

Modeling Self-Agency among People with Schizophrenia: Empirical Evidence for Consumer-Based Recovery

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Key Words

Self-agency · Psychoses · Structural modeling

Abstract

Background: Self-agency – the awareness of one’s own capacity to make decisions and to engage in deliberate action – is often interfered with or lost during the course of severe mental illness. Most existing literature on self-agency is either of experimental or qualitative nature, and empirical evidence is scanty. **Sampling and Methods:** This paper draws on a subset of empirical data from a larger recovery study that involved 204 people with schizophrenia in the community. Structural equation models are built to contrast the models with and without the contribution of self-agency. **Results:** The self-agency factor loads significantly on variables from five major areas of recovery (hope, empowerment, resilience, self-responsibility and self-mastery). Structural equation models show that the incorporation of this self-agency construct has vastly improved the modeling of the adverse effect of stigma on the quality of life of these subjects. The model with self-agency fitted the criteria better, and explained more total variance (increased from 56 to 80%) for the quality of life of these subjects. **Conclusions:** Cross-sectional empirical findings appear to support the

claim that self-agency is an important construct that cuts through many dimensions of recovery. Initial discussions are made on the nature and function of self-agency, and its relations with recovery concepts and components.

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Introduction

Concerns about agency cut across philosophy, psychology, sociology and neuroscience. Irrespective of differences in foci and the terms used, most scientists agree that agency, or more precisely self-agency, is important to our understanding of human actions and actors. Self-agency is the conscious awareness of the fact that one causes at least certain of one’s own actions (other actions may be autonomic and not lend themselves to this type of awareness) [1–3]. Such a sense of our own agency is considered fundamental to human self-perception, with Bandura [4], for example, arguing that having a sense of

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our own agency is at the core of our lives as human beings. There is also ample evidence that this sense of self-agency is threatened in different ways by different psychiatric conditions, with affected persons striving very hard to maintain or regain their sense of agency in the face of these threats. In acute states, for example, psychosis is often associated with extremities of either passivity or over-estimation of agency in causing actions and their consequences. Recovery from depression has been associated with increased self-agency including being actively involved in decisions about one's own treatment [5]. People with anorexia can be viewed as constantly facing a punishing choice between self-agency and nourishment in order to maintain a schizoid form of self-cohesion [6]. In the case of schizophrenia, a distortion in, or total loss of, a sense of self-agency consistently has been observed and hypothesized to be a core characteristic of the illness since the time of Bleuler [7].

It is important to clarify that self-agency refers to a fundamental level of awareness that provides a necessary foundation for other, more advanced forms of self-awareness that may have received more attention in the social science literature. Without a basic sense of agency, for example, people would not be able to have a sense of their efficacy as an agent, nor would they be able to have any degree of internal locus of control. Self-efficacy and an internal locus of control have been found to be important in coping with, and adaptation to, a range of chronic medical illnesses [8–12]. However, when it comes to psychiatric illnesses like schizophrenia, we may first have to take a step back to consider whether or not there is an enduring and positive sense of self, a basic sense of self-agency, in place as a foundation for these more advanced forms of self-awareness [13].

For instance, neuroscience research has confirmed and elaborated on the long-standing clinical observation that persons with schizophrenia have a diminished or distorted sense of self-agency [14–19], with Frith and Done [18], in particular, suggesting that many of the symptoms of schizophrenia can be attributed to 'a failure to recognize the self in action', resulting in the person attributing his or her own thoughts and actions to others. Jeannerod [20] has recently reviewed this growing body of literature and concluded that the sense of agency is 'deeply impaired' in persons with schizophrenia, with 'first rank symptoms, which represent one of the major features of the disease, testify(ing) to the loss of the ability of schizophrenic patients to attribute their own thoughts, internal speech, covert or overt actions to themselves'. While it is generally believed that this sense

of agency relies on multiple cues from multiple sources [21–26], and its development is a complex process, these misattributions are currently thought to be based on imprecise predictions about the sensory consequences of one's actions rather than on processing external agency cues [22–23]. Finally, most researchers believe that the match between anticipated and actual outcomes can enhance the sense of self-agency [24] and that this sense of agency is based on both low-level sensorimotor control between outcome and anticipation, as well as high-level contribution of the prefrontal cortex and personality traits [8, 12].

What both neuroscience research and first person accounts suggest is that, at times, there may not be a sense of self-agency and that the regaining of such a sense of agency may be a first and important step in recovery. At the moment, much of this discussion of self-agency is based on neuroscientific hypotheses and elegant experiments, with little attention paid to the actual experiences of persons with schizophrenia. However, further confirmation of the central role of self-agency can be found in the growing literature on personal (as opposed to clinical) recovery [27, 28]. This literature can be broadly divided into the stage perspective, in which recovery is described as a process that unfolds through progressive stages, and the component perspective, in which a set of essential recovery components are thought to contribute to a more global process that is nonlinear [29]. Stage theories of recovery typically begin with the dawning awareness of a more active self, and move through taking stock of oneself and putting oneself into action, to eventually appealing to the self as a safe haven as an alternative to, or in the midst of, disorder [30]. This form of recovery involves a journey from the decision to take initiative and rebuild independence to reconstructing one's personhood [31], from identity confusion and self-protective withdrawal to setting and actively pursuing meaningful goals, taking control of one's life, and reestablishing a positive sense of self [32].

The component view of recovery is perhaps best exemplified by the National Consensus Statement on Mental Health Recovery developed in 2004 by the US Substance Abuse and Mental Health Services Administration [33]. In this view, recovery as a process consists of ten basic components: recovery involves (1) self-direction and (2) empowerment, is (3) individualized/person-centered and (4) strength-based, requires (5) responsibility, is (6) holistic and (7) nonlinear in nature, and is promoted through (8) hope, (9) respect, and (10) peer support. As is evident from this list, fully half of these components (self-direc-

tion, empowerment, person-centered, strength-based, and responsibility) address or involve the person's sense of agency. It is clear that self-agency relates to many stages and components of recovery as it has been described and conceptualized by persons with lived experiences of schizophrenia and other serious mental illnesses, even though the exact term has not been directly named by the recovery literature. Only very recently, Lysaker and Leonhardt [34] discussed the broader view of 'agency' in recovery – an embracive term used to describe the basic recognition and experience of 'ownership and authorship of one's thoughts, feelings and actions'. As they rightly point out, the recovery movement is not just a reaction to paternalistic practices in relation to people with mental illness, but a paradigm shift to how these subjects make sense of their lives. They opine that it is important for such coherent, adaptive and subjective experience to be understood by others quantitatively, in spite of the many difficulties encountered in defining operationally the personal aspects of recovery raised by some researchers [35]. Leamy et al. [36] have done a comprehensive review on 97 selected papers on recovery and concluded that the conceptual framework of recovery is 'a theoretically defensible and robust synthesis of people's experiences of recovery in mental illness' and shall be a basis for future research and practice.

If self-agency is so basic to human decision and acts, and is considered to play such a central role in producing recovery, it should have been reflected and traceable in the empirical evidence. However, owing to the differences in the foci, choice of variables and boundaries, inclusion criteria and sampling frame, it is also difficult at this moment to make meaningful comparison between the agency-related constructs that researchers claim explicitly or implicitly. Because of the permeating nature of self-agency, we do not incline to interpret self-agency based on one or two specific variables. Rather, we intend to identify the general construct of self-agency from recovery component variables. This paper draws on a subset of empirical data from a larger recovery study that involved more than 200 people with schizophrenia in the community [37, 38]. Exploratory factor analysis is carried out to identify the unique self-agency factor out of proxy variables of basic recovery components proposed by the National Consensus Statement. Subsequently, structural equation models are built to contrast the models with and without the contribution of this unique factor drawn from the recovery component variables. A common and straightforward model of psychosocial symptoms, stigma and quality of life is put forward, against which the

latent factor, self-agency, is added. If the concept of self-agency is a valid one, the analysis should pass these two phases of analysis without major problems when each phase is measured against its own general criteria.

Sampling and Methods

Scales and Measurement

The Internalized Stigma of Mental Illness Scale (ISMI) was used. The validity and reliability of ISMI were well established so as to reflect the subjective experience of stigma among populations with mental disorders [39].

The frequency of psychosocial symptoms was measured by a 15-item psychosocial subscale of the Schizophrenia Quality of Life Scale (SQLS) [40]. The subscale has demonstrated excellent internal reliability and validity, with a Cronbach's alpha of 0.93.

Quality of life was measured by the Hong Kong Chinese World Health Organization Quality of Life Measure abbreviated version, WHOQOL-BREF (HK) [41]. The instrument has a well-established reliability and validity among Chinese people with schizophrenia. The WHOQOL perception was found to be negatively correlated with psychiatric ratings [42, 43]. The 28-item WHOQOL-BREF (HK) had four domains and two specific questions that indicated overall quality of life and overall health. The Cronbach's alpha coefficient of the four domains ranged from 0.67 to 0.79, and the test-retest reliability of items ranged from 0.64 to 0.90. Subjective rather than objective quality of life indicators were used because they tapped into multiple aspects of actual experiences and provided a more accurate reflection of personal well-being. A closer inspection of the WHOQOL-BREF items found that 17 out of 26 items in the instrument related to the meaningfulness of life (5th, 6th, 19th and 26th items), satisfaction with community (8th, 9th, 13th, 14th, 22nd, 23rd, 24th and 27th items) and human potential (3rd, 7th, 10th, 17th and 18th items) of the respondent. Therefore, it has been used as a proxy indicator of recovery outcome described by the Substance Abuse and Mental Health Services Administration statement.

The personal competence subscale of the Resilience Scale (RS) [44] was used to measure the strength of patients. The internal consistency coefficient of the RS ranged between 0.76 and 0.91. Empowerment was measured by a 9-item self-esteem, self-efficacy subscale of the Making Decisions Empowerment Scale (MDES) [45]. The MDES has been validated in the USA and Sweden, and good validity and reliability were found with a Cronbach's alpha of 0.90 [46]. Personal responsibility was measured by the initiative and self-responsibility subscale of the Exercise of Self-Care Agency Scale (ESCA) [47]. The 12-item subscale measured the initiative of the respondents with regard to maintaining their health. The ESCA scale has been validated in subsequent studies [48]. The sense of self-determination was measured by the 7-item Mastery Scale (MS) [49], which assessed the subjective rating of the ability of the respondent to exercise control in the daily course of life. The MS has demonstrated good validity and reliability among people with severe mental disorders [50, 51] and the Cronbach's alpha of the MS was estimated to be around 0.73. Hope was assessed by the Adult State Hope Scale (ASHS), a 6-item instrument that measures a respondent's optimism about achieving his/her goals. The measure demonstrates good internal consistency, with a Cron-

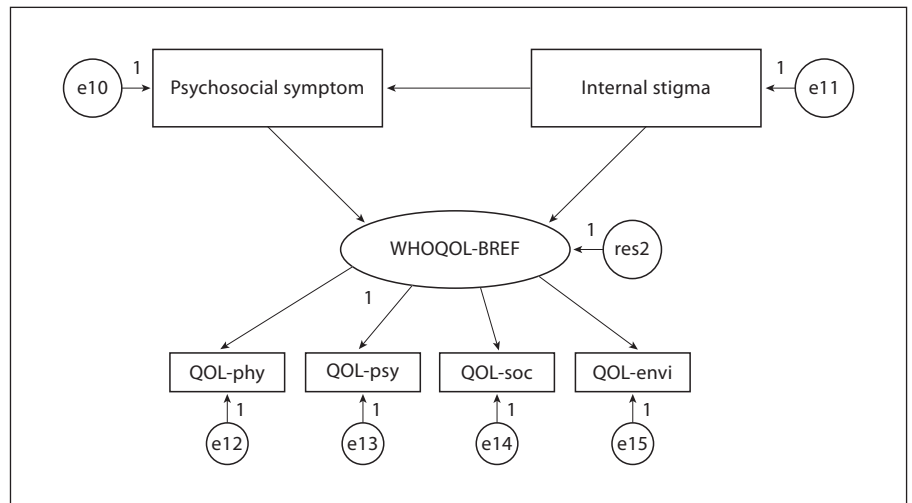


Fig. 1. Hypothesized base model 1.

Table 1. Reliability coefficients of scales used

	Cronbach's alpha (this study)
Internal stigma, ISMI	0.91
Psychosocial symptoms, SQLS	0.93
Quality of life, WHOQOL_HK	
Psychological domain	0.82
Physical domain	0.73
Environmental domain	0.79
Social domain	0.62
Strength-based, RS	0.90
Empowerment, MDES	0.87
Self-responsibility, ESCA	0.84
Mastery, MS	0.69
Hope, ASHS	0.78

bach's alpha ranging from 0.79 to 0.95 [52]. The reliability coefficients of the used inventories are listed in table 1.

Hypothesized Model

The choice of the base model (fig. 1) is founded on existing evidence that stigma would adversely affect one's quality of life [53, 54] and recovery [55]. A psychosocial symptom variable is also pulled in since there is evidence that psychosocial symptoms also adversely affect one's quality of life [56, 57], and one's internalized stigma would erode one's self-esteem [58] and subsequently interfere with coping with these psychosocial symptoms. The use of a factor structure (fig. 2) for certain recovery component variables is warranted for two major reasons: firstly, conceptually self-agency is multifaceted and would best be understood as essential competence permeating through many domains; secondly, the power will be improved if latent construct rather than the manifest variables is involved, particularly when the sample size is relatively modest.

Subjects

The data set contained interview data from more than 200 people aged 18–60 years with schizophrenia spectrum disorder. The mean age of the subjects was 41.6 (SD = 9.2) and the mean age of the first onset was reportedly 25.4 (SD = 7.7). Slightly more than half of the subjects (52%) were male. 61.3% of the subjects had never married and 56% received senior high school education. More than three quarters (78%) of them lived with family members and about one third (32.4%) were unemployed. Only about one third (32%) of the subjects had ever engaged in any kind of psychosocial rehabilitation services in the previous 12 months.

Results

The model fit summary (fig. 3) suggested that the base model (fig. 1) had an overall acceptable fit. Indicators like Normed χ^2 (3.44) and Tucker-Lewis index (0.938), comparative fit index (0.967), and a standardized root mean square residual of 0.035 all suggested a good fit. The only exception is the root mean square error of approximation which is slightly below the good-fit level. The base model explained a total of 56% of variance of the outcome variables. When the self-agency construct was put into the model, the explained variance increased significantly to 80%, without losing the shape of the model fit indicators. The base model was never meant to be a perfect one, as stigma studies have evolved with a better design and the identification of intervening and mediating variables. Model 1 (fig. 1) here served rather as a base for assessing the marginal contribution of the self-agency construct. It is evident that all model fit indicators (Tucker-Lewis index, comparative fit index, standardized root mean

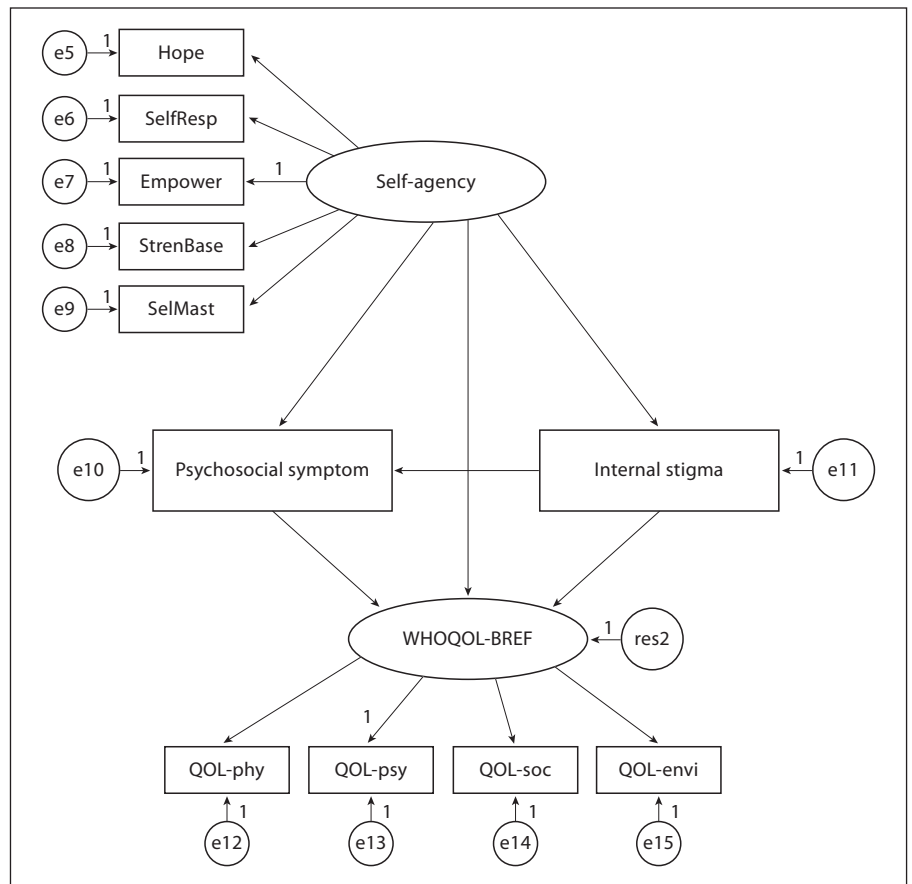


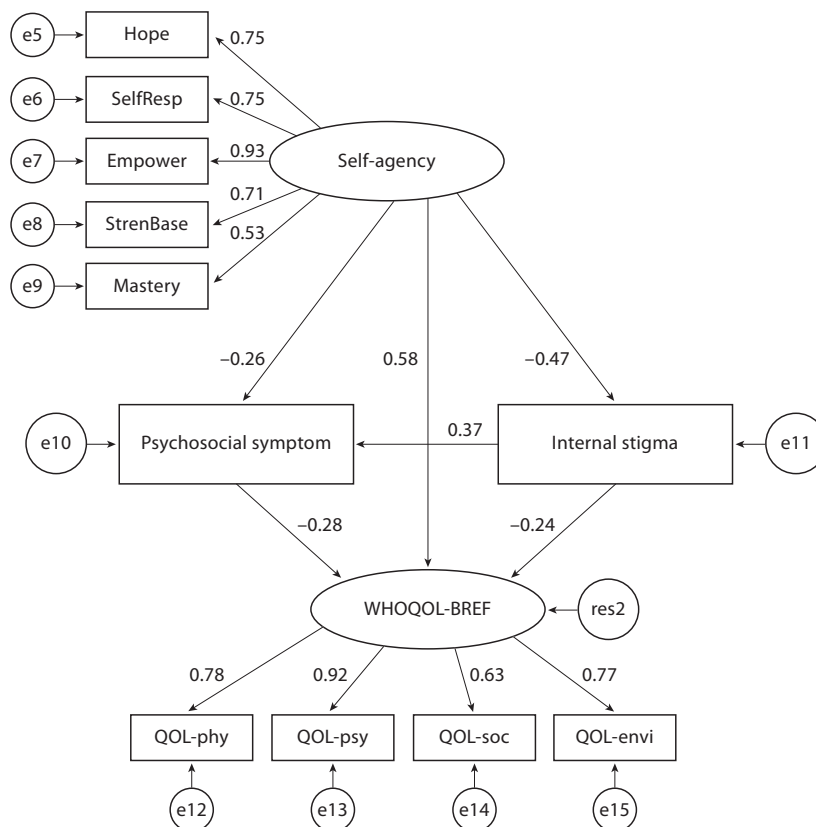
Fig. 2. Hypothesized structural model 2.

square residual and root mean square error of approximation) improved because of the joining of the self-agency construct. Given a sample size of more than 200 and the involvement of 6 variables, it was therefore well within the acceptable limit of the '1-to-10' rule.

Model 2 (fig. 2) showed a very reasonable pattern of positive and negative relations between the constructs and variables. First, self-agency loaded significantly and positively on the five recovery variables that are indicative of one's competence in different domains. Secondly, as expected, the self-agency construct loaded negatively and significantly on the two base model variables – internal stigma and psychosocial symptoms – though self-agency acted to a much stronger magnitude on internal stigma than on psychosocial symptoms. The better one's sense of control and mastery, the better one will be at coping with stigma and psychosocial symptoms. Thirdly, the self-agency construct contributed positively, significantly and directly to one's quality of life. It is evident that self-agency is a power construct that acts both directly and indirectly in determining one's quality of life.

Discussion

Some theorists may doubt whether there exists any truly autonomous decision and behavior [59–61], whether researchers have overromanticized Western conceptions of the individual agency, or whether nonconsciousness rather than one's sense of agency is part of, or the key driving force behind, human choice and behavior [62–64]. These doubts will continue but have provided little clue as to the possible directions of remedies and development towards the recovery of people with severe mental illness. This study chose to look at the argument from another side: if self-agency is something real and happening, can it be empirically identified from the recovery components? The findings from this study are affirmative, though never meant to be conclusive. One may argue what the factor really is, and it may not necessarily be self-agency as we called it. We long to be refuted conceptually and empirically. Judging from its significant relations with self-responsibility, hope, strength/resilience, empowerment and sense of mastery, it would be difficult to name it in a dif-



Summary of model fit with percentage of variance explained for recovery in different hypothesized models

Model	χ^2	d.f.	χ^2 /d.f.	TLI	CFI	SRMR	RMSEA	AIC	R ² (WHOQOL)
Model 1	27.531	8	3.441	0.938	0.967	0.035	0.110 ¹	53.531	55.9
Model 2	105.788	40	2.645	0.927	0.947	0.066	0.091	157.788	80.1

χ^2 /d.f. = Normed χ^2 (<1 poor model fit, 1–2 excellent fit, 2–5 acceptable fit); TLI = Tucker-Lewis index (≥ 0.95 good fit, 0.90–0.95 acceptable fit, <0.90 poor fit); CFI = comparative fit index (close to 1 excellent fit, ≥ 0.90 acceptable fit, <0.90 poor fit); SRMR = standardized root mean square residual (<0.08 good fit); RMSEA = root mean square error of approximation (<0.05 good fit, 0.05–0.08 adequate fit, 0.08–0.10 mediocre fit, >0.10 poor fit); AIC = Akaike information criteria (the lower the better).

¹ Indicated poor fit.

Fig. 3. Self-agency model with standardized parameter estimates.

ferent way. It is reasonable initially to call it self-agency. The empirical models have helped us at least to better appreciate that self-agency may possibly be a composite of many strengths and competences. Although the exact relation between self-agency and each recovery component involved is unclear, this new construct can be identified empirically. We now have a basic understanding that this core competence/attribute may counteract stigma and enhance one's quality of life, and there is much room for

discussion on how programs could be designed and implemented in such a way that brings similar results. Until now different programs and approaches have been designed to realize different goals (strength-based, empowerment, hope instillation, etc.). If only we come to know more about the nature of this construct and its working with the different recovery components, we will be able to design more targeted and holistic programs.

Conclusions

Since the interview data collected had no randomized design (due to practical problems), it is difficult to draw comfortable generalizations. Further studies, with a better design, are warranted. It will be another challenge to see how these findings, though initial, could be translated to inform our practices. Some earlier programs

such as knowledge-based, participatory empowerment training with caregivers have indicated that self-agency has to be impacted before empowerment takes place [65]. It is perhaps the right time to reexamine existing practice, to further research the construct, and to invite more discussion on what makes one's recovery a meaningful process.

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