Assessment of Capacity to Consent by Nurses Who Deliver Health Care to Patients Who Misuse Substances

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Abstract
This qualitative study explored the current practice that nurses use to assess capacity to consent to health care (CTC-HC) in street outreach settings. Key informant interviews were conducted with a purposive sample of nurses from each of British Columbia’s five regional health authorities, allowing nurses to describe their lived experiences with assessing CTC-HC. Content analysis was used to summarize information captured in the data. A total of 19 nurses participated in the study. Five themes emerged from the data: (a) internal guiding forces that contribute to the nurses’ assessment, (b) external influences that contribute to the nurses’ assessment, (c) measures that are important for assessing CTC-HC, (d) threshold setting, and (e) context (physical and interpersonal) within which assessment of capacity takes place. These elements will be incorporated into a capacity assessment tool that can be used in nursing best practices.

Keywords
addiction / substance use, ethics / moral perspectives, health care screening, homelessness, nursing

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Individuals who misuse alcohol and/or drugs and who are homeless disproportionately access health care resources (O’Connor et al., 2014) because they are often at high risk for acquiring communicable diseases such as sexually transmitted infections, HIV, Hepatitis, and other blood-borne infections. Behaviors associated with drug use, such as needle sharing, account for the high incidence of HIV infections (12.2% of HIV cases in 2012; BC Centre for Disease Control, 2012) and Hepatitis C (1,885 per 100,000 population detected in 2012; BC Centre for Disease Control, 2012). Likewise, serious morbidities such as psychosis, cardiovascular disease, hepatotoxicity, musculoskeletal disorders, and endocrine disorders are known to be prevalent in this population (Cregler, 1989; Satel, Southwick, & Gawan, 1991; Singleton, Degenhardt, Hall, & Zabransky, 2009; VanDette & Cornish, 1989; Varner et al., 2014; Whitesford et al., 2013). Risk of poor health is compounded when individuals who experience substance use also experience homelessness (Corneil et al., 2006; Vila-Rodriguez et al., 2013; Wolitski, Kidder, & Fenton, 2007), increasing the need for health care services.

However, individuals who misuse substances and who are homeless (IMSH) often avoid going to a primary care provider for their health needs. They are more likely to attend emergency rooms when they require health care, often when their health concern has advanced to a severe state (Fairbairn et al., 2012; Kerr et al., 2005; Palepu et al., 1999; Palepu et al., 2001). This delay in accessing care may be attributed to fear of stigma and provider discrimination (Griffiths, 2002; Gunn, White, & Srinivasan, 1998; Lightfoot et al., 2009; Pauly, 2008; Self & Peters, 2005). Little is known about whether stigma and provider discrimination affect clients’ willingness to exercising autonomy and self-determination.

Street outreach programs and low threshold clinics (clinics that minimize barriers that must be crossed to access a health service; Griffiths, 2002) have been developed over the past decade and shown to successfully reach individuals who are reluctant to access mainstream health care facilities.
Other clients may experience drug-induced psychosis resulting in halluci-
nations, and/or paranoia (Wild, 2007). Those who are under the influence of alcohol may experience dulling of the
mind (Inaba & Cohen, 2011), whereas clients who are withdrawing from a substance may experience anxiety and be too
distracted to obtain care. In addition, a large majority of clients who are homeless or living in unstable housing have mental
illness (such as depression and psychoses) making it difficult
for nurses to communicate and deliver care (Inaba & Cohen,
2011). Homelessness adds another important dimension
because individuals who are homeless have a tendency to
assume a subordinate role and, thus, are vulnerable to manipu-
lation and coercion (Beauchamp & Childress, 2009). The
combination of these factors creates challenges when nurses attempt
to assess capacity to consent to care.

The purpose of this qualitative study was to examine the
current practice for assessing capacity to consent used by
nurses who deliver care to IMSH in BC. This information will ultimately guide the development of a capacity assess-
ment instrument for nurses to use when delivering care to
IMSH. We approached this inquiry with the following over-
arching question: How do nurses who deliver care to IMSH
describe and explain the process they use to assess CTC-HC
among this population?

Method

Decision-making theoretical frameworks, such as analytical
information processing, moral knowledge, and intuitive-
humanistic models (Banning, 2008; Carper, 1978), were
used to guide our inquiry and to understand how nurses use
various information sources to make clinical decisions such
as determination of capacity to consent to care. In addition,
critical social theory was employed to examine the context-
ual effects of power, knowledge, and values within nurse–
client relationships (Manias & Street, 2000).

This study involved single semi-structured interviews
with a purposive sample of nurse volunteers from each of
BC’s five regional health authorities (Vancouver Coastal,
Interior Health, Fraser Health, Island Health, and Northern
Health). To determine whether the current practice to assess
CTC-HC differs in geographic areas throughout BC, we
aimed to recruit at least two clinicians in each of BC’s health
authorities. Recruitment was facilitated by the communica-
bility leader in each health authority. These leaders distributed an advertisement that described the study to nurses
working with IMSH. Volunteers contacted a member of our
research team who established eligibility and obtained
informed consent.

Inclusion criteria included nurses who (a) self-identified as
providing care to IMSH and (b) reported an ability to speak and
understand English. For the purposes of this research
study, individuals who are homeless were defined as people
who have no physical shelter (staying on the street, in door-
ways, in parkades, in parks, and on beaches) or are temporar-
ily accommodated in emergency shelters, safe houses, or
transition houses. It also included individuals with no fixed address found at hospitals or jails. Sampling continued until thematic saturation was achieved, that is, when we recognized that no new data were emerging from the interviews.

A semi-structured interview guide was created drawing on concepts and theories in the literature related to capacity to consent. The interview guide posed general questions that allowed participants to describe the environment that they delivered care in, the characteristics of individuals that they delivered care to, factors that they considered when assessing a client’s cognitive status, and how they determined whether the client had the capacity to provide informed consent. The interview guide was adapted throughout the interviewing phase to allow for deeper exploration into dominant themes emerging from the interviews and to probe for deviant cases. The aim was for participants to provide a rich description of all aspects of CTC-HC including their experiences and meanings with a focus on the processes involved in assessing capacity to consent.

Interviews ranged between 30 and 60 minutes and were conducted in a private room at the nurses’ work location. All interviews were audio recorded and transcribed verbatim. Field notes were recorded after each interview to document nuances of the interview and make note of non-verbal communication.

Analysis
A variety of approaches were used for the data analysis. Ethnographic coding methods were conducted as described by LeCompte and Schensul (2010). Two researchers independently coded the transcripts and codes were compared. This method is consistent with methods used in grounded theory. Development of a coding framework took place at the beginning of the interviewing process and was adapted as new data were collected. An interpretive description approach, described by Thorne (2008), was used as a methodological guide. This method identifies themes and patterns by broadening the interpretive lens within a practice-linked health care discipline. Common concepts and themes were identified in the transcripts to identify recurring, converging, and contradictory patterns/concepts/themes between cases. Coding was conducted using Nvivo Version 9. The analysis was iterative in nature (interviewing and analysis occurring simultaneously), and themes were used to provide an interpretive explanation for methods used to assess capacity. The analysis was constantly refined by confirming and challenging emerging themes with data from new interviews (Thorne, 2008).

Assessment of Rigor
Resulting themes were regularly discussed with the research team, and assessment of the trustworthiness of the data was established by presenting the results to a subset of research participants. These participants were asked whether the results resonated with them and whether we missed any important elements. A comprehensive audit trail was established consisting of field notes, analytic memos that documented all interpretations and conceptualizations of patterns in the data were recorded. Additional rigor was assessed, in a conventional way (contrary to interpretative description), by conducting double coding (Miles & Huberman, 1984) until a kappa coefficient of 80% or greater for 80% of the transcripts was achieved. Thereafter, double coding took place every fifth interview.

Ethics, Consent, and Permissions
This study was approved by the University of British Columbia Research Ethics Board (H09-01982). All participants were informed of the risks and benefits of participating in this research, and that their identities would be kept confidential before providing written informed consent. Participants were also informed that participation was entirely voluntary and refusing to participate would not have any detrimental effect on their employment. Participant names were substituted with a study number when the interviews were transcribed.

Results
Interviews took place between September 2011 and April 2012. A total of 19 nurses (17 female, two male) participated in the study. Participants represented each of health authorities in BC with the majority coming from the greater Vancouver area. Five major themes emerged from the data: (a) internal guiding forces that contribute to the nurses’ assessment, (b) external influences that contribute to the nurses’ assessment, (c) measures that were identified as important for assessing CTC-HC, (d) threshold setting for determining consent to health care, and (e) context (physical and interpersonal) in which assessment of consent to health care takes place. Table 1 provides a summary of themes and concepts.

Internal Guiding Forces
Internal guiding forces refer to the knowledge that nurses bring into a nurse–client encounter, including knowledge gained through professional education, knowledge of ethical and legal principles obtained through professional development, and knowledge gained through years of experience as a nurse, particularly years working with individuals with substance misuse and addictions. One participant described using the knowledge she gained from her nursing training, related to assessment of orientation to person, place, and time to frame how she approached assessing CTC-HC: “So you basically are assessing, are they oriented, are they making sense, do they know who I am, do they know what I’m asking them.”
The majority of nurses stated that they had some knowledge of the Nurses Code of Ethics (Canadian Nurses Association, 2008) but could not articulate the specifics of what is mentioned in the code. In general, participants were familiar with obtaining written informed consent to an invasive procedure and many expressed drawing on knowledge of this to guide their thinking about the ethics of getting verbal consent prior to delivering other health care interventions. Some recalled experiencing conflicting feelings when thinking about the legal requirements for capacity to consent while not wanting to deny impaired clients care if they are in need. This was particularly important to them if the client required treatment for a communicable disease.

In addition to knowledge obtained through formal education, participants placed value on knowledge of clients that they gain in previous encounters. They explained that this experiential knowledge often provided an understanding of the client’s baseline condition that would inform decisions about providing care or delaying care in a future encounter. One nurse explained, “A lot of it is having known people a long time, so knowing that this isn’t bizarre behaviour for them because they’re always in this sort of state or this is a pretty good state for them.” Veteran nurses (those with more than 1 year experience delivering care to IMSH) also described using their intuition as part of assessing CTC-HC with clients they were familiar with. These nurses talked about “just knowing.” Many referred to a “gut feeling” when determining whether the client was high or not. Conversely, novice nurses expressed feeling uncertain about whether they should deliver care to a client who may be high and often consulted a more experienced colleague to help them make a decision.

**External Influences**

External influences, such as safety, timing of the encounter, location, and urgency of care, are elements and concepts that are not necessarily used to assess the client’s CTC-HC but influence the nurse’s ability to make a thorough and accurate assessment. These elements are generally outside the control of the nurse.

Personal safety was an issue discussed by virtually all participants, and stems from concerns about how volatile the client might be as a result of the substance that they may have used. In these situations, nurses talked about delaying care until it was safer to engage with the client where possible. Participants stated that, in some situations, they were able to calm the client down or defuse the situation at which time they could continue to assess the client’s CTC-HC. Nurses also discussed the client’s emotional safety, which refers to whether the client is vulnerable to power imbalances, emotional abuse, or depression. Participants explained that under these circumstances, it is important to determine whether the client is consenting or refusing care to escape a potentially dangerous situation. In the following quote, a nurse talks about the limits she places on providing care if a client is impaired:

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**Table 1. List of Major Themes and Sub-Themes.**

| Major Themes                          | Sub-Themes                                                                 |
|---------------------------------------|---------------------------------------------------------------------------|
| **Internal guiding forces**            | Knowledge obtained through professional development                       |
|                                       | Knowledge obtained through years of experience as a nurse                 |
|                                       | Knowledge of Nurses Code of Ethics                                        |
|                                       | Knowledge of the client through previous encounters                      |
|                                       | Intuition                                                                  |
| **External influences**                | Safety (nurses’ and clients’ safety)                                      |
|                                       | Timing of encounter                                                       |
|                                       | Location                                                                  |
|                                       | Urgency of care                                                           |
| **Measures that were identified as important for assessing CTC-HC** | Physical indications of substance use (and type of substance) or withdrawal |
|                                       | Client’s ability to engage in a conversation                              |
|                                       | Understanding                                                             |
|                                       | Memory                                                                    |
|                                       | Orientation to person, place, and time                                    |
|                                       | Irrational or inappropriate conversation                                  |
|                                       | Ability to cope with adverse effects of an intervention                   |
| **Threshold**                         | Level of risk versus level of capacity                                   |
| **Context: Client’s past experiences** | Client’s reluctance to access health care                                 |
|                                       | Client assumes a submissive role                                           |
|                                       | Stigmatization                                                           |
|                                       | Trust of distrust                                                         |

Note. CTC-HC = capacity to consent to health care.
I care about the behaviour. As long as this person is breathing and their vitals are okay that’s a whole other issue. But if I’ve got a live person and I’m not going to have them coding on me then I care about the conversation we’re having, not the behaviour.

Timing and location of an encounter are factors that nurses often cannot control but affect their ability to assess clients. Participants stated that they deliver care in locations such as alleyways, doorways, churches, clients’ homes, hotel lobbies, parking lots, jails, on the street, or in restaurants. When nurses approach the client, they are conscious about the importance of being respectful about being in the client’s environment:

I think the defining characteristic is that these are mainly folks that won’t come to a clinic, right, so we go to them. So you’re meeting them on their turf that means in their home, on the street, alleyways, doorways.

Participants stated that timing and location are particularly important when a nurse is approaching the client in a street outreach setting (e.g., in a back alley). Caution is taken because the interaction between nurse and client may be unwelcomed if the client is involved in another activity such as trying to “turn a trick” (in the case of a sex worker), or in the middle of a drug deal.

**Measures Identified as Important for Assessing CTC-HC**

The majority of nurses described factors that could be measured when assessing CTC-HC. They stated that this process usually involves a pre-assessment to determine whether there are any physical indications of substance use, followed by an investigation about what substance(s) the client may be under. Similarly, nurses stated they assess whether the client is withdrawing from a substance, as this state may cause the client to be distracted and be unable to understand information about a health care intervention. Nurses talked about the physical indicators of substance use that act as an initial clue that the client might be impaired. These indicators include unstable or erratic walking, involuntary movements, slumping posture, and unusual dilation or constriction of the pupils. Rich description was provided about how clients who are unstable or erratic walking, involuntary movements, slumping posture, and unusual dilation or constriction of the pupils. Rich description was provided about how clients who are withdrawing from a substance (such as crack cocaine) may display gyrating movement, an inability to walk normally, or evidence that they have not slept in days: “... that are noticeably impaired to the point of being physical, they’re sketchy they can’t stop moving or they’re somberlant or they’re obviously drunk.”

These pre-assessments are followed by measuring the client’s ability to engage in a conversation, whether they can understand what is being said to them, whether their short-term (working) memory is intact, and whether the client is orientated to person, place, and time. The majority of nurses said that patients talked about the importance of clients being able to engage in a conversation with the nurse. Clients may be too sleepy or euphoric to be able to engage in a conversation or their speech may be too slurred to be comprehensible. The following quote demonstrates a nurse’s experience with this phenomenon. “Well right off the bat if [there is] somebody you’re trying to talk to and you can’t make out a word they’re saying, right off the bat that’s a dead sign.”

Alternatively, the client may be able to speak and engage in a conversation, but the conversation is either not rational or has nothing to do with the purpose of the conversation. When faced with these circumstances, nurses said they would offer to talk to the client at another time when “it’s better for them.” However, if the client could look the nurse in the eye and have a coherent conversation (about any topic), they would continue with their capacity assessment and provide care if appropriate.

Understanding is a concept that was raised by the majority of nurses. They referred to ensuring that the client understands what the medical intervention is, why they are getting the intervention, and what the risks are. They also talked about asking the client to repeat back what was said to them in their own words so the nurse could differentiate between the client’s capacity to understanding versus their ability to reiterating the words that were said to them. Several nurses talked about determining the minimum critical information that should be understood by the client before they deliver care.

Well I think it’s probably about just posing a series of questions and whether how appropriate they can answer them. Or whether they answer them at all; whether they’re actually hearing me. Some of them will be out of it so they can’t respond or if they respond they don’t really know what I’m saying. So it’s a question of answering questions and being appropriate with some kind of response it doesn’t have to be detailed but they at least have to understand my questions.

Orientation to person, place, and time was raised by participants as an important indicator of capacity. To assess orientation to person, place, and time, nurses asked clients to state their name and why they have come to the clinic. For some nurses, orientation to person, place, and time was the bare minimum they required in terms of capacity.

Well, I think if they’re oriented to time, place and date and all that, I think if they think they’re on Mars that’s... I mean it’s obvious they’re not in a place where they can make consent but if they know who they are, they know who you are, they know what you’re talking about, and they can... you can sense that they can understand what the conversation is about and the risk and benefit, I think that’s kind of where it comes down to... if they can repeat to you what you said to them, if they can repeat what they’re understanding of your plan or what the medications are for I think that is enough consent.
Threshold: Level of Risk Versus Level of Capacity

Nurses were asked how they determined the level of impairment they considered significant enough to delay care or seek an authorized substitute decision maker. Many nurses struggled with this question and some were not able to articulate exactly how they determined this threshold. Most agreed that the concept of "threshold" is on a continuum and needs to be balanced against the degree of risk involved with providing versus withholding a health care intervention. Some stated that if the client appeared to be impaired but required an intervention with virtually no risk (such as dressing an open wound), then they would proceed unless the client refused. Other nurses talked about the minimum amount of capacity that they required before they delivered care, such as orientation to person, place, and time as mentioned above. The following nurse demonstrates the minimum capacity he or she requires with his or her clients.

So yeah, I think that consent is a bit different with our population because I wouldn’t, I wouldn’t, I wouldn’t expect them to necessarily sit through what syphilis actually is and what it can do to the body.

Nurses talked about the need to intervene (regardless of the client’s CTC-HC) under life-threatening circumstances. They talked about some clients being unhappy if the nurse intervened without the clients’ consent and this created a practice dilemma for them.

Oh we have, like people get upset with us for even just narcaning, even though we tell them that “you had stopped breathing completely, like you were blue, your oxygen levels were like at 10 percent instead of a hundred percent, or whatever,” so we had to narcate them.

Context: The Client’s Past Experiences

Nurses talked about the importance of understanding the context within which the encounter is taking place prior to making a clinical assessment. By context, they were referring to the elements that the client brings to the encounter and influence how the nurse approaches the situation. These elements include the client’s past experience interfacing with the health care system, the client’s perception of being stigmatized, the client’s level of trust with health care workers, reluctance to access health care, and the role these elements play in the clinical encounter. All these elements can influence how well the client engages with the clinician, and thus affects the extent to which an assessment can be made. The following quote is from a nurse who confirmed that some clients are stigmatized while accessing health care, which often results in clients delaying seeking health care, even in serious situations:

Oh, it’s very clear that the . . . a lot of service providers have preconceived judgmental ideas about this population. They don’t understand where they’re coming from and why it’s difficult for them. They just . . . and so they make up stories from their perspective about why they’re not keeping their appointments and how they’re wasting professional time and resources.

Trust is a critical component of the nurse–client relationship and provides the foundation on which a clinical encounter occurs. Clients who have previous trusting relationships with health care providers may be more likely to adhere to health care recommendations (Alpers, 2016). The following quote describes how nurses who deliver care to clients with addictions strive to develop and maintain relationships of trust with their clients.

In our clinic, we do a lot of listening and our clinic is very relationship based. The success of our clinic is based on building relationships. In the beginning, we may not offer anything but a friendly face, a smile, somebody they can talk to and once we build a relationship it’s easier for us and we have quite a high success rate in our clinic for even our treatment for TB.

Nurses described delivering care to individuals who misuse substances and also have a low socio-economic status as challenging, especially if the individuals have a history of assuming a submissive role in society. Nurse participants talked about clients who are naturally submissive in personal or social relationships (such as sex workers) and transfer this way of relating to others to nurse–client relationships. They talked about these clients tending to consent to health care, not necessarily because they understand the need for it, but because they want to please the care provider. One nurse described a situation that involved offering a pap test with a sex trade worker. This nurse expressed a concern about not perpetuating the cycle of abuse in this woman’s life.

The ones that worry me the most are the really agreeable folks, especially First Nations women who say yes to anything despite the fact that they might not want to do it or their background or being female or whatever makes them say yes to everything that would probably worry me the most, in the sense of adding to a burden of pain in their lives.

Discussion

This study revealed the important considerations that will be included in a new instrument aimed at assessing CTC-HC among IMSH. The major themes that emerged can be found in Table 1. All these factors come into play while assessing capacity consent and should be considered while weighing the level of risk versus level of capacity.

Our study contributes to the body of literature related to assessment of CTC-HC by exploring external influences, internal guiding forces, and context that have not been described previously in the literature, or incorporated into existing instruments. These considerations are important due
to the unique environment of street outreach nursing, as well as the unique effects that alcohol and drugs have on cognition. As mentioned above, the majority of existing instruments have been developed and validated in patients with mental illnesses such as schizophrenia, and dementias such as Alzheimer’s, making them inappropriate for IMSH populations. The most widely used concepts incorporated into existing instruments include understanding, appreciation of the nature of the situation, reasoning, and expression of choice. The concept that has been cited by virtually all other sources is “understanding.” This concept was also a dominant theme among the participants of our qualitative inquiry.

In a recent review of psychometric instruments developed to assess capacity to consent, Dunn (Dunn, Nowranghi, Palmer, Jeste, & Saks, 2006) highlighted an important gap. He stated that contextual factors are sometimes referred to in the literature surrounding instrument development for assessing capacity, but these factors are understudied (Appelbaum & Grisso, 2001; Drane, 1984; Dunn et al., 2006; Kapp & Mossmann, 1996; Kim, Karlawish, & Caine, 2002). The results of our qualitative study have contributed to filling this important gap. Nurse participants expressed the view that internal guiding forces that influence nurse decision making, external influences such as safety, and issues related to the client’s experience with accessing health care, are all important contextual factors.

For the most part, veteran nurses have developed methods to assess CTC-HC through years of experience working with homeless populations who misuse substances. These nurses enter clinical encounters with confidence. However, when uncertainty surrounding their clients’ capacity occurs, nurses often feel they are in an ethical dilemma, which can only be resolved by a validated instrument aimed at assessing CTC-HC. Moreover, novice nurses regularly face uncertainty when delivering care to IMSH and would likely benefit from an instrument aimed at facilitating their assessing CTC-HC. We believe that our new instrument may facilitate decision-making about CTC-HC, thus providing evidence-based decisions when delivering care to IMSH. Our hope is that it will be incorporated into nursing best practices and become embedded in public health policy.

The authors recognize that there are limitations to this study. First, the data were collected from street outreach nurses who deliver care to IMSH in BC, Canada. There may be different important aspects of capacity to consent that should be considered in different jurisdictions. In addition, nurses may have different perspectives on capacity to consent among IMSH than other health care providers such as physicians and paramedics, and therefore, our results may not translate into the practices of these professionals. Furthermore, the methods for coding research (assigning labels to emerging ideas and concepts) are somewhat conventional but have the potential for limiting findings, and the researcher gets entrenched in the codes he or she has created. This coding method is inconsistent with what Sally Thorne describes as an interpretative description methodology. Thorne believes that labeling of concepts and themes should be done after the sorting of qualitative data is complete, and the final analysis and interpretation are being conducted (Thorne, 2016). Although our findings may have been excessively guided by early labeling (rather than the other way around), they resonated with participants when results were shown to study participants, thus ensuring rigor.

Future research will include the development of a validated instrument with good psychometric properties that nurses who deliver care to IMSH can use to facilitate decision making surrounding CTC-HC. Once developed, our focus will be on assessing capacity to consent in different jurisdictions and with other health care professionals who provide health services to IMSH.

**Summary**

This study has identified five overarching concepts that will be incorporated into an instrument aimed at assisting nurses to assess capacity to consent among IMSH. Our work forms part of the process for nurses to gaining an understanding of how to approach the issue of assessing capacity to consent to individuals who misuse substances. Once the instrument is developed and used by nurses, more research will be needed to determine how nurses incorporate this new knowledge in their practice.

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**Note**

1. “Narcaning” is a term that refers to administering an opiate antagonist (i.e., Narcan) for opiate overdoses.

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