



## Review

# Conceptualising and measuring the well-being of people with psychosis: Systematic review and narrative synthesis



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## ARTICLE INFO

## Article history:

Available online 31 May 2013

## Keywords:

Well-being  
Schizophrenia  
Psychosis  
Measurement  
Concept  
Interventions

## ABSTRACT

Well-being has become a prominent term in the political arena in recent years. However, in research the concept and use of well-being has been unclear, especially in the context of severe mental illness such as psychosis. This systematic review aims to characterise the evidence base relating to well-being in people with psychosis, by reviewing how well-being is measured, developing a new conceptual framework, and summarising empirical evaluations of psychosocial interventions to improve well-being. We conducted a systematic review and narrative synthesis of controlled trials of interventions investigating well-being in people with psychosis. The 28 studies meeting the inclusion criteria used 20 different measures of well-being. Five dimensions of well-being emerged: non-observable, observable, proximal, distal, and self-defined. Interventions to improve well-being vary widely. The investigated interventions have been targeted at non-observable, observable and proximal levels, while evaluation measures span all five dimensions. This review offers an evidence based conceptual framework of well-being which can provide an empirical basis for organising future well-being research in psychosis. The review also shows that the evidence base for interventions is small and methodologically weak. Recommendations are made for choosing well-being measures for future research.

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## Introduction

The term well-being has become popular in the political arena in recent years. Extensive work has been published on well-being and its determinants in the general population. In the UK the most comprehensive and prominent approach was taken by the Office of National Statistics (ONS, 2012). Overall, at least four academic phases of well-being conceptualisation and measurement can be identified. Economic concepts frame well-being in terms of national wealth, social determinants, development and general quality of life. Medical concepts of well-being frame it in relation to disorder and illness, i.e. health related quality of life. Psychological concepts view well-being in terms of subjective and mental

concepts, ranging from positive affect to life span development and self actualisation. Finally, integrative concepts are evolving and informed by economic, medical, and psychological phases. Throughout these phases, the notion of well-being has shifted from a collectivist concept with objective measures, to being conceived in individualistic terms, with subjective measures and a distinct focus on positive psychology and recovery research (Schrank, Riches, Coggins, Tylee, & Slade, submitted for publication). The latest ONS approach to national general population well-being reflects an economic perspective with an additional strong emphasis on subjective indicators of well-being, and views well-being in terms of three broad domains: individual well-being; factors directly affecting individual well-being; and more contextual domains (ONS, 2012).

The transition from objectivity to subjectivity has led to well-being becoming a key concept in mental health. In particular, well-being is also a central component of recovery from mental illness (Slade, 2009). Its importance is further supported by research showing an association between well-being and improved functioning, increased resilience and life satisfaction (Fredrickson &

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Joiner, 2002), and suggesting its protective value against the onset or re-occurrence of mental illness (Schueller & Parks, 2012).

So far, well-being research has focused on a variety of groups, including the general population across the life span and countries (Hatch, Harvey, & Maughan, 2010; Jin, Wen, Fan, & Wang, 2012; Liu, Dupre, Gu, Mair, & Chen, 2012), and groups with various disorders such as cancer (Schwarzer, Luszczynska, Boehmer, Taubert, & Knoll, 2006), traumatic injury (Kendall & Terry, 2009), or HIV/AIDS (Mak et al., 2007). Recently there have been calls for a stronger focus on well-being within psychiatry (Cloninger, 2006), especially in the context of recovery (Resnick & Rosenheck, 2006). Despite the increasing research focus on well-being, a consensus definition of well-being is missing (Schrank et al., submitted for publication). In the scientific literature the concept of well-being is differently and often only vaguely defined and empirical evidence is fragmented, especially when it comes to people with severe mental illness, such as psychosis (Wissing & van Eeden, 2002).

The aim of this study is to characterise the evidence base relating to well-being in people with psychosis to (1) understand how well-being is measured in high quality research studies involving people with psychosis, (2) develop an organising conceptual framework for well-being as used in these studies, and (3) summarise the empirical evidence on psychosocial interventions aimed at improving well-being in people with psychosis.

## Method

### Eligibility criteria

We included randomised and non randomised intervention studies investigating the effects of intervention compared with control on service users' well-being as primary or secondary outcome, available in full-text in English or German Language.

Studies were included if they used definitions of well-being from psychological and mental health research, i.e. those assuming at least a degree of subjectivity in the concept, ascertained by (i) standardised outcome measures of overall well-being according to any psychological and psychiatric definitions; (ii) single-question assessments of personal well-being; or (iii) scales containing a well-being factor or well-being subscale. We excluded studies that defined well-being: (i) as a solely economic construct (monetary measures and social indicators); (ii) as a solely physical construct (e.g. fitness, weight, heart rate or blood pressure); (iii) as lack of relapse or hospitalisation (i.e. "staying well"); (iv) as lack of psychiatric symptoms; and which used (v) non-standardised combinations of various scales purporting to represent well-being.

Inclusion criteria for participants were (i) aged 16–65 years; (ii) past or present diagnosis of a psychotic illness based on ICD-10 or DSM-IV or at least 70% in a mixed diagnosis sample (interpreted to be over-inclusive when the diagnostic description was unclear), and (iii) use or have used mental health services. This work was exempt from ethics review since it did not involve participants.

### Data sources and search strategy

Five sources of data were used. First, we searched 11 bibliographic databases from inception to May 2012: EMBASE, MEDLINE, PsycINFO, British Nursing Index and Archive (accessed via Ovid); Applied Social Sciences Index and Abstracts, British Humanities Index, Sociological Abstracts, Social Services Abstracts, International Bibliography of Social Sciences (accessed via CSA Illumina); CINAHL (accessed via EBSCOHost); and the Cochrane library. Databases were searched using the following terms identified from the title, abstract, key words or medical subject headings: ('well-being' OR 'wellbeing' OR 'wellness' OR 'happiness' OR 'happy' OR 'thrive' OR 'flourish' OR

'pleasure' OR 'joy' OR 'life ADJ1 satisfaction' OR 'satisfaction ADJ1 with ADJ1 life' OR 'strength\$' OR 'blessing\$' OR 'virtue\$' OR 'good ADJ1 life' OR 'fulfilment' OR 'eudaimonia' OR 'eudaemonia' OR 'hedonism') AND ('severe mental illness\$' OR 'severe mental disorder\$' OR 'serious mental illness\$' OR 'serious mental disorder\$' OR 'chronic mental illness\$' OR 'chronic mental disorder\$' OR 'psychosis' OR 'psychotic' OR 'schizophrenia' OR 'bipolar' OR 'manic' OR 'mania' OR 'schizo-affective' OR 'schizo-affective' OR 'paranoid' OR 'paranoia' OR 'catatoni\$' OR 'hebephreni\$' OR 'disorganised'). The search terms and the use of MeSH headings were adapted for the individual databases and interfaces as needed. Second, tables of contents from three journals that were identified in the search as frequently publishing potentially relevant papers (British Journal of Wellbeing, Journal of Positive Psychology, Psychiatric Rehabilitation Journal), and two special issues on positive psychology and well-being were hand searched. Third, we searched the Grey Literature Network Service and web-sites of relevant charities in the field (Mental Health Foundation, New Economic Foundation, Young Foundation, Mind, Rethink). Fourth, eight experts with a high research profile in the field were asked to identify research on the promotion of well-being in people with psychosis. Finally, the reference lists of all included studies, relevant reviews and opinion papers were hand searched, as were relevant Cochrane reviews and NICE guideline reviews of RCTs for psychosis.

### Data extraction and appraisal

The first 200 studies were independently rated for inclusion by two reviewers (BS, VB), achieving a concordance rate of 0.98. Disagreement was resolved by consensus. The remaining 19,137 studies were appraised by one review author (BS). Data were extracted into an Excel spreadsheet developed for a previous systematic review with narrative synthesis (Schrank, Stanghellini, & Slade, 2008). The methodological quality of the included studies was assessed using the Effective Public Health Practice Project "Quality Assessment Tool for Quantitative Studies" (EPHPP, 1998). This tool rates the extent to which bias may be present in eight different components of quantitative studies. Each of the areas is rated based on set criteria resulting in a global rating of strong, moderate, or weak.

### Data analysis

Objective 1. Understand how well-being is measured in controlled trials with people with psychosis: We reviewed available measurement tools for well-being and used the results as a source of information for objectives 2 and 3. We first descriptively listed the measures and counted the retrieved studies in which they were used (see Table 1). After constructing the conceptual framework (see Table 2), we used vote counting to assess how frequently the individual framework dimensions were included in the used measures (see Table 3).

Objective 2. Develop an organising conceptual framework for well-being and Objective 3. Summarise the empirical evidence on psychosocial interventions to improve well-being in people with psychosis: We used a modified narrative synthesis approach (Popay et al., 2006). Objective 2 corresponds to the first narrative synthesis stage of identifying and developing a theory. Its result is a conceptual framework of well-being in psychosis which then serves as the organising framework for the data synthesis for objective 3. Data synthesis for objective 3 maps on the narrative synthesis stages two to four.

For objective 2 we used the measures of well-being from the studies meeting our inclusion criteria as the individual data units. We started from the three broad domains of well-being and its

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