

Preparing Occupational Therapists to Address Sexuality in Practice

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Sexuality is considered an important and meaningful activity of daily living (ADL) (American Occupational Therapy Association, 2014). The scope of how sexuality is defined is vast, shifts throughout the lifespan, and is impacted by contextual constructs (Whitney & Fox, 2017). Sexuality is basic to one's sense of self and includes sex, gender identity, sexual orientation, sexual activity, and intimacy (American Occupational Therapy Association, 2013; Stead & White, 2019). It embodies the physical aspects of intimacy, such as sexual contact, the emotional aspects of intimacy, such as romantic connection shared between partners, and platonic bonding such as that which is shared between friends (Mohammed, 2017; Stead & White, 2019). Sexuality is an area of occupation that is within the scope of occupational therapy (OT) practice and occupational therapists (OTs) are well-equipped to address issues related to sexuality and sexual participation with clients (American Occupational Therapy Association, 2013; American Occupational Therapy Association, 2014; Hattjar, 2012; Mohammed, 2017).

Background

Sexuality is an important aspect of one's health and wellness, and individuals are still sexual beings during times of illness or disability (Young et al., 2019). Following onset of illness or disability, clients may have concerns about how their health issues will impact their self-esteem, their physical abilities, and their engagement in occupations including sexuality-based occupations. These concerns may extend to misconceptions of the impact their condition will have on their sexuality, or what is expected of others involved in aspects of their sexuality, including partners and caregivers (American Occupational Therapy Association, 2013; Hattjar, 2012). For example, in the event of a stroke and subsequent aphasia, the impact not only affects the stroke survivor, but also those they are close to as roles shift from romantic partners to caregiver and care recipient, leading to a loss of intimacy, a decrease in relationship satisfaction, and poorer health outcomes (Stead & White, 2019).

Furthermore, living with an illness or disability presents many obstacles in achieving optimal health and wellness which reduces one's ability to engage in their usual activities, including those related to sexuality (Whitney & Fox, 2017). These obstacles are not only internally, but externally based on societal perceptions as well (Esmail et al., 2010). Clients may look to health providers for guidance on issues of sexuality, and therefore addressing these issues in health care practice is of utmost importance in treating clients holistically. Stead and White (2019) suggest that rehabilitation teams have the greatest potential in addressing these issues early in the rehabilitation process, as well as offering community-centered events for the survivors and care partners after the rehabilitation ends. Since OTs often work with clients who may have concerns about their illness or disability impairing their ability to express their sexuality, and an OT is uniquely poised in the rehabilitation team to address these concerns, OTs must be prepared to provide support for this meaningful ADL in practice (Hattjar, 2012; Hyland & Mc Grath, 2013; Young et al., 2019).

Purpose

Despite sexuality being a meaningful and legitimate concern for clients, research from multiple countries suggests that sexuality is not being routinely addressed in many health care settings around the world, including OT practice (Esmail et al., 2010; Hattjar, 2012; Higgins et al., 2012; Hyland & Mc Grath, 2013; Mc Grath & Sakellariou, 2016; McGrath & Lynch, 2014; Mellor et al., 2013; Young et al., 2019). Additionally, many studies report that sexuality education is not adequately presented in OT curriculums (Areskoug-Josefsson & Fristedt, 2019; Egliseder et al. 2018; Hattjar, 2012; Lohman et al. 2017; Payne et al., 1988; Whitney & Fox, 2017). Since occupations related to sexuality are within the scope of OT practice, yet sexuality is not consistently addressed in either health care settings nor OT curriculums, it could be theorized that this lack of inclusion in both practice and academic contexts are interrelated (Whitney & Fox, 2017). The purpose of this literature review is to investigate why issues of sexuality are not consistently addressed in practice or OT curriculums from the perspectives of

providers, OT students and faculty. Identifying the gaps in knowledge may aid in understanding how to better prepare OTs to address sexuality in practice.

Sexuality in Health Care Practice

A large number of existing studies in the broader literature have examined the intersections of disability, sexuality, and health. This section presents a review of recent literature on health professionals' and students' perceptions towards sexuality and disability and addressing sexuality in healthcare practice settings.

Sexuality is Rarely Addressed in Practice

There exists a considerable body of literature which states that sexuality is an ADL, that sexuality has a connection to health outcomes, and that it is relevant to OT practice (American Occupational Therapy Association, 2013; American Occupational Therapy Association, 2014; Hattjar, 2012; Mohammed, 2017). However, studies in the literature have consistently reported that despite agreement among many OTs that addressing issues of sexuality is important to holistic, client-centered care, sexuality is rarely addressed in practice (Eglseder et al. 2018; Hattjar, 2012; Hyland & Mc Grath, 2013; Mc Grath & Sakellariou, 2016; McGrath & Lynch, 2014; Payne et al., 1988; Stead & White, 2019; Young et al., 2019). While most of these studies were developed from an OT perspective, and all include at least one OT participant, several include interdisciplinary health professionals in order to highlight that this is an issue for many health care professionals and not just OTs (Esmail et al., 2010; Mellor et al., 2013).

Barriers to Addressing Sexuality in Practice

A series of recent studies have indicated that providers face many barriers in addressing sexuality in practice. This section illustrates the most commonly identified barriers across the studies reviewed. A number of authors have recognized that sociocultural influences present foundational barriers in addressing sexuality (Esmail et al., 2010; Hyland & Mc Grath, 2013; Mc Grath & Sakellariou,

2016; McGrath & Lynch, 2014). Some authors have also suggested that providers' personal attitudes and beliefs about sexuality, as well as self-perceptions of competence and skills, pose the most significant barriers (Areskoug-Josefsson & Fristedt, 2019; Eglseder et al. 2018; Esmail et al., 2010; Hattjar, 2012; Higgins et al., 2012; Hyland & Mc Grath, 2013; Lohman et al. 2017; Mc Grath & Sakellariou, 2016; McGrath & Lynch, 2014; Mellor et al., 2013; Payne et al., 1988; Young et al., 2019).

Sociocultural Influences

The way in which people engage in day to day occupations is influenced by the larger society in which they live. Sociocultural influences include societal constructs which contextually impact the expression of sexuality (Whitney & Fox, 2017). Societal perceptions of sex tend to be reduced to a narrow genital and reproductive focus that fails to recognize the many occupational dimensions that sexuality encompasses. For example, people express sexuality through broad ranges of occupations such as self-care, grooming, caring for loved ones, dating, or having sex (Hattjar, 2012). Additionally, in western society there exists a social construct where sex is often depicted as a privilege reserved for those who are young, able-bodied, heterosexual, monogamous and white (Tepper, 2000). These constructs allow for exclusion and stigmas towards people who do not fit societal norms, such as people with disabilities, lesbian, gay, bisexual, transgender, queer plus (LGBTQ+), and aging populations, people in non-monogamous and non-traditional relationships, and people who express sexuality for purposes other than reproduction (Esmail et al., 2010; Hyland & Mc Grath, 2013; Mc Grath & Sakellariou, 2016; McGrath & Lynch, 2014, Tepper, 2000). The impact of social constructs and expectations on healthcare practices should not be underestimated as tensions in public discourse and societal stigmas are reflected in providers' attitudes and beliefs, thereby influencing how sexuality is addressed in healthcare practice (Esmail et al., 2010; Hyland & Mc Grath, 2013; Mc Grath & Sakellariou, 2016; McGrath & Lynch, 2014). Over time, an extensive body of literature has developed on the understanding of health providers' attitudes, beliefs, and sense of self-efficacy on addressing sexuality in practice. Studies of

provider perspectives are well documented (Hyland & Mc Grath, 2013; McGrath & Lynch, 2014; Mellor et al., 2013; Young et al., 2019), and while research in this area is limited, it is also acknowledged that OT student perspectives are worth consideration as the attitudes and beliefs which develop in school may carry over into practice (Areskoug-Josefsson & Fristedt, 2019).

Attitudes, Beliefs, and Sense of Competence of Skills Addressing Sexuality

Provider Perspectives. In several studies which assessed provider perspectives on sexuality, there was consistent recognition among providers that sexuality is meaningful and worth addressing in practice (Higgins et al., 2012; Hyland & Mc Grath, 2013; Mc Grath & Sakellariou, 2016; McGrath & Lynch, 2014; Mellor et al., 2013; Young et al., 2019). Additionally, some studies specific to the field of OT found that participants acknowledged sexuality is within the scope of OT practice (Hyland & Mc Grath, 2013; McGrath & Lynch, 2014; Young et al., 2019). However, other research has noted that providers have a limited view of sexuality, seeing it through a heteronormative lens as an activity that is reserved for those young, able-bodied, and married. Furthermore, these providers viewed sexuality as primarily associated with biological reproduction, excluding sexuality for purposes of desire and not viewing sexuality as including anything beyond penetrative sex, which further contributes to societal norms of heteronormative views of sexuality (Hyland & Mc Grath, 2013; McGrath & Lynch, 2014; Mellor et al., 2013). It was also found that providers often make assumptions about sexuality based on age, gender, sexual orientation, physical abilities, mental and cognitive status, relationship status and the stage of clients' rehabilitation process (Hyland & Mc Grath, 2013; McGrath & Lynch, 2014; Mellor et al., 2013; Young et al., 2019). As a result, some studies have found that providers tend to use their own discretion as to whom and when to bring up sexuality based on presumptions they have about the clients. Providers often perceive clients as not ready to discuss sexuality concerns, or they perceive that clients don't want sexuality addressed, or they fear that clients would feel embarrassed or offended by discussions about sexuality (Hyland & Mc Grath, 2013; McGrath & Lynch, 2014; Mellor et al., 2013).

In a large number of studies, providers perceived and self-reported that they have gaps in knowledge around sexuality. There is a notable lack of sexuality training and skills among providers which contributes to feelings of discomfort that impedes providers' confidence in addressing sexuality concerns with clients (Higgins et al., 2012; Hyland & Mc Grath, 2013; McGrath & Lynch, 2014; Mellor et al., 2013; Young et al., 2019). Many participants felt that addressing sexuality is a specialty for which they lack specific knowledge to handle because it is outside of their professional competence (Hyland & Mc Grath, 2013). In some studies, the participants felt that it would be more appropriate for other health providers to address sexuality issues (Hyland & Mc Grath, 2013; McGrath & Lynch, 2014; Mellor et al., 2013). On the other hand, in OT specific studies, the participants believed that other providers also lack knowledge and confidence on sexuality issues (Hyland & Mc Grath, 2013). Additionally, some participants noted that their poor levels of knowledge around sexuality were due to a lack of sexuality training during workplace onboarding in practice and during school (Higgins et al., 2012; Hyland & Mc Grath, 2013; McGrath & Lynch, 2014; Mellor et al., 2013; Young et al., 2019). Those participants who did get sexuality education in school noted that it was briefly covered and not in enough detail to adequately prepare them for addressing sexuality in practice (Young et al., 2019). While most studies found that providers were uncomfortable with sexuality, most participants in the study by Young et al. (2019) reported that if it was not for a lack of knowledge, they would be comfortable addressing issues of sexuality if their clients were to bring up the topic, but that they would not want to initiate these conversations themselves.

Additionally, providers felt that their own embarrassment keeps them from addressing sexuality. Some participants noted that fears come up as well, especially with mental health or cognitively impaired clients, that clients will perceive sexuality conversations as an invitation to engage sexually with therapist (Hyland & Mc Grath, 2013; Mellor et al., 2013; Young et al., 2019). Participants also mentioned concerns that clients would think less of the provider for bringing up the topic of

sexuality (Hyland & Mc Grath, 2013; Mellor et al., 2013). McGrath & Lynch (2014) found that providers felt anxious addressing sexuality concerns with older adults. Participants claimed that they would be able to assist with physical limitations, but that they would not be prepared to deal with complex emotional issues related to sexuality. There were also concerns that addressing sexuality would cause embarrassment or offense with older clients. Sociocultural influences were reflected in provider beliefs about engaging in sexuality discussions with older clients and providers felt that if they challenged social norms of silencing aging sexuality that it would damage their professional reputations (McGrath & Lynch, 2014).

Participants in numerous studies felt that structural and institutional factors pose additional barriers to addressing sexuality in practice. Participants stated that they have no guidelines to follow regarding assessment and treatment for sexuality issues, that they received no formal support, they observed a lack of multidisciplinary team involvement, and that they do not know whom to refer patients to when they are unable to address clients' specific sexuality issues (Hyland & Mc Grath, 2013; McGrath & Lynch, 2014; Mellor et al., 2013; Young et al., 2019). Additionally, providers have noted that some clinical or practice settings do not prioritize sexuality, that there may be a lack of privacy to discuss sexuality with patients, and that they lack sexuality resources to offer to clients such as handouts (Hyland & Mc Grath, 2013; McGrath & Lynch, 2014; Mellor et al., 2013; Young et al., 2019).

Many authors suggest more education and training around addressing sexuality issues in practice (Hyland & Mc Grath, 2013; Mc Grath & Sakellariou, 2016; Mellor et al., 2013; Young et al., 2019). Some ideas provided by these authors include the development of training courses with the intended outcome of changing attitudes and beliefs towards sexuality and disability, as well as the adoption of a rights-based approach to promoting the principle that all populations should have their sexuality acknowledged (Mc Grath & Sakellariou, 2016; McGrath & Lynch, 2014). Additionally, these authors suggest training for providers on building communication skills to effectively engage in sexuality

discussions with clients as well as training on OT interventions for specific sexuality issues (Hyland & McGrath, 2013; Mellor et al., 2013; Young et al., 2019). Young et al. (2019) states that there is a need to integrate sexual health into the basic occupational therapy curriculum through lecture and practicums to ensure OT competence in practice.

Student Perspectives. While research is still limited in this area, Areskoug-Josefsson and Fristedt (2019) investigated OT students' views on addressing sexual health in future practice; much of the results were similar to the previously discussed findings from research with practicing OTs. Focus groups conducted by Areskoug-Josefsson and Fristedt found that students had a limited definition of sexuality and tended to focus on definitions related to sexual intercourse or reproduction, which did not include broader aspects of sexual health and alternative ways of expressing sexuality and intimacy. Additionally, it was found that students had prejudices and misunderstandings about sexuality based on clients' age, gender, sexual orientation, ethnicity, cultural background, and religion. Surveys concluded by Areskoug-Josefsson and Fristedt also found that many of the students believed sexuality is relevant to client-centered OT practice and that it would be part of their future profession. Similar to provider perspectives, students felt that they lacked knowledge and skills to address sexuality concerns confidently and competently. Students expressed concern at their lack of professional knowledge in the area of sexuality and worried that they would say the wrong things or make clients uncomfortable and thought it wiser to avoid the subject, thus contributing to the stigma of silence around issues of sexuality. The authors suggest that there is a need for more education in order to encourage students to reflect on their attitudes and beliefs as to broaden their views prior to becoming practitioners (Areskoug-Josefsson & Fristedt, 2019).

Desire For Sexuality Resources

A lack of education and training in the area of sexuality poses significant barriers and leads to anxiety for providers (McGrath & Lynch, 2014). Many providers assert that they want more education

on sexuality and that given the opportunities, they would participate in workshops, continuing education offerings, or participate in studies assessing sexual education programs. (Higgins et al., 2012; Young et al., 2019). McGrath & Lynch (2014) noted that participants had received neither pre nor post-graduate education that would adequately support them in addressing sexuality needs of clients, which speaks to the challenges OT educators are facing in preparing graduates to include this in holistic practice.

By the same token, in a study conducted on the views of OT students, Areskoug-Josefsson and Fristedt (2019) found that students also want more resources regarding sexual health. Student participants noted a lack of evidence, limited research, and lack of literature and coursework on sexual health available to them in their OT curriculum. Many of the students questioned why sexual education was not part of their program considering the importance of sexual health in OT practice. The first year students were hopeful that this education would come later in the program and were disappointed when it was not covered. Student responses highlighted that not only did they want to know about addressing feelings and attitudes on sexuality but also about sexuality in everyday life. Students were interested in receiving more education on addressing sexuality with specific health conditions and populations such as aging and LGBTQ+, giving advice on accessible positioning or use of assistive devices, and on legislation advocacy in the realm of sexual health. To date, only one OT textbook specific to sexuality exists. In 2012, Hattjar collaborated with fellow OTs to create and edit *Sexuality and Occupational Therapy – Strategies for Persons with Disabilities*. Her interest in the topic of sexuality was spurred by her students' inquisitiveness about sexual activity and chronic disease, as well as by clinical patients who did not know whom to talk to about this personal and intimate topic.

Sexuality Education in OT Curriculums

Studies of addressing sexuality in OT practice are well documented, and it is also well acknowledged that there is a dearth of sexuality education in OT curriculums. This section reviews the

research literature on the inclusion of sexuality education in OT curriculums through three similar studies.

Surveys of OT Programs

Seminal contributions have been made by Payne et al. (1988), who were the first to investigate the status of sex education in OT curriculums. The authors note that many health professionals do not address the topic of sexuality with their patients due to personal discomfort, so it is important to consider the manner in which students are taught how to properly address clients' sexuality in future practice. The aim of the study was to survey department chairs at many OT university programs in order to gain a better understanding of the degree to which OT programs are preparing students to work with clients on sexual functioning. It was not until nearly thirty years later that a follow up survey of OT curriculums was completed by Lohman et al. (2017) where they expanded on the previous research. While Payne et al. limited survey participation to department chairs, Lohman et al. extended the survey invitation to any current faculty members who included the ADL of sexual activity in their courses. The following year, Eglseder et al. (2018), conducted a study that endeavored to duplicate the original Payne et al. study.

Many similarities and minor differences were found across all three studies with a few of which are discussed in this review. Respondents in all three studies indicated that sexuality is important and relevant to OT practice (Eglseder et al. 2018). Both Payne et al. (1988) and Lohman et al. (2017) found that approximately 3.5 hours of time was devoted to teaching about sexual activity in the entire curriculum, whereas Eglseder et al. (2018) found that 7.27 hours was spent addressing sexuality. Results for all three studies found that sexuality was taught through a variety of methods, though most participants in the studies taught primarily through lecture, with in-class discussion being the second most common teaching method (Eglseder et al. 2018).

As the Lohman et al. (2017) study was an expansion on previous research rather than a duplication, some of the findings were unique compared to both the Payne et al. and Eglseder et al. (2018) studies. For example, Lohman et al. included survey questions about the types of courses that were addressing sexual activity and which types of health conditions they applied to. Most of the content was focused on sexuality for aging clients or clients with physical dysfunctions, with less emphasis on sexuality for clients or patients with chronic conditions such as diabetes or cancer. A consistent finding across all three studies is that there is a lack of uniformity in pedagogy and that the amount of time spent on issues pertaining to sexuality may not be adequate in preparing students to address this area in their future practice.

Evidence to Support Sexuality Education

Although the research so far is limited, there is some evidence that providing more resources and education increases health providers' and students' levels of knowledge, skill, and confidence in addressing sexuality. Higgins et al. (2012) noted that many health practitioners are reluctant to address issues of sexuality with clients, especially for those with an acquired physical disability. To address this, the authors conducted a study on health practitioners' perspectives before and after a one-day interdisciplinary education program on sexuality for people with acquired physical disabilities. Questionnaires were given to the participants before and after the program to assess participants' knowledge, skills, and comfort levels in addressing sexuality. The results found positive changes in those areas after completion of the program. If even just a one-day training can make a difference in knowledge and skill, this raises a further question: how impactful would a more extensive module be for OT students, and potentially other interdisciplinary students?

In a recent study, Whitney and Fox (2017) spoke to the importance of sexuality as an occupation that occurs across the lifespan. It was asserted that addressing sexuality is part of OT's scope of practice and there must be a connection between current practitioners not consistently or confidently

addressing these issues and the fact that sexuality is not a major part of OT school curriculums. The authors argue that current teaching methods on sexuality are not congruent with evidence-based best practices in the field of education because they rely too heavily on lecture and do not promote active engagement. The authors employed a reflective practice methodology which prescribes the use of an intentional learning activity that contributes to a deeper understanding and competency for intuitive practice (Whitney & Fox, 2017). The curriculum module was designed to address sexuality after disability in OT practice and used several pedagogical methods such as lecture, lab time, and case studies where students were to come up with evaluations and interventions. Following the module, the students were graded based on a rubric of which they all passed in showing competency of the material. The students also completed a survey following the module which showed positive shifts in self-reported perceptions of comfort in discussing issues of sexuality with clients. The authors concluded that a well-crafted learning module that incorporates multiple teaching methods leads to a positive change in student attitudes and beliefs which will prepare them to be more competent practitioners in the future.

Discussion

This review emphasizes that sexuality is an important aspect of people's lives and that it is an activity of daily living that is within the scope of OT practice (American Occupational Therapy Association, 2013; American Occupational Therapy Association, 2014; Hattjar, 2012; Mohammed, 2017). However, many studies have found that providers are not adequately addressing clients' sexuality concerns in practice due to a myriad of barriers (Esmail et al., 2010; Hattjar, 2012; Higgins et al., 2012; Hyland & Mc Grath, 2013; Mc Grath & Sakellariou, 2016; McGrath & Lynch, 2014; Mellor et al., 2013; Young et al., 2019). Additionally, education on sexuality is limited in OT curriculums (Eglseder et al. 2018; Hattjar, 2012; Lohman et al. 2017; Payne et al., 1988). OTs, OT students and OT faculty face similar concerns and barriers about addressing clients' sexuality concerns due to personal beliefs, lack of knowledge, skills, and confidence in this realm (Areskoug-Josefsson & Fristedt, 2019; Hyland & Mc Grath, 2013; McGrath &

Lynch, 2014). In short, much of the literature pertaining to addressing sexuality in practice strongly suggests that the inclusion of in-depth sexuality education in OT curriculums would better prepare students in mastering this area of OT practice and that post-graduate continuing education would increase OT providers' knowledge, skills, and confidence in addressing the sexuality concerns of their clients (Higgins et al., 2012; Whitney & Fox, 2017; Young et al., 2019).

Conclusion

This literature review highlights the importance of OT's role in addressing client's sexuality concerns. Despite the barriers in curriculum and practice settings, many OTs and OT students agree that sexuality is a legitimate aspect to holistic, client-centered care and want more resources. Additionally, there is evidence that suggests that when students and providers participate in sexuality education, they gain more knowledge, skills, and confidence which better prepares them to address sexuality in practice (Higgins et al., 2012; Whitney & Fox, 2017; Young et al., 2019). To fill this literature gap, this paper suggests a capstone project in creating an educational module in sexuality for OT students to better prepare them to address sexuality in future practice.

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