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Review article

Sexuality in the lives of people with intellectual disabilities: A meta-ethnographic synthesis of qualitative studies

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ABSTRACT

Background: The normalisation movement calls for more recognition of the sexual rights of people with intellectual disabilities to challenge classically paradoxical cultural beliefs: ‘hypersexual’ versus ‘asexual’.

Aims: This meta-ethnographic qualitative synthesis aimed to explore the voices of people with intellectual disabilities in regards to their experiences and perceptions of sexuality using a Coordinated Management of Meaning framework to derive new conceptual understandings of how their sexuality exists within multiple contexts.

Methods and procedures: A systematic literature search and quality assessment yielded 16 studies that met the inclusion criteria and were synthesised following the method of meta-ethnography.

Outcomes and results: Four core themes were identified; ‘Sociocultural Norms’; ‘Under Others Power’; ‘Sexual Identity’ and ‘Sexual Experience’.

Conclusions and implications: Application of the hierarchical Coordinated Management of Meaning model suggested caregivers contextual beliefs about people with intellectual disabilities’ sexuality inhibited or facilitated positive expressions of sexuality over and above individual needs and desires. Rights-based cultural messages provided the only context that led to positive sexuality outcomes and research that explores sexuality within this context is much needed. The Coordinated Management of Meaning model identified by this research may act as a framework to support the reflective-practice of caregivers.

1. Introduction

Sexuality is ever-present in our everyday lives and is a fundamental human right for all ages, genders, sexual orientations and levels of cognitive development (Ailey, Marks, Crisp, & Hahn, 2003). It is a complex area of human experience involving emotions, biology, beliefs, morals and social behaviours strongly influenced by culture and context. A person’s sexuality can considerably influence the formation of their identity, self-esteem and relationships (Ailey et al., 2003; Penna & Sheehy, 2009).

Sexuality is further complicated by the power embedded within socially constructed meanings of phenomena such as gender and intellectual disabilities. This review will examine how those with intellectual disabilities experience their sexuality. The most recent statistics estimate just under 1 million people with an intellectual disability (PWID) live in the UK (Public Health England, 2016). Living with family or friends is now the most common living arrangement for PWID with long-term social care support. However, living in registered care homes and supported accommodation is still also very common for PWID (Public Health England, 2016).

Whether living at home or in supported accommodation, the lived experiences of PWID are shaped by social norms, often

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reflected in national and local policy. The normalisation movement led to national deinstitutionalisation for PWID in the 1970s. This change implied a shift in philosophy and ideology which emphasised the rights of PWID to live a ‘normal’ life and make their own choices (Barr, McConkey, & McConaghie, 2003; McCarthy, 1999; Parley, 2001). Before the 1970s, PWID’s sexuality was actively repressed and denied by the segregation of sexes, however this movement recognised the right of PWID to determine their own sexuality. As services moved towards a model of normalisation, services stopped explicitly denying the sexuality of PWID, instead managing the sexuality of PWID based on the social-cultural norms of the non-disabled (McCarthy, 1999). Brown (1994) suggested that normalisation is restrictive when applied to sexuality of PWID, as what is considered ‘normal’ is determined by mainstream socialisation and variations in sexual expression are not freely accepted. Therefore, a number of researchers have commented that a lack of direction, support, consideration and confidence in how the normalisation principle translates into clinical practice may present as a barrier to the development and expression of sexuality for PWID (Johnson, Frawley, Hillier, & Harrison, 2002; Löfgren-Mårtenson, 2004; Pownall, Jahoda, & Hastings, 2012; Taylor-Gomez, 2012).

1.1. *The paradoxical views of PWID sexuality*

A well-documented paradox exists regarding how services and caregivers often view the sexuality of PWID (Dotson, Stinson, & Christian, 2003). On one hand, PWID are viewed as needing protection from sex as they are viewed as ‘asexual’ (McCarthy, 1999; Yau, Ng, Lau, Chan, & Chan, 2009) without capacity for sexual desire (Bunyan et al., 1986; McCarthy, 1999; Taylor-Gomez, 2012), but on the other hand, PWID are viewed as ‘hypersexual’, and that society needs protecting against PWID’s sexuality (Lesseliers & Van Hove, 2002; Taylor-Gomez, 2012). These stereotypes may act to sabotage development of a realistic representation of the sexuality of PWID. There is now a third view: that PWID are sexual beings and are capable of, and show, a desire to have positive sexual lives (Deeley, 2002). However, as professionals and caregivers can hold one or all of these views, they may experience conflict over how best to support PWID, and commonly resort to strategies of over-protection (Deeley, 2002; Hollomotz, 2011). Cultural values can impact on the development of sexuality, and the more that PWID are ‘protected’ from sexuality, the more inexperienced, uneducated, vulnerable and dependent they may become. Therefore, overprotection becomes a self-fulfilling prophecy, disabling PWID from becoming socially and sexually competent.

However, there has been an increase in the positive promotion of PWID sexuality (DOH, 2001, 2009; Executive, 2000; McCarthy & Thompson, 1995). A growing number of self-advocacy groups and qualitative research publications are giving PWID a voice to express their views about sexuality and intimate relationships. Their aim is to reconsider the dominant assumptions of the non-disabled and empower PWID to influence practice, policy and ultimately their own relationships. PWID are aware of their rights to have relationships and want choices about the types of relationships they have and what support they need to have them (Kelly, Crowley, & Hamilton, 2009). Understanding how sexuality functions in the lives of PWID is critical to implementing assistive and supportive services.

1.2. *The coordinated management of meaning*

One model that may be helpful in unpacking how sexuality and intellectual disabilities intersect at the level of society and the individual is the Coordinated Management of Meaning (CMM) (Pearce & Cronen, 1980). CMM proposes that communication is performative in such a way that people co-construct their social realities through the process of communication within a multitude of contexts. CMM is interested in the form of the communication rather than its content and describes communication acts as ‘doing things’. Therefore, CMM describes communication as not just occurring through language, but as ‘acts’, for example someone choosing to express their sexuality and how they do this would be considered a communication. Communication is also reflexive, in that communicative acts and the social worlds that we create also affect and shape us. The hierarchical model of CMM proposes that meaning is dependent on the context in which it occurs, but that communication acts always occur in multiple contexts. No matter what the speaker says, the words of the story will only make sense if they are understood within the multiple contexts of culture, relationships, personal identity and momentary episodes. The layers of context are an essential component of CMM theory as the higher contextual levels have a greater influential force than the lower ones (the contextual force). Therefore, if culture is the highest context, the cultural messages about the sexuality of PWID will have more influence over the relationships, identities and episodes of sexuality. Whilst CMM began as an interpretive communication theory, it has now been established as a practical theory aiming to join people in various systems and situations to articulate the knowledge needed to act constructively.

To illustrate how CMM can be applied to explore how people engage in meaning-making across multiple contexts we can examine research exploring discrimination across cultural groups (Orbe & Camara, 2010). For example, one participant, a white male, became aware that a black colleague was using racial slurs as communicative acts but was initially unsure whether this was due to race or being new to the job. The white male was unable to make sense of the episodes of derogatory racial communication until he was able to reflect on the acts within their wider contexts of identity, relationships and culture. His identity as a white male that differed to the identity of the black colleague, the power imbalance in their relationship and the positive relationships between the black colleague and other black colleagues (even if new employees) and an increasing awareness of the segregated culture of the workplace, all contributed to the white male’s meaning making that he was being discriminated against due to race. Additionally, this process was reflexive, for example the segregated culture shaped the meaning of the racial communicative acts, just as the communicative acts shaped the segregated culture.

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