

# Measurement of individualised quality of life amongst young people with indicated personality disorder during emerging adulthood using the SEIQoL-DW

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## Abstract

**Purpose** To examine both the feasibility of applying the Schedule for the Evaluation of Individual Quality of Life—Direct Weighting procedure (SEIQoL-DW) as a routine outcome measure within an early intervention service for young people with indicated personality disorder and the overall quality of life (QoL) in this population.

**Methods** SEIQoL-DW was administered alongside the Standardised Assessment of Personality—Abbreviated Scale—Self-Report (SAPAS-SR), Patient Health Questionnaire (PHQ-9), Generalised Anxiety Disorder Scale (GAD-7) and the Post-Traumatic Stress Disorder—Primary Care (PTSD-PC) as part of routine service evaluation over a 16-month period. Descriptive statistics were calculated for data reflecting use of the SEIQoL-DW alongside demographic and outcome variables.

**Results** The SEIQoL-DW was administered to 52 young adults with indicated personality disorder, with 47 completing the measure, taking an average time of 27 min. Individual QoL was poor with a mean global index score of 55.07 (SD = 22.34). Individual QoL areas formed five main domains—‘Aspects of Daily Living’, ‘Relationships’, ‘Social Life and Leisure’, ‘Family’ and ‘Emotional and Physical Wellbeing’.

**Conclusion** This study further extends the application of the SEIQoL-DW for use as a routine outcome measure within a busy service setting, although ways to accommodate

administration time need to be considered. Poor QoL highlights the need for continued development of services to meet the needs of young adults with indicated personality disorder.

**Keywords** Quality of life · SEIQoL-DW · Personality disorder · Emerging adulthood · Service evaluation

## Introduction

Personality disorder is recognised by the Diagnostic and Statistical Manual of Mental Disorders [1] as an Axis II psychiatric disorder. It is seen as occurring when personality traits cause significant impairment or distress due to their inflexibility, maladaptive and chronic nature with detection often based upon a history of adverse life events, interpersonal difficulties and chaotic lifestyles [2]. This results in patients with borderline personality disorder often also meeting criteria for a mood or anxiety disorder [3]. Indeed, one study found that over 90 % individuals diagnosed with borderline personality disorder met criteria for a mood or anxiety disorder [4], with patients also at increased likelihood of meeting diagnosis for post-traumatic stress disorder [5]. Given such levels of impairment and co-morbidity, it is perhaps unsurprising that personality disorder has been identified as having a significant impact upon quality of life (QoL) in adults [6, 7]. For example, personality disorders have been reported to be significant predictors of low scores across a range of subscales on the SF-12 [8], including mental health, social functioning and role impairment due to emotional problems [9, 10]. Such an association between personality disorder and these subscales remains even when commonly occurring co-morbid Axis I disorders are controlled for [10].

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Developing a personality disorder during adolescence and emerging adulthood has also been shown to have a greater adverse impact upon QoL during adulthood than other adolescent risk factors including physical illnesses and Axis I disorders [11, 12]. This is perhaps unsurprising given the importance that emerging adulthood has within an individual's life and psychological development [13]. Corresponding to ages 18–25, during this period the young person is exposed to and provided with the freedom to experiment with a range of life experiences such as relationships, work and financial independence. Consequently, emerging adulthood has been identified as crucial to identity formation and a developmental period during which personality development is in a state of flux [14, 15]. Given the importance that this period has within a young person's life, there is growing interest in understanding [14, 15] and treating [16, 17] personality disorder during this period. However, as yet QoL in this population has not been well examined [18]. This is potentially due to the dearth of research that has identified appropriate domains related to QoL that would be required to examine QoL using an objective approach.

Although posing several methodological challenges [19], an individual approach to measuring QoL [20] in this group may be required. This approach enables the respondent to identify their own unique QoL domains and then subsequently rate the importance of these in their lives [20]. Consequently, QoL is acknowledged as being unique to an individual's personal experience, and it is recognised that QoL domains identified may vary across individuals [21]. Although a number of respondent-derived subjective QoL approaches exist, the Schedule for the Evaluation of Individual Quality of Life—Direct Weighting procedure (SEIQoL-DW) [22] has become increasingly adopted to examine QoL across a wide range of medical conditions [19]. However, the measure has been far less adopted when examining psychological disorders. Here examination of the feasibility of the SEIQoL-DW has been restricted to eating disorders [23], and within a single study [18], it was examined across a range of disorders including schizophrenia, mood disorder, personality disorder and psychosis. Additionally, although the feasibility of using the SEIQoL-DW has been established amongst children, adolescents and young adults with physical health conditions such as Type I diabetes [22, 25] and cancer [26], the measure has not been used amongst younger people experiencing mental health difficulties.

Focussing upon a population of young people with indicated personality disorder during emerging adulthood, the aims of this study are twofold: first, to explore the extent to which the SEIQoL-DW can be effectively and routinely employed within a busy community-based early intervention service for young adults with indicated personality disorder experienced alongside high levels of

depression, anxiety and post-traumatic stress disorder; and second, to use the SEIQoL-DW to explore QoL in this generally under-researched population.

## Method

### Study design and setting

The study was undertaken as part of routine service evaluation with the study population consisting of young people aged 16–25 who had been referred to a community-based early intervention service for young adults with indicated personality disorder during a period of 16 months (January 2010 to May 2011). The service is located within the city of Plymouth in South West England, which has a population of 258,710 [27] and ranks 31 out of 56 (where 1 = least deprived and 56 = most deprived) out of all cities across England for its level of deprivation.

Being based within a service evaluation, the study inclusion criteria were the same as those for entry into the service. Criteria therefore highlighted that respondents should be aged between 16 and 25, should have experienced a range of risk factors [28] and currently experiencing precursor signs and symptoms, such as depressive symptoms [28, 29], disruptive behaviour [28] and substance abuse [30] that commonly precede a personality disorder diagnosis. A significant history of involvement with mainstream mental health services served as an exclusion.

### Procedure

The SEIQoL-DW [22] was administered face-to-face to clients referred to the service, either within their homes or the service setting. It was administered as a semi-structured interview during a routine assessment session by one of six care coordinators assigned to the client as part of their routine care. To ensure fidelity to the administration protocol [22], care coordinators had been previously trained in the SEIQoL-DW standard administration protocol and received regular supervision from a member of the service evaluation team.

Prior to the first assessment session, a battery of paper-based questionnaires recommended for use within evaluations of services for people with personality disorders [31] examining demographic and mental health status variables were administered. Although being recommended, only the psychometric properties of the self-report Standardised Assessment of Personality—Abbreviated Scale—Self-Report (SAPAS-SR) [32] have been established in respondents with personality disorder. Other measures were included on the basis to which they were felt to be consistent with several criteria of reliability, validity, responsiveness,

precision, interpretability, acceptability and feasibility proposed when considering outcome measures [33].

## Measures

### *Individualised quality of life*

Individualised QoL was measured using the SEIQoL-DW [22], which has been demonstrated to have acceptable levels of convergent and discriminant validity [19]. It is based on the proposal that QoL should be determined on the basis of an individual's assessment of their own level of satisfaction across five domains of life that they consider to be personally important. The procedure regarding the administration of the SEIQoL-DW adopted in this study has been extensively reported [22]. In general, however, respondents were initially provided with a definition of QoL [22] and then supported as necessary to identify five domains they felt were of greatest importance to their current QoL. For each domain, respondents were asked to rate their level of satisfaction using a visual analogue scale ranging from 'worst possible' (0 mm) to 'best possible' (100 mm). These are referred to as Cue Levels, and scores are yielded from 0 to 100. Finally, they were asked to identify the importance that each domain had to their QoL by using a pie chart to provide a weighting. These are referred to as Cue Weights, which range from 0 to 100 depending on the proportion of the pie chart each domain is given. Based upon the satisfaction score (Cue Levels) and weighting for each domain (Cue Weights), an overall SEIQoL-DW index score was then calculated with scores ranging from 0 to 100, with a higher score indicating a higher QoL. Following administration, the care coordinator recorded the time taken to administer the SEIQoL-DW; rated the respondents understanding of the process, fatigue and boredom; and provided an overall rating of the validity of the data collected.

*Personality disorder screen* The self-report version of the Standardised Assessment of Personality—Abbreviated Scale—Self-Report (SAPAS-SR) [32] was used to screen for a potential diagnosis of personality disorder. The self-report version consists of nine items and is based on eight questions taken from the SAPAS [34] derived from the Standardised Assessment of Personality (SAP) [35], an informant-based interview that supports an ICD-10 or DSM-IV diagnosis of personality disorder [1, 36]. The SAPAS-SR has sensitivity of 0.94 and specificity of 0.85, and with scores of 4 or more, the self-report version has been found to correctly identify the presence of a personality disorder in over 80 % of respondents when compared to diagnosis undertaken using the Structured Clinical Interview for Depression-II [32].

*Depression and anxiety* The Patient Health Questionnaire-9 (PHQ-9) [37] and the Generalised Anxiety Disorder-7 (GAD-7) [38] were adopted to examine depression and anxiety, respectively. Both measures use a four-point Likert scale to record the frequency (1 = 'Not at all' to 3 = 'Nearly every day') with which respondents report experiencing the main symptoms associated with depression and anxiety during the last 2 weeks. Both measures are used extensively in primary care and community settings and are well validated for detecting and measuring change in levels of depression [37] and anxiety [39].

*Post-traumatic stress disorder* The Primary Care Post-Traumatic Stress Disorder Screen (PC-PTSD) [40] is a four-item screen that was designed for use in primary care and other medical settings. The screen includes an introductory sentence to cue respondents to traumatic events and requires participants to indicate ('Yes', 'No') whether they have ever experienced each of the following four factors—re-experiencing, numbing, avoidance and hyperarousal—associated with a diagnosis of PTSD. The screen indicates positive for PTSD in the event that respondents have experienced three or more of these factors. In addition to good levels of reliability (0.83), the sensitivity and specificity of the PC-PTSD are similar to those reported for the detection of depression in primary care (PRIME-M) [41] and its diagnostic accuracy (85 %) is similar to other established measures of PTSD [40].

*Demographics* Age, gender, accommodation type, educational background, employment status and ethnicity were recorded upon referral into the service.

### Data analysis

All data were entered and analysed using the IBM Statistical Package for Social Science (SPSS) version 19.0 software. Descriptive statistics were calculated for all the demographic and mental health status variables (SAPAS-SR [32], PHQ-9 [37], GAD-7 [39] and PC-PTSD [40]) and were expressed as mean (SD) and frequency (%) as appropriate. Differences in demographic and mental health status variables between those who completed the SEIQoL-DW, those for whom it was not administered and those who could not elicit five domains were examined using one-way analysis of variance and chi-squared tests as appropriate. The primary outcome measurement was the overall SEIQoL-DW Global Index Score [22]. Overall SEIQoL-DW index scores were calculated by multiplying the Cue Level by the Cue Weight for each domain elicited. Cue Levels yield scores ranging from 0 to 100. Cue Weights also yield scores of 0–100; however, each weight is divided by 100 in order to range from 0.00 to 1.00 so that the overall index calculated ranges from 0 to 100.

For each cue, the level is multiplied by the weight, and then totals are summed across the five domains to provide the overall index of quality of life for each participant, ranging from 0 to 100 with a higher score indicating a higher level of quality of life.

## Results

During the study period, a total of 115 young adults with indicated personality disorder referred into the service were allocated to assessment. Client flow into the study can be seen in Fig. 1.

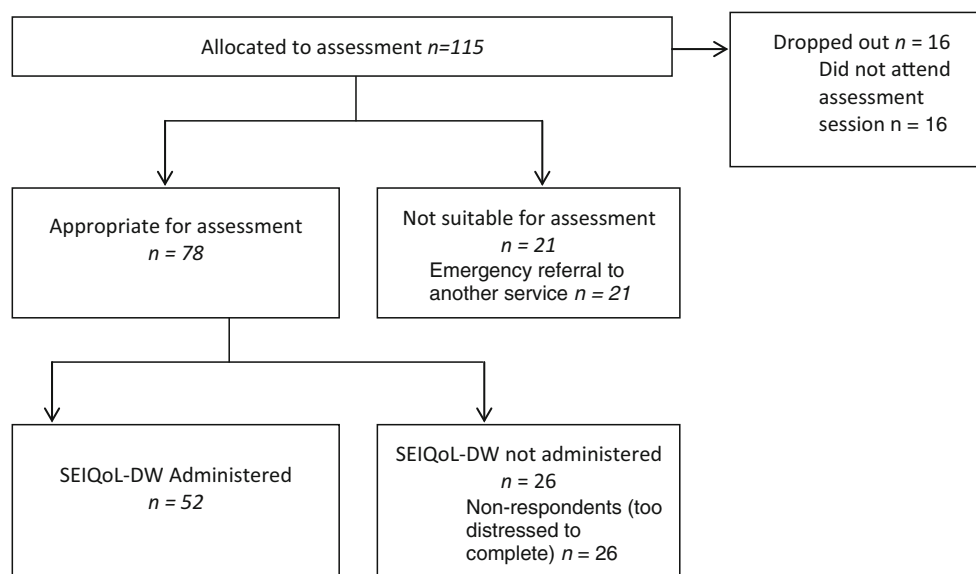
During the assessment session, it was considered inappropriate to continue with the standard assessment protocol for 21 clients as their difficulties were identified as requiring an emergency referral to another service. An additional 16 clients dropped out of the service by failing to attend three or more scheduled first assessment appointments and therefore did not complete the SEIQoL-DW. Of the remaining 78 clients on assessment, 52 completed the SEIQoL-DW, yielding a completion rate of 67 %. Managing high levels of risk and distress in the clients was reported by care coordinators as the main reason for them failing to administer the SEIQoL-DW. Additionally, five respondents were unable to elicit five QoL domains, four eliciting four domains and one three domains, and results were omitted from further analysis. Omitting respondents unable to elicit five QoL domains from further analysis is consistent with the majority of previous studies. A recent meta-analysis identified only one study that included respondents for further analysis who identified less than five QoL domains [19].

Full background demographics and mental health status variables for the 47 respondents completing the questionnaires, the five who could not elicit five QoL domains and 26 for whom the SEIQoL-DW was not administered can be found in Table 1. With the exception of the SAPAS-SR, there were no significant differences between the three groups with respect to demographic variables and all mental health variables. Interestingly, the young adults for whom the care coordinators did not administer the SEIQoL-DW had significantly lower SAPAS-SR scores than the other groups, although the mean score was still in excess of 4 indicating a high likelihood of personality disorder diagnosis.

With respect to respondents completing the SEIQoL-DW, scores across each of the measures highlight a generally poor QoL, with a mean Global Index Score of 55.07 (SD = 22.34). Furthermore, all respondents who completed the measures had a score of 4 or more on the SAPAS-SR meeting criteria for a probable personality disorder diagnosis ( $n = 41$ ) with all meeting a probable diagnosis of PTSD by scoring 3 or more on the PC-PTSD ( $n = 39$ ). Additionally, respondents presented with ‘moderately severe’ and ‘severe’ levels of depression and anxiety, respectively ( $n = 52, 84\%$ ;  $n = 42, 68\%$ ).

### Administration of the SEIQoL-DW

The average length of time required to administer the SEIQoL-DW was 27 min (SD = 9.7, range, 10–45). At the end of administering the SEIQoL-DW, care coordinators rated the extent to which they believed each respondent understood the method, their boredom and fatigue and overall validity of responses. All but one (98 %)



**Fig. 1** Client flow into the study

**Table 1** Background demographic and mental health status variable data for respondents who completed the SEIQoL-DW, could not identify five QoL domains and who were not administered the SEIQoL-DW during the study period

Variable (n, %)	Completed SEIQoL-DW (n = 47)	Could not identify five QoL domains (n = 5)	Not administered (n = 26)	p value
<b>Sex</b>				
Male	13 (27.7)	1 (20.0)	3 (11.5)	0.286
Female	34 (72.3)	4 (80.0)	23 (88.5)	
Mean age at referral (SD, range)	20.3 (2.2, 16–24)	20.16 (1.7, 17–21)	20.9 (2.3, 17–25)	0.573
<b>Ethnicity</b>				
White British	39 (83.0)	5 (100.0)	16 (61.5)	N.A
Missing	8 (17.0)	0 (0.0)	10 (38.5)	
<b>Deprivation percentile of residence</b>				
<25	27 (57.4)	2 (40.0)	14 (53.8)	0.638
26–50	17 (36.2)	2 (40.0)	6 (23.1)	
51–75	1 (2.1)		1 (3.8)	
76–100	1 (2.1)		0 (0.0)	
Missing	1 (2.1)	1 (20.0)	5 (19.2)	
<b>Accommodation</b>				
Parents/caregiver	8 (17.0)	2 (40.0)	3 (11.5)	0.896
Permanent <sup>a</sup>	21 (44.7)	2 (40.0)	9 (34.6)	
Temporary <sup>b</sup>	8 (17.0)	1 (20.0)	4 (15.4)	
Other	2 (4.3)	0 (0.0)	0 (0.0)	
Missing	8 (17.0)	0 (0.0)	10 (38.5)	
<b>Employment status</b>				
Unemployed	20 (42.6)	3 (60.0)	11 (42.3)	0.401
Student	9 (19.1)	1 (20.0)	2 (7.7)	
Employed	8 (17.0)	1 (20.0)	2 (7.7)	
Voluntary	0 (0.0)	0 (0.0)	1 (3.8)	
Childcare	1 (2.1)	0 (0.0)	0 (0.0)	
Missing	9 (19.1)	0 (0.0)	10 (38.5)	
<b>Minimum level of education</b>				
Not completed	3 (6.4)	0 (0.0)	4 (15.4)	0.656
Secondary education <sup>c</sup>	19 (40.4)	2 (40.0)	4 (15.4)	
Post-secondary education <sup>d</sup>	12 (25.5)	3 (60.0)	8 (30.8)	
University level education	2 (4.3)	0 (0.0)	0 (0.0)	
Missing	11 (23.4)	0 (0.0)	0 (0.0)	
<b>Mental health variables</b>				
SAPAS-SR	7.24 (1.34)	7.60 (2.1)	6.13 (2.1)	0.049
PHQ-9	19.50 (5.39)	20.60 (3.4)	19.82 (6.1)	0.907
GAD-7	15.62 (5.24)	15.40 (7.3)	16.59 (5.3)	0.812
PC-PTSD	3.46 (0.97)	3.60 (0.9)	3.47 (1.01)	0.958

Chi-squared tests were conducted on categorical variables and one-way analysis of variance on age and mental health variables

<sup>a</sup> Private rent, council rent or university residence

<sup>b</sup> Sheltered housing, hostel or sofa surfing

<sup>c</sup> High school education up to 16 years of age

<sup>d</sup> Post-16 high school or vocational education

respondents were rated as having no difficulty understanding the procedure, with 35 (73 %) displaying no signs of fatigue when completing the measures, 11 (24 %) some fatigue and 2 (4 %) a lot. Overall respondent

responses to the SEIQoL-DW were considered to be valid by the care coordinators, highlighting the utility of using this measure with young people with indicated personality disorder.

**Table 2** QoL domains and mean level of satisfaction elicited with the SEIQoL-DW

SEIQoL domains elicited	(n, %) max. <i>n</i> = 47	Mean level (SD)	General categories (number of times identified)	
Living conditions	19 (8.09)	49.88 (28.98)	Aspects of Daily Living (54)	
Finances	14 (5.96)	33.86 (17.09)		
Work	11 (4.68)	27.27 (19.54)		
Education	10 (4.26)	54.80 (28.58)		
Relationships—friends	21 (8.94)	66.19 (20.60)	Relationships (52)	
Relationships—general	14 (5.96)	51.07 (32.12)		
Relationships—partner	11 (4.68)	64.64 (25.45)		
Relationships—sibling	3 (1.28)	73.33 (23.09)		
Relationships—support worker	2 (0.85)	90.00 (14.14)		
Relationships—parents	1 (0.43)	55.00 (0.00)		
Leisure	27 (11.49)	62.07 (30.20)	Social Life and Leisure (41)	
Social life	14 (5.96)	38.14 (25.87)		
Family	30 (12.77)	52.53 (24.86)	Family (36)	
Children	6 (2.55)	58.00 (33.73)		
Health	17 (7.23)	41.94 (25.56)	Emotional and Physical Wellbeing (34)	
Mental health	5 (2.13)	24.00 (16.73)		
Alcohol/substance use	5 (2.13)	32.00 (17.89)		
Feeling safe	2 (0.85)	70.00 (42.43)		
Time to think	2 (0.85)	55.00 (35.56)		
Coping strategies	1 (0.43)	30.00 (0.00)		
Medication	1 (0.43)	60.00 (0.00)		
Distressing thoughts	1 (0.43)	30.00 (0.00)		
Pets	5 (2.13)	83.60 (8.65)		Pets (5)
Independence	3 (1.28)	82.33 (15.70)		Independence (3)
Religion/spiritual life	2 (0.85)	55.00 (7.07)	Religion/spiritual life (2)	
Creativity	2 (0.85)	75.00 (35.36)	Creativity (2)	
Ambition	1 (0.43)	30.00 (0.00)	Ambition (1)	
Organisation	1 (0.43)	50.00 (0.00)	Organisation (1)	
Respect	1 (0.43)	80.00 (0.00)	Respect (1)	
Structure	1 (0.43)	10.00 (0.00)	Structure (1)	
Trust	1 (0.43)	80.00 (0.00)	Trust (1)	
Time away	1 (0.43)	10.00 (0.00)	Time away (1)	

## QoL

A total of 32 different QoL domains were elicited. As can be seen in Table 2, the most frequently elicited QoL domains were ‘Family’ (30), ‘Leisure’ (27), ‘Relationships with Friends’ (21) and ‘Living Conditions’ (19). Individual QoL domains were then merged into general categories, and the total number of times QoL domains within each category reported was calculated. Five main categories accounted for the majority (92 % of total number identified) of the individual QoL domains reported—‘Aspects of Daily Living’ (54), ‘Relationships’ (52), ‘Social Life and Leisure’ (41), ‘Family’ (36) and ‘Emotional and Physical Wellbeing’ (34). Satisfaction was rated as worst across several of the domains concerned with ‘Aspects of Daily Living’ (‘Work’, ‘Finances’, ‘Living Conditions’). ‘Relationships with Partner’ and

‘Relationships with Friends’ were identified as the areas with greatest satisfaction.

Weightings for domains identified on 10 or more occasions are presented in Table 3. ‘Relationships General’ and ‘Relationships with Partner’ both had mean weights in excess of 30 %, with ‘Education’ and ‘Family’ having weights over 20 %.

## Discussion

Before the results are discussed, it is necessary to highlight several methodological limitations. First, statistical analysis has been undertaken on data collected as part of the routine data collection protocol employed within a wider evaluation of the early intervention service. Limitations

**Table 3** Mean weight (level of importance) for QoL domains elicited by 10 or more respondents

SEIQoL-DW QoL domains elicited	<i>n</i>	Mean weight (SD)	Range
Relationships—general	14	34.61 (24.07)	12.5–100
Relationships—partner	11	33.14 (16.54)	10–60
Education	10	26.05 (13.41)	12–60
Family	30	23.60 (16.21)	1–69
Relationships—friends	21	19.86 (10.29)	2–39
Finances	14	18.17 (15.73)	5–69
Health	17	17.03 (10.80)	0–50
Living conditions	19	16.11 (10.40)	4–45
Work	11	15.59 (5.32)	8–26
Leisure	27	12.48 (7.90)	0–31
Social life	14	12.39 (12.31)	1–50

such as completeness, accuracy and precision have been highlighted with respect to this type of data [42]. Within this study, however, significant efforts were made to try to minimise the impact of such limitations. For example, prior to the beginning of the evaluation, all care coordinators and administration staff underwent extensive training in the application of the SEIQoL-DW and wider questionnaire battery, and all were provided with ongoing supervision. Furthermore, throughout the evaluation, all data recorded were monitored in terms of accuracy and completeness. Regardless of these limitations, however, it should not be overlooked that an aim of the study was to explore the extent to which the SEIQoL-DW can be effectively used routinely within services. The methodology therefore does provide us with a good insight into this aspect of its use. A second consideration is that both the feasibility and acceptability of the SEIQoL-DW were assessed using the perceptions of care coordinators regarding its use and the number of respondents who were able to complete the measure. Although this information is commonly used to examine the acceptability and feasibility of the SEIQoL-DW (e.g. [19, 24]), potentially undertaking qualitative interviews with participants and care coordinators regarding aspects of the measure would have provided better information regarding acceptability.

Notwithstanding these limitations, results obtained in this study further extend our understanding concerning the feasibility regarding the application of the SEIQoL-DW and promote a better appreciation of QoL within an under-researched population of young people with indicated personality disorder. Previous research has identified the SEIQoL-DW to be a generally feasible and valid measure of individualised QoL for participants varying in age [24–26, 43] experiencing a variety of health [19] and to a lesser extent psychologically related conditions [18, 23]. This is the first study, however, to examine feasibility of using the SEIQoL-DW for groups of young adults with indicated personality disorder, who are often also experiencing a range of co-morbid psychological difficulties [3].

Furthermore, the current study extends the utility of the SEIQoL-DW beyond its application within research studies to include use within routine care, either as part of service evaluation as employed within this study or to support ongoing patient monitoring or influence clinical decision-making [44]. Potentially, however, consideration regarding the feasibility of adopting the SEIQoL-DW would first need to be directed towards the amount of time required to complete the SEIQoL-DW when used as part of routine care and the number of young adults with indicated personality disorder excluded by care coordinators from administration.

Within this study, the SEIQoL-DW took 27 min on average to complete. This would generally constitute around half the time scheduled for a standard patient appointment and could be considered excessive when other objectives of an assessment, such as developing a relationship and gathering information to inform clinical decision-making, are considered [45]. Although this could potentially be viewed as excessive, the time to administer the SEIQoL-DW for young adults with indicated personality disorder is consistent with that reported in previous studies for adults with a major mental health disorder (23 min) [18] and frail older people (20–30 min) [46]. Furthermore, it should be noted that improving quality of life is a key aim of the service within the current study [31]. Therefore, rather than the utility of the SEIQoL-DW being restricted to data collection purposes, the measure could also be seen to have a wider function with respect to fostering engagement and informing practice. Indeed, the use of outcome measurements in routine practice can aid practitioners monitor progress, facilitate the clinical decision-making process and influence the provision of better care and services [47]. Furthermore, the SEIQoL-DW has been reported to be of additional benefit in consultations by enabling clients to report symptoms that would not normally be addressed [44]. Potentially therefore, although taking a long time to administer, the SEIQoL-DW could also be seen as informing practice and facilitating a patient-

centred approach [48] to identifying treatment goals and priorities [49].

Despite potential advantages of incorporating the SEIQoL-DW into the assessment process, further consideration is still required regarding the time taken for practitioners to use it, on top of large caseloads and heavy administrative burden [50, 51]. Indeed, previous qualitative studies examining the acceptability of using the SEIQoL-DW in routine practice by oncologists have identified difficulties due to lack of time and limitations on resources [44]. Therefore, although it appears that the use of the SEIQoL-DW routinely within this care setting is potentially feasible with respect to administration time, it is important that further research is conducted to gain patient and clinician ratings of acceptability, relevance and clinical value of the measure [52], alongside further consideration given to alternative methods of administration. This could involve providing an additional number of sessions, or alternative methods of delivering the SEIQoL-DW to face-to-face interviews such as self-administration [23], telephone [26] and computer [53]. However, the extent to which different administration methods may be acceptable to varied participant groups and feasible within busy clinical settings has yet to be fully established.

The feasibility of adopting the SEIQoL-DW can also be explored by examining the perceptions of care coordinators regarding its use [19, 24]. Amongst young adults completing the SEIQoL-DW, care coordinators reported that overall respondents had low levels of boredom and fatigue alongside a good understanding of the procedure, further supporting the utility of employing the measure. Additional concerns arising when using the measure with young adults with indicated personality disorder given its reliance upon self-report data that is consciously accessible to the individual are also addressed [54]. Previous research has highlighted how introspective limitations are particularly salient amongst people with personality disorder given that this group are frequently unable to view their behaviour in a realistic manner [55]. However, given care coordinators felt responses to be valid and only five respondents were unable to identify QoL domains, this potentially highlights that introspective limitations on the SEIQoL-DW were of little significance.

It should, however, not be overlooked that during assessment, care coordinators failed to administer the SEIQoL-DW to a third of young people. On these occasions, care coordinators reported that respondents were in too much distress within the session to administer the SEIQoL-DW. This raises the possibility that there may be problems with administering the measure when respondents are either in too much distress or perceived to be by those undertaking the assessment. Indeed, concerns

surrounding the use of outcome measurements in routine clinical practice commonly centre on issues regarding the potential to over-burden clients [47]. Interestingly, however, with the exception of the SAPAS-SR, there were no significant differences on the demographic and mental health variables when compared with respondents who completed the SEIQoL-DW, and in the case of the SAPAS-SR, scores were lower although still representing a high likelihood of personality disorder diagnosis. Having a better appreciation regarding the acceptability of using the SEIQoL-DW from the perspective of both respondents and those administering the measure would potentially help to further inform reasons for non-administration.

Regardless of the potential limitations alongside wider considerations regarding ways to incorporate the SEIQoL-DW into routine clinical practice, the measure does provide a unique insight into QoL within young people with indicated personality disorder. Overall, whilst there was some individual variability concerning the identification of specific QoL domains, the vast majority of those identified could be organised into five main categories—‘Aspects of Daily Living’, ‘Relationships’, ‘Social Life and Leisure’, ‘Family’ and ‘Emotional and Physical Wellbeing’. These areas overlap considerably with those previously identified within a qualitative study [15] as being of importance, but significantly disrupted, for young people with indicated personality disorder. This triangulates well with the levels of satisfaction identified in this study with respect to the individual QoL domains, which was generally poor. Indeed, with the exception of ‘Relationships’, where satisfaction levels were, at best, modest (mainly in the region of 60–70 %), satisfaction across many other individual QoL domains was around or below a score of 50.

Poor levels of satisfaction within individual QoL domains are reflected within a SEIQoL-DW global index score of 55.07 (SD = 22.34) for the respondents in this study. This score is considerably lower than that obtained for other representative participant groups such as healthy adults (mean = 77.4, SD = 9.5) [56], patients with serious mental illness including schizophrenia, mood disorder, personality disorder and other psychoses (mean = 69.04; SD = 24.58) [18], or youth with Type I diabetes (mean = 78.6; SD = 11.7) [24]. The fact that QoL in young people with indicated personality disorder is considerably lower in comparison with these groups further supports the need to develop services targeted towards this patient group [16, 17]. This need is especially significant given that on the basis of the wider measures recommended when evaluating services for people with personality disorders [31], respondents in this study would already attract a probable diagnosis for personality disorder and post-traumatic stress disorder, alongside moderately severe depression with severe anxiety.



Support for the development of early intervention services for young adults with personality disorder is gaining momentum given an accumulating body of evidence highlighting the reliability and validity of diagnosing personality disorder in emerging adulthood [57, 58]. Overall, results of this study help to establish the use of the SEI-QoL-DW, as a subjective respondent-determined measure of QoL within a busy–community based early intervention service for young people with indicated personality disorder. Poor levels of QoL experienced by this population suggest a significant and urgent requirement to further develop services to target the needs of this under-represented population.

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