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Culture and Shared Decision Making for Individuals With Psychiatric Disabilities

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Abstract

The shared decision-making model represents a paradigm shift that invites the client to act as an equal partner in his or her recovery in a manner that is collaborative and empowering. There is some research indicating shared decision making in the treatment of individuals with psychiatric disabilities results in patient satisfaction. The shared decision-making process incorporates the client's culture and values in formulating a treatment plan and utilizing interventions. It is important that mental health practitioners utilizing the shared decision-making model have some knowledge of clients' culture when co-developing treatment plans and choosing counseling interventions.

Keywords: shared decision making, autonomy, psychiatric disabilities, serious mental illness, culture

Mental health practitioners (MHPs) make important decisions every day that directly impact the lives of clients with psychiatric disabilities. They make decisions that can affect all aspects of clients' lives including their physical health, mental health, ability to work, social relationships, romantic relationships, and spiritual health. Thus, in addressing clients' mental health concerns, there is no aspect of the client's life that treatment does not affect. Clients and MHPs use a variety of different models for making treatment decisions. One of these models is the shared decision-making (SDM) model, originally developed by the medical profession. This model incorporates the client's

values in formulating a treatment plan (Charles, Gafni, Whelan, & O'Brien, 2006). Client values are informed by their culture, calling for the MHP to be culturally sensitive when collaborating with clients to develop their treatment plans.

The Shared Decision Making Model

There is no universal consensus of what constitutes a SDM model (Charles et al., 2006). The professional literature on SDM offers several variations of the SDM model. Some of these perspectives include the identification of essential components, while others provide broad conceptualizations of the SDM model. Overall, much of the literature concurs that SDM is "...an interactive collaborative process..." between MHPs and clients (Schauer, Everett, del Vecchio, & Anderson, 2007, p. 55). The SDM model incorporates a process that integrates clinical information about treatment for mental health concerns with an individual's preferences, goals, beliefs, and values (Curtis et al., 2010).

Adams and Drake (2006) described SDM as a process between a client and MHP in which both partners make an important contribution. The MHP possesses expert information such as symptomatology, diagnosis, treatment options, and evidence-based practices related to disorders and disabilities. The client is an expert on his or her values, culture, preferences, and treatment goals. Through a dialogue between both partners, they aim to reach a mutual agreement. While a mutual agreement is not always the outcome, it is the goal. Adams, Drake, and Wolford (2007) described SDM as MHPs providing clients with information and choices, thus enabling clients to be active participants in their treatment.

Anthony (2010) described SDM as the collaborative process that incorporates sharing information, using decision aids, and involving clients in the decision-making process. Decision aids are visual aids, usually in the form of pamphlets or brochures, that guide the client through the decision-making process by addressing topics such as dialoging with practitioners, medication side effects, and cost of treatment.

Caldwell (2008) identified essential components of SDM. Both the MHP and client are involved in the decision-making process, both parties share information, both parties build a consensus about the preferred treatment, and both parties come to a mutual agreement on the treatment plan. In this model, MHPs have an opportunity to share their preference of treatment methods with the client. This process of asking and responding to questions and information-sharing may influence the client's decision (Charavel, Bremond, Moumjid-Ferdjaoui, Mignotte, & Carrere, 2001).

Charavel et al. (2001) identified other essential components of SDM. In this SDM model, the MHP must: create an environment in which the client feels valued and respected; evaluate treatment options consistent with the client's values; provide the client with unbiased information on treatment options; and help the client weigh risks and benefits to arrive at a decision that is based on factual information. In this model, MHPs help clients clarify their preferences and select treatment options that are consistent with their values (Charavel et al., 2001). In this version of the SDM model, MHPs do not have an opportunity to express their preferences of treatment methods. Thus this model may provide more input from clients' decisions.

The Caldwell (2008) and the Charavel et al. (2001) SDM models have some significant differences. In the Charavel et al. (2001) SDM model, MHPs provide clients with information about treatment options and supports them in their decisions about treatment, and MHPs do not have an opportunity to provide their opinions beyond identifying the costs and benefits of treatment options. In the Caldwell (2008) SDM model, both the clients and MHPs consider the clients' values and treatment options and mutually come to a consensus allowing for MHPs to provide their opinions on the most suitable treatment options. It is important to note that Caldwell's (2008) SDM model more fully allows for self-determination, a principle by which clients alone determine their own destiny. SDM is different from self-determination in that in self-determination the client ultimately makes the decision, regardless of the process used to arrive at a decision (Anthony, 2010).

Shared Decision Making in Practice

From an ethical standpoint, MHPs are encouraged to support clients' autonomy whenever possible. The *Code of Professional Ethics for Rehabilitation Counselors* (Commission on Rehabilitation Counselor Certification [CRCC], 2010) is based on six principles, one of which is autonomy. The CRCC Code defines autonomy as respecting the rights of the client "to be self-governing within their social and cultural framework" (p. 2). "Autonomy, or fostering the right to control the direction of one's life" is also one of the core professional values in the professional code of ethics of the American Counseling Association (2014, p. 3). Autonomy, self-determination, and informed choice are principles that are fundamental in the counseling profession. However, Edwards and Elwyn (2006) noted that there is often a disconnect between theory and practice. While shared decision making is widely emphasized in the counseling profession, it is not necessarily widely practiced.

The *process* of making a decision and *making* the actual decision are two distinct processes in the SDM model. Including clients in the process of decision making involves actively listening to what a client has to say, as well as the message behind it. It is a process that conveys deep respect for the client as both a recipient of services and as a fellow human being. SDM enables the client to retain some of the power that is often yielded to the MHP in other more paternalistic models of decision making.

An important feature of the SDM models is the inclusion of clients in the process of making pivotal decisions about their care. Some evidence suggests clients have difficulty recalling where the locus of control laid when asked to recall who made important decisions regarding their care. In a study by Edwards and Elwyn (2006), clients engaged in the SDM process with a physician could not recall if final decisions about treatment were decided by the physician, client, or both. Rather, clients recalled whether or not they were included in the decision making process. This finding underscores the importance of including clients in the decision making process and the utility of the shared decision making process.

Including clients in the process of making decisions about their mental health treatment increases clients' level of engagement in the decision-making process as well as their knowledge, confidence, and commitment to change (Adams & Drake, 2006). Including clients in making decisions about their treatment may lead to a stronger

alliance between the client and MHP, as well as improved treatment adherence and client satisfaction (Adams & Drake, 2006; Adams et al., 2007).

Torrey and Drake (2010) suggested that, overall, clients of mental health services desire active participation in decisions about their care. Some research has found that clients who participate in SDM are more satisfied with their treatment and their MHPs (Curtis et al., 2010). However, not all research supports the SDM model. Conversely, some clients may rely on MHPs as trusted sources of information and become dissatisfied with SDM when their expectations for their consultation with a MHP are not met. Some clients seek the professional advice of MHPs in hopes of receiving a directive. In such a case, being informed of treatment options and risks and benefits may not be a welcomed discussion. Edwards and Elywn (2006) described this as “unwanted responsibility” (p. 317). It is important to acknowledge that there may be instances where a client, when presented with the choice, does not wish to take an active role in the decisions regarding his or her care (Torrey & Drake, 2010).

It is not the sole responsibility of the MHP to engage the client in the SDM process. Nor is it the sole responsibility of the client to engage the MHP in the SDM process. The responsibility of incorporating SDM lies equally with the client and the MHP. MHPs are more likely to be aware of the principles of shared decision making and similar concepts such as client autonomy, informed choice, self-determination, and self-advocacy. It is less likely that a client will be familiar with these concepts. Thus, MHPs are more likely to initiate SDM with clients than the other way around.

Cultural Considerations When Using Shared Decision Making

A cultural group is comprised of individuals with shared beliefs, attitudes, values, behaviors, and customs (Hulme, 2010). Many aspects of culture are learned by members of the group and passed from one generation to another (Hulme, 2010). Culture is often associated with an ethnic group or national origin, but is not necessarily restricted to these domains.

Other examples of culture include groups whose members share attributes such as sexual orientation, disability status, veteran status, immigrant status, and language. Variation typically exists in ethnic groups, as few cultures are strictly homogeneous (Hulme, 2010). It is important to note that, while culture impacts the way in which clients and MHPs make decisions, culture is only one of many factors that affect the decision-making process (Charles et al., 2006).

Culture may impact a client’s values, attitudes, and beliefs, which are all carefully considered in the SDM process. Hence, culture has a profound impact on SDM. Moreover, cultural competency is needed in order to use the SDM model when working with clients. The following are a few examples of cultural considerations when using SDM.

Some cultures may regard hallucinations as a welcomed visit from the spiritual world. In such instances, hallucinations are not always understood as being a psychotic symptom. Clients’ cultural values may lead them to regard certain symptoms as positive, desirable experiences, while the MHP may regard the same symptoms as something to be eliminated or managed in treatment. This may affect the client’s willingness to take prescribed medications (Hulme, 2010).

Some Latino clients may self-refer for *nervios* (nerves), a culture-bound syndrome, when they are experiencing anxiety in addition to psychotic symptoms. Latino clients may wish to eliminate or reduce anxiety and have no inclination to treat psychotic symptoms. They may prefer anxiolytics in place of antipsychotics in order to get relief from symptoms such as anxiety that they perceive as troublesome according to their cultural values. This relief, coupled with the desire to avoid side effects from antipsychotics, may motivate Latino clients to prefer anxiolytics and refuse antipsychotic medications (Hulme, 2010).

In some Native American cultures, particularly the Navajo culture, reality and events are considered to be shaped by thoughts and beliefs. It is thought that if a possible outcome is contemplated or discussed, the likelihood of the outcome being realized is increased (Hulme, 2010). In this instance, a MHP must be sensitive to this cultural value by rephrasing and reframing risks and benefits to focus on positive possibilities while still conveying accurate information.

Some clients may use home remedies or consider certain types of food as part of their lifestyle and to promote wellness and treat physical or mental health issues (Hulme, 2010). Some home remedies or certain types of food may interact with medications or lead to unintended interactions with parts of a treatment plan. In probing the client about home remedies and cultural foods, the MHP has an opportunity to convey respect for the client's culture as well as attempt to mitigate potentially harmful interactions.

Some clients or MHPs may speak English as a second language. Clients and MHPs who have a firm command of the English language may have difficulty understanding some information conveyed by clients and their loved ones who do not speak English as a first language. Language barriers may exist even if both the client and MHP speak the same language. This may lead to misunderstandings or learning incomplete information. Important information, such as treatment options, benefits, risks, and basic medical information may be misinterpreted or lost altogether (Steinberg, Bain, Li, Delgado, & Ruperto, 2003). Additionally, limited availability of resources in one's native language or lack of perceived cultural sensitivity may contribute to sentiments of distrust (Hulme, 2010).

In selecting treatment options, the client and MHP must consider and evaluate risks and benefits when developing treatment plans and considering various interventions and services. The way risk is conceptualized and assessed is influenced by the client's cultural frame of reference. A treatment modality that is a high or low risk to an individual of one culture may be interpreted as a different level of risk to a client from a different culture. Furthermore, what is perceived as a "positive" outcome may also be influenced by culture (Charles et al., 2006).

Attribution of cause or origin of mental illness may impact the client's attitude toward treatment (Charles et al., 2006). For example, some clients may perceive illness as one's destiny or a punishment from a higher power. This may affect the client's perceived locus of control and, consequently, treatment preferences.

Culture also affects who should be involved in the SDM process and how much influence each person has (Charles et al., 2006). Some clients may choose to make independent decisions about their care. Other clients may choose to involve parents, a significant other, grandparents, cousins, and other loved ones. In some cultures, the head

of the family may have more influence than the client in terms of choosing treatment modalities.

Conclusion

SDM is an interactive, collaborative process that allows clients and MHPs to work together as partners in recovery. While there is no one rigid model for the SDM process, there are common themes associated with the variations of the SDM model. Common themes include the exchange of information between the client and MHP, the incorporation of the client's values and culture into the decision-making process, and the formulation of a treatment plan that has a mutual consensus. The SDM process is invaluable because it promotes client autonomy, a core principle in the counseling profession's code of ethics, and is also associated with high client satisfaction. Since the client's culture and values are thoroughly considered when applying the SDM model, it is imperative that MHPs explore clients' cultural values and how they might impact clients' treatment decisions.

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