King's Research Portal

DOI:

[10.1016/j.psychres.2017.11.074](https://doi.org/10.1016/j.psychres.2017.11.074)

Document Version

Peer reviewed version

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Leendertse, P., Myin-Germeys, I., Lataster, T., Simons, C. J. P., Oorschot, M., Lardinois, M., Schneider, M., van Os, J., & Reininghaus, U. (2017). Subjective quality of life in psychosis: evidence for an association with real world functioning? *Psychiatry Research*. <https://doi.org/10.1016/j.psychres.2017.11.074>

Citing this paper

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

General rights

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

Subjective quality of life in psychosis: evidence for an association with real world functioning?

Pien Leendertse, Inez Myin-Germeys, Tineke Lataster, Claudia J.P. Simons, Margreet Oorschot, Mariëlle Lardinois, Maude Schneider, Jim van Os, Ulrich Reininghaus

Berhoos Z. Alizadeh, Agna A. Bartels-Velthuis, Nico J. Van Beveren, Richard Bruggeman, Wiepke Cahn, Lieuwe de Haan, Phillipe Delespaul, Carin J. Meijer, Inez Myin-Germeys, Rene S. Kahn, Frederike Schirmbeck, Claudia J.P. Simons, Neeltje E. van Haren, Jim van Os, Ruud van Winkel

PII: S0165-1781(17)30814-4
DOI: <https://doi.org/10.1016/j.psychres.2017.11.074>
Reference: PSY11021

To appear in: *Psychiatry Research*

Received date: 12 May 2017
Revised date: 26 September 2017

Accepted date: 26 November 2017

Cite this article as: Pien Leendertse, Inez Myin-Germeys, Tineke Lataster, Claudia J.P. Simons, Margreet Oorschot, Mariëlle Lardinois, Maude Schneider, Jim van Os, Ulrich Reininghaus, Berhoos Z. Alizadeh, Agna A. Bartels-Velthuis, Nico J. Van Beveren, Richard Bruggeman, Wiepke Cahn, Lieuwe de Haan, Phillipe Delespaul, Carin J. Meijer, Inez Myin-Germeys, Rene S. Kahn, Frederike Schirmbeck, Claudia J.P. Simons, Neeltje E. van Haren, Jim van Os and Ruud van Winkel, Subjective quality of life in psychosis: evidence for an association with real world functioning?, *Psychiatry Research*, <https://doi.org/10.1016/j.psychres.2017.11.074>

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting galley proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Subjective quality of life in psychosis: evidence for an association with real world functioning?

Authors:

Pien Leendertse^{a*}, Inez Myin-Germeys^b, Tineke Lataster^c, Claudia J.P. Simons^{c,d}, Margreet Oorschot^c, Mariëlle Lardinois^c, Maude Schneider^b, Jim van Os^{c,e}, Ulrich Reininghaus^{c,e}; for Genetic Risk and Outcome of Psychosis (GROUP) investigators[§]

§ GROUP investigators are: Berhooz Z. Alizadeh^f, Agna A. Bartels-Velthuis^f, Nico J. Van Beveren^g, Richard Bruggeman^f, Wiepke Cahn^h, Lieuwe de Haanⁱ, Phillipe Delespaul^c, Carin J. Meijerⁱ, Inez Myin-Germeys^b, Rene S. Kahn^h, Frederike Schirmbeckⁱ, Claudia J.P. Simons^{c,d}, Neeltje E. van Haren^h, Jim van Os^{c,e}, Ruud van Winkel^{b,c}

^a Emergis, Institute for Mental Health Care Zeeland, Goes, The Netherlands;

^b KU Leuven, Department of Neuroscience, Research Group Psychiatry, Center for Contextual Psychiatry, Leuven, Belgium;

^c Maastricht University Medical Center, Department of Psychiatry and Psychology, School for Mental Health and Neuroscience, Maastricht, The Netherlands;

^d GGzE, Institute for Mental Health Care Eindhoven and De Kempen, Eindhoven, The Netherlands;

^e Center for Epidemiology and Public Health, Health Service and Population Research Department, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, United Kingdom;

^f University of Groningen, University Medical Center Groningen, University Center for Psychiatry, Groningen, The Netherlands;

^g Erasmus University Medical Center, Department of Psychiatry, Rotterdam, The Netherlands

^h University Medical Center Utrecht, Department of Psychiatry, Rudolf Magnus Institute of Neuroscience, Utrecht, The Netherlands;

ⁱ Academic Medical Center, University of Amsterdam, Department of Psychiatry, Amsterdam, The Netherlands;

* Corresponding Author: Pien Leendertse; Emergis, Institute for Mental Health Care Zeeland, Postbus 253, 4460AR Goes, The Netherlands. Phone: +31 113 267595. Email: Leendertse@emergis.nl

Abstract

Subjective quality of life (SQOL) is an established patient-reported outcome in psychosis. However, current self-report measures of SQOL may be affected by recall bias and may not fully capture dynamic changes in SQOL over time. This study aimed to examine the ecological validity of self-reported and momentary assessment measures of SQOL, and their association with emotional experience, social interaction and activity in real life, in both patients with psychotic disorder (n=56) and controls (n=71). Self-reported QOL was assessed with the WHO-QOL, momentary QOL and real life experiences were assessed with the Experience Sampling Method (ESM). Results show that both measures were significantly associated in patients and controls, and associations with emotional experience were most relevant, momentary QOL being a stronger predictor than self-reported QOL. The association between momentary QOL and negative affect was stronger in patients than in controls. Overall, momentary QOL was more consistently associated with affect, social interaction and activity, while self-reported QOL displayed a more narrow association with mostly affect. Concluding, concurrent assessment of self-reported QOL and momentary QOL showed that momentary QOL may enhance the ecological validity of SQOL measurement. Experience sampling research may broaden our perspective on SQOL and its associations with real life functioning.

Keywords

Experience sampling; Momentary quality of life; Real life experiences.

1. Introduction

In current debates about psychosis care, quality of life plays an important role. However, quality of life (QOL) in psychosis has long been researched. In 1947, the World Health Organization (WHO) broadened the definition of 'health', from just physical health to psychological health and social well-being (World Health Organization, 1947). Subsequently, the term 'QOL' was introduced in medical healthcare and later in psychiatry, where since the 1960s the quality of life of people with psychosis has received increasing attention and becomes a popular outcome measure for clinicians to guide and evaluate health care programs (Priebe and Fakhoury, 2008). Because of the prevailing concern that outcome assessment should include the patient's perspective, attention was paid to the development of measures of 'patient QOL' (Lehman, 1996). At present, QOL is an established patient

reported outcome (PRO) in psychosis, which has received much attention from researchers and service providers over the past decades (Reininghaus et al., 2012).

Despite the popularity of the concept, there is no consensus to date on the precise definition of QOL (Katschnig, 2006). A distinction is commonly made between objective QOL (patients' life circumstances in various life domains) and subjective QOL (satisfaction with life in general and in major life domains) (Priebe and Fakhoury, 2008; Ruhrmann et al., 2008). These distinct aspects of QOL appear to measure different underlying constructs (Ruggeri et al., 2001).

Subjective QOL is typically assessed with self-report questionnaires. It is a common concept to assess the impact of the illness on the everyday life of patients or as a therapy outcome measure in clinical trials (Ruhrmann et al., 2008). It has been suggested that when it comes to mental disorders, subjective reports of QOL are prone to measurement distortions (Katschnig, 2006), such as recall bias. Psychiatric symptoms and cognitive deficits are said to challenge the validity of self-reported measures. However, a recent review suggests that the influence of psychiatric symptoms and cognitive deficits on PROs in patients with psychosis is very limited (Reininghaus and Priebe, 2012). Subjective QOL may also be a construct dynamically changing over time (Priebe et al., 2011). Patients' ratings of subjective QOL elicited during traditional assessment situations are not necessarily the same as those occurring in the real world, outside the research laboratory (Barge-Schaapveld et al., 2006). If ignored, this may pose a threat to the ecological validity of subjective QOL measurement.

These problems have stimulated a search for new models and methods for assessing subjective QOL in daily life, with concurrent assessment of individual preferences and experience (Barge-Schaapveld et al., 2006). In the literature, this is referred to as 'daily or momentary QOL'. Measuring subjective QOL in the real world and in real time improves ecological validity and minimizes the influence of recall bias. The Experience Sampling Method (ESM), a structured, random time-sampling diary technique, offers such a strategy for measuring moment-to-moment variation in patients' subjective

experience of life in general and major life domains (Myin-Germeys et al., 2009). Barge-Schaapveld et al. (2006) argued that ESM assessment of momentary QOL will enhance our understanding of the dimensions of the concept of QOL and offers the additional advantage of concurrent assessment of real-world experiences including (positive and negative) affect, level of social interaction and level of activity (Delespaul, 1995; de Vries, 1995; Katschnig, 2006; Priebe et al., 2011). Of these experiences, negative affect has been consistently found to be most strongly associated with subjective QOL in people with psychosis using conventional self-report measures of subjective QOL (Ruggeri et al., 2001; Fakhoury and Priebe, 2002; Saarni et al., 2010; Priebe et al., 2011). Further, a recent study by Blum et al. (2015) has found low correspondence between retrospective and real-life measures of depressed mood in patients with psychosis. Differences in associations between subjective QOL and real world experiences between patients and healthy controls would provide important insights for improving clinical care, as specific associations for patients would enable us to develop more targeted ecological momentary interventions in the real world (Reininghaus et al., 2016a; Myin-Germeys et al., 2016), but such differences remain to be investigated.

The current study aimed to examine the ecological validity of self-report and momentary measures of subjective QOL (hereafter referred to as 'self-reported QOL' and 'momentary QOL', which both form part of subjective QOL) and their associations with experiences in the real world in patients with psychosis and controls. To this end, the following hypotheses were tested: (1) self-reported QOL is associated with momentary QOL within each group; (2) self-reported QOL and momentary QOL are associated with ESM measures of emotional experience, social interaction and activity within each group; and (3) the association between self-reported and momentary QOL, on the one hand, and negative affect, on the other, is stronger in patients compared with controls.

2. Methods

2.1 Sample

The sample consisted of patients diagnosed with a non-affective psychotic disorder and healthy controls recruited as part of wave 1 of the Genetic Risk and Outcome of Psychosis (GROUP) study. Patients were recruited from mental health services and patient organizations in representative geographical areas in The Netherlands and (the Dutch speaking part of) Belgium (Korver et al., 2012). Inclusion criteria for patients were: (i) aged between 16-60 years, (ii) sufficient command of the Dutch language, and (iii) DSM-IV diagnoses of non-affective psychotic disorder based on DSM-IV-TR assessed with the Comprehensive Assessment of Symptoms and History interview (CASH; Andreasen et al., 1992). Controls were selected through a system of random mailings in the same areas (Korver et al., 2012). The same inclusion criteria applied for controls; in addition, the CASH was used in controls to exclude those with a diagnosis of psychosis. The Family Interview for Genetic Studies (FIGS; NIMH, 1992) was used to exclude a diagnosis of psychosis in their first- and second degree relatives.

2.2 Experience Sampling Method (ESM)

Subjects were given a preprogrammed digital wristwatch and assessment forms collated in a booklet. Ten times a day on 6 consecutive days, the watch emitted a signal at unpredictable moments between 7.30 AM and 10.30 PM. After each 'beep', subjects were asked to record their thoughts, feelings, experiences and current social context in daily life. During an initial briefing session, all subjects were instructed about the ESM procedure and completed a practice form. To minimize potential bias due to memory distortions and post-hoc interpretation, subjects were instructed to complete their reports immediately after the beep and to note the time at which they completed the questionnaire. Reports were considered valid when participants responded to the beep within 15 minutes. At least one-third of the emitted beeps with valid responses were required for participants to be included in the analysis (Delespaul, 1995).

2.3 Real life experiences and momentary QOL

ESM was used to collect both real life experiences and momentary QOL based on previous experience sampling studies in individuals with psychosis (Delespaul, 1995; Myin-Germeys et al., 2000, 2001; Korver et al., 2012; Oorschot et al., 2012). Subjects were asked to rate their i) emotional experience, ii) social interaction and iii) activity, all rated on a 7-point Likert scale (1=not at all, 7=very). The ESM measure of emotional experience consisted of a positive (items: cheerful, relaxed, satisfied) and negative (items: insecure, lonely, anxious, irritated, down, guilty) measure, which were developed by Myin-Germeys et al., 2001 and have since been used in numerous experience sampling studies (e.g. Oorschot et al., 2012; Reininghaus et al., 2016b). Social interaction was assessed with the item 'We are interacting', in which moments spent alone were included and coded as 1=not at all. In addition, we focused on whether subjects were alone or not by creating the variable 'time spent alone' (alone: 1=yes, 0=no). To assess subjective activity level, the item 'I am active' was used. Further, subjects reported on their type of activity, which was used to create the variables 'goal-directed activity' (work, care, household or study, coded as 1=goal-directed, and e.g. performing hobbies or reading a book as 0=non-goal-directed), and 'doing nothing' (nothing: 1=yes, 0=no). ESM measures of social interaction and activities were developed by Delespaul (1995) and have since been used in several experience sampling studies (e.g. Myin-Germeys et al., 2001, Oorschot et al., 2012; Reininghaus et al., 2016b). Subjects were further asked to rate their momentary QOL on a 7-point Likert scale (1=not at all, 7=very) using the item 'Globally speaking, I feel well'. Previous studies have reported positive correlations of momentary QOL with different retrospective subjective QOL measures, supporting the concurrent validity of momentary QOL (Barge-Schaapveld and Nicolson, 2002). As the prevalence of 'doing nothing' was low for controls and the distribution of momentary QOL was slightly skewed, we encountered errors estimating models involving these variables, and therefore transformed momentary QOL into a binary variable, with scores of 1 to 4 coded as 0 (low), and scores of 5 to 7 coded as 1 (high). A description of the ESM measures and items can be found in Table 1.

[Insert Table 1 here]

2.4 WHO-QOL

The World Health Organization Quality of Life Scale Brief Version (WHOQOL-BREF) is a 26-item version of the WHOQOL-100 assessment (Skevington et al., 2004). It is a generic self-report questionnaire, asking subjects to rate their subjective QOL over the past two weeks retrospectively (World Health Organization, 1995). For the current study, the first item was used ('How would you rate your quality of life?'), scored on a 5-point intensity scale (1=very poor, 5=very good).

2.5 Statistical analysis

Stata 12.1 (StataCorp, 2011) was used for all analyses. T-tests and chi-square tests were used to test for differences between patients and controls in basic sample characteristics (i.e. age, sex, IQ on WAIS-III, number of beeps, WHO-QOL scores and ESM measures). ESM data contain multiple observations within one person, which requires the use of multilevel models. In order to investigate the ecological validity of self-reported QOL, a model with self-reported QOL as independent variable and momentary QOL as dependent (or criterion) variable was fitted, while controlling for potential confounders (i.e., age, sex, IQ). To investigate the ecological validity of both types of subjective QOL measurement further as reflected in their associations with real-world experiences, models with self-reported and momentary QOL as independent variables and the different ESM measures reflecting real-world experiences (positive affect, negative affect, level of social interaction, time spent alone, level of activity, goal directed activity and doing nothing) as dependent variables were fitted (see Figure 1)

[Insert Figure 1 here]

XTMIXED was used to perform analyses on continuous outcome variables (i.e., ESM measures of negative affect, positive affect, social interaction, and activity) and XTMELOGIT was used to perform analyses on binary outcome variables. Random slope models were used in the analyses with momentary QOL as independent variable. Analyses were conducted stratified by group (i.e. patients,

controls). In order to assess whether the associations between subjective QOL and ESM measures were stronger in patients than in controls, interaction terms for group $\times$ WHO-QOL score as well as for group $\times$ momentary QOL were fitted and assessed for statistical significance using likelihood ratio (LR) tests, and the LINCOM command for computing appropriate linear combinations. (Release number GROUP data: 3.02)

3. Results

3.1 Basic sample characteristics

Of the recruited participants, 4 patients and 2 controls were excluded because of an insufficient number of ESM reports, and 11 patients and 7 controls were excluded because of missing WHO-QOL, socio-demographic, cognitive or clinical data (see Figure 2). The final sample comprised 56 patients and 71 controls. Basic sample characteristics are summarized in Table 2. Controls had a significantly higher mean age, beep number and IQ than patients, and were more likely to be women. These demographic differences were controlled for in the multivariable analyses. Controls showed a higher subjective QOL (both self-reported and momentary QOL) compared with the patient sample. Finally, all ESM measures showed significant differences between groups, except time spent alone and level of activity. Negative affect and doing nothing were lower in controls than in patients. Positive affect, level of social interaction and goal directed activity were higher in controls than in patients. A Pearson's product-moment correlation was run to assess the relationship between self-reported and momentary QOL. For patients there was a strong positive correlation, $r = .519$, $p < .001$, for controls there was a moderate positive correlation, $r = .438$, $p < .001$ between both types of subjective QOL measurement.

[Insert Table 2 here]

3.2 Association between self-reported QOL and momentary QOL

There was evidence for higher self-reported QOL to be associated with higher levels of momentary QOL, in both patients ($OR=3.65$, $95\%CI=2.22$ to 6.00 , $p<0.001$) and controls ($OR=2.41$, $95\%CI=1.38$ to 4.21 , $p=0.002$). The LR-test showed no significant interaction effect for group on the association between self-reported QOL and momentary QOL ($LR \chi^2(1) = 0.38$, $p=0.536$).

3.3 Association between QOL and emotional experience

Both higher self-reported QOL and higher momentary QOL were associated with higher levels of positive affect and lower levels of negative affect, in both patients and controls (see Table 3).

[Insert Table 3 here]

As can be seen in Table 4, there was neither a significant interaction effect of group $\times$ self-reported QOL on positive affect, nor a significant interaction effect of group $\times$ self-reported QOL on negative affect.

[Insert Table 4 here]

Furthermore, group $\times$ momentary QOL showed no significant interaction effect on positive affect, but there was evidence of an interaction effect of group $\times$ momentary QOL on negative affect. This indicated that in patients momentary QOL was more strongly associated with negative affect ($B=-0.73$, $95\%CI -0.83$ to -0.62 , $p<0.001$) than in controls ($B=-0.48$, $95\%CI -0.57$ to -0.39 , $p<0.001$). Table 5 shows that, when examining the relative contribution of self-reported QOL and momentary QOL in one model, momentary QOL is more strongly associated with positive and negative affect in both patients and controls than self-reported QOL.

[Insert Table 5 here]

The findings for interaction effects remained unchanged (see Table 6).

[Insert Table 6 here]

3.4 Association between QOL and social interaction

We found higher self-reported QOL to be associated with higher levels of social interaction in patients, but not in controls (see Table 3). No significant associations were found between self-reported QOL and time spent alone, either for patients or for controls.

However, higher momentary QOL was associated with higher levels of social interaction in both patients and controls. Also, higher levels of momentary QOL were associated with lower levels of time spent alone in controls, but not in patients.

As displayed in Table 4, no significant interaction effects of group $\times$ subjective QOL (i.e. self-reported QOL and momentary QOL) on social interaction and time spent alone were observed. Momentary QOL was more strongly associated with level of interaction than self-reported QOL in patients (see Table 5).

3.5 Association between QOL and activity

No evidence was found that self-reported QOL was associated with level of activity, in both patients and controls. However, higher self-reported QOL was associated with higher levels of goal directed activity in patients, but not in controls. Self-reported QOL was not associated with doing nothing for either patients or controls.

Higher momentary QOL was associated with higher levels of activity in patients, but not in controls. There was no evidence of an association between momentary QOL and goal directed activity in either group. By contrast, in both groups a significant association between higher levels of momentary QOL and lower levels of doing nothing was found (see Table 3).

Table 4 shows no interactions effects of group $\times$ subjective QOL (i.e. self-reported QOL and momentary QOL) on activity, goal directed activity and doing nothing.

4. Discussion

4.1 Main findings

Our findings are consistent with the first hypothesis that self-reported QOL is associated with momentary QOL in both patients with psychotic disorder and healthy controls. Furthermore, we found evidence in support of our second hypothesis that subjective QOL (i.e. self-reported QOL and momentary QOL) is associated with positive and negative affect in both groups, with a stronger association for momentary QOL. However, findings on the association between subjective QOL and social interaction and activity were slightly more ambiguous: while self-reported QOL was associated only with level of social interaction and goal directed activity in patients, momentary QOL was associated with level of social interaction and doing nothing in both groups. Further, momentary QOL was associated with level of activity in patients and with time spent alone in controls. Finally, the stronger association between momentary QOL and negative affect in patients compared with controls was consistent with our third hypothesis.

4.2 Methodological considerations

The results should be viewed in light of several potential methodological issues. First, both self-reported QOL and momentary QOL were based on a single item, which could potentially limit reliability. For momentary QOL, however, the single question corresponded to, and has been validated in, previous work on momentary QOL by Barge-Schaapveld and Nicholson (2002). Also, single-item self-assessment questions are frequently used in clinical research and have been proven to be valid (Weiss et al., 1990; James et al., 2005). Further, the items that were used to assess momentary and self-reported quality of life related to slightly different aspects of subjective quality of life. However, the ESM requires items to be worded differently than items of conventional self-report measures in order to keep reactivity of repeated measures in such an intensive longitudinal design to a minimum. Nonetheless, this may be addressed by future research to enhance coverage and ensure similar content of self-report and momentary measures of subjective quality of life.

Second, the results are based on subjective reports. However, challenges on the validity of self-reported measures due to psychiatric symptoms and cognitive deficits in psychosis turn out to be minimal (Reininghaus and Priebe, 2012). Also, the valid use of ESM in psychosis research has been extensively demonstrated in the literature (Myin-Germeys et al., 2003; Oorschot et al., 2009).

Third, the ESM may be demanding on participants and lead to sampling biases, which may limit the extent to which the results can be generalized (Palmier-Claus et al., 2012). However, the use of paper and pencil ESM data has been reported to be valid (Jacobs et al., 2005), and potential back-filling of ESM booklets to be unlikely (Oorschot et al., 2013).

Finally, there were differences in demographic characteristics between patients and controls, namely in IQ, age and sex. While we controlled for these variables in the analysis, we cannot rule out that these are the result of selection bias. Hence, our findings require replication in larger, carefully selected samples before firm conclusions can be drawn.

The use of ESM provided this study with specific strengths. ESM allows assessment of the interaction between QOL and subjective experiences in real time and real-life contexts (Myin-Germeys et al., 2009). Using momentary QOL improves the ecological validity and minimizes recall bias. Moreover, the use of repeated sampling over 6 days takes into account that subjective QOL may dynamically change over time, thereby improving the validity even further.

4.3 Comparison with previous research

Many studies have investigated subjective QOL in psychosis (Katschnig, 2006). The current study has moved beyond previous research by concurrently looking at self-reported QOL and momentary QOL and their associations with individuals' subjective experience in the real world. Consistent with previous studies (Ruggeri et al., 2001; Fakhoury and Priebe, 2002), subjective QOL was consistently associated with affect. The stronger association between momentary QOL and negative affect in

patients is in line with prior research showing subjective QOL to be most strongly associated with negative affect in psychosis (Saarni et al., 2010; Priebe et al., 2011).

The proposed association of subjective QOL with social interaction and activity (Delespaul, 1995; Barge-Schaapveld et al., 2006) seems to apply rather to momentary QOL than to self-reported QOL, as well as to patients rather than controls: in addition to positive and negative affect, self-reported QOL was associated only with two ESM measures (i.e., level of interaction, goal directed activity) and only in patients, whereas momentary QOL was associated with level of interaction and doing nothing (patients and controls), time spent alone (controls), and level of activity (patients). One explanation for these differences between groups may be the influence of individual preference. Patients and controls may differ in their preference for social interaction, or type of activity. Future research may take into account this aspect of individual preference (e.g. by including 'I like to spent time alone', 'I like this activity') to further elucidate some of the differences found between groups and further impersonate outcome.

This research shows that for patients and controls subjective QOL is not necessarily reflected in experiences in the respective domains in daily life. For clinical care, this means using momentary QOL can help us develop more targeted interventions to improve QOL in patients. The consistent association with affect, with a stronger association between momentary QOL and negative affect for patients, may guide us in determining our focus in treatment. For instance, by placing more emphasis on feelings of guilt, insecurity and anxiety to improve subjective QOL in psychosis. Moreover, our findings suggest treatment plans should be personalized and tailored to individual levels of social contacts and activities in order to optimize subjective QOL.

4.4 Conclusion

Our findings suggest that self-reported QOL is associated with momentary QOL and that, for both measures, the association with emotional experience in the real world may be most relevant as a target of interventions for improving subjective QOL. Most associations with real life were of similar

magnitude in patients with psychotic disorder and in healthy controls, except for a stronger association between momentary QOL and negative affect in patients. Further, momentary QOL may more closely approximate real-life experiences than self-reported QOL, by showing not only a strong association with affect, but also with social interaction and activity. This suggests that momentary QOL enhances the ecological validity of subjective QOL measurement and, therefore, should inform assessment of outcomes of interventions that aim to improve the subjective QOL of patients with psychotic disorder in research and routine care. More generally, by taking into account dynamic changes of subjective QOL over time, and allowing assessment in real time and real life context, ESM broadens our perspective on subjective QOL and its associations with real life functioning.

Acknowledgment

We are grateful for the generosity of time and effort by the patients, healthy subjects, and all researchers who make this GROUP project possible.

Financial support

UR was supported by a VENI grant of the Dutch Research Council (451-13-022).

IM-G was supported by an ERC consolidator grant (ERC-2012-StG, project 309767 – INTERACT).

The infrastructure for the GROUP study is funded through the Geestkracht programme of the Dutch Health Research Council (ZON-MW, grant number 10-000-1001), and matching funds from participating pharmaceutical companies (Lundbeck, AstraZeneca, Eli Lilly, Janssen Cilag) and universities and mental health care organizations(Amsterdam: Academic Psychiatric Centre of the Academic Medical Center and the mental health institutions: GGZ Ingeest, Arkin, Dijk en Duin, GGZ Rivierduinen, Erasmus Medical Centre, GGZ Noord Holland Noord. Maastricht: Maastricht University Medical Centre and the mental health institutions: GGZ Eindhoven en de Kempen, GGZ Breburg, GGZ Oost-Brabant, Vincent van Gogh voor Geestelijke Gezondheid, Mondriaan Zorggroep, Prins Clauscentrum Sittard, RIAGG Roermond, Universitair Centrum Sint-Jozef Kortenberg, CAPRI University of Antwerp, PC Zieken Sint-Truiden, PZ Sancta Maria Sint-Truiden, GGZ Overpelt, OPZ Rekem. Groningen: University Medical Center Groningen and the mental health institutions: Lentis, GGZ Friesland, GGZ Drenthe, Dimence, Mediant, GGNet Warnsveld, Yulius Dordrecht and Parnassia

psycho-medical center (The Hague). Utrecht: University Medical Center Utrecht and the mental health institutions Altrecht, GGZ Centraal, Riagg Amersfoort and Delta.)

Conflict of interest

None

References

- Andreasen, N.C., Flaum, M., Arndt, S., 1992. The Comprehensive Assessment of Symptoms and Hystory (CASH): an instrument for assessing diagnosis and psychopathology. *Arch. Gen. Psychiatry* 49(8), 615-623.
- Barge-Schaapveld, D.Q.C.M., Nicolson, N.A., 2002. Effects of antidepressant treatment on the quality of life: An experience sampling study. *J. Clin. Psychiatry* 63, 477-485.
- Barge-Schaapveld, D.Q.C.M., Nicolson, N.A., Delespaul, P., de Vries, M.W., 2006. Assessing daily quality of life with the experience sampling method, in: Katschnig, H., Freeman, H., Sartorius, N., *Quality of Life in Mental Disorders*, second ed. John Wiley & Sons, Ltd, pp 91-101.
- Blum, L.H., Vakrusheva, J., Saperstein, A., Khan, S., Chang, R.W., Hansen, M.C., Zemon, V., Kimhy, D., 2015. Depressed mood in individuals with schizophrenia: A comparison of retrospective and real-time measures. *Psychiatry Res.* 227(2-3), 318-323.
- Delespaul, P., 1995. Assessing schizophrenia in daily life: The experience sampling method. Maastricht University Press, Maastricht.
- De Vries, M.W., 1995. Assessing "Quality of Life" in Schizophrenia, in: Delespaul, P., *Assessing Schizophrenia in Daily Life: The Experience Sampling Method*, University Press, Maastricht, pp 221-238.
- Fakhoury, W.K.H., Priebe, S., 2002. Subjective quality of life: It's association with other constructs. *Int. Rev. Psychiatry* 14, 219-224.
- James, B.D., Xie, S.X., Karlawish, J.H.T., 2005. How do patients with Alzheimer disease rate their overall quality of life? *Am. J. Geriatr. Psychiatry* 13, 484-490.
- Jacobs, N., Nicolson, N.A., Derom, C., Delespaul, P., van Os, J., Myin-Germeys, I., 2005. Electronic monitoring of salivary cortisol sampling compliance in daily life. *Life Sci.* 76, 2431-2443.
- Katschnig, H., 2006. How useful is the concept of quality of life in psychiatry, in: Katschnig, H., Freeman, H., Sartorius, N., *Quality of Life in Mental Disorders*, second ed. John Wiley & Sons, Ltd, pp. 3-19.
- Korver N, Quee PJ, Boos HBM, Simons CJP, de Haan L & Group Investigators, 2012. Genetic Risk and Outcome of Psychosis (GROUP), a multi-site longitudinal cohort study focused on gene-environment interaction: objectives, sample characteristics, recruitment and assessment methods. *Int J Methods Psychiatr Res.* 21(3), 205-221.
- Lehman, A.F., 1996. Measures of quality of life among persons with severe and persistent mental disorders. *Soc. Psychiatry Psychiatr. Epidemiol.* 31, 78-88.

- Myin-Germeys, I., Delespaul, P.A.E.G., de Vries, M.W., 2000. Schizophrenia patients are more emotionally active than is assumed based on their behaviour. *Schizophr. Bull.* 26(4), 847-854.
- Myin-Germeys, I., Delespaul, P.A.E.G., van Os, J., 2003. The experience sampling method in psychosis research. *Curr. Opin. Psychiatry* 16, 33-38.
- Myin-Germeys, I., Oorschot, M., Collip, D., Lataster, J., Delespaul, P., van Os, J., 2009. Experience sampling research in psychopathology: Opening the black box of daily life. *Psychol. Med.* 39, 1533-1547.
- Myin-Germeys, I., Steinhart, H., Klippel, A., Reininghaus, U., 2016. Ecological momentary interventions in psychiatry. *Curr. Opin. Psychiatry* 29(4), 258-263.
- Myin-Germeys, I., van Os, J., Schwartz, J.E., Stone, A.A., Delespaul, P., 2001. Emotional reactivity to daily life stress in psychosis. *Arch. Gen. Psychiatry* 58, 1137-1144.
- National Institute of Mental Health, 1992. Family Interview for Genetics Study (FIGS): A manual for FIGS. Clinical Neurogenetics Branch, Intramural Research Program, Bethesda.
- Oorschot, M., Kwapil, T., Delespaul, P., Myin-Germeys, I., 2009. Momentary assessment research in psychosis. *Psychol. Assess.* 21, 498-505.
- Oorschot, M., Lataster, T., Thewissen, V., Lardinois, M., van Os, J., Delespaul, P., Myin-Germeys, I., 2012. Symptomatic remission in psychosis and real-life functioning. *Br. J. Psychiatry* 201, 215-220.
- Oorschot, M., Lataster, T., Thewissen, V., Lardinois, M., Wichers, M., van Os, J., Delespaul, P., Myin-Germeys, I., 2013. Emotional experience in negative symptoms of schizophrenia – no evidence for a generalized hedonic deficit. *Schizophr. Bull.* 39, 217-225.
- Palmier-Claus, J.E., Dunn, G., Lewis, S.W., 2012. Emotional and symptomatic reactivity to stress in individuals at ultra-high risk of developing psychosis. *Psychol. Med.* 42, 1003-1012.
- Priebe, S., Fakhoury, W.K.H., 2008. Quality of life, in: Mueser, K.T., Jeste, D.V., *Clinical Handbook of Schizophrenia*. Guilford Publications Inc., New York, pp. 581-591.
- Priebe, S., McCabe, R., Junghan, U., Kallert, T., Ruggeri, M., Slade, M., Reininghaus, U., 2011. Association between symptoms and quality of life in patients with schizophrenia: A pooled analysis of changes over time. *Schizophr. Res.* 133(1-3), 17-21.
- Reininghaus, U., Depp, C.A., Myin-Germeys, I., 2016a. Ecological interventionist causal models in psychosis: Targeting psychological mechanisms in daily life. *Schizophr. Bull.* 42, 264-269.
- Reininghaus, U., Kempton, M.J., Valmaggia, L., Craig, T.K., Garety P., Onyejiaka, A., Gayer-Anderson, C., So, S.H., Hubbard, K., Beards, S., Dazzan, P., Pariente, C., Mondelli, V., Fisher, H.L., Mills, J.G., Viechtbauer, W., McGuire, P., van Os, J., Murray, R.M., Wykes, T., Myin-Germeys, I., Morgan, C., 2016b. Stress sensitivity, aberrant salience, and threat anticipation in early psychosis: An experience sampling study. *Schizophr. Bull.* 42(3), 712-722.
- Reininghaus, U., McCabe, R., Burns, T., Croudance, T., Priebe, S., 2012. The validity of subjective quality of life measures in psychotic patients with severe psychopathology and cognitive deficits: An item response model analysis. *Qual. Life Res.* 21, 237-246.
- Reininghaus, U., Priebe, S., 2012. Measuring patient-reported outcomes in psychosis: Conceptual and methodological review. *Br. J. Psychiatry* 201, 262-267.

Ruggeri, M., Bisoffi, G., Fontecedro, L., Warner, R., 2001. Subjective and objective dimensions of quality of life in psychiatric patients: a factor analytical approach: The South Verona Outcome Project 4. *Br. J. Psychiatry* 178, 268-275.

Ruhrmann, S., Paruch, J., Bechdolf, A., Pukrop, R., Wagner, M., Berning, J., Schultze-Lutter, F., Janssen, B., Gaebel, W., Möller, H.-J., Maier, W., Klosterkötter, J., 2008. Reduced subjective quality of life in persons at risk for psychoses. *Acta Psychiatr. Scand.* 117, 357-368.

Saarni, S.I., Viertiö, S., Perälä, J., Koskinen, S.J., Lönnqvist, J., Suvisaari, J., 2010. Quality of life of people with schizophrenia, bipolar disorder and other psychotic disorders. *Br. J. Psychiatry* 197, 386-394.

Skevington, S.M., Lotfy, M., O'Connell, K.A., 2004. The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial. A report from the WHOQOL group. *Qual. Life Res.* 13, 299-310.

StataCorp, 2011. Stata Statistical Software, Release 12.1. Stata Corporation, College Station, Texas.

Weiss, T.W., Slater, C.H., Green, L.W., Kennedy, V.C., Albright, D.L., Wun, C.C., 1990. The validity of single-item, self-assessment questions as measures of adult physical activity. *J. Clin. Epidemiol.* 43(11), 1123-1129.

World Health Organization, 1947. The constitution of the World Health Organization. *WHO Chron.* 1, 29.

World Health Organization, 1995. The world health organization quality of life assessment (WHOQOL), 1995. Position paper from the world health organization. *Soc. Sci. Med.* 41(10) 1403-1409.

Figure 1. Self-reported QOL, momentary QOL and real-world contexts and experiences

Figure 2. Participant flow

* ESM data were considered valid if at least 1/3 of the ESM reports (that is at least 20 of the 60 reports) were filled in, conform previous work (Delespaul, 1995)

Table 1. ESM measures of momentary quality of life (QOL), emotional experience, interaction and activity

<i>Domain</i>	<i>ESM measure</i>
Momentary QOL	Momentary QOL was assessed by asking participants to rate the item 'Globally speaking, I feel well' on a 7-point Likert scale ranging from 1=not at all, to 7=very, based on previous ESM studies on momentary QOL (Barge-Schaapveld and Nicolson, 2002).
Negative affect	The ESM negative affect measure we used consisted of 6 items ('I feel insecure', 'I feel lonely', 'I feel anxious', 'I feel irritated', 'I feel down', 'I feel guilty') rated on a 7-point Likert scale (Myin-Germeys et al., 2001).
Positive affect	We used a 3-item ESM measure for assessing positive affect. This item asks participants to rate the following items at each entry point on a 7-point Likert scale: 'I feel cheerful', 'I feel relaxed', 'I feel satisfied' (Cronbach's α 0.84) (Myin-Germeys et al., 2001; Oorschot et al., 2012).
Social interaction	ESM social interaction consisted of 2 measures. The first measure asking participants to rate their level of interaction ('We are interacting') on a 7-point Likert scale. This question in the ESM procedure was preceded by the question 'I am alone', rated yes (coded as 1) or no (coded as 2), which we used to generate the measure 'time spent alone' (Delespaul, 1995).
Activity	ESM activity consisted of 3 measures. The first measure asking participants to rate their level of activity ('I am active') on a 7-point Likert scale. This question in the ESM procedure was preceded by a question asking participants to indicate on a categorical item 'What am I doing' (e.g. work, care, household, performing hobbies, etc.), which we used to generate the second measure differentiating between goal-directed (coded as 1) and non-goal directed activity (coded as 0). As non-goal directed activity does not equal doing nothing, the third measure differentiated between doing nothing (coded as 1) and doing something (coded as 0). ESM measures of activity were developed by Delespaul (1995), generating of the second and third measure was based on previous ESM research (Oorschot et al., 2012).

Table 2. Demographics and sample characteristics by patient-control status

	<i>Patients</i>	<i>Controls</i>	<i>t (df)</i>	<i>χ² (df)</i>	<i>B (95%CI)</i>	<i>OR (95%CI)</i>	<i>p</i>
N	56	71					
Age, mean (SD)	27.77 (8.27)	32.30 (10.43)	2.66 (125)				0.009
Male, n (%)	39 (69.64)	20 (28.17)		21.65 (1)			<0.001
Educated to school level, n (%)							
Primary school	5 (8.93)	2 (2.82)					
Secondary school	14 (25.00)	4 (5.63)					
High school	22 (39.29)	21 (29.58)					
Vocational education	14 (25.00)	34 (47.89)					
University	1 (1.79)	10 (14.08)					
Mean IQ score (SD)	103.23 (14.82)	112.35 (14.35)	3.45 (122)				<0.001
Diagnosis, n (%)							
Schizophrenia	30 (53.57)	-					
Schizoaffective disorder	7 (12.50)	-					
Psychotic disorder NOS	7 (12.50)	-					
Brief psychotic disorder	5 (8.93)	-					
Delusional disorder	2 (3.57)	-					
Schizophreniform disorder	5 (8.93)	-					
Depressive disorder full/partial remission	-	10 (14.08)					
No diagnosis	-	61 (85.92)					
Mean number of beeps (SD)	39.14 (8.82)	44.54 (9.23)	-3.17 (125)				0.002
Aggregate scores on ESM measures *							
Momentary QOL							
Low, %	40.61	22.85				0.68 (0.55 – 0.85)	<0.001
High, %	59.34	77.15					
Negative affect , mean (SD)	1.75 (0.76)	1.29 (0.32)			0.15 (0.09 - 0.22)		<0.001
Positive affect, mean (SD)	4.46 (1.00)	4.97 (0.67)			-0.18 (-0.28 - 0.07)		0.001
Level of social interaction, mean (SD)	2.90 (0.81)	3.24 (0.77)			-0.10 (-0.19 - 0.00)		0.039
Time spent alone, %	37.82	36.55				1.02 (0.92 – 1.13)	0.716
Activity, mean (SD)	3.19 (1.18)	3.49 (1.00)			-0.09 (-0.21 - 0.03)		0.181

			0.04)	
Goal directed, %	20.99	40.51	0.69 (0.62 – 0.76)	<0.001
Doing nothing, %	5.12	2.60	1.69 (1.25 – 2.26)	0.001
Mean self-reported QOL (SD)	3.71 (0.87)	4.32 (0.63)	-0.20 (-0.22 – 0.19)	<0.001
Self-reported QOL, n (%)				
Very bad	-	-		
Moderately bad	5 (8.93)	2 (2.82)		
Good nor bad	16 (28.57)	-		
Moderately good	25 (44.64)	41 (57.75)		
Very good	10 (17.86)	28 (39.44)		

* Percentages for aggregate scores on ESM measures refer to ESM observations (level-1) not subjects (level-2).

T-tests and chi-square tests were used to test for differences between patients and controls in demographics and sample characteristics.

xtmelogit and xtmixed were used to obtain OR and B for ESM to account for the nested data structure of ESM data.

Table 3. Association between self-reported or momentary QOL (independent variable) and emotional experience, interaction or activity in the real world (outcome variables) for patients and controls

	Patients		Controls	
	Adjusted*		Adjusted*	
	β (95%CI)	P	β (95%CI)	P
Self-reported QOL				
- ESM negative affect	-0.33 (-0.55 – -0.11)	0.03	-0.12 (-0.23 – -0.01)	0.039
- ESM positive affect	0.30 (0.17 – 0.44)	<0.001	0.25 (0.11 – 0.39)	<0.001
- ESM level of social interaction	0.09 (0.01 – 0.16)	0.020	0.05 (-0.04 – -0.14)	0.252
- ESM time spent alone	-0.02 (-0.10 – -0.07)	0.720	0.00 (-0.09 – -0.10)	0.901
- ESM activity	0.06 (-0.07 – -0.20)	0.342	0.11 (-0.03 – -0.25)	0.121
- ESM goal directed	0.07 (0.01 – 0.13)	0.014	-0.01 -0.01 – 0.07)	0.672
- ESM doing nothing	-0.03 (-0.11 – -0.04)	0.261	0.00 (-0.03 – -0.03)	0.821**
ESM momentary QOL				
- ESM negative affect	-0.42 (-0.49 – -0.35)	<0.001	-0.28 -0.32 – -0.24)	<0.001
- ESM positive affect	0.49 (0.42 – 0.57)	<0.001	0.49 (0.44 – 0.53)	<0.001
- ESM level of social interaction	0.08 (0.04 – 0.13)	<0.001	0.13 (0.09 – 0.18)	<0.001
- ESM time spent alone	-0.02 -0.06 – -0.03)	0.440	-0.06 (-0.10 – -0.02)	0.003
- ESM activity	0.05 (0.00 – 0.11)	0.034	0.03 (-0.02 – -0.07)	0.207

- ESM goal directed	0.02 (-0.02 - 0.05)	0.472	-0.02 (-0.06 - 0.03)	0.298
- ESM doing nothing	-0.05 (-0.11 - -0.01)	0.008	-0.03 (-0.05 - -0.00)	0.021**

* Adjusted for age, sex and IQ ** Adjusted for age and IQ (due to non-convergence of model including sex)

xtnlogit and xtmixed were used to obtain standardised beta values in the logistic and linear regression analyses.

Table 4. Two-way interaction effect of group x self-reported QOL or group x momentary QOL and emotional experience, interaction or activity in the real world (outcome variables)

LR test	
Group x self-reported QOL	
- ESM negative affect	$\chi^2(1)=2.18, P=0.140$
- ESM positive affect	$\chi^2(1)=0.50, P=0.479$
- ESM level of social interaction	$\chi^2(1)=0.33, P=0.565$
- ESM time spent alone	$\chi^2(1)=0.41, P=0.520$
- ESM activity	$\chi^2(1)=0.00, P=0.996$
- ESM goal directed activity	$\chi^2(1)=0.76, P=0.384$
- ESM doing nothing	$\chi^2(1)=0.06, P=0.801$
Group x ESM momentary QOL	
- ESM negative affect	$\chi^2(1)=11.66, P<0.001$
- ESM positive affect	$\chi^2(1)=0.00, P=0.981$
- ESM level of social interaction	$\chi^2(1)=2.61, P=0.106$
- ESM time spent alone	$\chi^2(1)=2.13, P=0.144$
- ESM activity	$\chi^2(1)=0.61, P=0.435$
- ESM goal directed activity	$\chi^2(1)=0.77, P=0.379$
- ESM doing nothing	$\chi^2(1)=0.40, P=0.526$

Likelihood Ratio tests were used to test for significance of the interaction models

Table 5. Relative contribution of self-reported QOL and momentary QOL (independent variables) to emotional experience or interaction in the real world (outcome variables) for patients and controls

	Patients		Controls	
	B (95%CI)	P	B (95%CI)	P
Self-reported QOL*				
- ESM negative affect	-0.19 (-0.41 - 0.03)	0.084	-0.08 (-0.24 - 0.07)	0.279
- ESM positive affect	0.20 (0.02 - 0.38)	0.027	0.25 (0.07 - 0.43)	0.007
- ESM level of social interaction	0.20 (-0.04 - 0.44)	0.098		
ESM momentary QOL**				
- ESM negative affect	-0.71 (-0.84 - -0.59)	<0.001	-0.48 (-0.55 - -0.40)	<0.001

- ESM positive affect	1.34 (1.14 – 1.54)	<0.001	1.34 (1.22 – 1.46)	<0.001
- ESM level of social interaction	0.41 (0.17 – 0.65)	0.001		

* Adjusted for momentary QOL ** Adjusted for self-reported QOL

xtmixed was used to obtain B in the linear regression analyses

Table 6. Two-way interaction effect of group x self-reported QOL or group x momentary QOL and emotional experience in the real world

LR test	
Group x self-reported QOL*	
- ESM negative affect	$\chi^2(1)=0.74, P=0.390$
- ESM positive affect	$\chi^2(1)=0.02, P=0.883$
Group x ESM momentary QOL**	
- ESM negative affect	$\chi^2(1)=11.53, P<0.001$
- ESM positive affect	$\chi^2(1)=0.00, P=0.970$

* Adjusted for momentary QOL ** Adjusted for self-reported QOL

Likelihood Ratio tests were used to test for significance of the interaction models

Highlights

The association between subjective QOL and real life experiences is strongest for affect

The association between momentary QOL and negative affect is stronger in patients

Momentary QOL is more consistently associated with real life experiences than self-reported QOL