A qualitative study of the perspectives of people diagnosed with schizophrenia of their physical health risks and needs

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Abstract

People diagnosed with severe and enduring mental illness are known to have a higher mortality rate than the general population. Research shows that this appears to be largely related to high risk lifestyle choices, use of antipsychotic medication and compromised access to good physical healthcare. This study aimed to elicit the lived experiences of service users diagnosed with schizophrenia on their awareness of their physical health needs and risks. One focus group of five people and four additional individual interviews were conducted on an inpatient rehabilitation ward. A thematic analysis revealed five key themes: medications, lifestyle choices, weight gain, motivation and addressing physical health concerns. Overall services users had good awareness of their physical health risks and needs, but were unable to motivate themselves to act on this awareness. They had a number of ideas about what could be done and recognised that they needed nurses to compensate in helping motivate them in proactive ways. Interventions need to be negotiated around the services users opinions, consistent delivery, expressed need and with a firm understanding that any assumptions must be put aside.

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Introduction

Schizophrenia affects around 1% of the population (Rethink, 2015). It is considered a serious and severe mental illness (SMI, sometimes referred to as psychosis, The British Psychological society, 2000) and a disability (Equality Act, 2010). Symptoms of schizophrenia include apathy, passivity and social withdrawal which are related to lack of motivation (WHO, 1992).

It is well established that people diagnosed with severe mental illness have higher mortality rates compared to the general population (~~Brown, 2000;~~ Thornicroft 2011; Andrews et al., 2012; Vancampfort et al 2012; Andrews et al., 2012). Best practice in the UK is guided by Government policy (DH, 2011) which commits to improving mortality rates through provision of good physical health care, and this is a key indicator of the NHS outcomes framework 2015-2016 (DH, 2014). Annual physical health checks and adherence to ~~contemporary~~ physical health guidance should be available to patients with SMI (DH, 2006; National Institute for Health and Care Excellence (NICE) 2014) and nurses have a key role in this (Robson & Gray, 2007; Hardy, 2013). However, there appears to currently be little information about the service users' perspective on this topic and this study aims to contribute to this knowledge gap.

Literature review

The databases PSYCInfo, MEDLINE, CINAHL and the Cochrane library were searched for English language publications using the search terms 'physical health' 'mental health' 'morbidity' 'mortality' 'service user views' 'patient perspective' 'severe and enduring mental illness' and 'schizophrenia'. Nineteen articles were located.

From examination of this literature there appear to be three key themes; Mortality and morbidity, the nurses role and lifestyle factors.

Theme 1 Mortality & Morbidity

Connolly & Kelly (2005) highlighted the most predominant risk factors affecting physical health in people with severe mental illness as diabetes, hyperlipidaemia, obesity and cardiovascular disease. Follow up studies in Sweden and the UK have found that smoking lifestyle, poor diet and alcohol consistently contribute to early mortality (Brown 2000; Brown 2010). Cardiovascular disease for people diagnosed with schizophrenia has shown a mortality rate of twice the general population (Vancampfort et al., 2012). Brown et al. (2010) suggest that the excess mortality of people with schizophrenia is consistent in different populations, continents and eras. They found that mortality was higher in men and the most significant contributions to overall excess mortality was from circulatory disease which accounted for 33% of deaths and respiratory disease for a further 19%. A Cochrane review on general physical health for people with serious mental illness aged 18-65 years (Tosh et al., 2014) found only 6 good quality studies but conclude that physical healthcare advice for those with severe mental illness can improve their health-related quality of life, but only in relation to their mental health rather than their physical health.

A systematic review of thirty seven studies found that the introduction of second generation anti-psychotic medications in the 1990s were initially associated with better quality of life (Sacha et al. 2007). However, there is now increasing concern that these medications are implicated in adverse effects such as weight gain and metabolic syndrome (Saha et al., 2007; White et al., 2009).

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Theme 2 Nurses role in physical health

It has been found that mental health nurses need more training in relation to physical health monitoring and medication management and the impact these have on physical health (White et al., 2009). Mental Health in Higher Education & Middlesex University (2008) surveyed 208 people: mental health service users, carers, educators, practitioners and students (only 14 were service users and carers), on physical health and its connection with mental wellbeing. Ten service users stated that those providing mental health care had not asked about physical health, and of those ten only one was satisfied with the response received from mental health services in relation to physical health. Service users felt that practitioners needed more expertise in health promotion, physical side effects of medications and disability awareness.

Ratcliffe et al. (2011) audited the implementation of NICE guidance for physical health monitoring for patients with Schizophrenia or Bi-Polar disorder in two primary care settings. The study reinforces previous findings from other studies in relation to higher risk of cardiovascular disease in this patient group and the need for better integration between mental health care and physical health care services. This lack of integration between mental and physical health services has been found to be a barrier to good physical health care for people with mental illness (Happell et al., 2012; Blanner Kristiansen et al., 2015), as has the effects of stigma (Happell et al., 2012). Happell et al. (2014) found that nurses sometimes assume that expressed worries about physical health in the mentally ill are believed to be part of their mental illness. This process is known as 'diagnostic overshadowing' where medical staff, guided by uninformed stereotypes treat those with mental illness in a less thorough and effective manner (Thornicroft, 2011). However, people diagnosed with schizophrenia have been found to be less likely to spontaneously report physical symptoms (Connolly & Kelly 2005) which points to the need to be proactive in this area of practice for improved outcomes.

Theme 3 Lifestyle factors

Connolly & Kelly (2005) argue that the excess morbidity and mortality of this patient group is preventable through lifestyle modification and the recognition and treatment of common diseases. They suggest that those diagnosed with schizophrenia may fail to recognise early signs of physical ill health or avoid contact with services. Hardy et al. (2012) found that patients were not aware of their risk of cardiovascular disease. It is recommend that training and services emphasise the opinion of those diagnosed with schizophrenia when addressing physical ill health (Connolly & Kelly, 2005; Hardy et al. 2012).

Smith et al. (2007) carried out an evaluation study offering a well-being physical support programme to patients with diagnosis of severe and enduring illness over a 2 year period. 34 of 966 people initially recruited required urgent medical referrals picked up by the basic physical check. The baseline data showed high prevalence of obesity, hypertension, cigarette smoking, poor diet and lack of exercise. By the end of the consultations there was a significant reduction in the level of risk factors for cardiovascular disease overall. Haf Roberts & Bailey (2013) showed that participating in such programmes can also improve social relationships which can act as a motivator to engagement. They found that a key problem preventing initial attendance was social anxiety. The participants in Hardy et al. (2012) study found it helpful to have the same nurse each visit and they wanted more information on blood tests and medication.

A comparative study utilising questionnaires with 146 people diagnosed with psychotic and non-psychotic mental illness found that those with psychosis did not consider their physical health to be a priority (Buhagiar et al., 2011). They were also found to have poorer knowledge about physical activity, dietary habits and chronic physical problems compared to

the general population. In contrast Hardy et al. (2012) found good awareness of the importance of healthy diet and exercise in people with SMI attending physical health checks in primary care (perhaps an already motivated group). Buhagiar et al. (2011) argue that it is possible that this patient group may prioritise their physical health differently and exhibit different levels of motivation to change high risk behaviours associated with coronary heart disease such as smoking and lack of exercise. It is possible participants feel they have little control over their physical illness in the same way that they report lack of control in relation to mental health (Allan & Dixon, 2009; Wang, 2011). Those with non-psychotic illnesses had better physical health and saw their physical health as more of a priority possibly due to feeling more control of this area of their health. The study emphasises the need for focusing on lifestyle issues when working in clinical practice with those with SMI. However, the findings of Blanner Kristiansen et al. (2015) suggest that people don't have surplus energy to be bothered when they have mental illness. Fraser et al. (2015) found lack of motivation and fatigue were barriers to engaging in physical activity.

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Scheewe et al (2012) carried out a randomised clinical trial in the Netherlands that measured the effects of exercise on cardiorespiratory fitness in patients with Schizophrenia. The sample included 63 patients with Schizophrenia and 55 healthy comparisons matched for gender, age and socio-economic status. The patients with schizophrenia were assigned to exercise or occupational therapy and the controls were assigned to exercise or life as usual for 6 months. Cardio-respiratory fitness levels were found to be lower in those with schizophrenia compared to the healthy comparisons. Scheewe et al. (2012) suggest that a poor cardio-respiratory fitness is a key risk factor for patients with schizophrenia developing coronary heart disease. Results from the trial demonstrate that exercising for one hour twice per week improved cardio-respiratory fitness and consequently could lead to reducing mortality rates.

The study recommends that exercise therapy become part of the usual care of this patient group. Fraser et al (2015) found a preference for walking, an activity that can be done alone as part of a set routine, though women were more likely to share this activity with other women.

Haf Roberts & Bailey (2013) seem to provide the most detailed account of service user perspectives of their health issues, but these observations are made in a specific intervention group for out-patients. Therefore, to add our knowledge of this subject, this study aims to focus on inpatient service user perspectives of their physical health needs and risks, a population who could be considered amongst the most disabled.

Method

A phenomenological framework aimed to elicit the 'lived experience' of the views of a group of people residing in one stepdown rehabilitation inpatient unit on their perspectives of their physical health risks and needs. Nursing staff were briefed on the research so that they could answer questions. Participants who expressed an interest were written to individually inviting them to take part. The letters were accompanied by an information sheet which clearly defined what the expectations would be. Ethics and governance permissions were given by University, NRES & the local health and social care trust. Nine service users agreed to participate.

The original plan was to have focus groups with follow individual interviews, however, due to preference and practical challenges, there was one focus group of five people with individual follow-up interviews, and a further four individual interviews only. For the focus

group, a typical vignette based on the first authors experience of working in a rehabilitation setting, was used as a trigger for discussion to depersonalise the issues in a group setting (see table 1).

Table 1 Focus group vignette

John is a 44 year old male with a diagnosis of Schizophrenia he currently lives alone in a flat with his cat and receives 4 hours support from a STR (support time recovery) worker once per week. John uses the time with the STR worker to go to the local pharmacy to collect his medications, pay his bills, and do a small amount of shopping and cleaning. John volunteers at the local dogs home 2 days a week for 3 hours walking dogs. John spends the rest of his week in his flat watching TV. John smokes 30 cigarettes a day, drinks 4 cans of strong larger most days and has either fast food takeaway of chips from the chip shop 5 days a week. John reports that he has a poor sleep pattern struggling to sleep at night and consequently naps during the day. Recently John attended his local GP as he is struggling with increased breathlessness when walking routine checks by the GP show that John has a BMI of 30, raised cholesterol, blood pressure and faster than normal pulse rate.

The focus group questions in relation to the vignette that prompted discussion can be seen in table 2. A thematic analysis using Braun & Clarke (2006) framework resulted in the identification of five main themes: Medications, weight gain, lifestyle, motivation and addressing physical health concerns.

Table 2 Focus group

1. Do you think that John is at risk of physical illness? 2. Do you feel those involved in John's care see his physical health as important? If yes how? If no why do you think this is? 3. How do you think John's physical health needs can be looked after better? 4. Do you feel that those involved in John's care can support him better to look after his physical health? If yes how? If no what do they do that fully supports John? 5. What aspects of his lifestyle do you think John can change to improve his physical health? 6. If John wanted to learn more about physical health what way do you think is the best way for this information to be delivered and who do you think the best person to do this is?

The focus of group and individual interviews were transcribed and analysed by the first author and independently agreed by the second author.

Findings

Medications

Participants were concerned that medications taken to treat mental illness caused serious physical side effects:

> *''I think there is such a lot of side effects of antipsychotic drugs….so there is physical health needs'* (P.ANR10L34&35.T1)

and

> *'Get your consultant to lower your medication.....change your medication to a different time you know.'* (P.ANR8L123-129.T1)

Weight gain, physical needs, side effects and polypharmacy were all identified by participants as problematic:

> *'...avoid any medications being prescribed as well as psychiatric drugs that would be brilliant'* (P.ANR6L24T5).

as well as other concerns;

> *'well I just worry about the psychiatric drug and worried it doesn't end up like a lobotomy pill'* (P.ANR6L99T5).

There was a sense of helplessness however relating to how services could help with side effects and stopping medication apart from;

> *'Get your consultant to lower your medication.....change your medication to a different time you know.'* (P.ANR8L123-129T1).

Lifestyle choices

All nine participants made some reference to lifestyle factors. Most common was lack of exercise and poor diet:

> '*Yeah I eat a lot of fried foods you see it is a concern for the staff they always tell me to cut things down and like cook meals' (*P.ANR8 L18&19T2),

with an awareness of possible behaviour change

> *'Do things in a bit more moderation I suppose'* (L51 T2).

Concerns relating to smoking tobacco were also indicated:

> '*I find it really hard to stop....I have tried everything.....I have come off heroin, I have come off crack cocaine, I have come off hashish, come off every drug under the sun valium etc. But I can't get off nicotine for some reason you know it's so addictive it's unbelievable.'* (P.ANR9 L92,94,99-101T6).

Weight gain

Participants repeatedly raised concerns in relation to weight gain and the impact this has on physical health highlighting that lack of exercise and side effects from prescribed medications as contributing factors. Participants stated:

> *'I have put on a lot of weight...you start eating a little bit more....weight gain eating too much food, drinking too much fizzy drinks.'* (P.ANR3 L14&19T3)

and

> *'I keep piling on the weight sometimes, I don't know where it is coming from; you know I am about sixteen or seventeen stone when I should be about twelve or eleven'* (P.ANR6 L58-60T5).

Motivation

Participants indicated a sense of personal responsibility to carry out changes in order to improve physical health:

'... really it is up to you to help yourself your wellbeing' (P.ANR3L132T1).

The role of staff was *'to motivate you to be independent'* (P.ANR3L86T1) and;

'you take the responsibility but also you [staff] monitor that person's well-being as well' (P.ANR6 L205T1).

Staff could motivate*: 'even if it be a pest come on come on out the door get five minutes walking and fresh air* (P.ANR6 L238T1).

During the focus group participants discussed the amount input for helping motivation that should be given from mental health staff in relation to physical health as balanced with their own responsibility in looking after their physical health. Generally they felt that they should take the lead in their physical health care, accepting the main responsibility but being open to input from mental health services.

Addressing physical health concerns

Participants had ideas about addressing the problem*:*

'just leaflets innit, you know what I mean about your weight and stuff like that.' (P.ANR1L71&72T7)

but felt that;

'maybe information that you can decide for yourself that would be alright.....it's not always good to have too much knowledge.' (P.ANR8Ls88&111T2).

It was also expressed that it was important to understand that;

'you shouldn't bombard a person with …telling them what to do...let them make their own decisions…' (P.ANR3 L495-503T1)

Participants eagerly agreed with the researcher's summary of the nurse's role:

R: '*…giving you information, letting you make a decision and supporting you in taking action?*

P: *'Yes, yes, yes'.*

The findings of this study, focused on inpatients, appears to be consistent with the themes of existing literature. It offers several important key messages in relation to our understanding of this population: 1) that people have knowledge and awareness of what is needed 2) they have ideas about how this can be achieved 3) what they don't have is motivation to act. This suggests that engaging with the opinion of people with serious mental illness about their physical health as suggested by Connolly & Kelly (2005) is clearly necessary and achievable. Interventions such as those suggested in NICE (2014) guidance, for example healthy eating and physical activity programmes can be informed by implementing the findings of this study in the planning process in order to maximise potential for success.

It could be argued that the use of the vignette in the focus group could have influenced the findings; however this was a useful and successful way to elicit what the participants were thinking. It provided a tool for reflection and comparison and prompted discussion for people who were disabled by their mental illness.

Overall participants were aware of side effects of medication and the effect on physical health, but indicated a sense of helplessness, perhaps linked either to feeling unable to motivate themselves or to the conflict that can be experienced between doubts about continuing medication and the 'powerful message from supporters and professionals encouraging them to continue' (Roe et al. 2009: p42). This lack of a sense of control was indicated in the literature review, and this can adversely affect people given, as the Department of Health (2011) says, having control over your life is is associated with better mental and physical health. ~~Nevertheless, p~~There is potential for enhancing this in practice as personal responsibility for looking after their physical health was indicated and participants~~they~~ were open to intervention to enhance this. Provision of leaflets was acknowledged as a means to provide information in this study, however, access to healthcare

is a major challenge due to problems negotiating systems with healthcare information not received or inappropriate to the need (Radcliffe et al. 2011). This is of particular importance when, as indicated in this study motivation to act is a particular difficultly. There is no indication in this study about why people felt unmotivated but this could have various explanations: negative symptoms, sedating medication, institutionalisation or feeling isolated, though social anxiety and fatigue were indicated in previous studies (Haf Roberts et al 2013; Fraser et al 2015). It is indicated however that the motivating action had to be provided by nurses but with the awareness that personal choice remained important in health education and promotion. Smoking cessation for example, one of the concerns one participant identified, is one area nurses could ensure access, which would be congruent with NICE (2014) guidance which says it should be offered even where it has been unsuccessful previously. However, despite those with serious mental illness being more likely to smoke than the general population, there is no high quality evidence to guide cessation advice that healthcare professionals can pass onto service users (Khanna et al. 2016). NICE (2014) warns that there needs to be awareness of the potential significant impact of reducing cigarette smoking on the metabolism of antipsychotic drugs such as clozapine and olanzapine.

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Accessible advice however can only happen if nurses examine their own perceptions, be vigilant of any tendency toward overshadowing and suspend any disbelief in ensuring that health promotion is offered and encouraged. Good relationships need to be fostered as the findings indicate the role of good relationships in promoting motivation, where 'pestering' is tolerated. This is perhaps more likely when there is consistency in having the same nurse for appointments as Hardy et al. (2012) indicated. This is~~,~~ not an unreasonable goal ~~,~~for nurses working in any setting, whether primary care or specialist mental health services.

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The inpatient services users in this study demonstrated a good awareness of their physical health risks and needs. What they rely on others for however is intervention to motivate them

to act on their knowledge. Health promotion interventions need to be offered and proactively targeted at this client group with their specific needs in mind. Interventions need to be negotiated around the services users opinions, consistent delivery, expressed need and with a firm understanding that any assumptions must be put aside.

Key points

People with severe mental illness:

1 Have a broad awareness of their physical health risks
2 Show an awareness of personal responsibility for physical health
3 Have their own ideas about what could be done to change
4 Need nurses to be proactive to help compensate for their difficulties with motivation

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