VALUE IN HEALTH ▮ (2018) ▮▮▮–▮▮▮

Available online at www.sciencedirect.com

ScienceDirect

journal homepage: www.elsevier.com/locate/jval

Health-Related Quality of Life in People Living with Psychotic Illness, and Factors Associated with Its Variation

Amanda L. Neil, PhD[1,*], *Vaughan J. Carr, MD*[2,3,4], *Andrew Mackinnon, PhD*[5,6], *Debra L. Foley, PhD*[7], *Vera A. Morgan, PhD*[8,1]

[1]*Menzies Institute for Medical Research, University of Tasmania, Hobart, Tasmania, Australia;* [2]*Research Unit for Schizophrenia Epidemiology, School of Psychiatry, University of New South Wales, St Vincent's Hospital, Sydney, New South Wales, Australia;* [3]*Neuroscience Research Australia, Sydney, New South Wales, Australia;* [4]*Department of Psychiatry, School of Clinical Sciences, Monash Medical Centre, Monash University, Melbourne, Victoria, Australia;* [5]*Centre for Mental Health, Melbourne School of Population and Global Health, The University of Melbourne, Carlton, Victoria, Australia;* [6]*Black Dog Institute and University of New South Wales, Randwick, New South Wales, Australia;* [7]*Centre for Epidemiology and Biostatistics, Melbourne School of Population and Global Health, The University of Melbourne, Carlton, Victoria, Australia;* [8]*Neuropsychiatric Epidemiology Research Unit, Division of Psychiatry, Medical School, The University of Western Australia, Crawley, Western Australia, Australia*

ABSTRACT

Objectives: To establish whether the four-dimensional Assessment of Quality of Life (AQoL-4D) produces robust utility values in adults with psychotic illness, and identify health inequalities compared with the general population. **Methods:** The AQoL-4D was completed by 1613 individuals with an *International Classification of Diseases, Tenth Revision*, psychotic illness in the 2010 Australian National Survey of Psychosis. Utilities were assessed for this sample and 20 subgroups, and were compared with general population norms. Modified Cohen *d* was used as an index of effect size. Utilities were collapsed into 10 health-related quality-of-life (HRQOL) bands or decades. **Results:** HRQOL in people with psychotic illness was half of the maximum achievable utility (half-"full health") with a mean utility of 0.49 (95% confidence interval [CI] 0.48–0.51), and showing substantial variability across subgroups. Participants with essentially normal functioning had the highest mean utility (0.72; 95% CI 0.68–0.77), and those with very poor perceived mental health had the lowest (0.22; 95% CI 0.18–0.26). These subgroups showed the most variability. Negative symptoms also gave rise to substantial variation. Among diagnostic categories, only depressive psychosis had a large effect relative to delusional disorders. The distribution of utilities in people with psychotic illness differed markedly from that in the general population, with 6.8% versus 47.2% having values in the highest decade (>0.90–1.00). Utilities were lower in every age group in people with psychosis. **Conclusions:** Profound HRQOL impacts are revealed by the AQoL-4D in people with psychotic illness, and marked variations in utilities were observed for key subjective and objective measures. We provide a suite of utility values for economic modeling studies and recommend the AQoL-4D for assessing HRQOL in people with psychotic illness.

Keywords: economic modeling, health inequalities, psychotic disorders, schizophrenia, utility assessment.

Introduction

Psychotic illness comprises a heterogeneous group of disorders in which an individual's understanding and experience of reality is distorted, reflected in disturbances in the formation and content of their thoughts. The impact of psychotic illness is profound with mental, physical, and social well-being affected. Currently, there is no accepted source of valid and reliable utilities to assess health-related quality-of-life (HRQOL) impacts. Commonly used multi-attribute utility instruments (MAUIs), including the EuroQol five-dimensional questionnaire (EQ-5D), the six-dimensional health state short form (SF-6D), and the 15D, are considered problematic [1–4]. Concerns raised include insensitivity (inability to detect lower HRQOL in people with psychosis) and the lack of responsiveness to disease-specific symptoms and other phenomena. This lack of unbiased instruments compromises decision making. One instrument that has not been considered in the debate of the appropriateness and usefulness of MAUIs for psychotic disorders is the four-dimensional Assessment of Quality of Life (AQoL-4D) instrument [5].

This publication is based on data collected in the framework of the 2010 Australian National Survey of High Impact Psychosis. The members of the Survey of High Impact Psychosis Study Group at that time were V. Morgan (National Project Director), A. Jablensky (Chief Scientific Advisor), A. Waterreus (National Project Coordinator), R. Bush, V. Carr, D. Castle, M. Cohen, C. Galletly, C. Harvey, B. Hocking, A. Mackinnon, P. McGorry, J. McGrath, A. Neil, S. Saw, and H. Stain.

* *Address correspondence to:* Amanda L. Neil, Menzies Institute for Medical Research, University of Tasmania, Private Bag 23, Hobart, Tasmania 7001, Australia.

E-mail: Amanda.Neil@utas.edu.au.

1098-3015$36.00 – see front matter

https://doi.org/10.1016/j.jval.2018.02.012

The AQoL-4D differs from other MAUIs (EQ-5D, 15D, and SF-6D) in several important aspects. First, the AQoL instruments are the only MAUIs constructed using psychometric principles [6], including having a minimum of three items measuring the same underlying latent construct. Second, there are major differences with respect to their descriptive systems (see Appendix 1 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2018.02.012); the AQoL gives greater weight to social disability than do other instruments [7], and differences in descriptive/classification systems are the principal determinants of non-equivalence between MAUIs and the utilities they assess [8]. Finally, the AQoL-4D has good lower end sensitivity and has been validated for use in people with psychotic illness [9]. Together, these factors indicate that the AQoL-4D should have major advantages in the assessment of utilities in people with psychosis. We aimed to establish whether the AQoL-4D produces robust utility values in adults with psychotic illness, and to identify health inequalities compared with the general population.

Methods

Data for people with psychotic illness were collected as part of the 2010 Australian National Survey of Psychosis—the Survey of High Impact Psychosis [10–12], a large population-based cross-sectional survey of people with psychosis aged 18 to 64 years. The survey was undertaken at seven sites in five Australian states, and covered an estimated resident population of 1,464,923 people—about 10% of the Australian population in the age range. A two-phase design was used.

In phase 1 (March 2010), screening for individuals likely to meet diagnostic criteria for psychosis occurred in public specialized mental health services (inpatient, outpatient, ambulatory, and community mental health services) and nongovernmental organizations supporting people with mental illness. Administrative records were searched to identify individuals with psychosis who were in contact with public mental health services in the 11 months before census but not in the census month. In phase 2 (April to December 2010), 1825 of the 7955 people who were screened positive for psychosis in phase 1 were randomly selected for interview, stratified by age group (18–34 years and 35–64 years). At the interview, 1642 of this sample met *International Classification of Diseases, Tenth Revision* (*ICD-10*) criteria for a psychotic disorder.

Interview data were collected on symptomatology, substance use, disability, cognitive functioning, physical health, mental and physical health service utilization, medication use, education, employment, housing, community sector support, and HRQOL. For full methodological details, refer to the studies by Morgan et al. [10–12].

The study was approved by institutional human research ethics committees at all seven study sites. Participants gave written informed consent after receiving full information on the study.

Basic Analytic Approach

HRQOL was assessed for individuals meeting *ICD-10* criteria for a psychotic disorder across a range of 20 subjective and objective general and illness-related characteristics, and comparisons were made with relevant population norms.

Measures

The AQoL-4D

HRQOL was assessed using the AQoL-4D [5,7]. The AQoL-4D is the original of a suite of AQoL instruments (4D, 6D, 7D, and 8D) and was developed with specific reference to the World Health Organization's 1948 definition of health: "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" [5]. It comprises five health dimensions, each with three items of four levels of severity (see Appendix 1 in Supplemental Materials). Four dimensions are used in the assessment of utility: independent living, social relationships, psychological well-being, and physical senses.

With the AQoL-4D, utilities can range from −0.04, for states worse than death, to 1.00, full health (see Appendix 2 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2018.02.012). Utilities were calculated using the standard algorithm provided as AQoL-4D Algorithm for SPSS (http://www.aqol.com.au/scoring-algorithms/82.html). Utilities were also collapsed into decades, 10 equally spaced bands of utility scores, except for the lowest, which was extended to accommodate states worse than death. The bands thus ranged from (−0.04 to 0.10) to (>0.90 to 1.00).

The population utilities used for comparison [13] were based on data collected in the course of the 2007 Australian National Survey of Mental Health and Wellbeing, a nationally representative, face-to-face household survey of 8841 community residents aged 16 to 85 years, undertaken by the Australian Bureau of Statistics [14].

Demographic and functioning measures

Demographic variables comprised primary homelessness (sleeping rough) in the past 12 months (yes, no), difficulty reading and/or writing (self-report: yes, no), and completed final year of schooling (yes, no). Functioning was assessed by the interviewers, who were mental health professionals trained in the use of the survey instruments. Premorbid IQ was measured using the National Adult Reading Test [15] summary scores, and categorized as above, below, or within 1 SD of the sample mean (98.0 ± 11.3). Current cognitive function was based on the Digit-Symbol Coding task summary scores from the Repeatable Battery for Assessment of Neuropsychological Status [16], and categorized as above, below, or within 1 standard deviation (SD) of the sample mean (38.3 ± 10.6). Global independent functioning was measured using the Multidimensional Scale of Independent Functioning [17] and categorized as essentially normal, very mild disability, somewhat disabled, moderately disabled, significantly disabled, extremely disabled, and totally disabled. Social functioning was rated as no dysfunction, obvious dysfunction, or severe dysfunction.

General health variables

General health variables, for which there are published Australian norms [13], included perceived mental health status and perceived physical health status (excellent, good, fair, poor, very poor), self-reported lifetime cardiovascular disease (CVD; yes, no), and self-reported current and lifetime depressive symptoms (yes, no).

Disorder-specific health variables

Disorder-specific health variables included *ICD-10* diagnosis (schizophrenia, schizoaffective disorder, bipolar disorder with psychotic features, depressive psychosis, and delusional disorders), course of illness (single episode, multiple episodes with good recovery, multiple episodes with partial recovery, continuous chronic, and continuous chronic with deterioration), duration of illness (<1 year, 1 year, 2–4 years, 5–9 years, 10–19 years, 20–29 years, and ≥30 years), current and lifetime suicidal ideation (attempted suicide or ideation present at least 1 week, present at least 2 weeks, and present at least 1 month), number of negative symptoms, and presence of current positive symptoms and/or symptoms of mania and/or depressive symptoms.