



Published in final edited form as:

J Neurosci Nurs. 2013 February ; 45(1): 21–37. doi:10.1097/JNN.0b013e318275b23b.

Challenging Nurses' Cultural Competence of Disability to Improve Interpersonal Interactions

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Abstract

Worldwide, at least 6.9 billion people have an impairment producing health condition (IPHC). Insensitive encounters with health care providers (HCPs) can result in negative appraisals, fear, and avoidance, but little is known about what things are commonly perceived as insensitive. A review of published narratives describing negative encounters with HCPs was conducted. Narrative analysis was used to compare, contrast, and synthesize six themes describing the common negative encounters: (a) ignoring or minimizing their knowledge; (b) detached interpersonal interactions; (c) placing a negative skew on their life quality; (d) a lack of HCP knowledge related to their complete needs; (e) assuming they should be asexual and childless; and, (f) an inherent power differential. The medical model of disability is perceived by individuals with IPHCs to inform negative encounters perceived as insensitive. This preliminary knowledge is important so we can address education needs, plan future research questions, and establish clinical practice improvements.

Based on the most recent world estimates, about 6.9 billion people are living with some degree of an impairment producing health condition (IPHC) that can place them at risk for varying degrees of disability. This statistic is projected to grow exponentially in upcoming years due to population growth, the ageing of a large segment of the overall population, and continued medical advances that preserve and prolong life (World Health Organization, 2011). Despite efforts to improve the live quality of persons with IPHCs, several social disparities continue (Panko Reis, Breslin, Iezzoni, & Kirschner, 2004; Patja, Mölsä, & Iivanainen, 2001; World Health Organization, 2011).

Many health care providers (HCPs) conceive of disability as biologically inherent to IPHCs (the medical model of disability), but others have pointed out that identity categories like 'able-bodied' and 'disabled,' 'normal' and 'abnormal' are socially constructed labels, which by "way of legal, medical, political, cultural and literary narratives" can also compose exclusionary categories for those labeled, subsequently positioning them in a social minority group (the social model of disability) (Garland Thomson, 1997, p. 6). Gill (2006) argued that repeated negative encounters with HCPs explains why some persons with IPHCs fear, dread, or choose to forego seeking medical care. The notion that HCPs might at times play a role in constructing the vulnerability of persons with IPHCs is not typically acknowledged (Gill, 2006). Instead, there is an assumption that the nurse-patient relationship is caring and results in enhanced personhood for both parties (Brenckick & Webster, 2000).

In the last decade, the Institute of Medicine (2001) has called for measures aimed at improving the quality of interactions with patients and their family. The American

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Conflict of Interest: The author reports no conflicts of interest related to this article.

Association of Colleges of Nursing has responded to this need by calling for a nursing curriculum at all levels of nursing education to cover cultural competence, including cultural competence in the care of persons with disabilities (American Academy of Colleges of Nursing, 2010). Neuroscience nurses are one of the most likely HCPs to interact with this population at some point in their care. The purpose of this narrative review and synthesis was to gain a preliminary understanding of commonly perceived negative interactions between persons with IPHCs and their HCPs to initially inform more culturally sensitive care. The questions asked were: 1) what are the common types of negative encounters that persons with various IPHCs describe in their experiences interacting with HCPs; and, 2) what are the common explanations given for such negative interactions? This knowledge is important so we can begin to address the needs within nursing education, drive research questions, and improve cultural sensitivity in practice.

Methods

Design

This review and synthesis of first person narratives involved the following steps: a) identification of a broad source of published literature; b) appraisal of the narrative sources to decipher whether narrative data contained within articles met the aim of this review; c) comparing, contrasting, and coalescing narrative data to inductively inform the conceptualization of the themes; and e) recognition of the limitations of this approach in the final synthesis (Walsh & Downe, 2005).

The author first conducted a literature search between October 2009-February 2010 in Medline, CINAHL, and Social Sciences Citation Index, cross indexing variations of three basic text phrases: *qualitative AND experience or experiences AND disability or disabilities*. The only limitations were that articles were in the English language, published between 1990 and 2009, and contained first-person exemplars describing appraisals of negative encounters with HCPs. This broad search approach resulted in many articles that were not relevant to this review or were duplicates between databases. It was decided, however, that it was the only way to minimize arbitrarily limiting relevant articles (e.g., where negative interactions with HCPs was not the main purpose, but was discussed as a problem by the participants). Articles were evaluated to locate reports where narrative data describing negative experiences with HCPs was either the primary purpose or was a portion of what the participants' discussed in their entire experiences.

The number of relevant research articles recovered the initial search in Medline was low ($n = 11$) so the investigator then searched amongst a broad range of IPHCs common to neuroscience nursing (brain injury, stroke, multiple sclerosis, cerebral palsy, etc.) adding the cross index terms: *qualitative and experience or experiences* (an additional $n = 34$ for a total of 45 research articles). A librarian was consulted to assure that the search terms and data bases searched represented a reasonable approach. The author then also searched the narratives of memoirs ($n = 3$), published position papers containing first-person experiences from persons focusing on disability issues ($n = 2$), research published in books ($n = 2$); or films asking persons with IPHCs about their HCP encounters ($n = 1$). There was no systematic way to search for these alternative sources, so the author had to rely on sources already known by the author through coursework taken in a local disability studies program or referred by other disability ethics clinicians. These sources were used to further enrich the final synthesis by positioning an alternative perspective to also have input (Noblit & Hare, 1988; Walsh & Downe, 2005).

Analysis

A descriptive narrative approach was used. Descriptive narrative analysis is a rigorous, critical, and systematic way of investigating narrative accounts of people. A fundamental characteristic of this approach is the belief that personal realities are expressed in the stories a person tells about their daily life (Patton, 2002). Narratives from the same study or same author's personal experiences were considered as one source. Narrative data were hand coded, synthesized by the author and then inductively defined into themes from across the culmination of extracted narratives. The method, examples, and thematic summary was shared with two other qualitative researchers and then shared amongst a multidisciplinary group participating in a disability ethics fellowship at a rehabilitation hospital for feedback. External peer input helped keep the investigative process from being linear and having the author's input alone (Walsh & Downe, 2005).

Results

Six themes of negative encounters included: a) ignoring or minimizing their knowledge; b) detached interpersonal interactions; c) placing a negative skew on their life quality; d) a lack of HCP knowledge related to their complete needs; e) assuming they should be asexual and childless; and, f) an inherent power differential. Table 1 presents the resources used for this review and synthesis, describes the type of resource, whether the findings were a primary aim or a secondary finding, the health condition or conditions examined, and the themes supported by that resource. Exemplars were selected to illustrate each theme or subtheme in the text. The fact that this author also chose to use narratives from the non-research sources in addition to the research sources ultimately helped to enrich the final understanding of each theme because these narratives gave more detail about the individual's experience and appraisal, which allowed for a deeper understanding of the themes. It also illustrated that research data is building in recent years to support the claims made for years by disability rights advocates.

Ignoring or Minimizing their Knowledge

This theme centered on a perceived lack of respect for the individual with the IPHC having experience and expertise with their body and the HCPs' dismissal of their subjective input. Subthemes ranged from getting an accurate diagnosis, to giving them appropriate treatment based on their input, and in general realizing that their cognitive capacities to provide information might not be affected simply because of their initial IPHC.

Getting an accurate diagnosis—This subtheme mostly centered on conditions that are difficult to diagnose from objective information and may result in questioning the authenticity of the individual's reports:

I just remember, even...it was just an intuitive...it was just a thought of mine, could this be, have anything to do with my car accident. And he [general practitioner], instead of saying "Gosh, you know, let's...let's think about that," he said "No, it couldn't. That was too long ago" (Sample & Darragh, 1998, p. 862).

Giving them the appropriate treatment based on their input—Individuals often discussed their expertise after experiencing multiple interactions with various HCPs in various clinical settings, but they felt that their insight and experiential input was not valued and often outright ignored. The following woman with a neurodegenerative condition was about to have surgery and attempted to educate those who would be caring for her on her unique handling and transfer needs, but she felt that the HCPs didn't respect her input and

did exactly what she was concerned they would do, which put her at risk for an serious injury and showed a lack of respect for her dignity and psychological well-being:

I explain coolly that I can get hurt if handled the wrong way... I want one of my people to do it.....The next thing I know, I'm being grabbed by two women in shower caps. One has my knees and the other is scooping up my shoulders. It's the wrong lift. All my weight will hang from two sets of fragile joints. My curvy spine will dangle unsupported, putting the spinal cord and that bundle of nerves at risk. In a microsecond of terror I see the whole calamity. I mouth the word "Stop !" I'm despairing. They won't even notice. They won't understand. But one of them notices. Stops. Looks. "Are you saying "Stop"?" I nod my head. "We're just going to put you in this bed and then we'll be done." "No," I mouth. "No." "You don't want us to move you? We'll be careful. It'll just take a second"... . And a second is all it takes. A second in which panic sends my mind out of my body, as abused minds are said to flee when denied control over abused bodies, to look down at what seems like a pale shriveled corpse being tossed like trash from one place to another... . What silenced me was not voicelessness, but being in a place where what I said and what I wanted didn't matter (McBryde Johnson, N.D., para 2).

All aspects of their cognitive capacities might not be affected—Situations where persons with an IPHC later developed a secondary condition was perceived to set them up to be ignored because they believed the HCP thought they were likely just seeking attention. How this type of treatment affected them personally was perceived not to be considered by the HCP:

My first mastectomy was when I was 'in care.' Complaints to the doctor about lumps in my breasts were dismissed as being neurotic! The [residential] unit's doctor was extremely condescending and patronizing....I had a biopsy done, and was sent back for the result by myself. The verdict came as a shock, I had to have my breast off the next day (Thomas, 2001, p. 253).

Detached Interpersonal Interactions

Many described a history of demeaning interactions where they felt objectified by some HCPs. Their history likely influences their sensitivity to evaluating subsequent interactions with HCPs. The culmination of such interactions can leave persons with IPHCs feeling as if they are viewed as less than human:

Many adults with [spina bifida and in this support group] can remember things such as being paraded naked in front of medical professionals in auditorium-type settings, painful medical procedures being done without explanation, compassion, support systems present or informed consent (van Daalen-Smith, 2006, p. 266).

It was when I wanted to go to the toilet. And I couldn't manage at all. And I asked. [She said] "No, you've just been to the toilet." But, oh dear, I'll do it in my pants, I said. So she said: "Well I couldn't care less." So I complained 'bout her straight away. I cried, couldn't stand being here (Mangset, Tor Erling, Forde, & Wyller, 2008, p. 828).

Placing a Negative Skew on their Life Quality

While individuals expressed daily difficulties dealing with effects of their IPHC, they also discussed positive aspects of their life and countered that others, especially HCPs, should not assume what it means to live with an IPHC. Individuals wanted to be seen holistically for their many unique and positive attributes and their similarities to all other persons and not just their IPHC:

Most expressed surprise that I had a job, let alone a job as a professor who could teach people things. They were also surprised to learn that I lived in my own home, was married, and had young grandchildren. On their own, they could not conceive of my life being ordinary or lived outside of a healthcare facility... . They were trying to fit both my physical condition and the fullness of my world into their narrow conception of life with a disability. Most could not reconcile the two domains (Gill, 2006, p. 185).

A Lack of HCP Knowledge Related to their Complete Needs

Individuals often contested the one-size-fits-all approaches they experienced. They wanted HCPs to consider them holistically when figuring out recommendations and they wanted HCPs to include them in conversations about them and not talk ‘over them’ if they had an advocate present:

They used to ask my mum or dad. Then they asked me after, but first of all it used to be my mum or dad [even when I was an adult]....I was the one having the operations. [It made me] feel like I’m not there, just I’m there, but, ‘oh, well, he can’t understand’ (Hart, 1998, p. 475).

A large number of narratives addressed the sense that HCPs did not have adequate knowledge to assist individuals appropriately according to how their needs were the same or differed. Individuals often perceived that some HCPs did not want to learn and they perceived that the responsibility for teaching HCPs was theirs’ and had to be repeated over and over with each new HCP encounter. Many found this responsibility daunting:

They made me leave my hearing aids with my mother. Afterwards, they told me, “You took a long time to come out of anesthesia. We kept talking to you.” But I couldn’t hear them! There was no way for me to understand what was going on and get pulled out of anesthesia. It’s very scary (Iezzoni, O’Day, Killeen, & Harker, 2004, p. 360).

[As a child] I had to go to physical therapy a lot, but I hated it. No one could explain to me why it was important and so I was smart enough to just like blow it off [laughs]. You know, ‘cause it didn’t seem like it was any big deal. I think teaching and talking, interacting with the child and the parent at the same time, but always keeping the parent involved... . [What is important is] respect more than anything just respecting that child’s knowledge about their body and giving them that power to understand what’s going on with their body and understand the consequences (Savage, 2003).

Assuming they should be Asexual and Childless

Individuals described many HCPs’ as displaying discomfort regarding his or her sexual, reproductive, or family-planning needs, which resulted in an information barrier or stymied their access to appropriate care:

So I went to see her [nurse] and wanting to ask really about the sexual function [following Spinal Cord Injury] and you know can I have an orgasm, can I have sex, what do you do, she was just telling me all about fertility... (Samuel, Moses, North, Smith, & Thorne, 2007, p. 761).

When I was pregnant... .My obstetrician called an urologist to consult about the best way to treat these [urinary tract] infections. When my OB told the urologist that I’m quadriplegic, he said, “She’s what, and she’s having a baby? What is she doing? Why is she doing this?”... . That urologist had the typical perception of disability, of people nonfunctioning, not working, staying home. Once he met me,

he said, “This baby is wonderful! It’s a great thing” and now he’s my urologist. It’s amazing how people’s perceptions of disability can change once they get to know you as a person and get rid of their old conceptions (Iezzoni & O’Day, 2006, pp. 67–68).

This theme had fewer resources expressing this as a problem, but this could also be explained by the underlying problem expressed within the individual’s narratives. For instance, if sexuality and child bearing are not seen as a need for this population, then they may also not be seen as a problem to be researched. Individuals themselves may also have discomfort with raising this topic, if not asked specifically about the issues they face and the needs they have. Discussions of sexuality and sex are often culturally uncomfortable topics for many people, making it plausible that both sides would avoid, hoping the other will take the lead in starting the discussion.

An Inherent Power Differential

HCPs were perceived to wield a great deal of power and individuals believed that the health care systems were often set up to position the needs of the HCPs in the forefront versus the needs of patients or families:

Doctors are just people—some are great and some are awful. The problem is that the ones who are awful can still exercise a disproportionate amount of power....Some doctors seem to have a problem dealing with patients whose condition is difficult or impossible to treat. I can empathize with that. But some of them deal with it by projecting their negative emotions onto the patient, and that too is an abuse of power. Plus it only takes a word, a nod, a wink for some doctors to convince others that their patient is just a troublemaker who should be got rid of as quickly and expeditiously as possible, another abuse of power. Most patients seem to see themselves as dependent on doctors. Even if you want to take control and responsibility for your health—or perhaps *especially* if you want to –it seems to suit most doctors to keep their patients subservient (Thomas, 2001, p. 257).

When they come at 6:45 am, I say: “Nurse, I’m not getting up yet, I did not sleep well and I’m tired. Just let me stay in bed a little bit longer” and if you get the wrong one “Come on, get up, you have to get washed” (Proot, Crebolder, Abu-Saad, Macor, & Ter Meulen, 2000, p. 280).

Discussion

Underlying the negative interactions described from this synthesis is a common perception by individuals with IPHCs that they are seen as lacking any knowledge or expertise that might contribute to an improved understanding about their condition, care, or factors affecting their life quality. They believe that their expectations for quality health care and a life with quality are seen by some HCPs as improbable or not a reasonable goal for this population. They find it disparaging to deal with the negative attitudes and beliefs of some HCPs, whom they expect to be most caring and understanding of their complete needs due to their inside knowledge and frequent contact. The narratives captured, illustrated that they often perceived that it was HCPs’ cultural attitudes and beliefs about the drain of persons with IPHCs on society and the negative value of their lives, which explained the insensitive encounters they experienced.

Cultures

While culture is often assumed to be associated with a person’s ethnicity or a particular geographic region, Tylor (1920) posited the notion of culture to comprise a broader definition “the complex whole, which includes knowledge, belief, art, morals, law, custom,

and any other capabilities and habits acquired by man as a member of society” (p. 410). Tylor describes a socio-cultural system of understanding, interacting, and sharing information. That system can be the broader society (macro-system) or be a smaller systems (micro-system) within a society (i.e., medical science, religions, a work environment, etc.) and each system has their own system of symbols to view the same thing. Depending on the knowledge, beliefs, customs, laws, and depictions of IPHCs (cultural factors) that a given group has been exposed to and has focused on as contributing meaning to life quality, they may come to completely different conclusions about the meaning of living with an IPHC (e.g., HCPs versus persons with IPHCs). Through this complex interpretive appraisal, cultural clashes can be acknowledged as potentially explaining negative encounters at times between persons with IPHCs and HCPs (Philipsen, 1997).

Clashing of Cultures

The experiences of persons with IPHCs can vary drastically by geography and political factors. In developed countries, persons with IPHCs may be primarily fighting for access to care and more patient-centered care, but in less developed countries persons with IPHCs may be instead fighting for more basic human rights (Barnes, 1997; World Health Organization, 2011). Contrary to Nathenson’s (2009) statement that “people with disabilities have a distinct culture of shared experiences and healthcare needs” (p. 92), I would caution that there are as many differences in individuals’ experiences, beliefs, and needs as there are any similarities (Miles, 2000; Swain & French, 2000; World Health Organization, 2011).

Within the overall group of persons with IPHCs, there are many subgroups, some of whom are even more marginalized than others (i.e., those with intellectual or communicative abilities). In addition, individuals may infer different meaning of his or her IPHC due to their unique personal, spiritual, or other socio-cultural or demographic factors. To say that there is one universal culture minimizes the spectrum of different abilities, their distinct experiential components, and the intersection of other personal and social factors (age, ethnicity, race, economic status, demographics, societal culture, gender, sexuality, politics, and educational status), which can also be components of how persons are able to experience life, make meaning of their experiences, and voice their needs (World Health Organization, 2011).

What individuals with various IPHCs share is a need to be treated with dignity and as a valued part of their community and society, which are human needs not disability needs. Humanness or personhood are social constructs unconsciously applied to those individuals we believe are like us and taken away or minimized in those who we believe are different from us (Haslam, 2006). A lesser degree of humanness has historically been attributed to persons with many IPHCs.

Historical Influences on Constructions of Disability

There have been many laws, policies, or social actions that have served to oppress persons with various IPHCs, including social exclusion, institutionalization, experimentation, sterilization, infanticide, and euthanasia (Barnes, 1997). These policies, laws, and actions were based on fears of ‘differences’ and a drain on society due to their IPHC. While recent laws have attempted to improve the social conditions for persons with IPHCs, laws do not typically change attitudinal barriers.

Attitudinal barriers can be much more persistent in continuing to present obstacles and disparities such as in jobs, education, housing, social inclusion, healthcare access or treatment (World Health Organization, 2011). The medical model of disability has been a driving force on how the public has understood disability (Polsky, Willke, Scott, Schulman,

& Glick, 2001; Sackett & Torrance, 1978; Ubel et al., 2001; Ubel, Loewenstein, & Jepson, 2003). Evidence is mounting that HCPs' attitudes and beliefs affects their judgments and interactions related to persons with various IPHCs (Janvier, Leblanc, & Barrington, 2008a, 2008b; Kelly, Brillante, Kushner, Gehron Robey, & Collins, 2005; Oei, Askie, Tobiansky, Liu, 2000; ten Klooster, Dannenberg, Taal, Burger, & Rasker, 2009). What is revealed from this synthesis is a need to espouse cultural humility and cultural competence at all levels of learning and practice for all HCPs, in order to improve interactions.

Cultural humility speaks to our responsibility to provide patient and family interactions that are culturally sensitive and relevant (Tervalon & Murray-Garcia, 1998). Even with cultural competence training, however, HCPs may inadvertently detach ("they are not like me") and focus more on their disciplinary knowledge (i.e., objectivity and evidence based medicine) and assume a greater expertise of living with the IPHCs. HCPs may minimize or ignore the barriers they or the health care system can create (Foster, 2009). Thus, humility for and caring about the other's perspective and the broader socio-cultural realities affecting their everyday life can be lacking. This is what Swanson (1993) called the *knowing* component of caring and understanding the individual and broader sociocultural realities is important so nurses do not make assumptions for the other. Otherwise, there can be situations in which persons with IPHCs may "feel taken over, spoken for, undermined, disempowered or even neglected and abused" by those who believe they are caring (Shakespeare, 2006; Wadensten & Ahlstrom, 2009). Considering how the individual, their family, school or work, their neighborhood, their broader community, laws, policies, and societal beliefs all interact with each other to affect the individual's experiences and meaning, will help us put disabilities in context (Bronfenbrenner, 1977).

Limitations

This narrative synthesis could have excluded important information due to the databases excluded, the secondary extraction of data, which is limited by what the original investigator chose to present (or not present), and the inability to assure saturation of all themes. These factors together limit the external validity of the themes found from this synthesis. Yet, others argue that secondary analyses can still give important preliminary insights into a topic, which can later be tested (Thorne, 1993). The inclusion of literature that was not research-based could be criticized by some as biasing the findings, but others argue that considering alternative sources can enriched the final understanding (Noblit & Hare, 1988). In a population whose point of view has been historically marginalized, the author believed this approach was warranted. Rather than generalizing the findings from this review and synthesis, the findings make a case for considering HCPs roles in the construction of the meaning of disability in future research. Clinicians can also use it to begin to understand interactions from another point of view.

Implications

To provide culturally competent care, nursing leaders need to challenge students and all practicing clinicians with opportunities to reflect on their beliefs, learn, and practice and apply their new cultural skills (Campinha-Bacote, 1999). Table 2 presents some key things that individuals and organizations should consider to improve the setting and nature of future interactions with persons with IPHCs. Leaders need to ensure that the environment they work within and serve patients within does not create any physical or cultural barriers. Nursing educators and authors should be more cognizant of discussing the broader socio-cultural realities encountered by individuals with IPHCs and their family members, and not only the biophysical changes and treatments (Hahn, 2003). Finally, more research is needed on HCPs beliefs and the effect they can have on practice. By considering more subjective input from the patients we serve, they will more fully inform the services we provide and the

theories we construct. These initial steps will address social barriers currently overlooked. Providing critical thinking opportunities and challenging HCPs' clinical interpersonal skills at all levels of practice will improve the future quality of interpersonal care delivered to persons with IPHCs.

Acknowledgments

The author would like to thank Kristi Kirshner, MD, Debjani Mukherjee, PhD, Teresa Savage, PhD RN, and Rebecca Brashler, LCSW, of the Donnelley Ethics Program at the Rehabilitation Institute of Chicago for their training and guidance on the project that led up to this article. I also thank Karen Kavanaugh, PhD RN FAAN, for her postdoctoral mentoring and feedback on the initial manuscript. The author's postdoctoral training while conducting this project and writing the manuscript was supported by the Irving B. Harris Foundation Faculty Scholar Initiative awarded to the School of Nursing at the University of Illinois at Chicago. Manuscript revisions were supported by a National Institutes of Nursing Research postdoctoral training grant (2T32NR0007091), Interventions for Prevention & Managing Chronic Illness.

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Table 1

Summary of Reviewed Literature for Synthesis of Cultural Disparities When Interacting with Various Person with Impairment Producing Health Conditions

| CITATION | RESOURCE TYPE | PRIMARY AIM OR SECONDARY FINDING | HEALTH CONDITION(S) DISCUSSED | THEMES INFORMED |
|---|--|--|---|---|
| Andersson & Hansebo (2009) | Research: content analysis of individual interviews | Primary: nursing care | Persons with stroke | <ul style="list-style-type: none"> • A lack of HCP knowledge related to their complete needs • An inherent power differential |
| Becker, Stuitbergen, & Tinkle (1997) | Research: descriptive qualitative of individual interviews | Primary: reproductive health care experiences | Persons with multiple sclerosis, cerebral palsy, or paralysis | <ul style="list-style-type: none"> • Ignoring or minimizing their knowledge • Placing a negative skew on their life quality • A lack of HCP knowledge related to their complete needs • Assuming they should be asexual and childless • An inherent power differential |
| Begum (1996) | Book chapter (research): descriptive qualitative of open ended questionnaire questions and individual interviews | Primary: experiences with general practitioner | Persons with multiple health conditions not described | <ul style="list-style-type: none"> • Ignoring or minimizing their knowledge • Detached interpersonal Interactions • Placing a negative skew on their life quality • A lack of HCP knowledge related to their complete needs • An inherent power differential |
| Berglund, Anne-Cathrine, & Randers (2010) | Research: content analysis of narrative written stories | Secondary finding | Persons with Ehlers–Danlos syndrome | <ul style="list-style-type: none"> • Ignoring or minimizing their knowledge • Detached interpersonal Interactions • Placing a negative skew on their life quality • A lack of HCP knowledge related to their complete needs • An inherent power differential |
| Brown & Gill (2009) | Research: descriptive qualitative (participatory) from focus group data | Secondary findings | Persons with Intellectual Disabilities | <ul style="list-style-type: none"> • Detached interpersonal Interactions • A lack of HCP knowledge related to their complete needs |

| CITATION | RESOURCE TYPE | PRIMARY AIM OR SECONDARY FINDING | HEALTH CONDITION(S) DISCUSSED | THEMES INFORMED |
|--------------------------------------|---|--|--|---|
| Crocker (2009) | Research: interpretive phenomenology of personal interviews | Secondary findings | Persons with unexplained chronic fatigue | <ul style="list-style-type: none"> Ignoring or minimizing their knowledge Placing a negative skew on their life quality |
| Davidge et al. (2010) | Research: grounded theory analysis of personal interviews | Secondary findings | Persons post-sacrectomy with chronic pain | <ul style="list-style-type: none"> A lack of HCP knowledge related to their complete needs |
| Dewar, Gregg, White, & Lander (2009) | Research: descriptive qualitative of individual interviews | Primary: navigating the healthcare system | Persons with chronic back pain, neck pain, or chronic headaches | <ul style="list-style-type: none"> Ignoring or minimizing their knowledge Detached interpersonal Interactions Placing a negative skew on their life quality An inherent power differential |
| Dixon, Thornton, & Young (2007) | Research: descriptive qualitative of individual interviews | Secondary | Persons with stroke, traumatic brain injury, or other monophasic neurological impairment | <ul style="list-style-type: none"> Ignoring or minimizing their knowledge A lack of HCP knowledge related to their complete needs |
| Gill (2006) | Position paper with personal narrative account | Primary: inpatient construction of vulnerability | Person who survived polio | <ul style="list-style-type: none"> Detached interpersonal Interactions Placing a negative skew on their life quality A lack of HCP knowledge related to their complete needs An inherent power differential |
| Grabois & Young (2001) | Research: descriptive qualitative from individual interviews | Primary: managed care experiences | Persons with post-polio, spinal cord injury, lupus erythematosus, multiple sclerosis, bipolar, scleroderma, amyotrophic lateral sclerosis, asthma, or fibromyalgia | <ul style="list-style-type: none"> Ignoring or minimizing their knowledge Detached interpersonal Interactions Placing a negative skew on their life quality |
| Grealy (1994) | Memoir | Narrative life story | Person who survived cancer treatments that resulted in facial disfigurement and pain | <ul style="list-style-type: none"> Detached interpersonal Interactions |
| Harrison & Stuijbergen (2005) | Research: interpretive phenomenology of individual interviews | Secondary finding | Persons with paralytic polio | <ul style="list-style-type: none"> Detached interpersonal Interactions A lack of HCP knowledge related to their complete needs |
| Hart (1998) | Research: grounded theory from individual interviews | Primary: hospital experiences | Persons with learning impairments | <ul style="list-style-type: none"> Detached interpersonal Interactions |

| CITATION | RESOURCE TYPE | PRIMARY AIM OR SECONDARY FINDING | HEALTH CONDITION(S) DISCUSSED | THEMES INFORMED |
|---|---|--|---|--|
| Hay, Strathmann, Lieber, Wick, Giesser (2008) | Research: descriptive qualitative from individual interviews [with quantitative data] | Secondary finding | Persons with multiple sclerosis | <ul style="list-style-type: none"> A lack of HCP knowledge related to their complete needs Ignoring or minimizing their knowledge A lack of HCP knowledge related to their complete needs An inherent power differential |
| Holliday, Ballinger, & Playford (2007) | Research: descriptive qualitative from focus group data | Secondary finding | Persons with stroke, multiple sclerosis, subarachnoid hemorrhage, Guillian-Barré syndrome, or spinal cord lesion. | <ul style="list-style-type: none"> A lack of HCP knowledge related to their complete needs |
| Hughes, Sinha, Higginson, Down, Leigh (2005) | Research: descriptive qualitative from individual interviews | Secondary finding | Persons with motor neuron disease | <ul style="list-style-type: none"> Detached interpersonal Interactions A lack of HCP knowledge related to their complete needs An inherent power differential |
| Hunt, Matthews, Milson, & Lammell (2006) | Research: descriptive qualitative from individual interviews | Primary: counseling experiences of lesbian women with disability | Persons with rheumatoid arthritis, lupus, or ulcerative colitis | <ul style="list-style-type: none"> A lack of HCP knowledge related to their complete needs Assuming they should be asexual and childless |
| Iezzoni & O'Day (2006) | Book (research): descriptive qualitative from survey and focus group data | Primary: health care access and quality | Persons with multiple types of physical and sensory impairments | <ul style="list-style-type: none"> Ignoring or minimizing their knowledge Detached interpersonal Interactions Placing a negative skew on their life quality A lack of HCP knowledge related to their complete needs Assuming they should be asexual and childless An inherent power differential |
| Iezzoni & O'Day, Killeen, & Harker (2004) | Research: descriptive qualitative from focus groups data | Primary: Health care experiences | Persons who are deaf or hard of hearing | <ul style="list-style-type: none"> Detached interpersonal Interactions Placing a negative skew on their life quality A lack of HCP knowledge related to their complete needs |

| CITATION | RESOURCE TYPE | PRIMARY AIM OR SECONDARY FINDING | HEALTH CONDITION(S) DISCUSSED | THEMES INFORMED |
|---|---|--|--|--|
| Kroll & Neri (2003) and Neri & Kroll (2003) [‡] | Research; descriptive qualitative from telephone interviews | Primary aim (care coordination experiences) | Persons with cerebral palsy, multiple sclerosis, and spinal cord injury | <ul style="list-style-type: none"> • Ignoring or minimizing their knowledge • A lack of HCP knowledge related to their complete needs • Detached interpersonal Interactions |
| Leith, Phillips, & Sample (2004) | Research; descriptive analysis from focus groups | Primary: service needs and experiences | Persons with Traumatic brain injury (and family) | <ul style="list-style-type: none"> • Ignoring or minimizing their knowledge • Detached interpersonal Interactions • A lack of HCP knowledge related to their complete needs |
| Lempp, Hatch, Carville, & Choy (2009) | Research; content and discourse analysis of individual interviews | Primary: living with and receiving treatment | Persons with fibromyalgia | <ul style="list-style-type: none"> • Detached interpersonal Interactions • An inherent power differential • A lack of HCP knowledge related to their complete needs |
| Linton (2006) | Memoir | Narrative story and argument for broader considerations of disability | Persons with spinal cord injury | <ul style="list-style-type: none"> • Placing a negative skew on their life quality • An inherent power differential |
| Lunsky & Gracey (2009) | Research; descriptive qualitative from focus group data | Primary: psychiatric emergency services | Persons with intellectual impairments | <ul style="list-style-type: none"> • Ignoring or minimizing their knowledge • Detached interpersonal Interactions • An inherent power differential |
| Mangset, Tor Erling, Forde, & Wyller (2008) | Research; descriptive phenomenology from interviews | Secondary finding | Persons with stroke | <ul style="list-style-type: none"> • Ignoring or minimizing their knowledge • Detached interpersonal Interactions • Placing a negative skew on their life quality • An inherent power differential |
| McBryde Johnson (2005) and McBryde Johnson (N. D.) [‡] | Memoir and position paper with personal narrative | Narrative personal experiences and argument for broader considerations of disability | Persons with congenital neuromuscular disease | <ul style="list-style-type: none"> • Ignoring or minimizing their knowledge • Placing a negative skew on their life quality • An inherent power differential |
| Meldrum, Tsao, Zeltzer (2009) | Research; grounded theory from individual interviews | Secondary finding | Persons with headaches, functional neurovisceral pain disorder, myofascial pain, | <ul style="list-style-type: none"> • Ignoring or minimizing their knowledge |

| CITATION | RESOURCE TYPE | PRIMARY AIM OR SECONDARY FINDING | HEALTH CONDITION(S) DISCUSSED | THEMES INFORMED |
|--|---|--|--|--|
| Norman et al (2010) | Research: content analysis of individual interviews | Secondary finding | chronic regional pain syndrome, or fibromyalgia. | <ul style="list-style-type: none"> A lack of HCP knowledge related to their complete needs |
| Olofsson, Andersson, & Carlberg (2005) | Research: descriptive qualitative from individual interviews | Secondary finding | Persons with spinal cord Injury related chronic pain | <ul style="list-style-type: none"> A lack of HCP knowledge related to their complete needs An inherent power differential |
| Pellat (2007) | Research: ethnographic approach with individual interviews | Secondary finding | Persons with stroke (and family members) | <ul style="list-style-type: none"> A lack of HCP knowledge related to their complete needs An inherent power differential |
| Phillips & McCann (2007) | Research: descriptive qualitative from individual interviews | Secondary finding | Persons with spinal cord injury (and rehabilitation providers) | <ul style="list-style-type: none"> A lack of HCP knowledge related to their complete needs |
| Proot, Crebolder, Abu-Saad, Macor, Ter Meulen (2000) | Research: grounded theory analysis from individual interviews | Primary: discharge experiences from a nursing home | Persons with schizophrenia who receive neuroleptic depot injections in the community | <ul style="list-style-type: none"> An inherent power differential |
| Russell & Nicol (2009) | Research: descriptive phenomenology from individual interviews | Primary: experiences with general practitioner | Persons who experienced whiplash | <ul style="list-style-type: none"> Ignoring or minimizing their knowledge |
| Salisbury, Wilkie, Bulley, Shields (2010) | Research: interpretive phenomenology from individual interviews | Primary: rehabilitation experiences | Persons with stroke (and their informal caretakers) | <ul style="list-style-type: none"> Placing a negative skew on their life quality A lack of HCP knowledge related to their complete needs |
| Sample & Darragh (1998) | Research: descriptive phenomenology from individual interviews | Secondary finding | Persons with traumatic brain injury | <ul style="list-style-type: none"> Ignoring or minimizing their knowledge Detached interpersonal Interactions A lack of HCP knowledge related to their complete needs An inherent power differential |
| Samuel, Moses, North, Smith & Thorne (2007) | Research: grounded theory analysis from individual interviews | Primary: rehabilitation experiences | Women with spinal cord injury | <ul style="list-style-type: none"> Detached interpersonal Interactions Assuming they should be asexual and childless An inherent power differential |

| CITATION | RESOURCE TYPE | PRIMARY AIM OR SECONDARY FINDING | HEALTH CONDITION(S) DISCUSSED | THEMES INFORMED |
|---|---|---|---|---|
| Savage (2003) | Film (research): descriptive qualitative (retrospective) from individual interviews | Primary: adults retrospective pediatric experiences | Persons with several congenital health conditions | <ul style="list-style-type: none"> • Ignoring or minimizing their knowledge • Placing a negative skew on their life quality • A lack of HCP knowledge related to their complete needs |
| Sharts-Hopko, Smeltzer, Ott, Zimmerman, & Duffin (2010) | Research: secondary content analysis of focus group data | Primary aim: healthcare experiences | Persons with blindness | <ul style="list-style-type: none"> • Detached interpersonal Interactions • Placing a negative skew on their life quality • A lack of HCP knowledge related to their complete needs |
| Shade, Molloy, & Keating (2009) | Research: grounded theory analysis of focus group data | Secondary finding | Persons with non-specific chronic low back pain | <ul style="list-style-type: none"> • Ignoring or minimizing their knowledge |
| Solari et al. (2007) | Research: descriptive analysis from focus group data | Primary: receiving their diagnosis | Persons with multiple sclerosis | <ul style="list-style-type: none"> • Detached interpersonal Interactions • A lack of HCP knowledge related to their complete needs |
| Speraw (2009) | Case Study from larger research study: interpretive phenomenology | Secondary finding | Persons with disfigurement from multiple cancer therapies | <ul style="list-style-type: none"> • Detached interpersonal Interactions • Placing a negative skew on their life quality • An inherent power differential |
| Steinberg Barnett, Meador, Wiggins, & Zazove (2006) | Research: descriptive qualitative from focus group data | Secondary finding | Persons with deafness | <ul style="list-style-type: none"> • A lack of HCP knowledge related to their complete needs • An inherent power differential |
| Teh et al. (2009) | Research: grounded theory analysis from individual interviews | Primary: patient centered treatment | Persons with chronic pain | <ul style="list-style-type: none"> • Ignoring or minimizing their knowledge • Detached interpersonal Interactions • Placing a negative skew on their life quality • A lack of HCP knowledge related to their complete needs • An inherent power differential |
| Thomas (2001) | Research: descriptive qualitative from individual interviews, | Primary: receiving health care | Persons with multiple health conditions not described | <ul style="list-style-type: none"> • Ignoring or minimizing their knowledge • Detached interpersonal Interactions |

| CITATION | RESOURCE TYPE | PRIMARY AIM OR SECONDARY FINDING | HEALTH CONDITION(S) DISCUSSED | THEMES INFORMED |
|--|---|---|--|--|
| | self-recorded tapes, and self-generated letters | | | <ul style="list-style-type: none"> A lack of HCP knowledge related to their complete needs Assuming they should be asexual and childless An inherent power differential |
| van Daalen-Smith (2006) | Research: descriptive qualitative analysis from focus group data | Secondary finding | Persons with spina bifida | <ul style="list-style-type: none"> Detached interpersonal Interactions An inherent power differential |
| Van Den Tillaart, Kurtz, & Cash (2009) | Research: descriptive qualitative from focus group interviews | Primary: access to care and interactions for achieving wellness | Persons with mental health challenges | <ul style="list-style-type: none"> Ignoring or minimizing their knowledge Detached interpersonal Interactions Placing a negative skew on their life quality |
| Wadensten & Ahlstrom (2009) | Research: content analysis of individual interviews | Secondary finding | Persons with severe neurological disease or injury | <ul style="list-style-type: none"> Ignoring or minimizing their knowledge Detached interpersonal Interactions An inherent power differential |
| White, White, & Russell (2007) | Research: content analysis of written survey or telephone interview data | Secondary finding | Persons with multiple sclerosis | <ul style="list-style-type: none"> Ignoring or minimizing their knowledge Detached interpersonal Interactions An inherent power differential |
| White, Magin, & Pollack (2009) | Research: mixed methods with individual interviews using modified grounded theory | Primary: rehabilitation experiences | Persons with stroke | <ul style="list-style-type: none"> Detached interpersonal Interactions A lack of HCP knowledge related to their complete needs An inherent power differential |
| Widar, Ek, & Ahlstrom (2007) | Research: content analysis of individual interviews | Secondary finding | Persons with post stroke pain | <ul style="list-style-type: none"> Ignoring or minimizing their knowledge Detached interpersonal Interactions A lack of HCP knowledge related to their complete needs |
| Yeung, Passmore, & Packer (2008) | Research: descriptive qualitative of individual interviews | Secondary findings | Persons with cerebral palsy | <ul style="list-style-type: none"> Detached interpersonal Interactions Placing a negative skew on their life quality An inherent power differential |

† Reports from same person's writings or same investigator's reports are synthesized and summarized as one source.

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Table 2

Suggestions For Improving Cultural Competence Based on this Synthesis

| Concept | Suggestions |
|--------------------|--|
| Reflection | <p>Critically evaluate your: <u>Knowledge</u></p> <ul style="list-style-type: none"> • What sources of knowledge have informed your understanding of persons with disability and are they a limited or full representation? Could there be other resources that could give you a different perspective? • Think of the broader social context of caring (attitudes, policies, laws, social representations), and not only caring at the individual level. How does that change what could be done to help improve care? <p><u>Attitudes and Beliefs:</u></p> <ul style="list-style-type: none"> • How has history played a role in shaping how health care fields and the broader society see persons with disability? How have those historical attitudes and beliefs shaped the experiences and possible meanings of living with an IPHC? • Are the experiences and meanings the same for all persons, with all IPHCs, in all countries/cultures? • What more should you and others understand about the meaning of living with various IPHCs? <p><u>Expectations:</u></p> <ul style="list-style-type: none"> • How has and is disability and care of persons with IPHCs represented in the broader society in popular literature, medical literature, art, movies, laws, and policies? • How do these social and cultural representations influence the expectations that others have of persons with IPHCs? (think about autonomy, personhood, respect, and opportunities) • How does the period of time that you tend to interact with persons with IPHCs affect what you expect their life to be like (i.e., do you only see them in the critical period but have no idea what happens to them later?) • Sexuality is an intrinsic part of people's identity throughout the life cycle, despite IPHCs. Intimacy and childrearing can be strong desires for many people and barriers to parenting can often be overcome. |
| Learn | <ul style="list-style-type: none"> • Listen, ask and never assume. They are a person first and not their health condition. Learn about them beyond their health condition. • Expose yourself to literature on disability topics outside of health care fields, especially on life outside of the health care system (memoirs, disability studies, social science case studies, phenomenology or qualitative studies). • Attend patient/family panels to get insight/feedback from another perspective. • Look for coursework in programs or at conferences that are outside of health care fields (disability studies or social sciences). |
| Practice and Apply | <ul style="list-style-type: none"> • Respect their privacy, personal space, and personal dignity. Ask permission before doing anything and explain what you are doing. Monitor their physical and emotional responses and adjust your approach if necessary. • Talk directly to the person and not just their caregiver or family. Acknowledge persons with intellectual disability as you would any other person and do not talk over them as if they are not there. • Do not expect or assume their caregiver/family will be responsible for their needs when they are in your care. Ask how they would like to be involved and check in on them. • Ask for input on their care as appropriate. Make sure they have assistive aids when and where they need them, do not send them home. Communicate their needs when they go to other places or for procedures. |

| Concept | Suggestions |
|------------------|---|
| | <ul style="list-style-type: none"> • Ask the person (or their caregiver) to tell you about their personal life and the things that are important to the individual and the family. Incorporate these things into their care plan. • Make sure the information (verbal or written supplementary) and the interventions you develop for patients/family members are relevant to their needs and not generic. • Look for cues to how the setting or staff behaviors have affected the person or family member and honestly acknowledge when you have made an assumption or mistake. • Challenge your peers on beliefs or behaviors that could create cultural or physical barriers to patients/families. |
| Ask for Feedback | <ul style="list-style-type: none"> • As you apply new cultural skills, continuously reflect how each patient and family is different, even if they have similarities. • Invite patient/family anonymous and open feedback on the care setting, procedures, and the nature of interactions with staff in order to expose perceived power differentials and physical and attitudinal barriers. • Allow outsiders (family members, students, community members, or others) to do audits of your setting, ongoing HCP education, and care process in order to expose power differentials and potential physical or attitudinal barriers. • Involve persons/family members in the construction of knowledge, in particular research, unit/hospital policies, educational materials, and/or programs of care and support. • If you only see patients in the acute phase of their care, invite them at a later point in time to tell you how they are doing. This can be a powerful sharing opportunity for both sides! |