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Self-reported quality of life in a Scottish first episode psychosis cohort: associations with symptomatology and premorbid adjustment

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Background

There is increased interest in quality of life as a clinically relevant factor in adjustment to, and recovery from first episode psychosis. Given the subjective nature of quality of life it is proposed that this variable may be associated with compromised functioning prior to the onset of psychosis, and may also have an impact on an individual's adjustment to psychosis after treatment is initiated.

Aim

The current study aims to explore associations between subjective quality of life, symptomatology, premorbid adjustment, duration of untreated psychosis (DUP) and engagement with services after onset of treatment.

Method

A cross sectional cohort of Scottish individuals undergoing treatment for First Episode Psychosis (FEP) were characterised in terms of psychotic symptomatology, premorbid adjustment, DUP, and service engagement. Self-reported quality of life (sQoL) was measured using the WHOQOL-BREF, allowing for the measurement of physical, psychological, social relational and environmental aspects of quality of life.

Results

Higher scores for subjective quality of life components were associated with better premorbid adjustment, lower positive psychotic symptoms, lower negative symptoms and less cognitive disorganization. Childhood premorbid adjustment predicted both physical and social relationship QoL.

Discussion

Subjective Quality of life domains differ in their associations with clinical and premorbid factors. The relationship between premorbid adjustment and quality of life requires further exploration in FEP.

Key words:

Psychotic disorders, quality of life, premorbid adjustment

Introduction

Treatment outcome in psychotic disorders increasingly incorporates trajectories of symptomatic recovery and functional recovery. Quality of life (QoL) has emerged as an important indicator of functional outcome in chronic^{1,2} and first episode psychosis (FEP) samples³. Definitions of QoL are heterogeneous but encompass domains of physical, psychological, interpersonal and environmental well-being, reflected in assessment tools for QoL^{4,5}. As QoL is frequently measured subjectively (sQoL) it is an important variable in designing user-oriented services and treatments.

Compared to non-clinical controls, individuals with a FEP diagnosis have lower quality of life⁶. Correlates of lower QoL in FEP include greater depression⁶⁻¹⁴, greater positive psychotic symptoms¹¹⁻¹²; greater negative symptoms^{10-12,15,16}; comorbid personality disorder¹¹ and impaired functioning¹¹. Higher QoL has shown to be associated with lower carer burden¹¹ and improved subjective psychological wellbeing¹²⁻¹³; while improvement in QoL at 2 years after initiation of treatment was associated with reduced depressive symptoms, increased global functioning and level of activity¹⁷.

However, findings with regard to the impact of premorbid factors on QoL are more equivocal, with some studies reporting an association between poorer premorbid social adjustment and lower QoL^{8,18}, while other studies fail to find this association^{11,17}. Similarly, findings regarding the relationship between duration of untreated psychosis (DUP) and QoL also differ between studies reporting significant correlation between longer DUP and poorer psychological quality of life^{8,11,19}, and studies reporting no such relationship^{11,17}. This variation may represent sampling variability, but might also be reflective of conceptual overlap between the DUP and premorbid adjustment constructs¹⁸. Although there is some evidence for a relationship between carer-related variables such as emotional over-involvement and reduced QoL¹¹ there is a paucity of data on how engagement with clinical services correlates with QoL in FEP. Such data are of importance for treatment planning and for identifying differing trajectories of adaptation to psychosis^{3,11}.

Therefore the current study undertook to a) characterise a cohort of individuals in treatment for FEP in terms of symptoms, subjective quality of life, and premorbid factors; b) to determine the magnitude of association between these variables and sQoL; c) determine the degree of association between sQoL and engagement with treatment. We hypothesised that lower symptoms would be associated with greater sQoL; poorer premorbid adjustment would be associated with lower sQoL; longer DUP would be associated with lower sQoL; and that better clinician-rated engagement would correlate with higher sQoL.

Methodology

Participants

Participants were individuals presenting to early intervention for psychosis services in two Scottish cities, recruited between October 2005 and March 2008. Individuals were eligible if they were in the first 12 months of treatment for first episode psychosis. This was defined as presentation to clinical services with psychotic symptoms for the first time, with positive psychotic symptoms of sufficient severity and/or distress to require antipsychotic medication; meeting DSM-IV criteria for schizophrenia, schizoaffective disorder, delusional disorder or bipolar disorder ²⁰. Individuals were not eligible for consent if substance misuse, head injury or organic disorder were judged to be the primary cause of psychotic symptoms. Eighty-five FEP referrals were identified. Sixteen individuals were deemed unsuitable for consent by treating clinicians and five individuals declined consent. This left a total sample of n=64. All participants retained capacity to give informed consent. The study received ethical approval from Greater Glasgow & Clyde NHS and Lothian NHS Research Ethics Committees (REC: 04/S0703/91), and managerial approval from local Research and Development Departments in Lothian and Greater Glasgow.

Procedures

A cross sectional cohort design was used. Participants gave informed consent to involvement in the study. Measures were conducted by trained research assistants and the first author, independent of treatment. Symptomatology was measured at the first session after consent, followed by DUP at the second session, with premorbid adjustment and quality of life assessed thereafter. The service

engagement measure was collected from clinicians concurrent with the participation of their service user in the research project. Further details of the study are available elsewhere³⁰.

Measures

WHOQOL-BREF (WHOQOL-BREF)²³

The World Health Organisation Quality of Life measurement (Abbreviated version) is a 26 item self-report questionnaire assessing a respondent's quality of life across physical, psychological, social relationships and environmental domains. The physical domain refers to pain, sleep, energy, mobility, daily functioning, reliance on medical treatment and work capacity. The psychological domain reflects subjective ratings of positive and negative emotion, self-esteem, body image and beliefs. The social relationship domain incorporates aspects of personal relationships, social supports and sexual activity. The Environmental domain refers to the individual's appraisal of their own freedom, safety, financial support, access to health care, opportunity, transport and leisure activities. An overall rating of perceived quality of life can be derived, though in the current study we chose to focus subscale scores, as they provide greater detail on QoL domains. Internal consistency of domain scores is generally good (Cronbach's alpha; $r = .68 - .97$), and test-retest reliability is excellent ($r = .83 - .86$). Significant correlations have been observed between the measure and clinically rated quality of life in psychosis²⁴.

Positive and Negative Syndrome Scale (PANSS) ²¹

The PANSS is a 30 item semi-structured interview of psychotic symptomatology. We adapted a five factor scoring model, yielding scores for: positive symptoms, negative symptoms, cognitive disorganization, excitement and emotional distress²². Each item is scored on a Likert scale from minimal (1) to extreme (7). "Inter-rater reliability estimates for PANSS subscales were adequate (all intra-class correlation coefficients $>.82$)"

Duration of untreated psychosis interview (DUP)^{25,26}

This measure is an unstructured interview protocol adapted from Beiser and colleagues' methodology²⁵. Information regarding the circumstances of onset and development of psychotic symptomatology was collected from the individual and (where a clear DUP could not be estimated) a carer or loved one, cross-referenced with clinical case notes, and discussion with the individual's clinician. Date of onset of psychosis was calculated to the nearest week and transition to psychosis was indicated by presence of one or more symptoms on the positive symptom scale of the PANSS, rated as 4 or greater (indicating significant impairment). The DUP endpoint was considered to be the date at which antipsychotic medication was prescribed and/or multi-disciplinary team involvement initiated; and where compliance with the treatment plan could be ascertained at one month after initiation of treatment. DUP was established via a consensual judgement of the information gathered. Test-retest reliability of this measure has been reported as good (intraclass coefficient $r = .96$, $p < 0.01$)²⁶.

Premorbid Adjustment Scale (PAS)²⁷

The PAS is a semi-structured interview that retrospectively measures level of functioning prior to onset of psychosis. The measurement period is from birth till adulthood; sub-divided into childhood, early adolescence, late adolescence, and adulthood. Given the possibility that ratings for the late adolescence and adulthood components of the PAS could overlap with DUP we report data for childhood and early adolescence only. Data are also reported for academic and social functioning components.

Service Engagement Scale (SES)²⁸

This is a 14-item, clinician-completed scale to assess overall engagement with services. Items assess four subscales including availability, collaboration, help-seeking and treatment adherence. The scale has good reliability and discriminant validity (Cronbach's alpha = 0.76 – 0.90 for sub-scales).²⁹

Demographics

Demographics and treatment data were completed at 12 months after initiation of treatment, based on information from case notes and key-worker reports.

Data Analysis:

Data were analysed using SPSS version 16. All variables were checked for normality using the Kolmogorov-Smirnov test. Associations between variables were examined using Pearson correlations and t-tests for significant differences between groups. Cohen's criteria for interpreting the strength of correlations were used, whereby $r=0.1-0.3$ is considered a small effect, $r=0.3-0.5$ a moderate effect, and $r \geq 0.5$ is a large effect. Non-normally distributed PANSS and DUP data were transformed to their natural logarithms, with corresponding improvements in the normality of the data. Significant associations between sQoL and clinical measures were then entered into a series of multiple regression analyses, predicting sQoL domain scores. Regression analyses were conducted using the enter method. As the analyses were conducted on a relatively small sample the significance level (alpha) was set at 0.05.

Results

Sixty-four individuals were included in the sample (see Table 1). Forty-three (67%) were male. Mean age at first contact with clinical services for psychosis was 23.5 years (s.d. = 7.0; median = 22 years; range = 15 - 45 years). The majority of participants self-reported their ethnicity as White British (90.6%; $n=58$). Demographics, diagnostic information and descriptive data for symptoms, quality of life and clinical variables are presented in Table 1. The mean Duration of Untreated Psychosis was 41.7 weeks (s.d. = 74.5). There were no significant differences between males and females for mean scores on Quality of Life subscales. Age and quality of life subscale scores were not significantly correlated in the sample.

Table 2 displays correlations between the sQoL subscales, pre-treatment and clinical variables. With regard to pre-treatment variables, perceived lower psychological quality of life was associated with longer DUP. Poorer Childhood social functioning was significantly negatively associated with all quality of life domains ($r = -.31$ to $r = -.58$, 95% CI's = $-.72$ to $-.07$; $p = .03$ to $p < .001$). Poorer early adolescent social functioning

was similarly associated with all quality of life domains, but to a lesser extent than childhood social functioning ($r = -.29$ to $r = -.40$, 95% CI's = $-.58$ to $-.05$; all $p = .04$ to $p = .005$). Childhood academic adjustment was significantly negatively correlated with physical, psychological and environmental aspects of quality of life ($r = -.34$ to $r = -.38$, 95% CI's = $-.57$ to $-.06$; $p = .02$ to $p = .007$). Early adolescent academic premorbid adjustment was associated with the environmental quality of life subscale ($r = -.35$, 95% CI = $-.55$ to $-.11$; $p = .02$). Early adolescent academic adjustment was also negatively associated with physical quality of life ($r = -.35$, 95% CI = $-.54$ to $-.11$ $p = .02$).

Poorer perceived physical quality of life was associated with greater negative symptoms ($r = -.35$; 95% CI = $-.55$ to $-.11$; $p = .02$). It can be seen that reduced perceived psychological quality of life was associated with greater severity of symptomatology for PANSS positive, negative and cognitive disorganization symptoms ($r = -.29$ to $r = -.33$; 95% CI's = $-.53$ to $.13$; $p = .04$ to $p = .02$). Perceived quality of social relationships was associated with greater negative symptoms ($r = -.35$; 95% CI = $-.55$ to $-.11$; $p = .01$). Lower perceived environmental quality of life was associated with greater cognitive disorganization ($r = -.28$, 95% CI = $-.50$ to $-.04$; $p = .05$). PANSS Excitement and Emotional Distress were unrelated to sQoL. Poorer engagement with services was associated with poorer perceptions of social relationships and perceived quality of environment ($r = -.33$, 95% CI = $-.56$ to $-.05$; $p = .03$ and $r = -.46$, 95% CI = $-.66$ to $-.20$; $p = .003$). Engagement was not associated with physical or psychological quality of life.

Significant correlates of sQoL were entered into a series of regression analyses (Table 3). Due to the relatively small sample size we set the significant at $p < .05$ in the correlational analyses as the threshold for entry of predictors into the regression analyses. All assumptions of normality, homoscedasticity and linearity of variables were met in the regression analyses. Childhood social premorbid adjustment emerged as the sole significant predictor for both Physical and Social Relationship sQoL. No significant predictors emerged for Psychological, Environmental or General sQoL.

Discussion

We examined the effect of clinical, premorbid and service engagement variables on subjective quality of life in a cross-sectional sample of patients in the first year of treatment for a FEP. The data broadly support our hypotheses that lower symptoms would be associated with greater sQoL; and that better premorbid adjustment was associated with higher sQoL. The evidence was weaker for our hypotheses regarding relationships between sQoL and DUP; and between sQoL and clinician-rated engagement.

The current study replicates existing findings suggesting associations between QoL and negative symptoms^{3, 10-12,15,16}. Previous literature has suggested that negative symptoms are the strongest predictor of QoL when objective measurement of QoL (oQoL) is used^{3, 10}. However data is more equivocal regarding the strength of negative symptoms in predicting subjective QoL^{11, 14}. Consistent with previous research¹³, there is the possibility that due to the low mean age of participants in our study and evidence that negative symptoms increase with age and illness chronicity³¹ our measurement of negative symptoms lacked sensitivity to predict sQoL in a regression model.

In contrast to previous findings^{2, 11, 13}, we failed to find significant associations between depression and sQoL. Our measurement of depression was derived from the emotional distress factor of the 5-factor PANSS²². This factor is a combination of depression, anxiety, guilt and tension, therefore encompasses both cognitive and biological components of affective distress. It may be the case that the cognitive rather than the biological components of depression contribute to lower subjective QoL in FEP¹⁴. Therefore it may be the case that our PANSS derived measure of depression lacked the specificity to detect an association between depression/affective distress and sQoL.

Contrary to our hypothesis we reported significant associations of medium effect size between greater premorbid adjustment and higher quality of life scores. Our results are thus consistent with a previous review of the literature¹⁸, but in contrast with recent findings^{11,17} that have failed to report this association. However, the study by

Melle and colleagues¹⁷ reported findings at 2-years follow-up whereas the current study reported data for service users in their first 12 months of treatment. Indeed, findings for patients in the first 12 months of treatment for FEP suggest comparable levels of association between premorbid adjustment and QoL⁸. Similarly, we note the mean age of the current study was higher than previous samples¹¹. It may be the case that earlier age of onset of psychosis may mitigate the impact of premorbid adjustment on QoL, as earlier age of onset is generally associated with poorer prognosis (Hollis, 2000).

The presence of childhood premorbid adjustment as a predictor of physical and social relationship QoL also merits comment. Physical sQoL refers to the physical capacity to engage in activities of daily living, while Social Relationship sQoL measures social and relational support. There is conceptual overlap between social relationship sQoL and related constructs such as wellbeing¹³ and social support³². However, we did not find evidence to support Malla and colleagues³³ suggestion that better premorbid adjustment was a risk factor for poorer QoL, via appraisals of loss of premorbid goals. Instead we suggest that premorbid capacity to function in social domains and maintain a reasonable degree of academic function may be a marker of resilience and capacity to adapt to the experience of psychosis, reflected in preserved QoL. The prominence of childhood premorbid adjustment in the analysis is consistent with models of psychosis that emphasise the impact of psychodevelopmental factors in the illness trajectory in FEP^{30,34,35}. There was little evidence of an effect of DUP on sQoL. This is consistent with review evidence that suggests a differentially greater effect of premorbid adjustment on QoL compared with the effect of DUP on QoL¹⁸. As the evidence base remains inconsistent we suggest that measurement of premorbid function as a potential correlate remains important.

We note that the current study failed to find evidence for an association between service engagement and sQoL, with the exception of social relationship and environmental QoL. Environmental QoL reflects perceived access to resources, opportunity and safety. Our participants were receiving treatment from assertive, specialised treatment services, therefore it follows that good engagement with these

services could serve to bolster an individual's perception of their own access to both social and practical support. However it is notable that this did not translate to broader benefits in terms of physical, psychological or overall QoL. The current study also failed to find any association between gender and QoL. The literature on QoL in multi-episode and chronic samples suggests that QoL is greater in females than males³⁶. However evidence from FEP is mixed with some studies suggesting a general absence of any association between gender and QoL^{11,13,17}, while others support an association between better QoL and female gender^{37,38}.

There are methodological limitations in the study. The sample size was small and cross sectional, limiting the scope and complexity of our statistical analyses. The complexity of the data set also entailed a substantial number of analyses, increasing the likelihood of Type I errors in the reported result. We note conceptual overlap between measures of quality of life and engagement, and the limitation of using PANSS emotional distress as a proxy for depression and affective distress. In addition, it has been noted that aspects of psychosis such as depression and insight may influence self-report measures^{11,33}. Concerns have also been raised regarding the validity of applying general measures of sQoL to samples of complex mental health problems^{14,39}. It would therefore be useful for more studies to combine simultaneous measurement sQoL and oQoL (e.g. ^{8,10}), ideally using a combination of self-report and interview measures. We also note that participants were in a non-acute phase of illness and responsive to an integrated early intervention treatment program. Thus, compared with other cohorts our participants may represent a higher functioning group of individuals, with corresponding reduction of variance in the DUP and lower levels of positive and negative symptoms. However, it is of note that participants were by no means asymptomatic. In addition, we did not include a baseline level of general functioning, which could be a possible covariate of sQoL.

In terms of clinical implications, we highlight that subjective quality of life represents a promising measure of both process and outcome in FEP. The current study also underscores the importance of comprehensive assessment incorporating premorbid functioning and developmental history. Measurement of these factors has important implications for treatment planning and delivery, particularly from the point of view

of potential generalizability to broader treatment goals such as recovery and staying well ⁴⁰.

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