Decision making and self-determination among Chinese people with schizophrenia and their families: Implications for cross-cultural considerations

Introduction

In recent years, recovery has been a key component in psychiatric rehabilitation. 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. Self-determination theory posits that people are motivated by a need to grow and gain fulfillment (Deci & Ryan, 1985; Ryan & Deci, 2000). For that reason, self-determination is viewed as an important ingredient of successful recovery in psychiatric rehabilitation.

Self-determination presumes both moral imperative and psychological reality. From an ethical stance, the individual with a mental illness, like all people, should have ultimate control over treatment goals and options. From a behavioral perspective, goals and plans will only be successful if made by the person to whom they apply (Corrigan et. al., 2012)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 realistic and meaningful choices that are considered an *essential component for recovery.* Similarly, research showed that self-determination enhances patient motivation, treatment adherence, better rehabilitation outcomes and quality of life (e.g., Langer & Rodin, 1976; Ryan & Deci, 2000; Wehmeyer & Schalock, 2001).

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, this raises questions about how self-determination is defined and the extent to which different cultural interpretations of self-determination exist among individuals from other cultural backgrounds. Wehmeyer (1996) defined self-determination “ acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference” (p. 24). There has been concern that the concept of self-determination may not be applicable to Asian culture because of its collectivist orientation whereby the individual’s autonomous choices may be in conflict with the group or the family’s expectations. In Asian culture, in fact 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 individuals have internalized the choices made by trusted others (e.g., family members), they might experience autonomy although they did not actually make the decision (Bao & Lam, 2008). 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 a family unit (Triandis, Bontempo, Villareal, Asai, & Nihon, 1988).

Statement of the problem

In view of different cultural interpretations of the concept of autonomy and self-determination, it is warranted to examine how people from Asian cultures to view self-determination and how to make decisions. Since the Chinese are the largest ethnic group in Asian cultures, approximately one-fifth of the world’ s population, thus the Chinese were chosen as the target cultural group for the current study. In the ensuing literature review, most research on self-determination has been conducted on people with intellectual disabilities (e.g., Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997, 1998) and there is a paucity of research being done in the area with people with psychiatric disabilities, not to mention from a cross-cultural perspective. As to what, when, and how decision-making among the Chinese people with psychiatric disabilities is determined has yet to be studied. Thus the current study aims to fill the void in the literature by investigating how the collective cultural influences on Chinese consumers of psychiatric services in making their day-to-day decisions. Specifically the study intends to answer the following research questions:

1. What sorts of decisions Chinese persons with psychiatric disabilities like to make in day-to-day life?
2. What are the choices considered important and valued by persons with psychiatric disabilities?
3. How much control do persons with psychiatric disabilities feel they have over the decisions that are made about their lives?

Following the research questions, we formulated three hypotheses:

1. The consumers would defer decision making to family members on matters that they feel important and need family involvement.
2. The consumers would be more willing to make decision on less important matters, and
3. There would be a significant association on decision-making between the consumers and the parents.

Methodology

*Sample*

The sample consisted of 78 native Chinese consumers of psychiatric services and their respective family members from Chengdu, a major city of Sichuan Province in China. The participants were recruited from a discharge list of a local psychiatric hospital and their respective family members during August – October 2012. Eligible participants must have a major diagnosis of schizophrenia based on ICD-10 diagnostic criteria. People with organic brain dysfunctions, psychosis induced by substance abuse, developmental disabilities, or with severe impaired cognitive functions that would prohibit the completion of the questionnaire were excluded from the study. Written informed consensuses were obtained from the consumers and their respective family members. Table 1 shows the characteristics of the sample.

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As depicted in the table, the sample seems to be younger as compared to other studies (Hasson-Ohayon, Roe, & Kravetz, (2007; Mueser, Meyer, Penn, Clancy, Clancy, & Salyers, 2006). Their scores on the Positive and Negative Syndrome Scale (PANSS, Kay, Fiszbein, & Opler, 1987) indicated as having a mild mental illness (Leucht, et.al., 2005). The scores on the Personal and Social Performance Scale (PSP, Morosini et. al., 2000) indicate having noticeable functioning difficulties but are not interfering with their role performance. Thus the sample consists of young, stable, and adequately functioning individuals with schizophrenia.

*Instrument Development*

To develop an instrument to measure the consumer’s daily decision-making, several strategies had been used. First, through a focus group led by the senior author and a research assistant. The focus group consisted of seven volunteer consumers and five volunteer parents. The group discussions were focused on what kinds of decision making they faced on daily lives, decisions that were important to them in living with the mental illness, and areas they wished they could have more control. The focus group lasted 90 minutes and 22 items were generated. To make the measure more comprehensive, we reviewed relevant literature and identified additional 10 questions. To establish the content validity of the items, the authors (except Dr. Corrigan) reviewed and rated the relevance of the items using a 5-point Likert scale, with 5 representing most relevant and 1 representing least relevant. Cohen’s Kappa was used to measure inter-rater reliability. Through the analysis of the inter-rater reliability, 27 items were retained. Those deleted items deemed to be cultural irrelevant, e.g., whether to obtain a driver’s license, whether to live in a group home, whether to register to vote, to name a few. The CFDMS consists of 27 items with a six-point Likert scale, in which 1 = consumer made minimal decision, e.g., 0-10% of the time, 2. Consumer made little decision, e.g., 10-20% of the time, 3. Consumer made some decision, e.g., 30-40% of the time, 4. Consumer made frequent decision, e.g., 50-60% of the time 5. Consumer made most decision, e.g., 70-80% of the time and 6. Consumer made nearly all decision, e.g., 90-100% of the time. Thus, higher the score, higher is the degree of consumer self-determination.

The CFDMS has two versions: one version to assess the consumer’s own view on self-determination and the other to assess the family’s view on decision making. The items of the two versions were identical except the instructions were phrased to suit the specific group. Trained research assistants performed the administration of CFDMS. The interview was conducted on a one-to-one basis to the participants and their respective family members, either a mother or father of the participant. The administration time was about 30 minutes on average.

To determine the internal structure of CFDMS, an exploratory factor analysis (EFA) was performed on the total sample, i.e., consumers and parents, assuming that both groups would have similar responses to the items. Based on Cattell’s scree test and varimax rotation with Kaiser normalization, four factors, which accounted for 53.18% of the variance, were identified. Three items, “Whether return to work”, “Whether to purchase an expansive item (over $500), and “whether to move out from home” were not loaded in any factor and therefore were eliminated from data analysis. Thus the final version of CFDMS consists of 24 items. Table 2 shows the factorial structure of CFDMS.

* Factor 1—Personal/Social Function (8 items accounted for 29.27% of the variance): includes items such as choosing types of jobs, whether to return to school, choosing friends, whether to get married, whether to date, what to wear, whether to have a religion, and finding hobbies;
* Factor 2—Illness Management (6 items accounted for 11.57% of the variance): includes items such as whether to take medications, whether to stop medications, whether to decrease medication, whether to follow the medication regimen, whether to attend follow-up visits, whether to participate in rehabilitation programs;
* Factor 3—Daily/Community Living (7 items accounted for 6.59% of the variance): includes items such as, planning for daily activities, having a personal budget, participating in leisure/recreational activities, going on vacations, participating in community activities, doing volunteer work, purchasing medical insurances;
* Factor 4—Psychiatric Care (3 items accounted for 5.75% of the variance): includes items such as whether to be admitted to psychiatric hospital, whether to be discharged from psychiatric hospital, choosing a psychiatrist.

<< Insert Table 2 Here >>

To establish the CFDMS’s internal consistence, Cronbach’s Alphas for the four subscales were obtained for both the consumer and family member CFDMS. The family member’s CFDMS alpha score is presented in bracket. The Cronbach’s Alphas are as follows: I. Personal/Social Function = .87 (.73), II. Illness Management = .87 (.82), III. Daily/Community Living = .84 (.80), and VI. Psychiatric Care = .74 (.70). Overall CFDMS possesses sufficient internal consistency.

*Results*

To test hypotheses 1 and 2, paired t-tests on the four CFDMS subscales were performed. Table 3 shows the results. The results show that consumers rated four areas of decision-making with significant differences. As expected, the results support the hypotheses; consumers exercised more decision-making on matters that are less important and defer decision-making to parents on medically and illness related matters.

<< Insert Table 3 Here >>

To test hypothesis 3, a bivariate correlation was calculated to examine the relationship and a paired t-test was performed to find out the difference between the consumer’s and family member’s ratings on the CFDMS. Table 4 shows the results.

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The results showed that two groups had similar views on day-to-day decision-makings. Thus the hypothesis was supported. The correlation coefficients show a significant agreement on decision-making between consumers and their respective parents; Factor 1 Personal/Social Functions, r =.398, p <.05, Factor 2 Illness Management, r = .663, P < .001, Factor 3 Daily/Community Living r = .523, p < .001, and Factor 4 Psychiatric Care, r = .461, p <.001. Descriptive statistics provide further information on the consumers and family members’ decision-making tendency.

From the consumer’s perspective, the lowest degree of self-determination is in the area of Psychiatric Care (consumer mean = 2.21 (1.32) vs. family mean 2.31 (1.31)

followed by Illness Management (consumer mean = 2.75 (1.38) vs. family mean = 2.58, (1.29). Areas that consumers were more willing to make self-decision are Personal and Social Functions (consumer mean = 4.52 (1.12) vs. family mean = 4.71 (.98) and Daily and Community Living (consumer mean = 3.75 (1.07) vs. family mean = 4.09, (1.02).

Discussion

The results, while preliminary, shed light on Chinese consumers’ day-to-day life decision-making. Based on the factorial structure of the CFDMS, it is presumably that Chinese people with psychiatric disabilities are facing four major areas of decision-making in their daily lives. As expected, Chinese psychiatric consumers tend to yield decision-making to their family members on matters related to psychiatric care and illness management. This form of *Shared or Deferred Decision Making within Families* is common in Chinese culture (McLaughlin & Braun, 1998). In Chinese culture, important decisions tend to be made by families and groups, rather than by individuals. 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 a family unit (Triandis, Bontempo, Villareal, Asai, & Nihon, 1988). 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 the collective and/ or the others. Markus and Kitayama (1991) argued that the “independent self” and “inter-dependent 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 are manifested in individual thoughts and actions. Thus, the variability of independent and interdependent self construals frames our existential experiences and serves as an anchoring point in terms of how individuals view help seeking and medical decision-making (Lee, Lam, & Ditchman, in-press).

Bao and Lam (2008) offer another view on Chinese family decision-making. They found that 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. In that sense, if the consumers have internalized the choices made by trusted others (e.g., family members) they might experience autonomy although they did not actually make the decision. Our post research debriefing with the participants confirmed such observation.

Obviously, Chinese family has a strong influence on treatment and adherence in terms of family support as well as on consumer and parent beliefs about the efficacy of treatment and the consumers’ perceptions of their illness (Miller & Hays, 2000). Clinical implications of the results could be that family members typically assume that it is their responsibility to make treatment decisions and be with the consumer when the consumer talks to the professional. The professional who is unfamiliar with these cultural differences may perceive this as manifestation of the person’s dependency or family’s over-involvement (Lee, Lam, & Ditchman, in-press). If the professional attempts to confront or correct this behavior, it may lead to confusion and a sense of humiliation, potentially resulting in premature termination. Research findings support this assertion and highlight the importance of the family in treatment among Chinese consumers. In a cross-cultural study by Lin and colleagues (1991), Asian consumers with schizophrenia were accompanied by one or more family members when they showed up for a session, while Caucasian consumers attended sessions without family members. In addition, an Asian consumer’s first visit to the mental health service often is initiated by his or her family member instead of the consumer.

The results show that consumers were more willing to exert self-determination on personal and social matters than on medical and psychiatric care matters. Similarly, parents agree that consumers should have more say deciding personal and social matters (ratings between 4.09 – 4.71). Post research debriefing suggests that parents actually want to see the consumers be more assertive in decision making regarding social and community involvements. Such desire could be a reaction to the low self-initiation of the consumers and it also could be that parents recognize the value of autonomy and self-determination in the recovery process. However, parents are yet to allow consumers to have autonomy on deciding course of treatments. This could due to the fact that the parents believe the consumers do not have the capacity to make good decisions and are discomfort at the shift in roles of decision-making. The results highlight the tension between autonomy and beneficence.

The concept of individual centrality that is so elementary in the West stands challenged in the East. Research is needed to understand the consumer’s concept of autonomy and the role of the family as perceived by the consumer in medical decision-making. 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).

Finally, extent to which contemporary models of self-determination and shared-decision making apply and are useful for working with consumers from different cultures requires careful examination. Shared-decision making models that integrate family-centered decision making rather than a focus on the individual’s desires may be more appropriate for individuals from an Asian background. Strategies for improving involvement in decision making in order to reach optimum health outcomes for diverse populations must be identified through rigorous empirical studies. 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.

Limitations of the study and and implications for future studies

Several limitations of the study should be noted. The CFDMS items are by no means exhausive to represent actual day-to-day decision makings faced by Chinese people with psychiatric disabilities. It is quite possible that there are other areas of decision-making not included in the CFDMS. Future participatory research in this area should include more inputs from consumers and family members. The internal consistency of the four factor scales are quite acceptable except for the Psychaitric Care Scale, which has only three items. Future study may consider to increase items for this subscale. Possible items could include “whether to engage in psychotherapy”, “whether to attend family psycheducation workshops”, “whether to attend medication management and stress mangement training program”, to name a few.

It also should be noted the sample size of the study is small and has its unqiue characteristics such as younger and all are living with families. Thus it is natural for the family to have greater influence on the consmer’s day-to-day decision-making. Cautions should be made in the generalization of the results to other individuals with psychaitric disabilities. Future studies should employ a large sample size that includes participants who are older and not living with their parents. To further understand the concept of family decision and self-determination, other samples could be considered such as a normal control group, people with physical disabilities, people with medical conditions or with chronic illnesses. In addition, it will be benefitial to have a comparable sample from Western socities to compare cross-cultural differences on self-determination.

Table 1. Characteristics of the participants (N= 78)

|  |  |
| --- | --- |
| Characteristic |  |
| Age | 28.97 (11.05) |
| Gender |  |
| Male | 43 |
| Female | 35 |
| Education |  |
| Elementary | 18 |
| High school | 33 |
| Some college | 27 |
| Marital status |  |
| Single | 60 |
| Married | 14 |
| Divorced | 4 |
| Occupational status |  |
| Part time working | 8 |
| Not working | 70 |
| Diagnosis |  |
| Schizophrenia | 78 |
| Age of onset | 21.18 (SD 6.65) |
| Number of hospitalizations | 1.97 (SD1.36) |
| PANSS score | 54.93 (SD 13.73) |
| PSP score | 61.35 (SD 15.73) |

Note:

**PANSS** *=***Positive and Negative** Syndrome Scales

PSP = Personal and Social Performance Scale

Table 2. Factorial structure with loading on the CFDMS

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Items | Component | | | |
| 1  (29.27%) | 2  (11.57%) | 3  (6.59%) | 4  (5.75%) |
| To choose the type of occupations and jobs | .455 | .227 | .096 | .249 |
| Whether to return to school | .693 | .101 | -.034 | .242 |
| To choose friends | .783 | .125 | .124 | .170 |
| Whether to get married | .696 | .086 | .198 | .192 |
| Whether to date | .657 | .049 | .240 | .130 |
| What to wear | .611 | .230 | .348 | -.175 |
| Whether to have a religion | .595 | .062 | .243 | -.018 |
| To find some hobbies | .563 | .036 | .434 | -.250 |
| Whether to take medications | .329 | .772 | -.011 | -.019 |
| Whether to stop medications | .107 | .772 | -.077 | .215 |
| Whether to decrease medications | -.059 | .794 | -.011 | .113 |
| Whether to follow medication regiment | .222 | .813 | .135 | .065 |
| Whether to attend follow-up visits | -.067 | .605 | .327 | .316 |
| Whether to participate in rehabilitation program | .116 | .559 | .362 | .181 |
| To plan for daily activities | .474 | .010 | .657 | .051 |
| To have a personal budget | .136 | .320 | .530 | .027 |
| To participate in leisure and recreational activities | .379 | .100 | .580 | .132 |
| To go on a vacation | .094 | .097 | .644 | .304 |
| To participate in community activities | .178 | .097 | .769 | .018 |
| To participate in community volunteer activities | .196 | .034 | .814 | .097 |
| To purchase medical insurance | .120 | .330 | .427 | .399 |
| Whether to be admitted to the psychiatric hospital | .034 | .355 | .098 | .481 |
| Whether to be discharged from the psychiatric hospital | .026 | .107 | .120 | .823 |
| To choose a psychiatrist | .189 | .261 | -.045 | .696 |
| Whether to return to work\* | .163 | -.057 | .199 | .245 |
| Whether to move out from the family\* | .247 | .282 | .182 | .254 |
| Whether to purchase an expensive item (over $500)\* | .110 | .048 | .207 | .157 |

Note \* items did not load to any factor

Table 3 Consumers’ rating on CFDMS Factor Scales

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Factor1 | | Factor2 | | Factor3 | | Factor4 | |
|  | t | *p* | t | *p* | t | *p* | t | *p* |
|  |  |  |  |  |  |  |  |  |
| Factor1 |  |  |  |  |  |  |  |  |
| Factor2 | 9.417 | .000\*\* |  |  |  |  |  |  |
| Factor3 | 6.164 | .000\*\* | -5.988 | .000\*\* |  |  |  |  |
| Factor4 | 11.921 | .000\*\* | 3.089 | .003\* | 8.481 | .000\*\* |  |  |

\* p < .005

\*\*p < .001

Corrected alpha .05/6 = .008

Table 4 Consumers and Parents ratings on the CFDMS

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Consumer | Parent | *t* | *p* | *r* | *p* |
| **Factor 1**  **Personal/Social Function** | **4.52(1.12)** | **4.71 (.98)** | **-.981** | **.329** | **.398** | **.002** |
| To choose the type of occupations and jobs | 4.03(1.69) | 4.22(1.68) |  |  |  |  |
| Whether to return to school | 4.22(1.52) | 4.26(1.70) |  |  |  |  |
| To choose friends | 4.57(1.63) | 4.76(1.36) |  |  |  |  |
| Whether to get married | 4.40(1.68) | 4.48(1.60) |  |  |  |  |
| Whether to date | 4.48(1.65) | 4.64(1.47) |  |  |  |  |
| What to wear | 4.76(1.57) | 5.10(1.32) |  |  |  |  |
| Whether to have a religion | 4.81(1.33) | 5.07(1.26) |  |  |  |  |
| To find some hobbies | 4.88(1.30) | 5.24(.92) |  |  |  |  |
| **Factor 2 Illness Management** | **2.75(1.38)** | **2.58(1.29)** | **.735** | **.464** | **.663** | **.000** |
| Whether to take medications | 2.79(1.80) | 2.55(1.74) |  |  |  |  |
| Whether to stop medications | 2.40(1.63) | 2.28(1.52) |  |  |  |  |
| Whether to decrease medications | 2.52(1.59) | 2.41(1.52) |  |  |  |  |
| Whether to follow medication regiment | 2.76(1.82) | 2.34(1.59) |  |  |  |  |
| Whether to attend follow-up visits | 2.69(1.71) | 2.50(1.61) |  |  |  |  |
| Whether to participate in rehabilitation program | 3.40(1.74) | 3.38(1.85) |  |  |  |  |
| **Factor 3** **Daily/Community Living** | **3.75(1.07)** | **4.09(1.02)** | **-1.705** | **.091** | **.523** | **.000** |
| To plan for daily activities | 4.45(1.39) | 4.14(1.55) |  |  |  |  |
| To have a personal budget | 3.66(1.77) | 3.81(1.75) |  |  |  |  |
| To participate in leisure and recreational activities | 4.41(1.46) | 5.05(1.19) |  |  |  |  |
| To go on a vacation | 3.52(1.70) | 3.83(1.77) |  |  |  |  |
| To participate in community activities | 4.05(1.72) | 4.79(1.34) |  |  |  |  |
| To participate in community volunteer activities | 3.95(1.61) | 4.71(1.40) |  |  |  |  |
| To purchase medical insurance | 2.26(1.48) | 2.28(1.62) |  |  |  |  |
| **Factor 4** **Psychiatric Care** | **2.21(1.32)** | **2.31(1.31)** | **-.261** | **.759** | **.461** | **.000** |
| Whether to be admitted to the psychiatric hospital | 2.03(1.48) | 1.86(1.34) |  |  |  |  |
| Whether to be discharged from the psychiatric hospital | 2.26(1.51) | 2.51(1.65) |  |  |  |  |
| To choose a psychiatrist | 2.47(1.52) | 2.66(1.75) |  |  |  |  |

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