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ORIGINAL ARTICLE

Mental health service user participation in Chinese culture: a model of independence or interdependence?

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Abstract

Background: Current models of user participation in mental health services were developed within Western culture and thus may not be applicable to Chinese communities.
Aims: To present a new model of user participation, which emerged from research within a Chinese community, for understanding the processes of and factors influencing user participation in a non-Western culture.
Method: Multiple qualitative methods, including focus groups, individual in-depth interviews, and photovoice, were applied within the framework of constructivist grounded theory and collaborative research.
Results: Diverging from conceptualizations of user participation with emphasis on civil rights and the individual as a central agent, participants in the study highlighted the interpersonal dynamics between service users and different players affecting the participation intensity and outcomes. They valued a reciprocal relationship with their caregivers in making treatment decisions, cooperated with staff to observe power hierarchies and social harmony, identified the importance of peer support in enabling service engagement and delivery, and emphasized professional facilitation in advancing involvement at the policy level.
Conclusions: User participation in Chinese culture embeds dynamic interdependence. The proposed model adds this new dimension to the existing frameworks and calls for attention to the complex local ecology and cultural consistency in realizing user participation.

Keywords

User participation model, mental health service, Chinese culture, recovery

History

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Introduction

Is the conceptualization of service user participation (SUP) a universally understood and implemented ideology in mental health services (MHS)? What are the key dimensions to which we must attend in turning the rhetoric regarding SUP into reality? Grounded in Western ideologies of consumerism and citizenship (Beresford, 2002), SUP is defined as service users' involvement in decision-making processes regarding all aspects of their mental health care, beginning with but going beyond situations that directly involve their treatment and life (Hickey & Kipping, 1998, p. 84). These processes involve ''a shift of power distribution from providers to service users'' (Storm & Davidson, 2010, p. 112). A clear framework of how SUP is conceptualized and can be realized in non-Western cultures is yet to be developed.

Hickey & Kipping (1998) suggested that user participation manifests across a ''participation continuum'' in four positions: ''information/explanation,'' ''consultation,'' ''partnership'' and ''user control.'' Their proposition echoes the ''ladder of participation'' (Arnstein, 1969) that distinguishes eight forms of participation, from manipulation to citizen control. Although the work of Arnstein, Hickey and Kipping provides useful frameworks for understanding SUP in different degrees and intensities as well as the power relationships between service providers and users, they offered little discussion of how service users could navigate along the continuum or ladder. Moreover, these conceptualizations of SUP, with their core focus on decisional control and independence in a linear approach, may not fully capture or explain the complex dynamics that affect implementation processes and outcomes, especially in non-Western cultures (Tse et al., 2015). (2014)

In a different approach, Tambuyzer et al. (2011) proposed a comprehensive model of patient involvement in mental health that offers a more elaborate framework for the incorporation of the complex components of participation. Similarly, their model also depicts a linear process of SUP and under-emphasizes the cultural dimension in the realization of SUP (Tse et al., 2015). Storm & Edwards (2013) examined various care models in association with user participation and involvement in mental health. Placing patient-centeredness, patient participation and shared decision-making under the overarching recovery model, their work provides a wider context for understanding varying

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degrees of SUP rather than looking into the influencing factors or SUP processes.

All these conceptual models make a unique and valuable contribution to understanding the forms and orientation, determining forces and outcomes of SUP in MHS. However, they were developed predominantly within Western cultures and each has its own limitations. The extent to which these models are relevant and sensitive to Chinese culture remains an unanswered question. Tse et al. (2015) argued that the implementation of SUP needs to consider the influence of cultural ideologies and beliefs. Highlighting a deep-rooted Confucian and paternalistic culture in Chinese communities, which emphasizes respect of authority, social harmony, and interdependence among family members, they further proposed that user involvement is a culturally bound concept that demands culturally consistent models for operationalization.

Although studies on mental health SUP in Chinese communities (Lam, 2014; Leung & Lam, 2014; Ng et al., 2013) are emerging, we have found no conceptual model for SUP responding to this cultural context. Given the recent emergence of the recovery orientation and the growth of SUP in mental health care in Hong Kong (Davidson & Tse, 2014), there is a pressing need to identify a culturally responsive conceptual model for informing the practice of SUP in MHS among Chinese communities. In this paper, the authors aim to discuss further the conceptualization of SUP in non-Western culture based on a study conducted in Hong Kong, an international city under China's sovereignty. Building on a model first proposed by Tang & Tse (2015), this paper presents a new version of the SUP model in mental health care with emphasis on the dynamic interaction of all parties in the processes to influence its intensity and outcomes. This model offers an alternate framework for understanding SUP from a cultural dimension and to fill the conceptual gap in the literature.

Design

This was a collaborative study designed to involve individuals with personal experience of mental illness and of using MHS, as peer researchers. It was based on the assumption that the participatory approach may contribute to the construction of new knowledge about health inequalities and the resources required to challenge such inequalities (Beresford, 2007). Involving service users in research is an under-cultivated practice in Hong Kong and other Chinese communities (Leung & Lam, 2014). In engaging service users in the research process, we attempted to achieve a power balance between them and the researchers (Faulkner, 2012) which would also contribute to the rigor of the research (Balazs & Morello-Frosch, 2013). Peer researchers were recruited with the aid of a local self-help organization for persons in recovery from mental illness. The first author conducted a short interview with potential peer researchers to clarify the study's goals and both parties' expectations of the collaboration. One female and three male participants aged between their early twenties and early fifties were engaged as peer researchers. The first author also organized two training sessions to provide them with basic knowledge on conducting focus groups and data analysis. A research team comprising the authors and four peer researchers was formed to carry out the research design, data collection and data analysis in various stages.

Adopting social constructivist grounded theory (Charmaz, 1994) as the overarching methodology, multiple qualitative methods were employed, including focus groups, individual in-depth interviews and photovoice (Wang, 1999) to generate data and attain data source triangulation. Photovoice was adopted as a community-based participatory approach to capture the voices of marginalized groups (Mizock et al., 2014). Participants involved in the individual in-depth interviews and photovoice study also completed a self-administered questionnaire including the 45-item Stages of Recovery Scale (SRS) (Song & Hsu, 2011) and eight questions on demographic details. The scale assessed the component processes of recovery in three dimensions: regaining autonomy, disability management or responsibility taking and sense of hope. It also evaluated the outcomes of recovery in relation to general well-being, social functioning and assisting others. The first author also conducted three face-to-face interviews with advocates in the mental health user movement during a study visit to the United Kingdom to gather first-hand data for comparison with local SUP experiences. The number of participants in the study was not pre-set but rather, informed by an emerging process of the constructivist grounded theory. Guided by the theory, data collection was terminated as constant comparisons found that codes and themes arrived at a saturated state with limited new data identified. Further details of the methodological design, procedures and data analysis have been reported in Tang & Tse (2015), while the findings of the photovoice study are discussed in a separate paper (Tang et al., 2016).

Results

Participant characteristics

Altogether 15, 23 and 3 participants took part, respectively, in three focus groups, two rounds of individual in-depth interviews,, and a photovoice study over 5 months. The participants included 22 females (one of whom attended both a focus group and an individual in-depth interview while another joined an individual in-depth interview and the photovoice study) and 17 males, with a mean age of 44.7 years. They were all living in the community when the study was conducted. The majority had completed secondary school education ($n = 21$, 53.8%), and nine (23.0%) also had a tertiary education. Among the participants with a tertiary education, three reported active involvement in various self-help organizations for individuals with mental illness. Detailed demographics of participants were outlined in Table 1.

Twenty-four of the participants completed the self-reported SRS. More than half (58.3%) reported a mid-range (living with disability) or advanced stage (living beyond disability) of recovery. While one participant felt ''overwhelmed by disability,'' the rest (37.5%) found themselves ''struggling with disability.'' Among those ''living beyond disability,'' three were leaders in self-help organizations. The participant ''overwhelmed by disability'' was a young man

Table 1. Demographics of individual in-depth interview participants.

Participant	Gender	Age	Diagnosis	Years since diagnosis	Marital status	Education	Employment status
Alice	F	62	Depression	40	Married	Secondary	Housewife
Becky	F	33	Schizophrenia	7	Single	Tertiary	Seeking job
Charles	M	64	Schizophrenia	30	Divorced	Primary	Retired
Danny	M	60	Paranoid schizophrenia	12	Married	Secondary	Retired
Florence[a]	F	25	Schizophrenia and depression	7	Single	Secondary	Student
Gloria	F	58	Bipolar disorder	32	Single	Tertiary	Retired
Howard	M	43	Schizophrenia	17	Single	Secondary	Not seeking job
Ivan	M	41	Schizophrenia	18	Single	Secondary	Not seeking job
John	M	54	Schizophrenia	31	Married	Primary	Retired
Karen	F	49	Schizophrenia	19	Married	Primary	Housewife
Lucy	F	64	Unknown	7	Divorced	None	Housewife
Michelle	F	16[b]	Bipolar disorder	3	Single	Secondary	Student
Natalie	F	54	Paranoid schizophrenia	2	Divorced	Secondary	Not seeking job
Oscar	M	51	Depression	20	Single	Tertiary	Not seeking job
Peter	M	54	Paranoid schizophrenia	22	Married	Tertiary	Seeking job
Queenie[a]	F	56	Bipolar and Schizophrenia	20	Divorced	Secondary	Retired
Rex	M	24	Bipolar disorder	0.5	Single	Tertiary	Not seeking job
Sally	F	47	Schizophrenia	31	Single	Tertiary	Retired
Tom	M	56	Schizophrenia	30	Single	Secondary	Retired
Venus[c]	F	40	Schizophrenia	15	Single	Tertiary	Seeking job
Winnie[d]	F	49	Schizophrenia	19	Single	Secondary	Working part-time
Xavier	M	52	Depression	14	Single	Secondary	Retired
Yates	M	29	Schizophrenia	12	Single	Secondary	Working part-time

[a]Two diagnoses were identified in the participants' medical records. The psychiatrists performing the diagnostic assessment could not be reached for clarification and the information was thus preserved.
[b]Verbal consent was obtained from the mother of this participant via the responsible social worker.
[c]This participant also joined the focus group discussion.
[d]This participant also joined the photovoice study.

who had experienced a recent onset of illness 6 months preceding the research interview.

Concepts of SUP

Findings from the three qualitative methods show no unified understanding of the concept of SUP among participants in the current context. Participants in the focus groups and individual in-depth interviews defined the concept as ''attending program activities'' in MHS. ''Exercising rights and control'' and ''advocacy for rights and change'' in service management and policymaking were identified among a few participants who were also members of self-help organizations.

On the other hand, participants in the photovoice study offered a wider range of the meanings of the concept, including ''self-direction and taking charge,'' ''citizenship and community contribution,'' ''advocacy and anti-stigma education,'' and ''peer support'' (Tang et al., 2016). Yet the findings showed that involvement in individual care was predominantly oriented toward self-management for the achievement of personal well-being, rather than as a demonstration of user rights or citizenship.

Relational dynamics in SUP

Further to these personal definitions of the concept, the participants recounted experiences that revealed dominant themes around *power inequality*, *giving trust to professionals*, *family involvement in decision-making* and *peer support.* Since the findings of this study have already been reported in Tang & Tse (2015), only a brief account of the results that gave rise to the proposed model will be given here.

Remarkably, professionals were identified as both barriers and enablers in SUP across findings of the focus groups, individual in-depth interviews and the photovoice study. Despite the unequal power relationships between service providers and users, and the associated diminished control in individual care and service management described among users, the participants showed a tendency to cooperate with mental health professionals in the course of service use. Many gave their trust to the professionals with respect to treatment and care, and some valued professional input in enabling their involvement in a policy-level participation.

In the familial context, many participants, especially the younger ones in the late teens or early adulthood, valued reciprocal care with their caregivers. Giving weight to the love and concern of family members, parents in particular, they subordinated their thoughts and feelings to carers' suggestions and needs in treatment-related decisions. A sense of relatedness and interdependence was indicated. Dependence on family involvement was found more often in the early stages of illness. The participants involved in self-help organizations also identified resources, support and freedom from family demands as critical to a higher level of participation at the advocacy and policy levels.

Lastly, some of the participants highlighted peer support as an enabling force for SUP in service engagement and delivery. They found it to be a powerful bridge for engaging individuals with lived experience of mental illness in service use, service delivery and management as well as for promoting recovery. Detached relationships and lack of deep connection among peers were identified as factors diminishing commitment to SUP.

In short, the findings of the current study show that SUP is a notion involving complex, intertwining contacts and

interactions between persons in recovery from mental illness and mental health professionals, the recovering individual and their close kin and among peers. On the other hand, personal factors of the service users, like their choice to trust professionals, also influence the interactive process of SUP. In an earlier conference paper, we proposed a preliminary model to present the results (Tang & Tse, 2015). Based on the interaction and exchange at the conference, the first author revisited the data and reviewed the analysis with experienced researchers, including the co-authors. Several limitations of that model were identified: bi-directional interactive (enabling/deterring) dynamics between persons in recovery and the three other significant players – family, professionals and peers – were not indicated; the relatedness between these players was not clearly represented; the presentation of the four players in a top-down sequence may lead to a misinterpretation of their power hierarchy. Further to these reflections and comparisons made with the existing conceptualization models, a new model of SUP (Figure 1(a)) embedding the interdependence of these multi-relational forces was developed and proposed in the present paper.

In this model, SUP is conceptualized as a complex, dynamic process in which an individual navigates through various levels and degrees of participation in a continuum in response to micro-interactions between enablers and barriers within specific relational contexts. The individual in recovery from mental illness, mental health professionals, family and peers may all influence the process to facilitate or hinder SUP in individual care, service management and advocacy and policymaking. While barriers work to diminish control and involvement, enablers work to support meaningful and higher participation, which may in turn bring positive outcomes for the individual or the MHS. Equally, the positive outcomes may reinforce service users' further involvement. In Figure 1(a), circles and dotted lines are used to denote the possibility of change as well as variation in the influence that each party may exert in SUP. Each circle can inflate or deflate in connection to the stage of recovery, specific service context and culture during the participation process. Figure 1(b) demonstrates how this model applies to the findings emerging from the current study. Within the Chinese community, professionals and the family play the most important role in influencing SUP, while peers exert the least force.

The story of Yates, a participant in the in-depth interviews, may further illustrate how the conceptualization applies. At the time of interview, Yates was 29 years old and working as a peer support worker (PSW) in a residential facility for persons in recovery from mental illness. Before he became a PSW, he had received vocational training in supported employment but he could not accomplish the training. With information, encouragement and facilitation from a mental health professional, he enrolled on PSW training, graduated and became a PSW. To Yates, the access to information about an alternative vocational opportunity, and the support and trust of the professional enabled him to progress in his personal recovery and, later, to get involved in service delivery. Although he valued professional involvement, he also asserted himself as an active agent and made the final decision and determination to pursue the pathway he believed to be most helpful to his recovery.

In the familial dimension, Yates pointed out that the financial support of his father and brother and their respect of his choices relating to service use and vocational development were essential. He would not otherwise have been able to exercise autonomy in deciding his own recovery pathway. While acknowledging the significant role of family in Chinese culture, Yates also highlighted a need to examine and respect the individual's will and thoughts about family involvement. This interactive force between the family and the person in recovery is captured in the proposed model.

After Yates became a PSW, he acted as a bridge between service users and the staff team. He found himself trusted by service users, experienced a stronger degree of involvement in supporting his peers and was able to offer a peer perspective on service delivery. At the same time, he also faced challenges in exerting a genuine influence on decision-making in the multidisciplinary and paternalistic staff team. Despite this, he strived to enhance his ability to make users' voices more audible, and to get involved in user-led initiatives and self-help organizations. Navigating the barriers encountered at various levels of involvement, Yates felt empowered, enjoyed personal growth and a sense of worth and progressed in his recovery.

Discussion

A model of independence or interdependence

Existing conceptual frameworks for SUP emerged from Western cultures and ideologies, place the service user at the center, and put great emphasis on consumerism, citizenship and self-direction (Arnstein, 1969; Barnes et al., 2004; Borg et al., 2009; Davies et al., 2014; Hickey & Kipping, 1998; Lammers & Happell, 2003; McDaid, 2009; Storm & Edwards, 2013). Within these frameworks, individuals are seen as more distinct and independent entities with rights to self-determination, personal strengths and capabilities for growth. In Chinese culture, however, individuals are connected to each other and there is an emphasis on relatedness, interdependence and social harmony (Tse et al., 2015; Yip, 2004). Respect is usually given to experts, authorities and significant others, as stipulated by the Confucian social hierarchy of Five Relationships (*wulun*, 五倫) and the core tenet of propriety (*li*, 禮). While *li* lies at the root of social stability, which develops and maintains social order and harmony (Sun, 2008), *wulun* defines the role of an individual within the family and society on a superior/inferior basis. When the hierarchical order in *wulun* is respected, there is no conflict or tension (Yeung & Ng, 2011). The extent to which Western models may fit the understanding and realization of SUP in Chinese communities is open to question.

Firstly, trusting professionals and respecting their knowledge matches the Confucian culture of *wulun* and the core tenet of *li*. These Confucian teachings guide the individual to observe social order and to maintain social harmony and stability rather than to assert personal rights and control. As one of the photovoice participants stated, despite his discontent with the routine service, he chose to respect, cooperate and maintain a good relationship with the professional. The participants with leading positions in self-help organizations

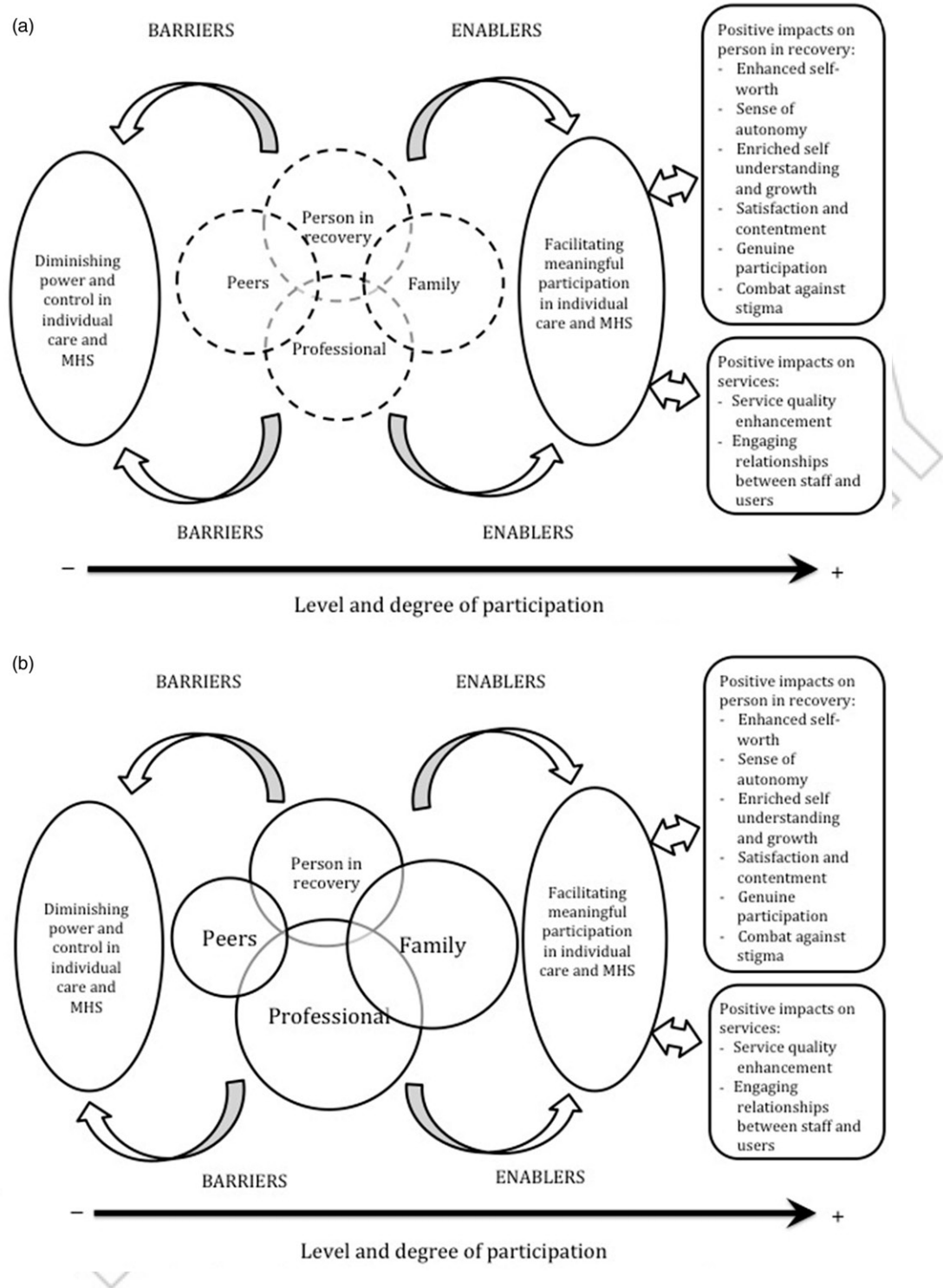

Figure 1. (a) Multi-relational model of SUP in mental health services. Circles and dotted lines are used to denote the possibility of change as well as variation in the influence that each party may exert in SUP. (b) Multi-relational model of SUP in mental health services in a Chinese community. The different size of the circle denotes the varied importance that each party exerts in influencing SUP.

also valued input from professionals which enhanced their involvement.

To honor a person with expertise in a particular profession, as a *teacher*, is another demonstration of respect (Sun, 2008). An independence model focusing on individual rights and self-determination may induce tension in service users who hope to observe social hierarchy and value a harmonious relationship with authority. Focusing on personal strengths and capabilities may also put pressure on participants with low educational levels, who look upon professionals as their teachers and refrain from making self-directed decisions. Without considering these cultural values, the advocacy and direct application of an independent and rights-oriented SUP model could be counter-productive.

Conversely, dependence on professionals and the preservation of traditional social hierarchy may perpetuate the paternalistic relationship that, in turn, counteracts SUP and disempowers service users from meaningful participation.

Maintaining order and harmony may come at the price of ''human rights and freedom'' (Yang, 1992, p. 212). As indicated in Figure 1(b), the role of professionals can be both enabling and deterring. On the one hand, the data emerging at this time clearly suggested that service users in a predominantly Chinese community see mental health professionals as integral partners in SUP. On the other hand, mental health practitioners might diminish the power of service users through maintaining a professional-driven version of SUP that hides behind the mask of Chinese tradition.

Secondly, the involvement of family in mental health care has attracted increasing discussion in the Western literature in recent years (Cohen et al., 2013; Davidson & Tse, 2014; Dixon et al., 2014; Eassom et al., 2014; Ryan et al., 2015; Tambuyzer & Van Audenhove, 2013). To the authors' knowledge, the familial context, the interactions between close kin and persons in recovery, and their impacts on SUP have not yet been incorporated into the existing conceptual models generated in Western countries. Most participants in the current study highlighted reciprocal care and the role of family members in their decision-making relating to individual care or their involvement in service delivery and advocacy. This may reflect the obligation to observe the roles, rules and norms of duties defined by the power hierarchy for sustaining harmony in the family and wider society of China's collective culture (Kolstad & Gjesvik, 2014). In Chinese families, it is common for kin to care for family members who are ill (Tse et al., 2015). On the other hand, listening to or following parents' views and decisions is often understood as an expression of filial piety (*xiao*, 孝), a fundamental virtue emphasized in Chinese culture. To protect one's own body, provided by one's parents, is a core dimension of filial piety (Yang, 1992). Conceptualizing SUP merely from an orientation of independence may threaten the relations and harmony among family members. Given the present findings, embedding the *family* as a collective force (Lam, 2014; Yip, 2004) in influencing decision-making and higher level of involvement would provide a culturally consistent framework for supporting and informing practices of SUP in the Chinese context. The newly proposed model may also point to future research and examination of the conceptualization of SUP with an interdependent perspective in Western cultures.

Thirdly, connection with and support from peers were identified by participants as enabling factors that foster SUP in MHS. The positive effects of peer support on recovery have been examined and identified (Chinman et al., 2014), although mixed results have also been found (Lloyd-Evans et al., 2014). Yet research and discussion on the unique contribution of peer connection and support in enabling SUP is limited. Similarly, this interpersonal force is rarely discussed in the existing models of SUP. Given the identified value and the emerging peer support workforce in the MHS of some Eastern cultures, such as Hong Kong and Singapore, the inclusion of this significant player is warranted in the proposed model in order to reflect the complex interdependence relevant to non-Western cultures (Davidson & Tse, 2014).

Lastly, although over 90% of Hong Kong citizens are of Chinese descent, the authors suggest that Chinese culture is not homogenous. Despite the predominant value given to authority and family, a few participants, such as Yates, have called for greater respect of service users' will and decision to involve other significant players in their treatment and care. The implementation of SUP in MHS thus calls for careful consideration of differences to guard against simplistic application of a one-size-fits-all approach in both non-Western and Western cultures.

In short, the conceptualization of SUP in MHS is heavily based on Western ethos (Beresford, 2002; Davies et al., 2014; Roe & Davidson, 2005). The existing conceptual frameworks posit different forms of SUP on a linear continuum (Hickey & Kipping, 1998), as a unidirectional process (Tambuyzer et al., 2011), or within the larger frame of recovery-oriented practice (Storm & Edwards, 2013). Despite different purposes, they share a common orientation of independence in SUP that is insufficient for capturing and explaining the multifaceted and dynamic processes of SUP within Chinese culture. A new conceptual framework underscoring the interdependent forces of SUP in MHS has been proposed to fill this gap.

Limitations

The proposed model offers new understanding to the complex dynamics of SUP that impact the intensity and outcomes of participation. Nonetheless, it is mainly derived from service users' perspective in a single Chinese community, and close to 60% of the participants were at an advanced stage of recovery. The findings may not be generalizable to the wider service user community. Future research is thus recommended to examine its generalizability to other Chinese communities or interdependence-focused cultures. Culturally responsive principles and guidelines building upon this model are yet to be developed for informing facilitative practices toward SUP. Further research should investigate the perspectives of other significant players involved in the interdependent model.

Conclusions

This paper unveils the multiple dimensions and the enabling and hindering forces in the complex process of mental health SUP within a non-Western community. Caution is warranted against implementing the right-based and independence models regardless of the unique characteristics of the Chinese ethos. Nonetheless, Chinese culture is not homogenous: attention to individual differences, significant others and cultural ecology is called for in order to realize genuine and meaningful participation in recovery-oriented practice.

Declaration of interest

No potential conflict of interest was reported by the authors.

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