INVITED COMMENTARY


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The Center on Adherence and Self-Determination (CASD) housed at the Illinois Institute of Technology (IIT) is a multi-university center grant funded by the National Institute of Mental Health (NIMH). With IIT as the Principal Investigator, the other universities include Yale, Penn, Dartmouth, Rutgers, Temple, New York University, and University of Illinois. While serving as a Co-investigator at CASD, I was intrigued by the different positions taken on adherence and self-determination. I am particularly interested in the cross-cultural differences on conceptualizing self-determination. I found several cultural issues salient to the understanding and embracing of self-determination and I would like to put these issues on the table for dialoguing and discussion.

In American mental health circles, autonomy, the leading principle of modern biomedical ethics, is regarded as a core component of self-determination (Deci & Ryan, 1985). This Western conceptualization of autonomy upholds the value of individual independence and self-control. For that reason, self-determination is viewed as an important ingredient of successful recovery in psychiatric rehabilitation. Self-determination theory argues that autonomy, competence, and relatedness are three core components of self-determination and they are universal concepts—in other words, people from all cultures share these basic needs. However, there has been concern that the concept of self-determination may not be applicable to Chinese because an individual’s wellbeing may be threatened when cultural context blocks or interferes with the fulfillment of the three basic needs. Among the three basic needs, the concept of autonomy represents the most distinctive cultural difference between Chinese culture and mainstream American culture.

Markus and Kitayama (1991, 1994) attempted to examine how culture may influence how the self is perceived. They suggested two types of self-construal (independent and interdependent) and argued for the systematic influence of these differing self-concepts on cognition, emotion, and motivation. According to their self-construal theory, independent construal identifies the “self” as an entity that (a) comprises a unique, bounded configuration of internal attributes (e.g., preferences, traits, abilities, motives, values, and rights), and (b) that it behaves primarily as a consequence of these internal attributes. On the other hand, the interdependent construal view grants primacy to the relationship between self and others. This view of the self and the collective requires adjusting one’s self to fit in with important relationships, occupying one’s proper place in the group, engaging in collectively appropriate actions, and promoting the goals of others. Markus and Kitayama (1991) argued that the two construals of self are assumed to be present in every culture, but cultures vary in ways in which these orientations are weighted and organized in social life and how they manifest in individual thought and action. Thus, the variability of independent and interdependent self-construals frames our existential experience and serves as an anchoring point in terms of how individuals view communication-related behaviours such as help-seeking and medical decision-making.

Research appears to support these differences across cultures. In an investigation by Iyengar and Lepper (1999), European-American children were found to be motivated by...
making their own choices to play anagrams. Meanwhile, their Asian counterparts were found to be more motivated by choices made by in-group others such as family members or peers. Iyengar and Lepper argued that the lack of choice did not diminish the motivation of Asians because the self-construal of these children was different from that of their American counterparts. In self-construal theory, people from Asian cultures tend to endorse interdependent self-construal. They value interdependence and are more likely to perceive themselves as part of a group. Due to their desire for in-group belonging, Asians are eager to promote the goals of their groups. In fact, in collectivistic cultures, problems are not managed by the specific individual but shared by the family as a whole because the interdependent self is inseparable from other important relationships such as the family unit. Thus, Asian families have a strong influence on treatment and adherence in terms of family support as well as on patient and caregiver beliefs about the efficacy of treatment and the consumers’ perceptions of their illness (Miller & Hays, 2000). In Western mental health circles, it is generally believed that fostering an individual’s engagement in self-determination about care and providing choices will increase sense of personal control (e.g., Taylor, 1989; Taylor & Brown, 1988) and feelings of intrinsic motivation (e.g., Deci & Ryan, 1985). However, from an Asian perspective, being presented with more choices may in fact bring more confusion and reduce the level of motivation. Amartya Sen, a Noble Laureate of economics, echoed similar concerns. Sen (1992) stated that “facing more alternatives need not invariably be seen as an expansion of a person’s freedom to do the things she would like to do” (1992, p. 63) and the essential component to freedom is whether the options available are important and of value to the individual judging. Thus, a forceful adoption of autonomy and self-determination to Asian cultures has been questioned.

Writings from Western mental health literature, however, unequivocally endorse autonomy and self-determination in clinical practice and service delivery. According to The President’s New Freedom Commission on Mental Health (2003), self-determination is important and of high value because it offers people with psychiatric disabilities real and meaningful choices, which are considered an essential component for recovery. Similarly, research has shown that self-determination enhances client motivation, treatment adherence, better rehabilitation outcomes and quality of life (e.g., Langer & Rodin, 1976; Ryan & Deci, 2000; Wehmeyer & Schalock, 2001). Thus, the fundamental cultural difference on self-determination can have significant implications for mental health practice. It is clear that making their own choice without support or input from family members will create disharmony and distress among Chinese consumers.

A related issue on self-determination is the ethical dilemma that mental health professionals have to face. As health care professionals, we are taught to follow ethical principles of autonomy or respect for persons. We are also bound by a second guiding ethical principle—the right to beneficence or protection from undue harm. If self-determination is predicated on the ability of a person to act as the primary agent in one’s life, free from undue external influence—doesn’t having a mental illness (which, at times, may interfere with decision-making capacity) impair one’s ability to act in such a manner? And at some point, isn’t it our ethical and moral obligation to ensure that people do not make decisions that could in fact put them in harm’s way? How can we then talk about self-determination as a mechanism towards treatment adherence and engagement when many people with mental illness may not have the capacity for self-determination? How does one balance the obligation to ensure that those who need care the most receive it while at the same time respecting individual autonomy and choice? How can we help to enhance the degree to which an individual leads a self-determined life when in all societies there are natural limits to individual self-determination based on resources, opportunities, culture, and law? There are no easy answers to these questions and we all need to face these ethical dilemmas in our daily practice.

To resolve these dilemmas, we may have to rely on research evidence for guidance and direction. Most research on self-determination, however, has been conducted on people with intellectual disabilities (e.g., Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997, 1998). Among psychiatric consumers as to what, when, and how decision-making is determined has yet to be studied. Wouldn’t it be helpful if research can give us the answers to the following questions?

- What sorts of decisions are persons with psychiatric disabilities making in day-to-day life?
- What are the choices that are important and valued by persons with psychiatric disabilities?
- How much control do persons with psychiatric disabilities feel they have over the decisions that are made about their lives?

In an attempt to answer these research questions, Lam and his colleagues in China (Lam, Chen, & Deng, 2013) conducted a survey on a group of ex-psychiatric patients, their families and psychiatric care providers. The sample consisted of 76 ex-patients of a local psychiatric hospital and their family members. Psychiatric service providers such as case managers, psychiatric nurses, and psychiatrists who had worked closely with the consumer were also asked to complete the scale as well. Based on literature review and input from a focus group, the Consumer and Family Decision Making Scale (CFDMS) was constructed. The scale consists of 27 items that cover various aspects of day-to-day decision-making. A six-point Likert scale was used to assess its degree of self-determination. The scaling of the instrument divided into two vectors (consumer vs. family members, consumer vs. health care providers) at three levels (All, Most, Small), with 1 = family/health care provider made all decisions, 2 = family/health care provider made most decisions, 3 = family/health care provider made small decisions, 4 = consumer made small decisions, 5 = consumer made most decisions, and 6 = consumer made all decisions. Thus, the higher the score, the higher the consumer self-determination.

The CFDMS has three versions: one version to assess the consumer’s own view on self-determination, one to assess the family’s view, and the last one to assess health care providers’ views. The items are identical but the instructions
are phrased to suit the three distinct groups. Based on factor analysis, four factors were identified on the CFDMs (Table 1 shows the results).

- Factor 1—Personal/Social Function: includes items such as choosing types of jobs, whether to return to school/work, choosing friends, whether to get married, whether to date, what to wear, whether to have a religion;
- Factor 2—Illness Management: includes items such as whether to take medications, whether to stop medications, whether to follow the medication regimen, whether to attend follow-up visits, whether to participate in rehabilitation programmes;
- Factor 3—Daily/Community Living: includes items such as whether to purchase an expensive item (defined as costing >RMB$500), planning for daily activities, having a personal budget, participating in leisure/recreational activities, going on holiday, participating in community activities, doing volunteer work, purchasing medical insurance;
- Factor 4—Psychiatric Care: includes items such as whether to be admitted to psychiatric hospital, whether to be discharged from psychiatric hospital, choosing a psychiatrist.

ANOVA was conducted to compare the differences among the three groups for the four factors of the CFDMS; no significant differences among the three groups for all four factors were found. The results showed that all three groups have similar views on consumer self-determination. They were in agreement that decisions on mental illness management and psychiatric care should be delegated to family and health care providers. Consumers should be more engaged in self-determination in personal and social function and daily community living. Patient-reported items with the least degree of self-determination included whether to be admitted to psychiatric hospital (2.08, parents = 2.17), discharge from psychiatric hospital (1.9, parents = 2.28), and choosing a psychiatrist (2.47, parents = 2.31). Patients felt they should have most self-determination (highest ratings) on choosing friends (4.18, parents = 4.69), planning daily activities (4.29, parents = 4.59), participating in leisure/recreational activities (4.37, parents = 4.38), choosing what to wear (4.78, parents = 4.83), and finding hobbies (4.88, parents = 4.97).

The results, while preliminary, do shed light on Chinese consumers’ day-to-day life decision-making. Chinese psychiatric consumers tend to yield decision-making on psychiatric illness and treatment-related matters to their family and health care providers. They do, however, feel high autonomy in making choices on some personal and social matters. Bao and Lam (2008) view this type of decision-making as a “win-win” style of self-determination. It is possible for individuals to feel autonomous when they follow a choice made by others as long as they concur fully with and endorse this choice. If the consumers have internalized the choices made by trusted others (family and health care providers), they might experience autonomy although they did not make the choice. It seems that the “family-determination-oriented principle” is more relevant than the Western view of self-determination when working with Chinese consumers. Thus, the current system of health care decision-making, which is solely based on consumer autonomy and self-determination, may not be applicable in the same way to Chinese consumers and may actually create barriers to engagement in mental health services.

Although there is a heavy volume of literature indicating the importance of cultural differences and cultural values, the study of cultural variations and health care decision-making is still in its infancy. Therefore, it is important to investigate how different cultural values may intersect with those of the dominant culture, especially in the mental health care arena. More research is needed on how decision-making may be delegated or shared between consumers and family members as well as health care providers (Koenig, 1997). Until there is more research evidence to support self-determination among Asian consumers, the Western push for autonomy and self-determination may not be culturally relevant. I welcome readers who are interested in replicating the study to contact me; I look forward to further dialoguing on the issue and welcome your thoughts and discussion.

References


