

The Concept of Quality of Life in Schizophrenia: From “An Ethereal Entity” to a Valued Health Outcome

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The economic prosperity and the enhanced standard of living in western societies that followed post-Second World War, brought in psychological expectations such as satisfaction and a sense of fulfillment and well-being, which were picked up by social scientists and has led to extensive population-based quality of life research focused on social indicators. In its very beginning, quality of life as a general concept was referred to as “a vague and ethereal entity, something that many people talk about, but which nobody clearly knows what to do about it...” [1]. Broadening the definition of health in 1947, the World Health Organization (WHO) included mental health in addition to physical health, which added a significant impetus to research interest and led to a much useful narrowing of the general concept of quality of life in its application to health [2]. The new concept of “health-related quality of life” was quickly embraced by modern medicine in its emphasis not only on prolonging life, but also to improve of quality of life. Though the concept of quality of life in the mental health field seemed to be a bit slow in the beginning, the de-institutionalization movement in the early 1960s, with the precipitous discharge of many chronic psychiatric patients from mental hospitals to a community not prepared to welcome them, added urgent concerns about the deteriorated living conditions of those patients. Such concerns generated a good deal of research interest in development of measurement scales that allowed for documentation of the poor quality of life among psychiatric populations

placed in the community [3]. Schizophrenia, a long-term chronic illness, provided a unique opportunity as a bio-psychosocial disorder for embracing the new concept of quality of life. On the other hand, schizophrenia by virtue of its psychopathology and its significant impact on functioning, presented a number of challenges [4]. Over the years the lack of agreement on a definition has led to a multiplicity of definitions, depending on the theoretical orientation of the particular researcher. Having a multiplicity of definitions based on different conceptual models and theoretical orientations without a common metrics to compare measurement data, somewhat undermined the usefulness of such an important concept, though eventually the research field settled around the notion that there may not be a single definition of health-related quality of life in schizophrenia. It may be that the multiplicity of definitions and conceptual models may have actually enriched the concept of quality of life in schizophrenia, provided that researchers clearly define what is meant by quality of life in their research.

As a new scientific field, quality of life research has to follow the rigors of scientific inquiry, in terms of development of conceptual models that can enhance the understanding of the underpinnings of the concept itself. Though the question of reliability of persons with schizophrenia to provide accurate and consistent information has been extensively researched and documented, there is still some lingering doubt about the reliability of the broad spectrum of presentations in schizophrenia to be able to judge their quality of life, such as those patients in the very acute stage or in the late chronic deteriorated phase. However, a consensus seems to have been developing, that the majority of stable persons with schizophrenia are capable of assessing their subjective quality of life. As schizophrenia is a multi-dimensional disorder, such multi-dimensionality has to be

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reflected in its measurement. Bridging the subjective/objective dichotomy has led to a consensus that subjective and objective measures, though different and maybe overlapping constructs, have to be integrated into the concept of quality of life in schizophrenia. In order to retain the original subjective nature of quality of life as different from other objective measures, a proposal has been advanced to group all objective measures, such as vocational and economic sufficiency, etc., under the rubric of “quality of living”, and retain the concept of quality of life to include the subjective component of the concept [4].

Over the past 50 years the field of quality of life measurement in schizophrenia has phenomenally expanded, as reflected by the number of publications and the broader acceptance of the concept itself. Yet, in recent years there has been a noticeable erosion of research interest in the field of quality of life in schizophrenia. The perception has been that measurement of quality of life in schizophrenia is not useful, in terms of its lack of impact on clinical care. A good part of the challenge has been the lack of integrative clinical models, as the majority of studies did not go beyond measurements into how to use the collected data. Without appropriately demonstrating the usefulness of the concept of quality of life in clinical care, and also as an important tool in pharmacoeconomics and health policy decision-making, the concept, unfortunately, will continue to fade away, particularly in a mental health system that is not rich in resources. There needs to be a concerted effort and requirement for inclusion of quality of life studies in the process of approval of new antipsychotics. Instead of being an after-thought in new medications clinical trials, there needs to be specific purpose-built studies that examine the role of quality of life as an important outcome by itself. The rising cost of health care is evolving as a societal concern, and one approach for cost containment is to prove the value of various interventions using quality of life as an indicator.

The issue of quality of life and economic and cultural differences across various societies warrants more exploration, not only in terms of identifying the determinants of quality of life underpinning the concept itself in various societies, but also the impact of available resources such as

housing and economic support, as well as availability and accessibility of rehabilitation programs [5].

I believe that the concept of quality of life as applied to schizophrenia continues to be an important and a valid construct, reflecting the modern image of psychiatry, it is incumbent, then, on researchers to enhance the utility of the construct itself by going beyond assessment into demonstrating its broader application [6]. Schizophrenia is a costly disorder, particularly as it generally has an early onset in life and requires long-term clinical and socioeconomic support. Though enhancing quality of life and increasing the level of functioning for persons with schizophrenia can be expensive, at least initially, it can pay-off eventually in terms of an improved health outcome and lower health expenditure. Such a goal is not only relevant to patients and their families, their clinicians and providers of care, but also equally important to the society at large. I believe the concept of quality of life is no more an “ethereal entity”, but has become an important and aspired goal of psychiatric treatment. For that to happen, the concept of quality of life has to be invigorated and almost reinvented.

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