Health and Quality of Life Outcomes

BioMed Central

Research

Open Access

Quality of life in schizophrenia: A grounded theory approach

Louise Gee*[1], Emma Pearce[2] and Mike Jackson[3]

Address: [1]Kemple View Psychiatric Services, Longsight Road, Langho, Blackburn, Lancashire, BB6 8AD, UK, [2]Merseycare NHS Trust, Mersey Forensic Psychiatric Services, 36 Rodney Street, Liverpool, Merseyside, L1 9AA, UK and [3]Psychology Department, Hergest Unit, Ysbyty Gwynedd, Bangor, North Wales, UK

Email: Louise Gee* - louisegee4@aol.com; Emma Pearce - epearce@supanet.com; Mike Jackson - Mike.Jackson@nww-tr.wales.nhs.uk

* Corresponding author

Published: 16 August 2003

Health and Quality of Life Outcomes 2003, **1**:31

This article is available from: http://www.hqlo.com/content/1/1/31

Received: 29 April 2003
Accepted: 16 August 2003

Abstract

Background: Research into health related quality of life (HRQoL) in schizophrenia has predominantly been conducted using lengthy interviewer administered questionnaires, many of which have not been validated for use with schizophrenic samples. The present study seeks to address the dearth of qualitative research by conducting a small-scale qualitative exploration of the impact of schizophrenia on HRQoL.

Method: The study was conducted using the qualitative approach of grounded theory. Six individuals with a diagnosis of schizophrenia participated (3 men, 3 women). Mean age of participants was 33.3 years (range 20–55), mean length of illness was 12 years (range 2–38 years) and average length of interviews was 47 minutes (range 20–70).

Results: Ten HRQoL domains were identified as being important: (1) barriers placed on relationships; (2) reduced control of behaviours and actions; (3) loss of opportunity to fulfil occupational roles; (4) financial constraints on activities and plans; (5) subjective experience of psychotic symptoms; (6) side effects and attitudes to medication; (7) psychological responses to living with schizophrenia; (8) labelling and attitudes from others; (9) concerns for the future and (10) positive outcomes from experiences.

Conclusions: Domains identified by participants encompassed a wide range of factors that may be expected to contribute generally to engaging in a positive quality of life. Participants identified that it was the loss of these things as a direct consequence of having schizophrenia that influenced their HRQoL. It would appear that in the main, factors that are secondary to the experience of schizophrenia are of most importance to participants. Suggestions are also made in the discussion for future research.

Background

Globally, the incidence of schizophrenia is 1% of the population [1,2]. Schizophrenia is a chronic disorder with a heterogeneous presentation, marked by an array of symptomatology [1,3], variations in outcome [4] and responses to treatment [1]. The course of schizophrenia is largely characterised by acute psychotic episodes, which often require hospitalisation. Symptomatology is split into two clusters [3]: (1) positive symptoms – delusions, hallucinations, conceptual disorganisation, suspiciousness, agitation, and hostility. (2) negative symptoms – blunted affect, emotional and social withdrawal, lack of spontaneity and poverty of speech. These disturbances have the propensity to have a pervasive impact on many areas of life functioning and subsequently on health related quality of life (HRQoL). From an HRQoL perspective schizophrenia shares some of the clinical characteristics of other chronic illnesses such as arthritis, diabetes or cystic fibrosis. However, in keeping with other disorders, schizophrenia also has specific issues [5]: *shared issues* – chronicity, palliative rather than curative treatments, social stigma, subjective nature of illness; *specific issues* – distressing inner experiences, side effects of anti-psychotics.

The onset of schizophrenia is in late adolescence or early adulthood [4] with 90% of males and 70% of females becoming ill before the age of 30 years [1]. Since the 1950's, the mainstay of treatment has been anti-psychotic medication, which brings variable relief of symptoms in around 70–80% of patients. However, a further 20–30% have an inadequate response to medication with 15–20% relapsing each year [1,4]. Use of medication is also associated with an array of side effects. Contemporary approaches to the treatment of schizophrenia aim at incorporating multidisciplinary interventions [6,7]. Because of this, it is possible to have an impact on a number of areas of life functioning and improve HRQoL for these individuals. Consequently, it is vital to generate information from a patient perspective that indicates clearly what areas of life functioning impact on HRQoL.

Interest in health related quality of life (HRQoL) measurement in schizophrenia emerged following widespread de-institutionalisation in the 1950's [8,9]. Initial interest was aimed at assessing the impact of the move of patients into the community on HRQoL [10–13]. This interest faded following rapid development of HRQoL measurement technology in medical disorders, limitations in HRQoL measurement for schizophrenia, lack of clarity regarding conceptual issues and doubts about the reliability of self-report in schizophrenic patients [14–16].

HRQoL measurement reflects a subjective biopsychosocial patient perspective of their disorder [16] and as such is parallel to current multidisciplinary intervention methods in schizophrenia. The HRQoL literature is dominated by research utilising lengthy questionnaires [17–23], which require administration by trained interviewers. These measures have not always been developed specifically for schizophrenic populations [24,25]. Alternatively, questionnaires that have been developed for schizophrenia [26–28], have limited application [29,30]. The content of questionnaires varies and whilst there are some similarities in the domains that are represented, there are numerous differences. This makes comparison of findings across studies difficult. A search of MEDLINE, PYSCHINFO, CINAHL and EMBASE suggested that several HRQoL questionnaires had been used in research with schizophrenic samples. Closer inspection of the literature indicated that many of the samples in this research were not restricted to participants with schizophrenia, but that often other diagnoses were included. Focusing on literature whose inclusion was on the basis of a diagnosis of schizophrenia only, it would appear that there were six more frequently used questionnaires [24–28,31–37]. Taking into account the overlap in the domains that are presented in these questionnaires, the number of dissimilar domains represented across the questionnaires is 30. The number of total items across questionnaires also varies from 21 items to 143. The questionnaires represent generic HRQoL [31–37], HRQoL in general psychiatric populations [24,25] and HRQoL measures for schizophrenia [26–28]. It is worth noting that one of the measures detailed, the Schizophrenia Quality of Life Scale (SQLS) [27,28] has only been relatively recently published and so does not yet appear widely in the published research. Despite being developed using schizophrenic populations, the SQLS has received some criticism for being a symptoms scale rather than a true HRQoL scale [38].

The domains collectively covered in the questionnaires referenced in this paper include; intrapsychic foundations, interpersonal relationships, instrumental role, common objects and activities, living situation, family relations, leisure, work, finances and safety, health, religion, psychosocial, motivational / energy, symptoms / side effects, sleep and rest, eating, home-management, ambulation, mobility, bodily care, alertness behaviour, emotional behaviour / communication, physical functioning, social functioning, role limitation physical, role limitation mental, mental health, pain and general health perceptions.

With the exception of the Schizophrenia Quality of Life Scale [27,28], questionnaires have not been developed from a qualitative patient perspective, which first determines the life domains of importance to individuals with schizophrenia. The general psychiatric measures have been primarily generated from the perspective of others such as mental health professionals with further development and validation including mixed psychiatric groups. The generic health measures have focused on general populations from the perspective of developing and validating these questionnaires. Because of this, there is a certain amount of item redundancy across measures, making it uncertain exactly which issues and domains are relevant to people with schizophrenia. The items across each of the questionnaires are framed in a very general manner and the relationship between the items and responses is assumed to be due to mental health issues. A hypothetical example would be the difference between asking a person to endorse to what extent they agree with the following two statements on a 6 point scale; (1) during the last week

I have not left my house or (2) over the last week, my mental health problems have made it difficult for me to leave the house. Each item is asking the same question, but the focus of why this activity has not occurred is made explicit in the second of the questions whilst in the first it is assumed. However, a further dimension is that in neither case has it been established what the impact of not conducting this activity is. Both questions merely assess the presence or absence of the activity. Because of these ambiguities and some methodological weaknesses with the scales, which are beyond the scope of this paper, it is important to elicit directly from individuals with schizophrenia how their experience of the disorder affects their HRQoL. Currently, the qualitative work that has been conducted is either not from an individual perspective [39], or applies limited methodology in expanding the meaning of HRQoL issues to patients [40].

Development of HRQoL measurement in schizophrenia should be from a bottom up perspective, starting with qualitative interviews with schizophrenic people [30]. This is at odds with the majority of current methodologies, which mainly apply HRQoL measures developed from a top down perspective using judgements from people other than the patient population. HRQoL research in medical and mental health populations has demonstrated that proxy ratings of HRQoL, clinical status and objective living conditions do not necessarily correlate with patient rated HRQoL [9,20,40–44]. The current study aims to apply grounded theory methodology to the analysis of interviews with a small group of people with a diagnosis of schizophrenia in order to elicit subjective reflections regarding the impact of schizophrenia on HRQoL. The research takes a positivist perspective in that it seeks to find truths about the impact of schizophrenia on HRQoL for the present sample. In keeping with this, methods of validation will be applied which attempt to provide corroboration of the conclusions offered by the primary researcher.

Methods

Sample

Six individuals with a recorded diagnosis of schizophrenia were interviewed. Psychiatric diagnosis was confirmed by examination of medical records to determine whether presenting symptomatology and history conformed to DSM IV criteria for schizophrenia [45]. All participants met DSM IV criteria. Individual participant characteristics are presented in Table 1. Participants were recruited via local Community Mental Health Teams and an acute inpatient unit.

Inclusion and exclusion criteria

Patients with a diagnosis of schizophrenia were included in the study. Exclusion criteria included patients with a primary diagnosis of depression, bipolar illness, or dual diagnosis with either learning disability, substance / alcohol abuse, personality disorder or evidence of organic pathology that could explain the presenting symptomatology. This information was clarified from patient notes.

Methodology

The current study used the grounded theory (GT) approach. GT was developed by a group of sociologists investigating institutional care of the terminally ill [46], and from which the term GT subsequently emerged [47]. The term reflects the concept that theory emerging from this type of work is grounded in the information gathered directly from a target group of individuals, and places emphasis upon the individual's account of their experience [48]. GT is an appropriate approach for conducting research with no strong theoretical basis [48] and is aimed at analysing data rather than a specific technique of data collection [49]. However, data collection for GT involves an iterative process in which data from one interview is analysed before conducting the next interview. From this, it is possible to introduce information into subsequent interviews, which is 'grounded' in the information collected from earlier interviews.

Table 1: Participant characteristics

Patient no.	1	2	3	4	5	6
Status	I/P	I/P	comm.	comm.	comm.	comm.
Gender	male	female	female	female	male	male
Age	30	24	42	20	55	30
Duration of illness	7 yrs	2 yrs	13 yrs	2 yrs	38 yrs	10 yrs
No. of episodes	5	2	3	2	i/n	4
Employment	unemp.	unemp.	seasonal	voluntary	unemp.	unemp.
Accommodation	rented	rented	owner	parents home	partners home	parents home
Living status	alone	alone	spouse	family	partner	parents
Education	secondary	1st degree	1st degree	vocational	vocational	1st degree

I/P = inpatient, comm. = living in the community, i/n = incomplete notes, unemp. = unemployed.

Procedure

Potential participants were identified by their key-workers or ward staff as being well enough to take part in the study. Identification of potential participants was approached in three stages:

(1) Presentation of the research project at team meetings and a request for key-workers to think of people on their caseload who may be appropriate. This was followed by mutual agreement of a method of contact by the researcher that was acceptable to the team. Each key-worker was given a précised copy of the research proposal so that they were aware of the main ethos of the research and inclusion and exclusion criteria.

(2) Agreement was made to initially contact the key-workers via a letter with the researcher's contact number so that the key-workers were able to contact the researcher with appropriate participants. All key-workers across the locality were contacted at this stage. This resulted in 39 contacts with individual key-workers, each holding a caseload of clients.

(3) Further contact was made by the primary researcher (LG) via the phone as a follow up to the letter and to ascertain whether key-workers had any suitable clients. Only 4 key-workers responded to this final stage of contact.

Having contacted key-workers on three different occasions using three separate methods, it was assumed that they had made a decision not to participate in the research by failing to suggest appropriate clients. Once three contacts were established, the research was not pursued any further with key-workers. Only 4 key-workers and 1 psychologist came forward to suggest appropriate participants. It is unclear why there was such a low response rate from key-workers. Although it was stressed to key-workers that their involvement would be minimal, shortages of staff and high caseloads may have contributed to reluctance to take on what was perceived as additional work.

Permission from consultants and GPs was gained before approaching the individual. Key-workers and psychologists identified twelve individuals. Of these, 6 agreed to participate, 2 refused because they did not believe they were ill and didn't think they would have anything to contribute, the consultant refused access for 1, 2 refused because they did not want to be tape-recorded and 1 was excluded due to the presence of a personality disorder. An initial meeting was arranged to explain the study to each participant and answer any questions they had. At this point, an information leaflet and consent form were left with the participant. Participants were given 1 week to consider their decision. A further appointment was made for the following week to collect written consent and to conduct the interview. Ethical approval for the study was granted by the local National Health Service Research and Ethics Committee and the University of Wales Bangor.

Interviews

All 6 interviews were carried out by the same interviewer (LG). The interviewer was a psychologist working locally and had a therapeutic relationship with 2 of the participants. The remaining 4 participants were unknown to the interviewer. For those participants who did not already know the interviewer, a preliminary session was arranged with each for introduction and to familiarise the participant with both the researcher and the project. The quality and quantity of the interviews did not seem to be determined by prior contact with the researcher. The interviews were tape recorded and lasted between 20 and 70 minutes (average length 47 minutes). The length of interviews reflected the participants' ability to articulate their beliefs and the level of impact they believed mental health had on their quality of life. Participants were asked an initial core question and allowed to respond to this as fully as possible:

'In what ways do you feel that the mental health problems you have experienced have affected your quality of life – either positively or negatively?'

If participants indicated that they didn't understand the question then it was reframed i.e. 'do your mental health problems stop you from doing anything that you'd like to do in life?' This was only necessary in one interview. Participants generated their own thoughts regarding how their quality of life had been affected. During the interview, notes were made about the topics they raised. Once interviewees had exhausted their own ideas, themes from existing HRQoL questionnaires were introduced but only if these topics had not been spontaneously raised. These themes included the following: social and family relations, safety, employment, finances, concerns for the future, intimate relationships, leisure, objective living conditions, stigma, emotional well being, religion and health (including treatment issues and symptoms) and are collectively covered in varying degree across the currently available measures. Each of the themes was introduced in a neutral question, allowing participants to reflect their own experiences. For example:

'Do you think the mental health problems you have experienced have affected your employment situation at all?'

Participants were able to confirm or refute whether these areas of life had been affected. All respondents spontaneously raised the following topics without prompting: relationship issues, occupation, psychological and behavioural issues, sense of stigmatisation, concerns for the future and medication issues. Consistently left out of interviews was the issue of positive responses to the experience of having mental health problems. Two respondents did not raise the issue of finances and had to be prompted. The following three themes were introduced from the questionnaires for all of the interviewees: safety, religion and health. None of the respondents thought these were problematic for them. In addition, the issue of living conditions was raised to four interviewees whilst two volunteered this spontaneously. The tape-recorded interviews were transcribed verbatim. The transcripts were then reviewed for accuracy by re-listening to the interviews whilst reading the transcript and checking for anomalies. The transcripts were then analysed to determine the presence of any themes. Qualitative analysis focused on comments relating to the impact of schizophrenia on quality of life. Each interview was transcribed and analysed before the next interview took place.

Data analysis

The text was closely inspected on a sentence-by-sentence basis, which resulted in the generation of several themes. Themes that arose were consistent across interviews. An indexing system of themes was generated with cross-references between themes and specific interviews and points in the text where the theme emerged. The aim of this process was to arrive at a range of indicators, which reflected the impact of schizophrenia on HRQoL domains. The whole process was iterative, starting with transcription of the interviews, highlighting pointers on the interview transcripts, writing memos, linking themes together, arriving at core themes, further integration of categories by creating links between them and defining what the core themes were. The process was repeated until the researcher arrived at the stage where no further themes emerged and saturation point was reached.

As a validity check on this process, the transcripts of the interviews were also blind rated by a second psychologist (EP) who followed the same process as above to arrive at core themes and contributory sub-themes. Between raters, there was an average 77% agreement rate on the final 10 core themes and contributory sub-themes. Discrepancies were discussed until a final agreement was arrived at. This related to agreement on the content of the 10 primary themes (ie interpersonal relationship, occupational factors etc) and of the sub-themes that contributed to each. These are detailed under each main theme in the results section.

The inter-rater agreement calculation took the form of a quantification of the content of themes between raters and resulted in the above mean inter-rater agreement value. An example of a calculation would be: Identification of main theme of 'loss of opportunity to fulfil occupational roles' from an agreement on the primary theme being related to occupation / work. Within that theme, the main researcher (LG) identified 11 sub-themes and the second researcher (EP) identified 9 themes. All 9 of the second researchers sub-themes matched 9 of those identified by the main researcher however, there was no match for two sub-themes, therefore: $9 \div 11 \times 100 = 81$. This means an agreement rate of 81% on the sub-themes within the occupation / work category. The nine sub-themes are detailed in the results section under the main theme of 'loss of opportunity to fulfil occupational roles'.

As a further validity check, 4 of the original participants were given a summary of the emergent themes, with a full transcript of quotes that illustrated these themes. Participants were asked to simply put a tick if they agreed that either the theme or the quote were within their realm of experience and a cross if they did not agree. The between participant agreement rate of content was 75% to 90%. Participants were asked if they had anything further to add. No further information was volunteered at this stage. Only 4 of the original 6 were included in the validity check due to one participant moving from the area and a second participant being unwell at the time of this second contact.

Results

At cessation of the sixth interview, it was clear that no further novel themes had emerged since the fourth interview. With a high level of concordance between interviews, it was felt at this point that sufficient data saturation had been achieved. The validity check across participants indicated high levels of between participant agreement regarding the content of the interviews. In addition, the validity check offered each individual an opportunity to consider the observed interview material and add any information they thought was relevant. Nothing further emerged at this stage.

From the process detailed in the data analysis section, ten themes emerged which represented HRQoL domains. The emerging themes were: (1) barriers placed on interpersonal relationships, (2) reduced control of behaviours and action, (3) loss of opportunity to fulfil occupational roles, (4) financial constraints on activities and plans, (5) subjective experience of psychotic symptoms, (6) side effects and attitudes to medication, (7) psychological responses to schizophrenia, (8) labelling and attitudes from others, (9) concerns for the future and (10) positive outcomes from experiences. Each theme is detailed below with a selection of representative quotes. Each quote is preceded by a number that designates which interview the quote was taken from (i.e. I.1, I.2).

Barriers placed on interpersonal relationships

Respondents indicated that generally, they felt alone and isolated because of their mental health problems and were worried about what others thought of them. There was concern about family and close companions because they were worried, helpless and unsure about what to do. Friends were frightened about their psychiatric status and both friends and family tried to avoid the person. There was a general perception that this was due to lack of education and ignorance about the illness.

I.1 "I didn't really have a relationship with them [family] at the time because of the problems I was having. It put a lot of strain on my mum. She was very worried about me, she didn't know what to do about me. She didn't know how to help me."

I.2 "Ehmm... I don't know if it's just that they don't know much about it and they just.... Maybe they're scared that it's going to affect them maybe. If they have contact with you then some of the mental illness may rub off on them. They aren't aware about mental illness themselves and they want to keep as far away as possible from that kind of thing because they themselves will become ...."

I.3 "It's [mental illness] had an effect on my relationships with people. I felt all alone and that I didn't want to talk to anybody. Ehmmm........ I was worried about what they would think of me. I never used to go out."

I.4 "I think people think if you've been in hospital you're the type of person that's going to flip in a social situation. So there's a little bit of standoffishness. [It's] Ignorance I guess. I suppose just the fear of weird behaviour............. unpredictability as well. Particularly in families you know mothers and fathers want to sort of map out the future for you and this is something they can't help, and all of that just drops away."

Reduced control of behaviour and actions

Respondents commented that their mental health problems led them to behave in ways they would not choose to. This also involved choosing to be isolated because of concerns regarding how they may appear and trying to appear normal. Avoiding situations that they had previously enjoyed because of fear of how they would appear or whether the stress associated with these situations would mean deterioration in mental health. Other behaviours such as disinhibition, staying in bed all day, lowered personal hygiene and self-harm were also detailed.

I.1 "They [voices] have affected me quite a lot. They've made me try to harm myself and do things like that, that I don't want to do. I didn't feel that I could talk to people about these things because of what they may think. I felt that I had a problem that I had to deal with on my own. Yes, I felt like that.......... on my own."

I. 2 "You don't want to get up in the morning, you don't want to have a bath or wash your hair, although those things make you feel better. You don't want to go out, you don't want to open the curtains."

I. 3 "Ehmm.. yes it just seems to be true. Well, ehmmmm how I feel is when I ehmm... when I'm ill then I tend to be spending lots of money which I don't have and then when I'm better I sort of sort things out rationally and I have more money and I don't really have the need to spend it at all."

I.4 "Yes very much so, I've cut down on the sort of positions I get myself in..... situations... because of bad experiences in the past. .... you think once bitten twice shy so you just try less things with the fear that you're going to get very ill again and go to hospital."

I.6 "Well I always try to look normal but some days everything like .... It's quite ehmmm...... how do you put it? Sort of... everything's technicolour, but very clear I get strange thoughts about........ and I'm always afraid that I'm acting them out while I'm going down the street and that I'm talking to myself....... and something tells me I'm not but something else tells me I am."

Loss of opportunity to fulfil occupational roles

Having no occupation meant that the participants experienced a loss of contact with others. They all commented that their illness made it difficult for them to work leaving them feeling useless, experiencing loss of respect and having no value in the job market. Because of mental health problems it was felt they had reduced choices in the job market. Benefits of having a job were perceived as being helpful to others, having a sense of camaraderie and maintaining a routine and structure to the day.

I.1 "I lost my job through being ill. It's a year nearly a year. I haven't had a job for quite a while and I think that was mainly due to my mental health. Because I couldn't hold down a job due to the way I was feeling."

I. 2 "Because one of the main issues is that you have to have a medical and they aren't going to employ somebody with a mental health record. Because they probably have access to your medical notes and I don't know anything about the bar of voice hearing."

I.3 "The routine of going to work every day and having something to do during the day, every day is like the same. You just count the days and look forward to days that are different or special."

I.3 "I'm sure my choices have been affected because it's affected my personality and my confidence and so the job I might have had once is no longer...... (pause) you know. Ehmm.... I don't think there are opportunities for me..."

I.4 "Camaraderie. Even when you're feeling separate like the way I do from people. There's still these feeling of ehmmm........ ehmm...... sort of combining with other people to do one thing."

I.5 "The feeling of uselessness is one of the strongest things. Because you've got no self esteem and I'm always sort of comparing myself with people who do work. There's no .... you've got no respect in a way."

Financial constraints on activities and plans

The financial elements of having schizophrenia fell into two areas: (1) Practical limitations such as not being able to travel, go on holiday, pursue activities or live where they might choose and (2) experiential aspects such as not planning too far ahead, conscious of being careful with money, feeling of reduced choices and a sense of financial uncertainty.

I.2 "Well, I'd have had more money if I'd stayed in the health services working for ------------. I'd have been able to board the animals and go on holiday. I would have been able to afford a bigger house maybe even have some help with some of the domestic tasks.......... Yes it has it's limited my choices, I have to be frugal because we can't count on my salary so when I have a salary it's a bonus."

I.3 "You're only taking things one day at a time. You can't plan for the future. I take one day at a time, literally one day at a time."

I.4 "Lack of control I guess and lack of control of your finances because what you get in benefits goes immediately what with all the things you have to pay out for. So you have to be very careful and I can understand people working on the side. That's another sort of loss of control of part of your life which doesn't make you feel very good about yourself."

I.6 "I can't do things .... I'd like to go fishing but......... I can't buy the equipment. I'd like to go out and visit places but I can't."

Subjective experience of psychotic symptoms

Respondents described an array of symptoms, including feeling quiet and withdrawn, tiredness, feeling agitated, suspicious, nervous or anxious, hearing voices, aching, sleeplessness, lowered motivation, loss of energy, paranoia, and depression.

I.1 "I just like ..... didn't want to get up. Didn't think there was nothing to live for. I didn't have energy which felt horrible....... I felt drained and aching. I couldn't find the energy to do anything."

I.3 "There's sort of voices and all sorts of mayhem going on inside and there's not enough of your brain left to concentrate on what people are saying. You're sort of dealing with all of this."

I.4 "Primarily... also I get very paranoid and ehmmm..... but I've always got this background.. I don't know how can I put it? I'm very interested in science and the scientific approach to things rather than religious mumbo jumbo stuff so I've always got that little thing to aim for in understanding what's going on."

I.6 "Being quiet and not sociable. Not wanting to go anywhere and being suspicious of people and what they were thinking of me. Feeling tired, agitated, nervous, hearing voices, thinking that people were after me."

Side effects and attitudes to medication

None of the participants identified any particular effects from medication, either positive or negative. There was a general sense that they continued to take their medication because of concern regarding what would happen if they didn't. Most respondents highlighted some side effects from medication that they found problematic, but these were few.

I.2 "I think it affects your motivation....... It compounds with the illness to affect your motivation because you just feel sort of (blowing out sound) and you see it very much in hospital when people are over prescribed you just feel like a sack of potatoes... you can see it."

I.3 "It just helps you over the worst it just deadens things down enough ehmmm..... I don't look upon the drugs as therapeutic it's just that I don't want to feel like I do when I give them up. It's quite frightening."

I.4 "Yeah well side effects are a real problem. Lack of sex drive. Diminishing sex drive and that affects your self esteem and it affects the way you feel about yourself and how you feel about being in a relationship. Ehmmmm.... and of course the putting on weight... those two things combined can make you feel a bit bad. I'm on chlorpromazine now and ehmmm....... all it really does is deaden things down a bit."

I.5 "I don't want to take it. It doesn't make me feel anything, so I can't see why I am taking it. It doesn't have any effect on me."

I.6 "The only thing is a dry mouth and that's the only thing. I'm not really sure it [medication] has any benefits."

Psychological responses to schizophrenia

Some of the themes that emerged and have been categorised as psychological factors included: thinking that you were the only one that had the problem, low self-esteem, lowered morale, worry regarding the opinions of others, fear, feeling helpless and useless.

I. 1 "When I was first ill .... I thought I was the only one to have problems like this. One of the things that has helped me was finding out that there were other people who had the same things happening to them."

I.2 "It was awful........ I felt useless and helpless .... I couldn't talk to anyone about it, I stayed in bed nearly every day."

I.3 "The low self esteem seems to affect every area and it's not something where someone can say 'oh write down what you did and look at it and look how good it is' now that to me doesn't help me at all."

I.4 "Well ehm.............. feeling like a weakling you know as though you can't take charge of your life. Also the stigma goes along with that and you realise you're different in some way. And that's a bit of a blow when you've tried to pretend to be normal. Which I think most people do, you try very hard to appear you know like everybody else. Ehmmmmm............ paranoia is probably the worse voices I can get used to but I'll never get used to the paranoia. It's the one that changes things the most."

I.6 "Ehmmm. it makes you feel like you can't cope with it all, you get down and the idea that you can't live on your own and things."

Labelling and attitudes from others

The stigma attached to having mental health problems seemed to impact on a number of areas of life including relationships, social life, work, the image that people have of mental health and schizophrenia resulting in people writing you off because you have that label.

I.1 "Yeah it's like being stereotyped and people have an opinion of you based on that. I was worried about that when I was ill. Not now, but when I was ill. I was worried about friends and family as well. I was aggressive, shouting all the time. I was quite angry about that."

I.2 "There is a stigma about mental illness and people seem to write people off if they are mentally ill."

I.3 "Yes.................. lots of people have.... Yeah that's true [written him off]. Yeah.. maybe yeah. I don't think. No, I don't think I have actually [written myself off] I still have a serious glimmer of hope but I'm sure lots of people have written me off you can tell by the way they sort of look at you and comment on things."

I.4 "Once people you work with know you've been in hospital .... It's amazing what people can find out about you. Then there's the......... I don't think it's just a feeling on my part...... there's a definite look you get, and they won't take it seriously. So that, that's really hard."

Concerns for the future

A number of ongoing concerns for the future were highlighted during the interviews, these included: worrying about having to go into hospital again, concern about how the illness will progress, feeling uncertain about the future, not being able to plan into the future and worry about relapses occurring.

I.2 "I worry that I may have to go into hospital again. When my mental health problems are worse, it worries me that it may have to be an option and that thought is stressful."

I.3 "Ehmmmm... there's the financial part....................... but also there's the feeling that this things not going to burn itself out so this is going to be a burden for the rest of my life....... And ehmmmmm I'm not that confident that it's not going to get worse."

I.4 "Is that going to be me? Oh yeah ....yeah, yeah part of me felt well, because I recognised this then maybe I'm not like them, but when you realised that they all felt like that in somebody else's eyes you were just one of them. A nutcase kept away from civilisation."

I.5 "It's just that I think there's not going to be anything good about the future and that I'm always going to be like this. Well, I think that things can't change and that things are going to stay the same."

Positive outcomes from experiences

All participants were asked if they felt there had been any positive outcomes from their experience. Three out of the six respondents felt that there had been nothing positive whilst the remaining three felt that it had improved their relationships with the family, improved communication with family members and had made them appreciate their own situation a bit more.

I.1 "I've seen reality, I've seen people suffering on that ward and it makes me value my life and to think how lucky I am."

I.3 "Ehmmmm............. I think I'm .... I can't think of the words to describe it...................... there's just sort of something that's better within me now because of the time that I've spent being ill. Ehmm...... it's hard to put a finger on this one I can't really explain what it is. It's a sense of being more wise really .... Sort of thing....... About knowing about the problems people have. I think that's the closest I can say."

I.5 "They've [relationships with family] improved a lot now. I can talk much more to them now, we're closer now than we were. I think she can sense if I'm going ill again now. Yeah ..... it makes me feel more confident that things would be different."

Discussion

Schizophrenia is a debilitating long-term disorder with the potential to impact profoundly on HRQoL. The present exploratory study focused on the qualitative accounts of 6 people with a diagnosis of schizophrenia. The main aim of the study was to elicit a series of individual accounts regarding the impact of schizophrenia on HRQoL and to determine what commonalities lay between these individuals and the life domains they reported were affected. As described in the introduction the domains, which appear in the majority of HRQoL measures that have been applied in schizophrenia have largely not been determined by people with schizophrenia. The present study represents a novel approach with this population and provides a description of ten life domains that were independently defined by the participants in the study.

Regarding comparisons with domains from other questionnaires and qualitative work, there is some consistency with the type of domains expressed. However, a number of domains were not detailed as problematic for this group: health, religion, safety and objective living conditions alongside many of the somatic domains detailed in the introduction. Many of the domains in the generic measures are reflective of the type of somatic concerns that individuals living with medical disorders may express, but are not common to people with schizophrenia. The absence of these domains may be reflective of the size of the group and their generalisability, but equally it may also reflect some redundancy regarding the content of the more commonly applied questionnaires. It is possible that subjective reflection of HRQoL in schizophrenia is based on a smaller number of domains than appear in the present generation of questionnaires and is more in keeping with the 10 domains expressed in this study. Taking this one step further, development of an HRQoL measure, which reflects only those domains expressed in the present study may be more representative of the HRQoL concerns of these individuals. The logical progression from this exploratory qualitative study would be to generate a questionnaire to further test the veracity of this outcome.

An advantage of the present methodology relates to the potential use of participants own language in the development of the item wording for a new questionnaire. Wording of items in participants own language makes questionnaires more acceptable having additional resonance for this group. This may avoid some of the objectivity, functionality and ambiguity that is endemic amongst the questionnaires discussed in the introduction. This is an important factor given that lack of relevance in questionnaires has been shown to reduce the acceptability of a measure to psychiatric respondents [1].

With regard to presenting a model of HRQoL, the present study is not methodologically able to achieve this. To do this would require a quantitative approach utilising a questionnaire drawn from the 10 domains that have been identified by the current sample. This would facilitate statistical modelling using either regression or path analysis to determine the hierarchical structure of HRQoL for these individuals and arrive at a more robust model. Further development of quantitative approaches would also allow statistical analysis of possible predictors of HRQoL for this population.

Although not specifically analysed with this in mind and not fully represented in the data presented in the study, the extended interview data provided several indices that would be worth further exploration. There appeared to be 5 predominant factors represented throughout the interview data. These were (1) uncertainty and lack of control, (2) responses from others and responses to others, (3) sense of detachment and isolation, (4) fear and (5) reduced choices. These factors were expressed in varying degrees across each of the domains. The most dominant across all domains was uncertainty and lack of control, which was expressed in all of the 10 domains, with reduced choices being expressed across 8 out of the 10 domains. The least represented was detachment and isolation, which was only expressed in 5 out of the 10 domains. It is possible that these factors represent mediators or moderators of HRQoL and warrant further more focused investigation. Although speculative, it is also possible that the variable representation of these factors across each of the domains in turn represents level of impact upon HRQoL.

Conclusion

The present study marks a starting point in clarifying and describing HRQoL domains in schizophrenia. It adds a systematically approached qualitative perspective of HRQoL in schizophrenia. The outcome replicates and confirms existing domains but adds to this by beginning to suggest some domains that may not be relevant. In addition, the sub-text of the present study also raises factors that may function to either mediate or moderate HRQoL. As with most qualitative research a weakness of the study was the small number of participants and how typical their accounts were. The present interview material suggests a consistency across reports as clarified by participants' relevance ratings of themes and the quotes made by fellow participants. In addition, the present sample came from rural and semi-rural areas. However, there is nothing to suggest in the interview data that the problems they described were exclusive to this population.

Although the present data is insufficient to provide any speculation with regard to a precise hierarchical model of HRQoL for schizophrenia, it offers some suggestions for further research in the form of expanding the detailed themes into a preliminary disorder specific HRQoL questionnaire. This would be a valuable addition to outcome measurement in schizophrenia especially in response to the UK government's clinical guidelines for the treatment of schizophrenia, which state that HRQoL should be a recognised outcome measure for this group [6]. In addition, it may prove fruitful to pursue the 5 factors that have briefly been alluded to in the discussion with regard to potential predictors of HRQoL for this group. Extension of the current findings into further research may help to improve our understanding of the impact of schizophrenia on HRQoL and how this may be ameliorated.

Authors contributions

LG – initiation and design of the research, collection and analysis of the data and writing the paper.

EP – co-analysis of the data and editorial revision of draft papers.

MJ – supervision of the project and editorial revision of draft papers.

References

1. Awad AG, Voruganti LNP and Heslegrave RJ: **Measuring quality of life in patients with schizophrenia.** *Pharmacoeconomics* 1997, **11(1):**32-47.
2. Patterson TL, Kaplan RM and Jeste D: **Measuring the effect of treatment on quality of life in patients with schizophrenia: focus on utility based measures.** *CNS Drugs* 1999, **12(1):**49-64.
3. Awad AG, Lapierre YD, Angus C and Rylander A: **Quality of life and response to negative symptoms in schizophrenia to haloperidol and the atypical antipsychotic remoxipride.** *J Psychiatry Neurosci* 1997, **22(4):**244-248.
4. Revicki DA, Genduso LA, Hamilton SH, Ganoczy D and Beasley CM: **Olanzapine versus haloperidol in the treatment of schizophrenia and other psychotic disorders: quality of life and clinical outcomes of a randomised clinical trial.** *Qual Life Res* 1999, **8(5):**417-426.
5. Voruganti LNP, Heslegrave RJ and Awad AG: **Quality of life measurement during antipsychotic drug treatment of schizophrenia.** *J Psychiatry Neurosci* 1997, **22(4):**267-274.
6. National Institute for Clinical Excellence: **Schizophrenia: Core interventions in the treatment and management of schizophrenia in primary and secondary care.** *National Institute for Clinical Excellence* 2002.
7. The British Psychological Society: **Clinical Psychology in services for people with enduring mental illness.** *British Psychological Society London* 2002.
8. Awad AG and Voruganti LNP: **Quality of life and new antipsychotics in schizophrenia: are patients better off?** *Int J Soc Psychiatry* 1999, **45(4):**264-275.
9. Katshnig H: **Schizophrenia and quality of life.** *Acta Psychiatr Scand* 2000, **102(suppl 407):**33-37.
10. Becker M: **A US experience: consumer responsive quality of life measurement.** *Can J Commun Ment Health* 1998, **3:**41-52.
11. Cramer JA, Rosenheck R, Xu W, Thomas J, Henderson W and Charney DS: **Quality of life in schizophrenia: a comparison of instruments.** *Schiz Bull* 2000, **26(3):**659-666.
12. Kaiser W and Priebe S: **The impact of the interviewer-interviewee relationship on subjective quality of life ratings in schizophrenia patients.** *Int J Soc Psychiatry* 1999, **45(4):**292-301.
13. Lefley H: **Foreword.** *Commun Ment Health J* 1998, **34(5):**455-457.
14. Awad AG: **Quality of life issues in medicated patients.** In: *Contemporary Issues in the Treatment of Schizophrenia* Edited by: *Shriqui CL, Nasraltah HA. American Psychiatric Press*; 1995:735-747.
15. Awad AG: **Quality of life rediscovered: implications for clinical outcome and health economics in schizophrenia.** *J Psychiatry Neurosci* 1997, **22(4):**229-230.
16. Awad AG and Voruganti LNP: **Intervention research in psychosis: issues related to the assessment of quality of life.** *Schiz Bull* 2000, **26(3):**557-564.
17. Browne S, Garavan J, Gervin M, Roe M, Larkin C and O'Callaghan E: **Quality of life in schizophrenia: insight and subjective response to neuroleptics.** *J Nerv Ment Dis* 1998, **186:**74-78.
18. Doyle M, Flanagan S, Browne S, Clarke M, Lydon D, Larkin E and O'Callaghan C: **Subjective and external assessments of quality of life in schizophrenia: relationship to insight.** *Acta Psychiatr Scand* 1999, **99:**466-472.
19. Hansson L, Middelboe T, Merinder L, Bjarnason O, Bengtsson-Tops A, Nilsson L, Sandlund M, Sourander A, Sorgaard KN and Vinding H: **Predictors of subjective quality of life in schizophrenic patients living in the community: A Nordic multicentre study.** *Int J Soc Psychiatry* 1999, **45(4):**247-258.
20. Heinze M, Taylor RE, Priebe S and Thornicroft G: **The quality of life of patients with paranoid schizophrenia in London and Berlin.** *Soc Psychiatry Psychiatr Epidemiol* 1997, **32:**292-297.
21. Landeen J, Pawlick J, Woodside H, Kirkpatrick H and Byrne C: **Hope, quality of life, and symptom severity in individuals with schizophrenia.** *Psychiatr Rehab J* 2000, **23(4):**364-369.
22. McCabe R, Röder-Wanner U-U, Hoffmann K and Priebe S: **Therapeutic relationships and quality of life: association of two subjective constructs in schizophrenia patients.** *Int J Soc Psychiatry* 1999, **45(4):**276-283.
23. Stallard J and Joyce E: **The impact of olanzapine on attitude to medication and quality of life in schizophrenia.** *Psychiatr Bull* 2001, **25:**378-381.
24. Lehman AF: **A quality of life interview for the chronically mentally ill.** *Eval Prog Plann* 1988, **11:**51-62.
25. Oliver JPJ: **The social care directive: Development of a quality of life profile for use in community services for the mentally ill.** *Soc Work Soc Sci* **3:**5-45. 1991–1992
26. Heinrichs D, Hanlon E and Carpenter W: **The quality of life scale: an instrument for rating the schizophrenia deficit syndrome.** *Schiz Bull* 1984, **10:**388-398.
27. Wilkinson G, Hesdon B, Wild D, Cookson R, Farina C, Sharma V, Fitzpatrick R and Jenkinson C: **Self-report quality of life measure for people with schizophrenia: the SQLS.** *Br J Psychiatry* 2000, **177:**42-46.
28. Wilkinson G, Wild D, Jenkinson C, Fitzpatrick R and Hedson B: **The Schizophrenia Quality of Life Scale (SQLS): Users manual for the SQLS.** *Oxford Outcomes* 1999.
29. Klijnsma MP: **Assessing quality of life in schizophrenia.** *Br J Psychiatry* 2001, **178:**181.
30. McKenna SP: **Measuring quality of life in schizophrenia.** *Eur Psychiatry* 1997, **12(suppl 3):**267s-274s.
31. Bergner M: **Development testing and use of the Sickness Impact Profile.** In: *Quality of Life Assessment: Key Issues in the 1990's*

Edited by: *Walker SR, Rosser RM. Dordrecht, Kluwer Academic Publishers*; 1993:95-110.
32. Bergner M, Bobbitt RA, Kressel S, Pollard WE, Gilson BS and Morris JR: **The Sickness Impact Profile: conceptual formulation and methodology for the development of a health status measure.** *Int J of Health Serv* 1976, **6(3):**393-415.
33. Bergner M, Bobbitt RA, Pollard WE, Martin DP and Gilson BS: **The Sickness Impact Profile: Validation of a health status measure.** *Med Care* 1976, **14(1):**57-67.
34. Bergner M, Bobbitt RA, Carter WB and Gilson BS: **The Sickness Impact Profile: Development and final revision of a health status measure.** *Med Care* 1981, **19(8):**787-805.
35. Ware JE and Sherbourne CD: **The MOS 36-item Short Form health survey (SF-36): I. Conceptual framework and item selection.** *Med Care* 1992, **30:**473-483.
36. McHorney CA, Ware JE and Raczek AE: **The MOS 36-item short-form health survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs.** *Med Care* 1993, **31:**247-263.
37. McHorney CA, Ware JE, Lu JFR and Sherbourne CD: **The MOS 36-item short-form health survey (SF-36): III. Tests of data quality, scaling assumptions and reliability across diverse patient groups.** *Med Care* 1994, **32:**40-66.
38. Klijnsma MP: **Assessing quality of life in schizophrenia.** *Br J Psychiatry* 2001, **178:**181.
39. Laliberté-Rudman D, Yu B, Scott E and Pajouhandeh P: **Exploration of the perspectives of persons with schizophrenia regarding quality of life.** *Am J Occup Ther* 1999, **54:**137-147.
40. Angermeyer MC, Holzinger A, Kilian R and Matschinger H: **Quality of life as defined by schizophrenic patients and psychiatrists.** *Int J Soc Psychiatry* 2001, **47(2):**34-42.
41. Abbott J, Dodd M and Webb AK: **Different perceptions of disease severity and self-care between patients with cystic fibrosis, their close companions and physician.** *Thorax* 1995, **50:**794-796.
42. Andersen RM, Davidson PL and Ganz PA: **Symbiotic relationships of quality of life, health services research and other health research.** *Qual Life Res* 1994, **3:**365-371.
43. Gaite L, Vazquez-Barquero JL, Arrizabalaga AA, Schene AH, Welcher B, Thornicroft G, Ruggeri M, Vazquez-Bourgon E, Retuerto MP, Leese M and and the epsilon study group: **Quality of life in schizophrenia: development, reliability and internal consistency of the Lancashire Quality of Life Profile – European Version: Epsilon study 8.** *Br J Psychiatry* 2000, **177(suppl 39):**s49-s54.
44. Guyatt GH, Feeny DH and Patrick DL: **Measuring health related quality of life.** *Ann Int Med* 1993, **118:**622-629.
45. American Psychiatric Association: **Diagnostic and Statistical Manual of Mental Disorders.** *American Psychiatric Association, Washington DC* 41994:291-292.
46. Glaser BJ and Strauss AL: **Awareness of Dying.** *Chicago, Illinois, Aldine* 1965.
47. Glaser BJ and Strauss A: **The Discovery of Grounded Theory.** *Chicago, Aldine* 1967.
48. Pidgeon N: **Grounded Theory: theoretical background.** In: *Handbook of Qualitative Research Methods for Psychology and the Social Sciences* Edited by: *Richardson JTE. British Psychological Society Books*; 1996:75-85.
49. McCleod J: **Qualitative Research in Counselling and Psychotherapy.** *Sage Publications Ltd* 2001:70-89.