E. (2003a) Sexual difficulties in a representative sample of adults, *Australian and New Zealand Journal of Public Health*, 27(2), 164–170.
- Richters, J., Grulich, A. E., de Visser, R. O., Smith, A. M. & Riseel, C. E. (2003b) Autoerotic, esoteric and other sexual practices engaged in by a representative sample of adults, *Australian and New Zealand Journal of Public Health*, 27(2), 180–190.
- Sant Angelo, D. (2000) Learning disability community nursing: addressing emotional and sexual health needs, in: R. Astor & K. Jeffreys (Eds) *Positive initiatives for people with learning difficulties* (London, Macmillan), 52–68.
- Shakespeare, T. (1998) Choices and rights: eugenics, genetics and disability equality, *Disability & Society*, 13, 665–681.
- Weeks, J. (1985) *Sexuality and its discontents: meanings, myths and modern sexualities*, (London, Routledge & Kegan Paul).
- WHO/Canadian Public Health Association (1986) Ottawa Charter for Health Promotion, *Health Promotion*, 1, 3–4.
- Whyte, A. (2000) How should nurses respond to patients' sexual needs? *Nursing Times*, 96, 35.