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Quality of life disparities between persons with schizophrenia and their professional caregivers: Network analysis in a National Cohort

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ABSTRACT

Background: Disparities between mental health patients and their professional caregivers in quality of life appraisals have been identified, however, the structure that such disparities assume is unknown.
Aims: To examine the network structure of quality of life appraisals and disparities using network analysis.
Methods: Participants were 1639 persons with schizophrenia using psychiatric rehabilitation services and their primary professional caregivers (N = 582). Quality of life for persons with schizophrenia was measured based on an abbreviated version of the Manchester Short Assessment of Quality of Life. Appraisals were made self-reported and by professional caregivers. Disparities scores between the aforementioned were computed. Network analysis was performed on all quality of life appraisals. Sensitivity analyses were conducted.
Results: The self-appraised network significantly ($p < 0.05$) differed by network strength compared to the caregiver-appraised network. Self-appraised network communities (clusters of quality of life items) were health conditions and socioeconomic system, whereas caregiver-appraised network communities were social activities, and combined socioeconomic and health conditions. Strength centrality was highest for self-appraised social status and for caregiver-appraised residential status (Z = 1.63, Z = 1.12, respectively). The disparity scores network clustered into two communities: social relations and combined financial and health conditions. The most central appraisal disparities were in social status.
Conclusions: Quality of life differed when self-appraised by persons with schizophrenia compared to when appraised by their professional caregivers, yet the salient role of social relations was shared. The latter may be an initial focus of discussion by persons with schizophrenia and their caregivers.

1. Introduction

Agreement on central aspects of life and treatment between professional caregivers and their patients is regarded as a significant facet of mental health care and closely related to positive treatment outcomes, including treatment-retention, social support, appraisals of improvement, and reduction in depression (Laws et al., 2016; Schöttke et al., 2014; Tryon and Winograd, 2011; Daniels and Wearden, 2011; Bordin, 1979; Tryon et al., 2007).

However, most inter-personal appraisal studies have shown that disagreement, manifested in appraisal disparities, between mental health patients and their professional caregivers, is much more prevalent than agreement (Laws et al., 2016; Schöttke et al., 2011; Schöttke et al., 2014; Tryon et al., 2007). Disparities between self-appraisals and exterior appraisals may be explained by the Self–Other Knowledge Asymmetry Model (Vazire, 2010) as resulting from the different types of information available to each party and from different personal motives. Accordingly, self-appraisals may be based on thoughts, feelings, and physiological states, while exterior appraisals may be based on observable behavior.

Disparities between patients and their caregivers have been reported in appraisals of treatment (Morton et al., 2010; Heppner et al., 2008), recovery (Roe et al., 2011), everyday functioning (Harvey et al., 2016) and life aspects such as interpersonal skills, community activities, and work skills (Bowie et al., 2007). Appraisal disparities between patients and caregivers were associated with negative implications for treatment outcomes, including premature termination of treatment (Corning et al., 2007), lower session quality ratings (Marmarosh and Kivlighan Jr, 2012), higher depressive symptoms and impaired cognition (Ermel et al., 2017), a lesser ability to recognize emotion, poor insight and more positive symptoms (Lysaker et al., 2013) and real world functional outcomes (Gould et al., 2015).

The current study will focus on quality of life appraisals a desirable outcome of mental health care (Mashiach-Eizenberg et al., 2013). Existing literature shows that appraisal disparities in quality of life

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between patients and caregivers are the rule rather than exception (Bowie et al., 2007; Bengtsson-Tops et al., 2005; Doyle et al., 1999; Hayhurst et al., 2014; Kusel et al., 2007; Olsson et al., 2015; Atkinson et al., 1997; Hasson-Ohayon et al., 2011). Studies examining inter-personal appraisals of mental health related quality of life are limited and are mostly focused on small samples of patients diagnosed with schizophrenia. Across all studies, concordance was partial between patient appraisals of their own quality of life and those attributed to them by external raters (Doyle et al., 1999; Fitzgerald et al., 2001; Kravetz et al., 2002). Most studies found a weak correlation between inter-personal appraisals of quality of life (Bengtsson-Tops et al., 2005; Hayhurst et al., 2014; Kusel et al., 2007; Nakagawa and Hayashi, 2013; Voruganti et al., 1998).

To date no study has examined the structure of mental health related quality of life disparities. Knowledge of the structure and central elements of quality of life disparities may lead to better outcome interpretations (Marmarosh and Kivlighan Jr, 2012; Atwater and Yammarino, 1997; Dimaggio et al., 2011). Existing understanding of disparities may be elaborated on by using network analysis. Network analysis can be used to identify an inter-related system of elements within a construct (Harary, 1969). The key concepts of network analysis are summarized in Table 1. A construct lending itself to network analysis is quality of life appraisals and disparities (Kossakowski et al., 2016). Network analysis can account for complex interactions between elements of quality of life. It may be used to identify clusters of elements of quality of life, and visually represent them. In addition, it can highlight the extent that each element is central to quality of life. One study has examined self-appraised health related quality of life as a network among samples of cancer patients and healthy adults (Kossakowski et al., 2016). Results showed that the network structure and central elements of both samples were remarkably similar. Hence, like cancer patients, this approach may also be promising in studying the quality of life of persons with schizophrenia.

The current study aims to examine the structure of mental health related quality of life, focusing on appraisal disparities between persons with schizophrenia and their professional caregivers, using network analysis.

Table 1
Key aspects of network analysis.

Network concept	Standard-term/definition	Concrete MSA-QoL example
Nodes	Observed items (graph circles)	Self-appraised social status
Edges	Relations between items (lines between graph circles)	Relations between self-appraised mental health and physical health conditions
Edges weights	Strength of relations between items (thickness and saturation of lines)	Relations between self-appraised residential status and financial status have stronger magnitude
Communities	Clustered groups of items (graph circles colored identically)	Self-appraised health condition community = self-appraised mental health and physical health conditions
Modularity	A measure of clustering strength	Dense connections between items within the self-appraised health condition community and sparse connections between self-appraised health conditions and other network items such as social status
Network connectivity (overall connectivity)	Deviation in absolute weighted sum scores of the connections (higher for more densely connected networks)	The caregiver-appraised network is more densely connected than the self-appraised network
Centrality scores	Assessment of the magnitude of the contribution by each node to each network, based on the pattern of network connections	Self-appraised social status is the most important item in its network
Strength centrality	The weighted sum, in absolute value, of all the associations between a given item and all other items	Self-appraised social status may influence leisure activities without considering the mediating role of financial status
Betweenness centrality	The proportion of shortest paths between two items that travel across the focal item	Self-appraised financial status is not found on the shortest pathway of social status and leisure activities
Closeness centrality	The inverse of the sum of the distances of the focal item from all other items in the network	Self-appraised social status may quickly influence leisure activities (because they are connected by short paths)
Parsimony	The simplest network that can present the observed data	The caregiver-appraised network is more parsimonious than the self-appraised network

2. Methods

2.1. Participants

The current study cohort was part of the Psychiatric Rehabilitation Routine Outcome Measurement Project (Roe et al., 2015). The study was approved by the Helsinki committee at the Ministry of Health and by the Institutional Review Board at the University of Haifa. A total of approximately 35% (N = 4595) of all psychiatric rehabilitation service users (irrespective of diagnosis) consented to participate and actually completed the self-reported questionnaires. Assessments were supervised by an internal service staff member or externally trained individuals (Gelkopf et al., 2015). Questionnaire administration was conducted at the participants' agencies for housing, work, and education and social clubs.

The current study inclusion criteria were all participants with a last diagnosis of schizophrenia (N = 1639) who received national psychiatric rehabilitation services in Israel. The exclusion criteria for psychiatric rehabilitation services are illicit drug addiction, violence and lack of psychiatric monitoring. Participants completed the research questionnaires from January 1st, 2013 to August 19th, 2015. In total, 61% of the participants were men, mean age was 47.19 (SD = 12.27), and mean age of first hospitalization was 26.79 (SD = 10.17).

Primary professional caregivers (N = 582) were given instruments that mirrored the one designed for self-appraisals. Some caregivers appraised more than one person with schizophrenia: 43% appraised one person, 21% appraised two persons, 12% appraised three persons, 24% appraised four or more persons.

2.2. Data source

Demographic, psychiatric diagnostic and hospitalization information was obtained from the Israeli National Psychiatric Case Registry. The registry contains listing of psychiatric hospitalizations in Israel, and includes ICD-10 diagnoses by an Israeli medical board certified psychiatrist. Registry diagnoses include almost all people with schizophrenia (Weiser et al., 2012), were found to be reliable over time (Rabinowitz et al., 1994), and have acceptable sensitivity compared to research diagnostic criteria (Weiser et al., 2005).

2.3. Quality of life appraisal

Mental health related quality of life was measured and validated (Roe et al., 2015) based on the Manchester Short Assessment of Quality of Life (MSA-QoL), an abbreviated version of the Lancaster Questionnaire Life Quality Profile (Priebe et al., 1999). Scale items were rated on a 5-point Likert scale and coded so higher scores on the assessment indicated better quality of life. Eight items measured satisfaction with one's work or volunteering activities, financial status, social status and activities, family relations, leisure activities, residential status, physical

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