

Use of a Patient-Educator to Train Doctor of Physical Therapy Students Regarding Sexuality and Disability

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Introduction

Sexuality is a natural part of the human experience. In physical therapy education, it is therefore expected that Doctor of Physical Therapy (DPT) students are taught about sexuality in the context of physical disability.¹⁻⁶ However, data from Australia,^{3,7,8} Sweden,⁹ the Netherlands,^{10,11} and the United Kingdom⁶ indicate a lack of professional readiness among healthcare students in the area of sexuality and disability such that the implementation of non-traditional teaching methods¹⁰ may be warranted.

The purpose of this article is to describe a teaching method involving a paired approach between a faculty member and an individual with a spinal cord injury (SCI) in order to bridge the gap between didactic and experiential concepts related to sexuality and disability. This method provides a path for experiential learning that teaches interview skills and captures the students' attention to potentially improve retention of the content over that of a traditional didactic method. By weaving the personal narrative of an individual's lived

experience with SCI into the presentation, the content is enhanced and becomes more relatable. The interjection of personal life stories takes a potentially intimidating topic into a more relatable realm. The connective power of sharing personal stories has been documented.¹² Use of personal stories in this classroom situation offers an opportunity for students to challenge preconceived beliefs and biases about sexuality and disability that would not likely be encountered in a traditional lecture or when reading from a textbook. This article presents the background, theory, and methods applied to this classroom experience—and includes available student responses to the experience—so that other educators may consider applying this teaching method in their own classrooms.

Background

The International Classification of Functioning, Disability and Health¹³ provides a framework for healthcare professionals to consider the personal and environmental factors relevant to an individual with

disabilities. This model also explores barriers and facilitators when forming an understanding of the holistic needs of the individual. Regarding sexual health, these needs include personal and cultural norms, beliefs, and preferences. While there are individuals who do not experience sexual desire or attraction and may identify as asexual,¹⁴ this personal identity is not to be confused with a change in sexual activity or engagement that may result from the onset of a physical disability.¹⁵⁻²⁰ Despite the onset of a chronic or progressive condition affecting physical function and independence, individuals do not lose their sexual interests or change their sexual preferences.²⁰⁻²⁵ However, sexual activity may be altered by changes in physical ability, functional independence levels, and social perceptions following illness or injury.^{20,21,24,26,27}

Research shows the importance of addressing sexuality, at an appropriate age, for individuals with conditions affecting physical development from childhood.^{19,28-30} If sexual health is left unaddressed for clients with physical disabilities, relationship instability and other issues are likely to result.^{24,25,27,31-34} Clinicians working in rehabilitation settings often develop rapport and trust with their patients, and are well-situated to discuss sexual health in a professional manner.^{1,32,35,36} In most cases, patients expect healthcare providers to broach this subject and offer professional advice.^{11,34,37,38} Unfortunately, most clinicians and clinicians-in-training feel unprepared to educate and advise patients about sexual health;^{4-9,39-41} as a result, the topic is often avoided.^{15,19,32,36,42}

Several aspects of sexual health are particularly pertinent to rehabilitation practice. Sexuality in the presence of pervasive physical disability is one such aspect. Educating patients and caregivers affected by physical disability about the expression of their

sexuality can be empowering for the patient and their partner.^{5,20} Therefore, knowing how to converse with patients about the sensitive topic of sexual health and sexuality is an important skill for the entry-level physical therapist.

SETTING AND CURRICULUM

The DPT program at the university described in this article follows a block-style curriculum with a lifespan orientation that is included in all blocks as curricular threads. In the final neuromuscular block, the students participate in entry-level lectures and labs about a myriad of neuromuscular conditions including SCI, multiple sclerosis, and Parkinson's disease. For many conditions encountered in the DPT program, community-dwelling adults volunteer to be present during laboratory learning sessions. These volunteers offer students first-hand experience at delivering physical therapy to individuals with particular diagnoses. Just as they would in the clinic, the students perform examinations and interventions under a licensed physical therapist's guidance. The volunteers function as "patients" for the students but are in fact "patient-educators" as they offer valuable feedback to the students in a familiar and supportive environment.

ROLE OF THE PATIENT-EDUCATOR

A patient-educator is an individual with lived experience who is willing to share their perspective and knowledge with healthcare students. The inclusion of patient-educators in a DPT program enhances learning by combining interview training, psychomotor skills training, and direct feedback from the patient-educator. Students value this feedback, as it comes from someone who has life experience with the condition or diagnosis about which they are learning. Students have expressed their preference for this

method over the alternative of role-playing either by faculty or fellow students. With limited experience and knowledge about a condition or diagnosis, students often consider themselves ill-equipped to realistically portray these simulated scenarios. Although faculty can demonstrate some aspects of impairments or functional limitations commonly associated with a condition, it is impossible to fully convey the social and experiential aspects of that same condition as these are factors that can only be learned by the human living with the condition. Students often express gratitude to the patient-educator in the moment and share reflections of this gratitude on course evaluations at the end of the semester. The patient-educators add immensely to the confidence and self-perceived readiness of the students in this DPT program.

Throughout the SCI content presented within our curriculum, students are introduced to several patient-educators with spinal cord injuries during laboratory sessions. One patient-educator in particular has been present for most if not all of the SCI labs for more than seven years. He has become particularly well-known to students while leading lab stations related to mobility. His effectiveness led the curriculum's block leader to ask whether he would consider a joint teaching opportunity to present the sexuality and disability content. Since the patient-educator has had experience in teaching this subject matter to peers and caregivers, as well as students of other health professions (ie, occupational therapy), he gladly accepted. The plan was for the faculty member and patient-educator to team up and teach the material from a physical therapist and patient perspective, respectively.

Teaching Methodology

Knowing that sexuality and disability can be a difficult topic for some students, the patient-educator first

makes students aware of the upcoming learning experience over the course of the SCI labs. He sets the expectation that the topic will be handled as a discussion rather than a lecture and encourages students to develop questions for him ahead of time. These preparatory steps promote student comfort with the subject matter and lessen the perceived barriers surrounding conversations about sexual health. The patient-educator also meets with course instructors ahead of his session to adjust his content based on student responses to the SCI lectures and labs that lead up to the sexuality and disability content.

The goals of the lecture on sexuality and disability are that, following the lesson, students will be able to:

Analyze common myths about sexuality and disability.

Develop strategies to converse with patients about basic sexual health issues.

Recommend physical therapy interventions as appropriate (strengthening, stretching, etc.) to optimize patients' sexual health.

Identify situations in which a patient should be referred to another team member for issues related to sexual health (sex therapist, psychologist, relationship counselor, social worker, etc.).

FACULTY-MEMBER PRESENTATION

The sexuality and disability class session begins with a core faculty member introducing the topic to the students and explaining the Permission, Limited Information, Specific Suggestions, and Intensive Therapy (PLISSIT) model⁴³ with an emphasis on permission-giving in each stage.³⁸ The intent of the model is to provide a framework for discussing

sensitive information such as sexuality with patients across various healthcare settings.⁴³ The patient-educator is present for this portion of the discussion to provide input as needed. The students are guided through the utility of the PLISSIT model, and the patient-educator offers clinical vignettes and personal stories to help them understand what a conversation with a patient might be like.

The discussion also uses vignettes to point to collaboration with other relevant clinicians and the referral of some patients for certain sexual health issues—to help students realize they are not meant to solve all of the patient’s sexual health problems independently. One example illustrating this model is of a young woman with newly-diagnosed multiple sclerosis who is interested in having a family. While she has many questions that the physical therapist can help to answer about her sexual health and sexuality, including some pertaining to stretching and positioning, she also has questions pertaining to fertility difficulties. Since dealing with fertility is outside the physical therapist’s scope of practice, it is decided that a referral to a fertility specialist familiar with disorders of the spinal cord will be the best course of action for this aspect of her care. (See Table 1 for other vignette examples).

Table 1. Examples of Vignette Topics and Possible Healthcare Team Members

Examples of Vignette Topics	Possible Healthcare Team Members
A PT is clearing a teenage patient for contraindications to intervention and the patient discloses she is in the early stages of pregnancy	<ul style="list-style-type: none"> • Social work • Gynecology • Primary care

A patient asks for ideas about body positioning to avoid autonomic dysreflexia during sexual activity	<ul style="list-style-type: none"> • Occupational therapy • Psychiatry for possible spasticity management
A newly injured male patient has questions about his ability to participate in future sexual activities	<ul style="list-style-type: none"> • Occupational therapy • Urology • Primary care

PATIENT-EDUCATOR PRESENTATION

Following this brief topic introduction from a physical-therapist perspective, the faculty member leaves the room and the patient-educator conducts the remainder of the session. His objectives are guided by the PLISSIT model and include the overall lesson objectives. He arrives with prepared material to share with the students; however, he uses a dialogue-based question-and-answer format to enhance student engagement and guide the discussion. He also shows and explains various adaptive devices that can be used for sexual activity by people with physical disabilities and their partners. His use of personal stories about negotiating his social and sexual life as a person with a physical disability allows the students to put the information in context. Rather than reading about what *could be possible* for a person with the same level of injury, they hear first-hand what *is* possible and how addressing sexuality improves quality of life.

Students are often initially reluctant to ask questions. As the patient-educator is experienced in this subject matter, he is able to initiate the conversation and increase student participation. Once the students realize they are in a safe environment for asking

sensitive questions, they often have so many questions that they stay after the scheduled end of the class to continue the conversation. Common questions that arise are:

How should a person with a physical disability discuss sex and sexual health with a partner?

Is sex still the same after a disability, specifically, how does it change after SCI compared to a more short-term disability?

How do you deal with bowel and bladder issues that may arise during sex, and how do you discuss this with a partner?

For people with SCI, can you explain the difference between orgasm and ejaculation?

How can we as physical therapists counsel patients about safe positions for sexual activity?

What types of orgasms can a woman with SCI have and how is sensation a factor?

How should a person with SCI prepare for and handle autonomic dysreflexia during sex?

How should we as physical therapists bring up this delicate subject so a patient feels supported and acknowledged, and that we're not prying too much into their personal life?

If a patient can't have sex the same way as before, what options can they look into?

Can people with SCI or other physical disabilities still have a biological family, and how does this differ for men and women?

How would a person with limitations of their own

physical function and independence care for a child, specifically, an infant? How does this differ for people with tetraplegia versus paraplegia?

Results

Student feedback about the course is obtained via formal course evaluations, and informally as unsolicited feedback offered verbally and via email. Written student evaluations are collected at the end of the term as anonymized data and account for the bulk of the feedback received about this learning experience.

STUDENT FEEDBACK ABOUT THIS SESSION

The feedback for this particular session was generally good. Most students reported finding the experience valuable for their future professional work, as they could better support their patients' overall recovery—including its social and personal aspects. Students in this class have said that it changed their perspective on what is possible for someone with a physical disability regarding social engagement including the expression of sexuality.

One student offered the verbal feedback that he'd thought that, after SCI, men "just couldn't do anything sexually." He noted this was "the best lecture of PT school," as he realized what was actually possible for these patients. Several students mentioned in course evaluation feedback that they had questions for a female patient that the male patient-educator was unable to answer fully. Based on student feedback, a consideration for future courses is to also include a female patient-educator.

Another student offered the following written

reflection about the classroom experience:

“Hearing the perspective of an individual who has experienced things that we previously only heard about through lectures provided us with helpful insight into the subject of sexuality and disability. Furthermore, it gave us a safe space to ask questions about what would have otherwise been an uncomfortable conversation. Being able to talk directly to the patient-educator gave us practice navigating a topic that most healthcare providers neglect. Having the exposure during school, through the perspective of his real-life experiences, allowed us to break down the barrier I had personally felt when thinking about sexuality and disability.

Aside from bridging the gap between patient and therapist, the patient-educator was able to highlight the importance of preparing a patient for these experiences not only for comfort, but for safety as well. He emphasized the importance of planning and positioning to avoid unsafe situations (ie, to accommodate for spasms, etc.). The way that the topic of sexual health was introduced to our class provided us with confidence that will prevent us from having an ‘awkward talk’ and allow us to have an open discussion with our patients to address a topic that is so often forgotten.

Finally, the patient-educator provided us with invaluable insight into how important the topic of sexuality and disability is for quality of life.”

FEEDBACK FROM THE PATIENT-EDUCATOR

As the implementation of a patient-educator seems to be uncommon when teaching about sexuality and disability, it is useful to acknowledge the background and purpose of this patient-educator. He approaches his teaching with a unique perspective and has specific

objectives for the lessons that are undoubtedly influenced by his own journey.

The patient-educator offered the following reflections:

“As a teenager I broke my neck in a surfing accident, becoming a C5-C6 incomplete quadriplegic. At that point in my life I had the typical 17-year-old-male knowledge of sex and sexuality. Basically, that means I had already had the ‘birds and the bees’ talk with my father, and all other knowledge before actually having sex was gained from watching R-rated movies and guys talking amongst ourselves.

Since I had been sexually active prior to my injury I did have knowledge of ‘able body’ sex. After my injury I was not informed or educated on sexuality either because of the uncomfortableness of the topic or the unawareness of the importance sex and sexuality can have on an individual and/or a relationship.

Considering the way healthcare is nowadays in terms of patients getting kicked out of the hospital really fast, talking about sexuality is a big need because it’s one of the questions on the forefront of the patients’ minds and it’s necessary for them to know. Sexuality may not be on the top of the list of things the hospital thinks the patient needs to know or worry about, but the patients may have a different perception. Patients need opportunities to discuss this and get answers to these questions. The topic of sexuality can be mixed into therapy sessions if the therapist is comfortable enough in discussing it and the privacy of the location is appropriate for the conversation and the people involved. This way of having the conversation can make it more comfortable and casual for the patient, rather than sitting down as a formal meeting, which can be uncomfortable.

My role as a patient-educator is important to help

students become better practitioners and to be as comfortable as they can in dealing with sexuality and the many facets of it. This way they become more comfortable in their own skin to make their patients more comfortable to open up to them with questions or concerns. It also gives students the opportunity to realize that if they are not completely comfortable themselves that they'll be able to hand off discussions of sexuality to someone else with more comfort or knowledge, and not to be afraid of doing so. We all know that when a practitioner has hesitation the patient can pick up on that.

I also do this because I think it takes students beyond the books they may have in school. It gives them examples of what may already be out there that is useful and therapeutic, including being able to go to a higher-class adult store to inform choices and recommendations to their patients and fellow practitioners. This open conversation kind of learning gives them a chance to be more comfortable asking a former patient, as opposed to hearing a lecture from a professor. I think this is important in my work as a peer mentor when I'm dealing with new patients and I hear their concerns and questions about sex and sexuality. When that comes up I will answer their questions but also bring that up with their therapist as well so they are in the loop.

Having this experience to teach has meant the world to me. If it wasn't for my therapists, I wouldn't be where I am in life today. This is my way to give back and educate future therapists with new ideas that will make things better for the patients they treat. It's also nice to run into students after the fact to see that they understand the lessons better. This is an added benefit from teaching since I know what I'm doing is making a difference. Besides making a difference to the soon-to-be PT, it also gets passed on to their patients, which

can help that patient be successful in their current and future relationships.”

COMMUNITY INVOLVEMENT

Following the class, the patient-educator makes the students aware of some of the opportunities in their local community in which they can become involved. These opportunities include adapted recreation options such as team and individual sports for people with various diagnoses, and a support group for people with SCI. Some students who have taken this course take an interest in the topic of SCI and decide to go beyond the classroom to attend a community-based patient-caregiver support group for people affected by SCI. The group has rotating topics; the one that typically occurs shortly after this classroom experience happens to be sexuality and disability. Students who choose to attend do so voluntarily and often report back to the course instructors about how valuable it is to consider the social-emotional aspects of care as a health services provider. It is the belief of these authors that the students would not be as inclined to participate in the support group if they had not first met and become acquainted with the patient-educator.

Discussion

The above-described teaching method is meant to dispel the stereotype of asexuality regarding individuals with physical disabilities by presenting the content with the help of personal narratives from the patient-educator. Additionally, and just as importantly, it is intended to diminish the stigma of discussing sexual health with the future patients of DPT students. Implementing topic-specific interview training should aid in normalizing the patient-therapist interaction surrounding sensitive topics.

LIMITATIONS

Although this method garners mostly positive feedback from the students, we do not know at this time if it results in meaningful changes in their readiness to converse with patients about sexual health once they are in a clinical setting. An area for future research would be the implementation of a survey tool to assess student knowledge and comfort with the subject matter before and after educational programming. Such data are currently unavailable for physical therapy students in the United States.

RECOMMENDATIONS

Areas for expanding and potentially enhancing this teaching methodology also include the addition of a female patient-educator to offer the perspective of another gender. If a symbiotic combination of patient-educators were available, a panel-style discussion could include individuals living with different forms of physical disabilities and representing various gender identities and sexual preferences. In such a scenario, it would be important to assess the teaching styles of each panel participant to formulate a collaborative teaching team. It would also be prudent to assess relative parity in terms of comfort level between participants regarding discussing sexual health so as not to set up one patient-educator to dominate the conversation.

Conclusion

While still emerging, this methodology seems to have potential for changing clinicians' perceptions about the importance of understanding and discussing sexual health with patients. By seeking out and acknowledging the individual's personal story, we are able to connect with the patient on a deeper level and possibly be more

effective as clinicians. A seasoned clinician likely recognizes the importance of each patient's individual differences and that such information is most commonly obtained by asking patients to share very personal narratives. As academic and clinical educators, we must also recognize the importance of teaching this to students as it may not come naturally. Cultural norms and expectations, upbringing, and life experience may influence the clinician's comfort with inquiring about a topic they believe is taboo.

Considering the combined reflections of the students and the patient-educator, we can see the positive impact that this non-traditional teaching method can have. We feel that when topics like sexuality and disability are explored within the classroom through personal narratives, and integrated into the education of future physical therapists, these practitioners will be more aware of the links between the humanities and medicine, thus making them more well-rounded and likely to consider holistic approaches beyond the treatment of physical impairments alone. Further, engaging with an educator who has personal experience with the topic allows students to increase their comfort level with direct, interpersonal inquiry and enhance their readiness to discuss a sensitive topic in the clinic.

In summary, we advocate that healthcare educators consider inviting a patient-educator to teach healthcare students about addressing sexual health as a routine part of clinical care; the impact on students and their future patients can be life-changing.

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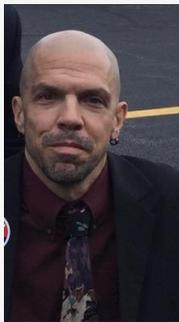
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Buz Chmielewski has been educating students in the Doctor of Physical Therapy program at University of Maryland, Baltimore for over 10 years. Additionally, he teaches in the Occupational Therapy program at Towson University and the Nursing program at University of Maryland, Baltimore. Buz is a peer mentor at University of Maryland Rehabilitation and Orthopedic Institute and helps to organize and facilitate the monthly spinal cord injury support group there. He combines his life experience and teaching skills to facilitate conversations about sexuality and disability.



Alexandra Gurton, PT, DPT, is a recent graduate from the University of Maryland, Baltimore, School of Medicine. Prior to enrolling in her physical therapy program, Alexandra completed her kinesiology degree through the School of Public Health at the University of Maryland, College Park where she was afforded the opportunity to work and learn about diverse populations through the scope of Public Health efforts. In addition, she has experience educating aspiring professionals as various teaching assistant positions in both the under graduate and graduate settings. Throughout her schooling, Alexandra developed a passion for education with the goal of fostering compassion and awareness for underserved populations. Her work on this piece contributes to the integration of sexual education for the individual with disabilities through the lens of a student with the unique background of an educator.



Kelly Westlake, PT, PhD, is currently an assistant professor at the University of Maryland Baltimore Department of Physical Therapy where she conducts research and teaches content related to adult neurologic rehabilitation. Dr. Westlake is actively researching ways in which physical therapy interventions may be individualized and improved for individuals with stroke and older adults at risk of falling. Her research has been supported through the American Heart Association and NIH and she has published in *Physical Therapy*, *Archives of Physical Medicine and Rehabilitation*, *Journal of Motor Behavior*, *Gait and Posture*, *Journal of Neurophysiology*, among others. She believes that teaching DPT students should include a lived perspective from patients to encourage students to integrate evidence based practice with everyday patient experiences.