Transcultural care and individuals with an intellectual disability

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Abstract
Healthcare delivery today reflects a history of change, which has responded to lifestyle changes, cultural diversity, population needs and expectations. In today’s health-care environment it is crucial for health-care professionals to be mindful of cultural factors that affect health. These factors include the intricate interdependent biological, intellectual, psychological, social and spiritual needs of the individuals they work with. However, challenges exists for those who provide healthcare to people with intellectual disability. This article presents the transcultural care challenges for people with intellectual disability, through highlighting the biomedical/sociocultural perspectives of healthcare, communication and inequality experienced by those with intellectual disability. As a population group, people with intellectual disability can often be considered part of a larger culture rather than a culture within itself, and this article endeavours to emphasize that intellectual disability is in itself a coterminous culture. By highlighting intellectual disability as a cultural community within a larger community, requiring a transcultural response to care on several levels health-care professionals can provide culturally compatible care to those with intellectual disability within a transcultural framework to augment a person-centred approach to care

Keywords
transcultural care, intellectual disability, communication, cultural models, inequity

Introduction
People presenting with an intellectual disability remain among the most vulnerable members of society and often face many barriers in healthcare (Emerson and Baines, 2010; O’Hara, 2008; Leeder and Dominello, 2005). The aim of transcultural care is to provide culturally congruent healthcare. Transcultural care transcends all diverse ethnic backgrounds and cultural attributes and focuses primarily on the individual, thereby allowing transcultural care to be correlated with the provision of person-centred care for people with intellectual disability as a heterogeneous culture within a culture. This notion is supported by the Health Service Executive (2007) which recommends providing culturally aligned care to people with disabilities and highlights the importance of implementing and providing appropriate individualized care to not only individuals from diverse ethnic backgrounds but already established minority groups such as people with intellectual disability. Healthcare delivery today reflects a history of change, which has responded to lifestyle changes, cultural diversity, population needs and expectations. (Ham et al., 2012; Rebar and Parker, 2013; Shi, 2012). Thus, acknowledging the amalgamation of multifaceted elements influencing and predisposing a person to factors that affect their health. Such factors include the intricate interdependent biological, intellectual, psychological, social and spiritual needs of the individual (Giger and Davidhizar, 2004; Naidoo and Wills, 1997). In essence, this places a person within the context of a culture and reflects Leininger’s (1995) characterization, where culture is depicted as a community concept where individuals share specific unanimities through belief, communication, behaviour and values.
Culture is a dynamic active state of being, therefore for individuals to receive culturally congruent care health-care professionals must continuously strive to work effectively within a cultural context (Campinha-Bacote, 2002b). Through this recognition, the theory of transcultural care was proposed, where transcultural healthcare is seen as a formal area of study and practice, focused on comparative holistic cultural care and health patterns of people with respect to differences and similarities in their cultural values, beliefs and life ways, with the goal to provide culturally competent and compassionate care (Narayanasamy, 2003). To provide cultural care, health-care professionals require frameworks that facilitate, a high standard of practice, assimilating an understanding of individual cultures and practices in providing appropriate healthcare to that specific culture. However, recognition is required that cultures within themselves are heterogeneous, thereby in essence cultures exist within cultures. Considering this notion, this article addresses cultural care with regard to people with intellectual disability by discussing the biomedical/sociocultural perspective, communication and inequality experienced by those with intellectual disability and offering guidance for health-care professionals to culturally align their care approaches to become more person centred.

**Biomedical/sociocultural perspectives of care**

Intellectual disability, in addition to its cognitive and genetic aetiologies, is also a sociocultural phenomenon (Skinner and Weisner, 2007). Intrinsically, how intellectual disability is defined, responded to and accepted within society is a cultural paradigm (Graham, 2005). In essence, the understanding and acceptance of intellectual disability can be forged in opposition to different cultural beliefs and discourses pertaining to intellectual disability. Medical and sociocultural models are interpretive frameworks that act as a guide to society, to assist in describing concepts that are unfamiliar, undesirable and perturbing (Klotz, 2004). Skinner and Weisner (2007) suggest that both families and general society utilize sociocultural and biomedical models of both intellectual disability and normative development to facilitate their understanding of intellectual disability. Cultural and personal ideologies also determine which model is considered by an individual. This is consistent with Spector's (2002) cultural model of heritage consistency, which emphasizes that ones' central belief is to follow ones’ traditional inherent beliefs. Inherent beliefs stem from intrinsic multifaceted origins such as family, social experience and socioeconomic background. These origins consecutively determine individuals’ or societies’ attitude to intellectual disability (Graham, 2005) and sequentially determine whether the biomedical or sociocultural model is subscribed to.

Several studies have theorized that families of a person with intellectual disability construct and collaborate their understandings of intellectual disability by the biomedical and sociocultural concepts (Dowling and Dolan, 2001; Goodley and Tregaskis, 2006; Weisner and Skinner, 2007). The biomedical model enlists the beliefs that disability is seen before the person and the individual is often delegitimatized by medical and aetiological discourse. According to Graham (2005), there is a direct association between families and societies from a higher socioeconomic position adopting this model of cultural understanding of intellectual disability. Conversely, the sociocultural model describes intellectual disability as a social construct not inherent in the individual but in societies’ inequitable practices and understandings of people with intellectual disability (Kuntz et al., 2005) and is employed predominantly by families and societies of lower socioeconomic status. The interpretation of this hypothesis that cultural understandings of intellectual disability are directly related to socio-economic status is relatively unexamined. However, research exists in the area of faith and religious beliefs in lower socioeconomic groups and how these concepts impact on
families’ understandings pertaining to intellectual disability (Scorgie and Sobsey, 2000; Skinner and Weisner, 2007; Skinner et al., 1999). Although not mutually exclusive to biomedical or sociocultural models of understanding, religion and faith seem to provide reasoning and clarity to accepting and understanding intellectual disability. Aligning the experience and understanding of intellectual disability with religion and faith does not negate the fears and challenges facing the family (Skinner and Weisner, 2007) and regardless of which preferred cultural model or individual faith is chosen, the ability of a family to acquire support and additional care for the individual presenting with intellectual disability is where the role of the health-care provider is evident.

For health-care professionals to provide culturally competent care to individuals with intellectual disability, a complex integration of skills knowledge and attitudes that cross cultural boundaries is paramount (Black, 2008). The health-care professional must demonstrate respect and understanding of families’ inherent beliefs pertaining to the cultural model employed by that family. In essence, the health-care professional modifies his/her approach to care of the individual, conditional on which perspective the family views intellectual disability. For example, if a family from a low socio-economic background hold very strong religious beliefs and incorporate these beliefs as a way of making sense of why this happened to their child, the health-care professional would ensure to respect those beliefs and provide care for that individual within their own beliefs and the beliefs of their families, whilst still affording the highest level of care to the individual thus showing cultural competence in providing care. This is in accordance with the national standards for services of people with disabilities (Health Information and Quality Authority, 2013).

The initial sign of cultural competence is being culturally aware of one’s own cultural heritage and then respecting and appreciating the values and cultural beliefs of others (Black, 2008). This principle is consistent with Campinha-Bacotes’ (2002a) ASKED model of cultural competence (2002), which will assist health-care professionals to become culturally aware by conveying the importance of:

- Awareness of one’s own personal beliefs, heritage, and ethnocentric attitudes in addition to an awareness of the individual’s cultural background and beliefs.
- Skills related to the delivery of care, that is, the ability to perform an effective and efficient culturally aligned assessment for an individual presenting with intellectual disability.
- Knowledge of individuals’ cultural beliefs and background.
- Encounters hitherto with the individual with an intellectual disability and their culture are a necessity to become culturally competent.
- Desire to be culturally competent in providing care for the individual presenting with intellectual disability.

Through the use of such a model, the health-care professional who develops his/her cultural competence will exhibit tolerance of ambiguity, communicative awareness, respect for differences and empathy. Fundamental constituents to achieving this cultural competence are education, environment, communication and advocacy, and the factor that often precludes health-care professionals delivering culturally competent care to a person with intellectual disability is communication (Giger, 2007).

**Communication**
Communication occurs when two or more people correctly interpret each other’s language and or behaviour (Coger, 2005). However, for a large proportion of individuals with
intellectual disability, cognitive/communication impairments associated with intellectual disability exist and result in a level of difficulty with communication being present for these individuals (Tuffrey-Wijne and McEnhill, 2008). This includes any one or combination of the following: speech that is difficult to understand, problems in comprehension, problems in expression and formulation skills (Iacono and Johnson, 2004). Communication is essential in providing transcultural care, and to provide cultural care to an individual with intellectual disability, the health-care professional must ascertain transcultural communicative competence which involves cultural communicative competence and intercultural communication (Gerrish et al., 1996). Cultural communicative competence is the unambiguous enhancement of knowledge into the specific communication methods and processes of an explicit culture (Papadopoulos, 2006), and intercultural communication is an awareness of one’s own ambiguities towards communication and the ability to recognize the need and challenges of communicating effectively to provide transcultural care (Giger and Davidhizar, 2004). Both intercultural communication and communicative competence are crucial in providing culturally congruent care to an individual with intellectual disability due to communicative deficits inherent in this particular population (Tuffrey-Wijne and McEnhill, 2008).

Communication as a cultural component is fundamental and a significant constituent within transcultural care models. The ACCESS model (Narayanasamy, 1999), for example, has been acknowledged and deemed effective in transcultural care literature (Narayanasamy, 2002; Serrant Green, 2001; Shanley, 2000) and will assist in culturally aligning the health professional to provide a person-centred approach to care. Within the model the following is highlighted:

- Assessment: of cultural aspects of the individuals’ lifestyle, health beliefs and health practices;
- Communication: taking note of variations in verbal and non-verbal responses;
- Cultural negotiation: become aware of aspects of the individuals’ culture and understanding their views and explaining their problems and needs;
- Empathy: formation of a therapeutic relationship that portrays genuine respect for the individuals’ beliefs and values;
- Sensitivity: deliver diverse cultural-sensitive care individualistically; and
- Security: enable individuals to derive a sense of cultural safety in expressing their own feelings needs desires in an environment where there is no judgement.

The model is action centred to facilitate planning and implementation of culturally compatible care that is sensitive and compassionate in nature. The model articulates that the health-care professional should have an optimum awareness of cultural variations in verbal and non-verbal communication. Most notably, non-verbal communication is particularly intrinsic in the area of intellectual disability, and for people with intellectual disability, non-verbal characteristics of communication include facial expressions, touch, gestures and interpersonal posture. Regnard et al. (2007) found an average of 24 variances in non-verbal communicative behaviour per individual during a health needs assessment. This shows that to facilitate and provide transcultural care to a person with intellectual disability, the health-care professional must have an inherent awareness of the individuals’ mode of communication and explicit meanings of non-verbal indicators. The health care professional needs to represent a supportive role and assist the individual where necessary, as the ability of an individual with intellectual disability to identify and communicate their needs is hindered without the appropriate supports (Bollard, 2002; Halmes and Carlson, 2006; Powrie, 2001). Supports such as the use of family members to ascertain the relevant information regarding the needs
of the individual have widely been used in the area of intellectual disability (Sutherland et al., 2002). However, the use of proxy respondents does not always thoroughly reflect the individuals’ desires and needs which casts doubt on the accuracy of culturally congruent care provided (Perry and Felce, 2003). Raising a dilemma regarding the individuals need to be both independent in expressing their needs and dependent on the health-care professional to understand their articulation.

The drive to promote appropriate cultural care has also led to the development of a range of approaches collectively described as augmentative and alternative communication which are used widely in the area of intellectual disability. Many people with intellectual disability benefit from various communication supports to augment their articulations (Tuffrey-Wijne and McEnhill, 2008), and these supports can vary from, objects of reference, signs and symbol-based systems such as Makaton, picture association cards to sign language and modified sign language such as LAMH. Through awareness and the use of such supports, the health-care professional can realize the attainment of cultural communicative competence in the area of intellectual disability. However, where the development of such supports increase communication skills for individuals, the fact that communication difficulties exist can instigate other cultural challenges for the individual with intellectual disability such as inequity and health-care disparities, owing to the fact that individuals may not be able to communicate their health needs.

**Inequity and health-care disparities from a cultural perspective**

People with intellectual disability remain among the most vulnerable members of society and often face many barriers and a difference in the level of healthcare they receive (Leeder and Dominello, 2005; O’Hara, 2008). There are many ways to define difference, and the way this difference is defined helps structure the exact configuration of a country’s multicultural praxis (Garner, 2008). One fundamental concept of transcultural care is the categorical identification of a culture and to provide care congruently to that particular culture. Differences are thus articulated by the term ‘culture’ and specific populations within a community are posited as ‘cultural groups’. Considering this, cultural differences resulting in health inequities and disparities are experienced by people with intellectual disability. A health disparity/inequity is a particular type of difference in it is a difference in which disadvantaged social groups who have persistently experienced social disadvantage or discrimination systematically experience worse health or greater health risks than more advantaged social groups (Braveman, 2006). Kuntz et al. (2005) posit that health inequities occur due to the presence of disparities in health and its key individual-related and social determinants. The inclusion of individual-related and social determinants of health in the concept of inequity consigns inequity to a cultural context and emphasizes that equity in health means equal opportunity to be healthy and have individual needs met. Whitehead (1991) identified determinants of health inequities and disparities for people with intellectual disability (Table 1) highlighting the complexity and interrelatedness of health determinants with health equity and health disparities. These determinants and the concepts of health equity were developed further by the (Solar and Irwin, 2007) who define this as ‘the absence of unfair and avoidable or medial differences on health amongst specific social groups’.

Two of the determinants of inequity and health disparities articulated in Table 1 considered the concept of health-damaging behaviour, and according to Emerson (2005), two-thirds of people with intellectual disability present with some form of challenging or self-injurious behaviour therefore are considered health damaging. Furthermore, Crotty et al. (2014) found prevalence rates of aggression against property and aggression against others which can cause
harm to be 48.9% and 50.7%, respectively, within the intellectual disability community. Considering this, these specific behaviours place people within a culture. Therefore, transcultural care must transcend into providing cultural care to individuals presenting with health damaging/challenging behaviours in order to provide culturally appropriate care. Furthermore, community participation and appropriate person-centred healthcare are accepted aspirations for people with intellectual disability (Doody, 2012; Milner and Kelly, 2009). However, the extent to which these aims have been achieved in health-care settings for people with challenging behaviour and intellectual disability is questionable (McClean et al., 2007).

Table 1. Determinants of health inequities and disparities for people with intellectual disability.

- Natural biological variation
- Health-damaging behaviour if freely chosen.
- Transient health advantage of one group over another when that group is first to adopt health promoting behaviour.
- Health-damaging behaviour where the degree of choice of lifestyles is severely restricted.
- Exposure to unhealthy, stressful living conditions.
- Inadequate access to essential health and other public services.
- Natural selection of health-related social mobility involving the tendency for people to move down the social scale.


The introduction of care in the community for people with intellectual disability and challenging behaviour has raised concerns regarding inadequate primary care services, health disparities and inequitable cultural care (Crotty et al., 2014; Parrish and Birchenall, 1997). Members of the primary healthcare and community nursing teams have expressed a need for expertise and further training in the area of intellectual disability and its’ associated behaviours (Aspray, 1999; Crotty et al., 2014; Duff et al., 2000; Lakhani and Bates, 1999). Research also indicates that health inequities and disparities are often related to the poor quality of local services in effectively supporting individuals with intellectual disability and challenging behaviour in local community and residential settings (Beadle-Brown et al., 2006; Crotty et al., 2014).

There are copious other examples of further health inequities and disparities for those presenting with intellectual disability within society. Wilkinson et al. (2011) articulated that adults with intellectual disability are a medically underserved population who experience disparities in screening and preventative care. They found that adult females presenting with intellectual disability were (due to inadequate effective individualized communication supports) poorly prepared and under-informed regarding mammography, and as a result of inadequate knowledge and insufficient preparation, they were less likely to self-promote preventative healthcare, attend screening appointments and harboured a fear of the screening process.

Depression and associated health-limiting behaviours have also been highlighted as a serious determinant of health disparity for those with intellectual disability. Hartley et al. (2009) state that people with intellectual disability have a higher prevalence rate of depression and associated attributes than those in the general population resulting from high stress social interactions and negative social criticism. Depression can go unnoticed in individuals presenting with intellectual disability for many reasons such as limited ability to communicate inherent feelings, feelings of worthlessness and being different and a lot of the
time owing to the possibility that those providing care have not undertaken appropriate effective culturally congruent assessments.

Furthermore, obesity prevalence in the intellectual population has been found to be higher when compared to the general population with prevalence ranging between 59 and 68% in comparison (Doody and Doody 2012; McGuire et al., 2007). Health promotion and healthy eating programmes have been found to be ineffective when not modified to the ability of those presenting with intellectual disability thus not adopting a culturally congruent approach. Positive behaviour support In essence, both health-care professionals and services need to become culturally competent in their provision of care to individuals with intellectual disability. One such way for health-care professionals and related services to provide transcultural care is by adopting a specific model of care for people with intellectual disability. One model that has emerged over the past years that is considered culturally aligned to the care of people with intellectual disability is positive behaviour support (PBS).

PBS incorporates the use of a comprehensive functional assessment of behaviours (La Vigna and Willis, 2005). This element aligns with Narayanasamy s’ (1999) ACCESS transcultural care model, which states the importance of a culturally appropriate assessment. PBS also assimilates altering deficient environmental conditions, altering deficient behavioural repertoires and achieving lifestyle change and improved quality of life through multicomponent treatment plans whilst decreasing the frequency of health-limiting behaviour. Used effectively, this model reduces incidents of health limiting behaviour (La Vigna and Willis, 2005), thus reducing health inequities and disparities for the individual presenting with intellectual disability, whilst promoting culturally sensitive congruent care which is the essence of transcultural healthcare. For example, a person presenting with intellectual disability who displays severe self-injurious behaviour would require a culturally congruent assessment to determine the causation of the health-limiting behaviour along with thorough observation and support to highlight any triggers or predisposing factors to the behaviour. Proactive and reactive strategies could then be implemented to reduce the health limiting behaviour and health-care professionals can work to support positive health behaviours congruent with the communicative and cognitive ability of the individual. However, training and support in such areas is needed for all those who work with people with intellectual disability and has been openly expressed by those working in this area (Crotty et al., 2014).

Conclusion

Healthcare must acknowledge the amalgamation of the multifaceted elements that influence and predispose a person to factors that affect their health. These factors include the intricate interdependent biological, intellectual, psychological, social and spiritual needs of the individual. In essence, these integrated needs of the individual places a person within the context of a culture. Understanding and describing intellectual disability from a cultural perspective is paramount when considering the cultural components of cultural competence in care, communication, inequity and health disparities in relation to the individual presenting with intellectual disability. Considering the factors outlined in this article, health professionals will be become cognizant of the differing cultural elements within the intellectual disability culture and will subsequently become culturally aligned in providing person-centred care. Numerous models such as ASKED, ACCESS and PBS can be utilized to provide transcultural care that incorporates a person-centred approach when working with individuals with intellectual disability.
Key points
- We must recognize that intellectual disability is in itself a legitimate culture often lost within other defined cultures.
- Communication/health inequity/challenging behaviour as cultural components are fundamental and significant constituents within intellectual disability.
- Cultural competence in the area of intellectual disability can be achieved utilizing already recognized models of transcultural care.

Transcultural skills needed to work with the intellectual disability population
- Individualized cultural assessment.
- Congruent individualized health assessment.
- Recognition of health-affecting behaviours.
- Recognition of health inequities due to aggressive or challenging behaviours.
- Recognition of health inequities due to the individual’s cultural attributes such as communicative and cognitive ability and level.
- Implementation of individualized health-promoting plan.
- Congruent individualized communication assessment.
- Augmented/modified communication application based on assessment.
- Implementation of PBS plan.

References
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