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The experience of living with schizophrenia and psychosis in Scotland: Results of the Scottish Schizophrenia Survey

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Foreword from our Chair

Mental illness has a devastating impact on the lives of people affected by it. The ripple effect of it touching the lives of the family and friends of the person with the illness in a multitude of ways. For many people the help that they need is not there quick enough to avoid a crisis in their lives – one that could perhaps have been avoided had it been treated in the same way as other health conditions. And so we are often left with a mountain to climb in terms of accessing the right treatment at the right time with the resulting chaos affecting lives for months and sometimes years.

While some mental illnesses have become more acceptable in the public eye due to a variety of high profile celebs putting their heads above the parapet and speaking out….this is not the case with Schizophrenia. A recent survey in a national newspaper makes claims that coverage of schizophrenia on television, film and other mediums, the portrayal is of a negative nature with 80% of the emphasis on 'dangerousness'. More myths and misconceptions with the reality being somewhere around the 0.01% of people with schizophrenia – and who knows if even this number could have been prevented? The most likely scenario for someone with schizophrenia is that they will harm themselves in some ways. But why let the facts get in the way of a good story…

Public perception takes a long time to change and until those with schizophrenia are afforded the same access to equal healthcare and the media is persuaded to change their ways, we have a long way to go. So it is hoped that this report which although based on a small survey but mirrors the results of the English Report 'Abandoned Illness' will throw some weight to the concerns that those with schizophrenia and their families are facing.

Sadly unlike in England we were not able to secure the important funding needed to do a Scotland wide survey in any great depth. Had it not been for the small team of volunteers supported by Graham Morgan (Spirit Advocacy and HUG), Dr Paul Cavanagh (Royal College of Psychiatrists), Professor Stephen Lawrie (Scottish Mental Health Research Network). Professor Andrew Gumley (University of Glasgow), Dr Tom White, retired (The Scottish Government), Dr Paul Hutton (University of Edinburgh) and Amanda Larkin (University of Edinburgh) who gave their time freely we would not have had this valuable information and I would like to thank them all for their input.

It is time that policy makers, media and healthcare professionals tackled this devastating illness with the same vigour that we have seen put into the Wellbeing Agenda over the last few years – as they keep telling us – there is no health without mental health – and schizophrenia is at the very sharp end of that.

Carolyn Little.
Chair, Support in Mind Scotland

About Support in Mind Scotland

Our Aim is to improve the wellbeing and quality of life of people whose mental health issues or mental illness has a serious impact on their lives and the lives of others, including family members, carers and supporters.

Support in Mind Scotland has been an independent Scottish charity since 1984, when we were constituted as the National Schizophrenia Fellowship (Scotland).

Our expertise is in understanding serious illness like schizophrenia, and that is one of the main reasons we carried out this survey; but we also support people and their families who are coping with conditions such as:

• schizo-affective disorder
• bi-polar disorder
• personality disorder
• post-traumatic stress disorder

These conditions can all have a debilitating impact on people's lives.

Member-led
As an organisation one of our key values is that everything we say and everything we do is informed by the experience and expertise of our members and the people we support. Creating an evidence base for our work, and to ensure that we influence the decisions that affect the work of others is an important aspect of what we do. We engage with our membership and the people who use our services in a variety of ways – including carrying out surveys such as the Scottish Schizophrenia Survey.

Influencing Decision-makers
We have an important role in not only promoting the rights of the people we support, but also contributing to Government working groups, awareness raising, consultations and other partnerships.

 We produce reports on topics of relevance including:
• A major research study into the experiences of family members of people in forensic mental health services;
• A members' survey on the importance of maintaining physical health and wellbeing;
• A report with case studies on the experiences of people in distress who have been taking into custody as a place of safety and for whom this is not the appropriate place to be.

We convene both the National Mental Health Carers Forum and the Forensic Mental Health Carers Forum and sit on the Forensic Network Advisory Board.

We are members of the Advisory Groups for See Me, Scotland's anti-stigma campaign, and the Mental Welfare Commission, and we work closely with a range of professional bodies including the Royal College of Psychiatrists in Scotland, the NHS and the Scottish Government.

Delivering Services

Support in Mind Scotland is a service provider, providing services to both people with mental health issues and mental illness and family members, friends, carers and supporters.

Local - we deliver local services to around 2,000 people a year through 21 projects across Scotland. We employ just under 90 professional staff and 45 volunteers, and support people though:
- Accessible resource centres;
- Group work to develop skills, learning and improve employability;
- Physical health and wellbeing activity and healthy eating programmes;
- Emotional support, including one-to-one support, stress management, counselling and developing coping skills;
- Information and guidance on issues like benefits and housing support.

National - we also provide national services and run national projects. We deal with around 700 enquiries a year from members of the public, and we produce publications and information that aims to empower people by informing them of their rights and the services that can help them

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Why This Survey?

"When the press write about cancer they write with admiration or sympathy; when they write about schizophrenia, we're always chopping someone up with an axe"

This is one of the comments from a participant in the survey and this is one of the reasons that this piece of work is so important to us as an organisation. When we asked our members in 2013 what they valued most about being part of Support in Mind Scotland, they said overwhelmingly that it was about acceptance – being accepted and valued for who they are, and not being seen as a diagnosis or a condition that needs treated.

We also know that people with schizophrenia and psychosis find it difficult to find the right support at the right time. Families have told us over and over about the time wasted and the lives devastated by not being offered help early enough to make that critical difference. Early identification of a problem and possible illness with the appropriate intervention for that first episode – be that pharmaceutical or in the form of talking therapy – has been shown to be extremely effective in achieving much better long term outcomes for people.

An earlier review of Schizophrenia services in 2004 had produced recommendations that have never been followed up or implemented, and the need for a clear and supportive pathway for people diagnosed with schizophrenia has to be prioritised to end this lottery that is being played with people's lives where chance referrals or conversations are what makes the difference.

For far too many families, the crisis has to happen before help is provided and by then the police are involved, and the courts – and then a lifetime of restriction or compulsion with all that that brings. Not all crises could be avoided, but many could; and the outcomes for people could be greatly improved.

English Schizophrenia Commission 2012
The starting point for this initiative was the publication of the English Commission's report "The Abandoned Illness" as this was exactly the spotlight that we wanted to be shone on this illness and the impact it has on individuals and families. The findings of this report are echoed in this much smaller survey – and we hope that the 2 reports together give impetus to the need for improvements across the range of services and interventions that are needed to improve people's lives.

We convened a small Advisory Group in 2013 to help shape this work and ensure we addressed the appropriate range of issues. We also tested out some initial thoughts and approaches with 10 people with schizophrenia and carers – and we are extremely grateful to all of those individuals for helping with this work.

When we failed to identify significant funding to enable us to run a survey on the scale of the English work, we decided to that this was too important to abandon and so undertook the work ourselves with the support of The University of Edinburgh.

The University of Edinburgh
Support in Mind Scotland is delighted that the University of Edinburgh Department of Clinical Psychology supported the Scottish Schizophrenia Survey.

Dr Paul Hutton, Chancellor's Fellow in Clinical Psychology, University of Edinburgh, supervised Amanda Larkin, Trainee Clinical Psychologist, to work with us to gather the responses from our members and others across Scotland who have experience of schizophrenia and their families and have produced a report that will enable us to make strong recommendations for improving people's lives.

We are particularly pleased that the links with the English Study have been made to strengthen our report, and we are now looking to Scotland's decision-makers and policy-makers to read this report and work with us to bring about change.

Priorities for Action

This small study of Support in Mind Scotland members, shows results that follow the direction of other research and tells us that people in Scotland face the same issues and barriers to change as in the rest of the UK.

Priorities for action for Support in Mind Scotland arising from this report are:

• Continuing to work with See Me to highlight the stigma and discrimination experienced by people with schizophrenia/psychosis

• Highlighting the impact that mental illness has on physical health and the need to achieve much more joined up healthcare

• Raising awareness of the rights of carers and the need to and benefit of involving carers much more in the decisions that impact on their relatives and the wider family – within the appropriate confidentiality boundaries

• Developing more specific information and support services for carers of people with serious mental illness – generic carers support is not enough on its own

• Testing what recovery means for people with what in reality can be long term conditions and working with the SRN to achieve recovery outcomes for people

• Ensuring that protecting the rights of people affected by mental ill-health are paramount in decision-making at strategic and individual service level

In addition to the priorities arising specifically from this work, we are keen to address the missing 10 years in terms of policy development for people experiencing schizophrenia. A new strategic approach to mental health services will be developed in 2016 by the Scottish Government and this report, the findings of the English Commission and the growing body of evidence we will continue to gather from our membership must inform that strategy.

Frances Simpson
Chief Executive, Support in Mind Scotland

ADVISORY GROUP MEMBERS

This Advisory Group met 4 times in 2013 to help shape the ideas and the focus of the survey, and although the survey was designed by Support in Mind Scotland, it reflected the range of issues and priorities discussed within this group.

The members of this group were:

• Frances Simpson, CEO Support in Mind Scotland

• Carolyn Little, Chair Support in Mind Scotland

• Graham Morgan, Project Manager, Spirit Advocacy and HUG

• Dr Paul Cavanagh, Consultant Psychiatrist, Royal College of Psychiatrists

• Professor Stephen Lawrie, Network Director, Scottish Mental Health Research Network

• Professor Andrew Gumley, Professor of Psychological Therapy (Mental Health & Wellbeing), University of Glasgow

• Dr Tom White, Principal Medical Officer (Forensic Psychiatry), The Scottish Government

Introduction

Approximately 1-2% of the population of Scotland have a diagnosed psychotic disorder (Mental Health Strategy for Scotland 2012-2015). While these disorders are prevalent, it has been recognised that schizophrenia and psychosis are among the most stigmatised and publicly misunderstood mental health conditions. People endorse more statements about the perceived dangerousness of people with psychotic disorders than other mental health issues, and also indicate that they would keep greater social distance from people diagnosed with a psychotic disorder (Kasow & Weisrich, 2010). This stigma and misinformation surrounding these disorders has a recognised impact on the lives of people living with schizophrenia and psychosis.

There has been a growing recognition across research of the many areas of life affected by a diagnosis of psychosis or schizophrenia. Some of this effect is due to the nature of the symptoms. However, some aspects of a person's life are affected by the stigma of the diagnosis. People with schizophrenia are more likely to be unemployed, are more likely to smoke, have a poor diet, and take less exercise (von Hausswolff-Juhlin et al., 2008). Some research has found a role for the mediating effect of stigma, as perceived self-stigma has been shown to lead to lower self-efficacy and poorer coping (Kleim et al., 2008).

A large worldwide study by Salomon et al. in 2012 ranked schizophrenia as the condition associated with the most disability, out of 220 mental and physical health disorders or conditions. One of the main reasons behind this ranking is the well evidenced lower life expectancy for people diagnosed with schizophrenia compared to the general population. On average people with schizophrenia die 20 years earlier than the general population (Laursen et al., 2014). It has been proposed that this is due to under-diagnosis of physical health conditions in people with schizophrenia, as well as the impact of lifestyle (Laursen et al., 2014).

As summarised above, a diagnosis of schizophrenia affects many areas of a person's life. In line with this, supporting recovery from schizophrenia and psychosis should encompass a holistic approach from services. This direction is supported by government strategies such as the Mental Health Strategy for Scotland 2012 – 2015. This position has also been endorsed by the British Psychological Society in their recent publication Understanding Psychosis and Schizophrenia (2014). Recovery as defined by service users has been shown to be idiosyncratic, and to have less focus on symptom reduction. A recent study by Wood et al. (2013) found that the factors important to service users in defining recovery were collaborative support and understanding, emotional change through social and medical support, regaining functional and occupational goals, and recovery that was self-focused. The Scottish Recovery Network has emphasised the challenge of ensuring that opportunities and support for self-directed recovery are enhanced outside of statutory services (Bradstreet & McBrierty, 2012).

NICE (National Institute for Health and Care Excellence, 2014) and SIGN (Scottish Intercollegiate Guidelines Network, 2013) guidelines recommend that people suffering from schizophrenia be offered cognitive behavioural therapy (CBT) and family interventions. A National Audit of Schizophrenia carried out by the Royal College of Psychiatrists in England and Wales in 2014 found significant gaps in the provision of cognitive behavioural therapies and family interventions. Data provided by Health Trusts for this audit demonstrated that only 19% of service users with a diagnosis of schizophrenia had been offered and had taken up CBT. Service users themselves reported that only 18% of them had received CBT (Royal College of Psychiatrists, 2014).

The evidence summarised so far shows that a diagnosis of schizophrenia affects all aspects of a person's life. It has also been shown that meaningful recovery needs to take place across a number of these areas. For these reasons, it is important to have an understanding of the challenges and experiences faced by people with schizophrenia in their daily lives. The research evidence shows that stigma, physical health, experience of services and quality of life may be as important to recovery from psychosis as access to treatment and services. To improve the experience of people diagnosed with psychosis, we first need to understand the challenges and experiences that people with psychosis encounter in these domains. This information will become increasingly important if service design in the future is to take account of the importance of public attitudes and community based approaches, as advocated by the Scottish Recovery Network (Bradstreet & McBrierty, 2012), as well as Scottish government policies, including the current Mental Health Strategy for Scotland 2012 – 2015.

The Schizophrenia Commission published a report in 2012 called The Abandoned Illness, which highlighted the experiences and difficulties encountered by people living with psychosis and schizophrenia in England. This study was large in scale and was carried out over a number of years. The present study aimed to take a survey of people living with psychosis in Scotland using similar areas of enquiry to understand the experiences of Scottish people living with schizophrenia and psychosis, and to compare and contrast this with the report of The Schizophrenia Commission.

Aims:
This study aimed to explore the experience of people living with schizophrenia and psychosis and their family and carers in Scotland using a survey based method.

Research questions:
1. How many people living with schizophrenia and psychosis and their carers experience stigma and discrimination?

2. What services do people with schizophrenia and psychosis and their carers access?

3. What is the impact of schizophrenia and psychosis and caring for someone with schizophrenia and psychosis on physical health?

4. How do people living with psychosis and schizophrenia experience stigma, care, treatment and services, physical health and wellbeing, and quality of life and recovery?

Method

Ethics

Ethical approval was granted by the University of Edinburgh. The study used pre-existing data collected by a third party organisation (Support in Mind Scotland), and a self-evaluation carried out by the researcher and supervisor revealed no ethical issues.

Participants

A questionnaire survey containing open and closed questions was designed by Support in Mind Scotland. Two versions of the survey were constructed, one aimed at people with lived experience of schizophrenia and psychosis, and the other aimed at family and carers affected by schizophrenia and psychosis.

The survey was made available through a link on the website of Support in Mind Scotland, sent by email to a distribution list containing nationwide professional organisations including mostly carers' organisations and local authorities, and distributed by post and email to 219 current Support in Mind Scotland members and 175 lapsed members. The survey was available to be completed from October 2014 until January 2015. The sample was therefore a self-selecting convenience sample.

The survey received 138 total responses; 22 hard copies received by post or in person, 15 completed through the Facebook link, and 101 completed on SurveyMonkey through the website link.

Of these 138 responses 87 (70%) were completed by a participant who identified as a "family member, friend, carer or supporter" and 37 (30%) identified as a person with lived experience of schizophrenia or psychosis. 14 participants did not answer this question.

Analysis

Descriptive statistics were calculated using Statistical Package for the Social Sciences Version 22. The quantitative analysis was carried out prior to the qualitative analysis.

Qualitative data from open ended questions was collected from the 37 participants who had identified as having lived experience of schizophrenia and psychosis. Of these 37, between 8 and 25 participants had completed each open ended question. This data was extracted and grouped under the 4 headings; Stigma; Care, Treatment, and Services; Physical Health and Wellbeing; and Quality of Life and Recovery.

The data was thematically analysed under each heading. The data was read and re-read by the researcher. Initial codes were attached to the data. The data extracts were then grouped together under each code. Codes were integrated into themes. The entire data was set was re-read to see if the themes fit the qualitative data. Following this re-reading the themes were organised under major themes and subthemes to fit the patterns that the researcher had drawn across the data. These themes have been used in the results section to illustrate and elaborate on some of the quantitative findings of the survey.

Results

Demographic Information

The sample of participants was 69% female (89), and 31% male (40), with 9 participants not answering this question. Table 1 provides a summary of the age range of participants. 64 participants were in employment (49%), 62 reported that they were not in employment (47%) and 5 participants were in sessional employment (4%). 7 participants did not report their employment status. The majority of participants identified as White and British / Scottish (n = 128, 87.7%), 10 participants (7.2%) declined to record their ethnicity. The rest of the participants identified as Australian (n=2), Mixed White/Asian (n=1), Italian (n=1), Irish (n=1), Spanish (n=1), and Chinese (n=1).

Age range	%	N
Under 18	0.0%	0
18 to 25	3.1%	4
26 to 35	16.2%	21
36 to 45	22.3%	29
46 to 55	24.6%	32
56 to 65	17.7%	23
66 to 75	13.1%	17
Over 75	3.1%	4

Table 1. Age breakdown of participants.

Stigma

51% (39) of carers and family members thought that having a diagnosis of schizophrenia was helpful, 13% (10) thought that the diagnosis was not helpful, and 36% (27) thought that it depended on the circumstances. 11 carers and family members did not answer this question. The participants with lived experience of schizophrenia and psychosis answered similarly, 44% (14) responded that having a diagnosis of schizophrenia was helpful, 19% (6) thought that having a diagnosis was not helpful, and 36% (12) thought that it depended on the circumstances. 5 people with lived experience did not answer this question.
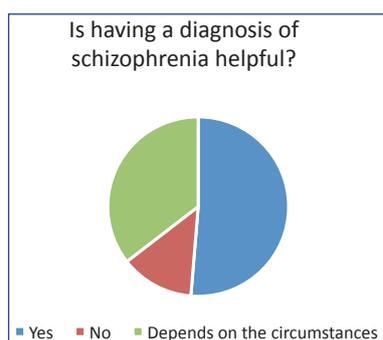
Figure 1. Responses of carers.   Figure 2. Responses of participants with lived experience.
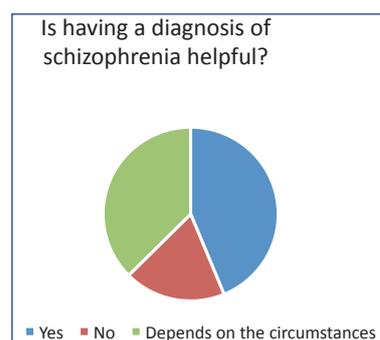
An equal percentage of carers and people with lived experience thought that the word "schizophrenia" should be dropped and another word found for their and their loved ones' experiences, with 50% (carer group N = 38, lived experience group N = 15) of both groups agreeing with this. 29% (N=22) of carers thought that the word "schizophrenia" should not be dropped and 21% (N=16) responded that they didn't know. 11 participants in the carer group did not answer this question. 37% (N=11) of the lived experience group thought that the word should not be dropped and 13% (N=4) responded that they didn't know. 7 participants in the lived experience group did not answer this question.

Do you think the word 'schizophrenia' should be dropped and another term found for the symptoms that the person you support experiences?

Yes ■ No ■ Don't know

Figure 3. Carers group

Do you think that the word 'schizophrenia' should be dropped and another term found for the symptoms that you experience?

Yes ■ No ■ Don't know
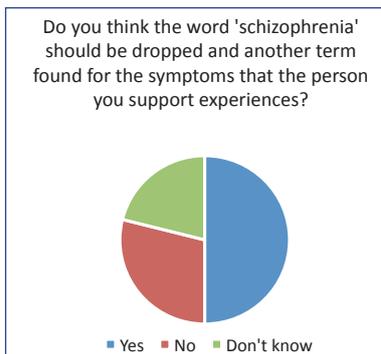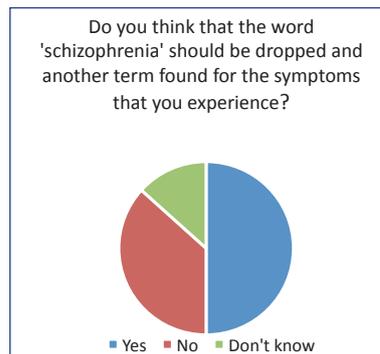
Figure 4. Lived experience group

77% (23) of the participants with lived experience reported that they had experienced stigma or discrimination from others, while 66% (50) of carers and supporters had experienced stigma. 17% (5) of the lived experience group reported that they had never experienced stigma or discrimination, while 7% were unsure (2). 7 participants in the lived experience group did not answer this question. 26% (20) of carers and supporters had not experienced stigma, while 8% were unsure (6). 11 participants in the carer group did not answer this question.


We know that the way that others react to schizophrenia can be difficult to deal with. Have you experienced stigma or discrimination from any source - the public, people you have met, friends, family?

Yes ■ No ■ Don't know

Figure 5. Carers group

We know that the way that others react to schizophrenia can be difficult to deal with. Have you experienced stigma or discrimination from any source - the public, people you have met, friends, family?

Yes ■ No ■ Don't know
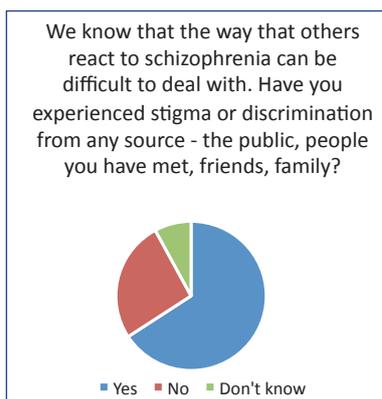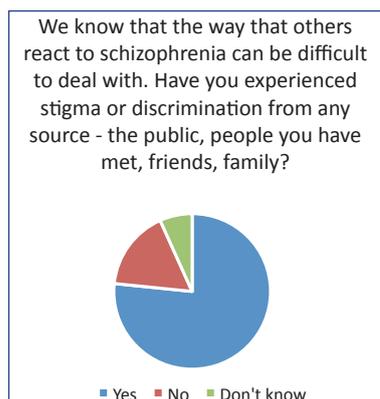
Figure 6. Lived experience group

Two main themes were constructed from the experiences of stigma reported by the participants in the lived experience group. One theme was Identity – with two subthemes; Finding Information and Others who Understand, and We're Just People, It's Not the Whole Me. This theme appeared to reflect the mixed feelings that participants had towards the label of schizophrenia. Sometimes participants thought it was helpful in understanding their experiences and helping to separate their illness experiences from their idea of their self

"For years I had problems that I could not seem to get to the bottom of. Then when I was diagnosed it all became clear."

"With a diagnosis I have access to information and support services and can understand my experiences."

However, while it appears that at times the label of schizophrenia gives people a framework to understand their experience, participants also reflected a frustration at times when their identity is reduced to the label and the attributions and prejudices that others attach to the label of schizophrenia. These themes help to illustrate the differing opinions of those who think the label is helpful and those who do not.

"Some of "us" are able to work, raise a family and be actively involved in our community. Many people think the illness is due to some personality defect rather than the biological, psychological and social issues that can cause the medical condition."

"(Want) people to still see you for who you are and not the schizo person."

Another theme that was constructed was Misunderstanding and Misinformation. This theme was divided into subthemes; Perceived Dangerousness and Hiding, Concealment, and Vigilance. Participants appeared to be aware that others have prejudices based on the label that lead them to hide their experiences, and to be wary of how others may respond.

"When the press write about cancer they write with admiration or sympathy when they write about schizophrenia, we're always chopping someone up with an axe."

"When I reveal my illness although some understand others still immediately have the impression of me as the serial axe murderer that is often portrayed in the media."

This awareness of the public perception leads some participants to feel they have to hide their diagnosis, and be careful about who they reveal this information to. This may be related to the high proportion of the sample that had experienced stigma and discrimination using hiding and concealment to protect themselves from these experiences.

"I have to gauge people and calculate how they will react before telling them. Workplace reactions to mental health problems are bad enough without mentioning schizophrenia at times."

"You hopefully learn to read faces but this can be difficult so I guise my feelings and tend to avoid talking."

Care, treatment and services
87% (N=26) of the lived experience group reported that they accessed services from statutory or voluntary service providers, while 88% (N=60) of the carers reported that their relative or loved one accessed services. 10% (N=3) of the lived experience group reported that they did not access any care, treatment or services, and 12% (N=8) of the carers and supporters reported that their relative or loved one did not access any services. 3% of the lived experience group (N=1) reported being unsure about whether they access services or not. 7 participants in the lived experience group did not answer this question, and 19 participants in the carer group did not answer this question. Please see Table 2 below for services that were reported as being accessed. Participants rated the average positive difference that these services made as 7 out of 10.

Services	Carer / Supporter report Percentage (N)	Lived experience group Percentage (N)
Medication	90.6% (58)	96.2% (25)
CBT	9.4% (6)	23.1% (6)
Other talking therapies	9.4% (6)	26.9% (7)
Resource centre / day service	20.3% (13)	19.2% (5)
Help to access community facilities	14.1% (9)	7.7% (2)
Community Mental Health Teams / CPN	71.9% (46)	65.4% (17)
Advocacy	21.9% (14)	19.2% (5)
Employability or skills support	12.5% (8)	7.7% (2)
Art, music, walking or social support groups	20.3% (13)	26.9% (7)
Housing and / or benefits	56.3% (36)	61.5% (16)
Inpatient / hospital care	25% (16)	19.2% (5)
Other	10.9% (7)	23.1% (6)

Table 2. Services accessed by carers, family and supporters.

29% (N=19) of carers and supporters reported that the services were provided under a Compulsory Treatment Order (CTO), while only 3% of the lived experience group (N=1) reported that any of the services were provided under a CTO.

Only 17% of carers and supporters (N=12) felt that professionals involved them enough in helping to make decisions with the person they support about their care and treatment.
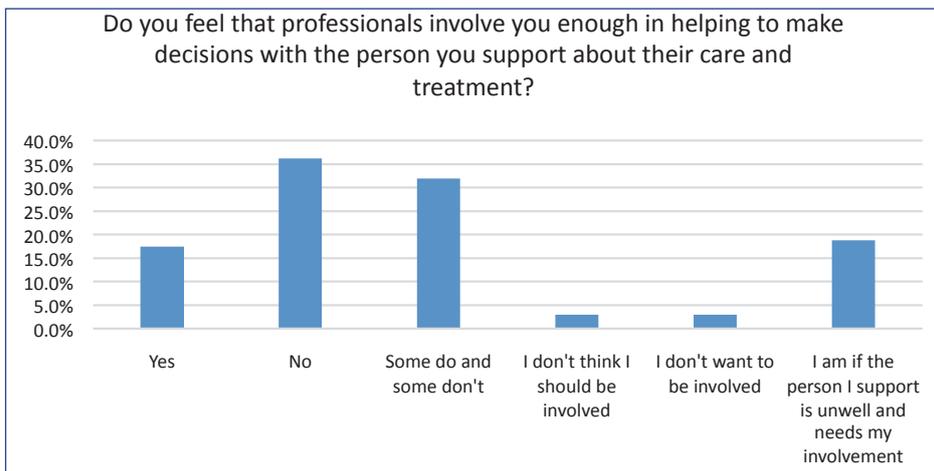

Figure 7. Involvement in decisions about care and treatment.

51% (34) of carers and supporters reported that they did not access any support services for themselves, while 24% accessed services currently (N=16), and 16% (N=11) had in the past. 20 participants in the carer group did not answer this question. Overall, carers and supporters reported that these services made a moderate degree of impact on their quality of life (5 / 10).

Services accessed by carers	%	N
Generic carers support group for emotional support	29.2%	14
Specific mental health carers support group for emotion support	56.3%	27
Groups for arts, music, skills, interests	8.3%	4
Groups for social contact	18.8%	9
One to one support from statutory services	16.7%	8
One to one support from voluntary sector services	22.9%	11
CBT	8.3%	4
Other talking therapy	8.3%	4
Advocacy	10.4%	5
Information - helpline or use of info sheets/packs/websites	39.6%	19
Other	25.0%	12

Table 3. Services accessed by carers and supporters.

The qualitative responses of the participants with lived experience under the heading of Care, Treatment, and Services were contained within two themes Whole Life, Not Just One Aspect, and Effort and Time.

Under Whole Life, Not Just One Aspect an understanding of participants' experiences was captured under two subthemes; Distinctions between Physical and Mental Health, and Benefits and Other Life Stresses. Many participants expressed that services were often unable to cater for their physical and mental health simultaneously. Physical health difficulties were reported as barriers to engaging with some services. These barriers may help to explain the low percentages of people accessing day services and resource centres.

"I am unable to access many day services. Mobility problems with my chair – not accessible – mental health / physical health."

"Because I now suffer – toxic meds on central nervous system, staff had no experience to support me. Physical challenges ignored by mental health staff – no knowledge lacking in empathy."

Participants also expressed that other areas of their life impacted on their wellbeing. This may help to illustrate the breadth of services that people with experience of psychosis require to feel fully supported.

"Having enough money to live on is a big priority because financial insecurity can really rock the ship."

"Sometimes I feel that a wider sense of being a person is obscured by a superficiality from case notes that are medical."

Under the theme Effort and Time, participants appeared to express that services under pressure often don't have the resources available to fully understand their experience.

"There isn't always time for professionals to get into the nub of what can affect my wellbeing. I just don't always have that insight myself."

"Not having a chance to sometimes get down to the nitty gritty of my worries can be very frustrating. In the time available, it may not be possible. I can sidetrack. I also may have a bad or good day and I suppose that can influence others."

Participants also expressed that recovery and using services can require a great deal of effort from those accessing them. Participants gave an average 7 out of 10 rating for the positive difference that accessing services had had on their lives. This theme may highlight that making changes with the support of services may be difficult, but ultimately beneficial.

"I can't access employment because I've been off sick too long and have no references – it's not through lack of trying."

Health and Wellbeing

Carers and supporters rated their physical health as an average of 6.6 out of 10. Those with lived experience rated their overall physical health as a lower 5.6 out of 10. 46% (N=13) of those with lived experience thought that living with schizophrenia and psychosis had had a significant impact on their physical health, while a further 46% (N=13) thought it had had some impact. Only 7% of those with lived experience (N=2) thought that living with schizophrenia had had no impact on their physical health. 9 participants in the lived experience group did not answer this question.
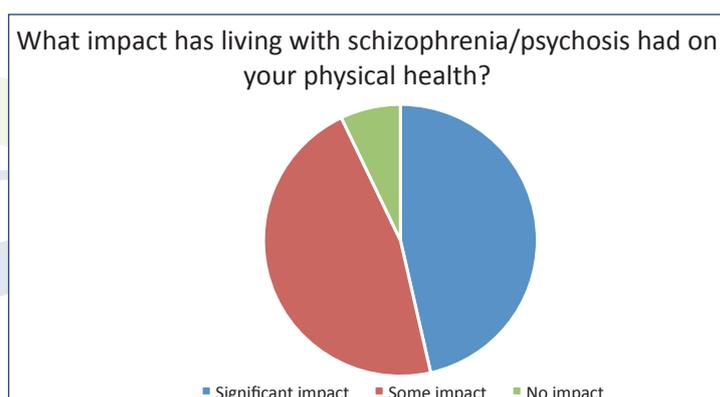

Figure 8. Impact on physical health of lived experience group.

31% (N=20) of the carer group thought that caring for someone with schizophrenia and psychosis had had no impact on their physical health. 26% (N=17) reported a significant impact, with the majority 43% (N=28) reporting that caring had had some impact on their physical health. 22 participants in the carer group did not answer this question.
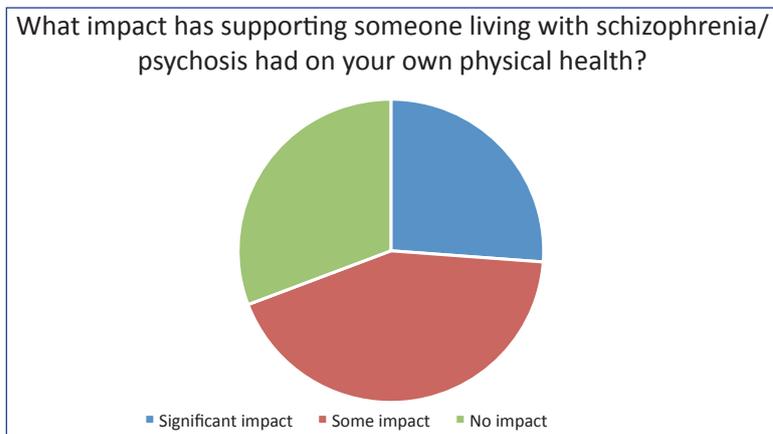

Figure 9. Impact on physical health of carer and supporter group.

The qualitative data from the lived experience group helped to illustrate this impact on physical health. Participants' responses were grouped around two themes Impact of Medications, and Balance between Physical and Mental Health.

Many participants expressed a belief that medications prescribed to them for schizophrenia and psychosis had a detrimental impact on their physical health.

"I have many physical health problems. Many are due to the medication I take for my schizophrenia."

"The medication for schizophrenia (antipsychotics) helped to destroy my physical health with its side effects."

The qualitative responses in this section also appeared to reflect a view that people living with schizophrenia and psychosis have to balance their physical and mental health. This could be broken into two subthemes – Prioritising (either physical or mental health) and Continuum (physical and mental health inextricably linked).

Participants who discussed prioritising aspects of their wellbeing spoke about having to make choices. Often lifestyle changes that may help with physical wellbeing were expressed in terms of the possible cost to mental wellbeing.

"My mental health comes first. I have to keep on top of that."

"Being off medication would balance my appetite, but I won't do that until I'm told."

In contrast, other participants also spoke about how their mental health impacted on their physical health and vice versa. These participants seemed to recognise their health as being on a continuum, so less prioritising was evident.

"When feeling apathetic I eat more so-called convenience/junk foods which are detrimental to my physical health. I do try to cook from scratch so I know what's in my food but regularly I falter – I put it down to my illness."

"Taking part in sport and going to the gym makes a difference to my mental health."

These themes help to illustrate possible processes through which a diagnosed mental health condition such as schizophrenia can affect physical health and wellbeing, which 94% of the participants reported as having an impact on their physical health.

Quality of Life and Recovery

Responses in this area were grouped under two main themes: Others Accepting and Understanding and Managing not Curing.

The importance of social support was highlighted by the responses of many of the participants with lived experience of psychosis, with many expressing their gratitude at having supportive family and friends. 25 participants in total mentioned family and friends when discussing their quality of life. Social support was expressed as something to be thankful for rather than to be expected.

"Friends certainly. There is an element of compartmentalisation. I do value what friends I have. Good friends – not many just a few."

"I am lucky my family have stuck by me all of the time and some other people."

Under the theme of Managing not Curing, three subthemes contributed: Self-Awareness, Routine and Structure, and Ups and Downs to be Expected. This theme reflected participants' experiences of recovery being hard work at times. Within this theme, participants reflected the personal knowledge required for recovery.

"I think recovery is a journey – you will always be aware that you had an illness, and be aware of your triggers. I think mental illness can make you more compassionate and understanding towards others."

"I work full time so I am always tired, but having a routine keeps me focussed."

"Recovery does not go in a straight line and there are downs as well as ups. For some people recovery is limited because their illness is a constantly disabling reality. I hate the crap about everybody supposedly having hope and the right to a positive experience of recovery. It's just not feasible for some people and setting up this overwhelmingly positive view of recovery risks stigmatising those who cannot "measure up".

Discussion

The results of the 2014 Scottish Schizophrenia Survey provide a snapshot of the experience of people living with schizophrenia and psychosis and their carers in Scotland. The majority (77%) of participants who were diagnosed with psychotic disorder reported having faced stigma and discrimination at some point. These results echo the recent findings of the Schizophrenia Commission in England (2012), where 87% of people with psychosis and schizophrenia reported experiencing high levels of stigma and discrimination.

The themes constructed from the open ended survey responses pointed to the role of public misunderstanding, in particular the perception that people living with schizophrenia and psychosis are dangerous and violent. This may be indicative of the way that mental illness, in particular psychotic disorders, are reported and represented in the media. A study by Cain and colleagues found that violence featured in 47.3% of news stories that referenced schizophrenia. 46% of these stories were judged to be stigmatising (Cain et al., 2014). Several mental health strategies from charities and from statutory services have aimed to reduce the stigma and discrimination associated with mental ill health. While it is clear that these endeavours are necessary, it is unclear how effective they have been in reducing the stigma experienced by people living with psychosis and schizophrenia. The Schizophrenia Commission report recommended continued investment in anti-discrimination programmes.

87% of the lived experience group reported that they currently access services, and a similar 88% of the carers and supporters reported that their loved one accessed services. It is positive to note that those people accessing services rated the positive difference these services made to their lives as 7 out of 10. However, although 90% of the lived experience group reported access to medication, only 23% said they had accessed cognitive-behavioural therapy (CBT). Only 9% of the carers and supporters reported that the person they supported accessed CBT. Although NICE guidance (National Institute for Health and Care Excellence, 2009; 2014) has, since 2009, recommended that CBT should be offered to all people with psychosis or schizophrenia, these results suggest that approximately three quarters of the sample do not currently access CBT. SIGN guidance recommends that CBT for psychosis should be offered to all individuals diagnosed with schizophrenia whose symptoms have not adequately responded to anti-psychotic medications (Scottish Intercollegiate Guidelines Network, 2013). The Schizophrenia Commission report (2012) cited evidence that up to 22% of people offered CBT refused it during a trial conducted in Manchester. However, this figure still would not account for the low percentage of the sample who reported that they had access to CBT. In addition to clinical guidelines, the survey conducted by the Schizophrenia Commission found that CBT was the most valued service alongside medication (43% of participants ranked it as most valuable). These results combined suggest that although CBT is effective and is valued by service users, not enough people with schizophrenia and psychosis have access to this therapy.

In contrast to the participants with lived experience of schizophrenia and psychosis, only 51% of carers and supporters reporting accessing services for themselves despite 70% reporting that supporting someone with psychosis and schizophrenia had an impact on their physical and mental wellbeing. Previous research has shown that carers of people living with schizophrenia and psychosis were nearly ten times more likely to be socially isolated than matched controls, with this having the expected impact on the carers' own mental health and quality of life

(Hayes et al., 2015). The theme of the importance of social support was evident throughout the responses of the people living with schizophrenia and psychosis. It appears that despite carers and loved ones being important to a person's recovery, carers may not always have the support they require to provide care and social support to the person with schizophrenia and psychosis.

Previous research has shown that being diagnosed with schizophrenia and psychosis affects a person's physical health and life expectancy (Laursen et al., 2014). The responses of the participants in this survey showed that people living with schizophrenia and psychosis attribute a significant impact on their physical health to the mental illness. Many participants ascribed changes in their physical health since diagnosis to the impact of medications. In collecting evidence the Schizophrenia Commission (2012) reported that they "repeatedly heard the concerns people had about the medications they had been prescribed and the negative effects this had on their physical health" (p. 38). However, the qualitative results of the current study found that an understanding of the complex interplay of mental and physical health was also evident in the responses given by the lived experience group. These experiences should be taken into account when designing services, and ensuring that people living with psychosis receive the best possible physical health care. People living with psychosis may benefit from access more integrated services where physical and mental health needs can be addressed through a multidisciplinary service. For example, the Schizophrenia Commission recommended that greater emphasis be placed on physical health in severe mental illness in the training of all doctors, nurses and mental health practitioner (2012).

The qualitative responses of participants showed the importance of social support and integrated physical and mental health care on people's experienced quality of life and recovery. Previous research has shown that a diagnosis of schizophrenia impacts on several areas of a person's life (von Hausswolff-Juhlin et al., 2008; Salomon et al., 2012). These results highlight that effective services should be able to offer holistic interventions for physical health, social, and employment problems that may affect a person's mental health and vice versa. This is in line with the recommendations set out in The Abandoned Illness (2012) that primary and secondary care services should be co-ordinated and operate in a co-operative manner to ensure that service users' physical and mental health needs are addressed.

Overall, this report has shown that people living with psychosis and schizophrenia in Scotland have reported similar experiences and priorities as those who participated in the Schizophrenia Commission's review of services in England. The importance of integrated multidisciplinary care, and social support was evident throughout participants' responses. The majority of people living with psychosis who responded to this survey are accessing services, but these services may be limited to medication with fewer reporting accessing services such as talking therapies and advocacy. Future research should focus on replicating these results with a larger, more representative sample that may be more generalisable to the population of people living with schizophrenia and psychosis in Scotland.

Limitations of the study

The small and self-selecting sample of participants who had experience of schizophrenia and psychosis suggests caution in generalising the results to the experience of all people living with schizophrenia and psychosis in Scotland. All participants in the lived experience group

self-identified as having a diagnosis of schizophrenia or psychosis, which suggests they may have had higher levels of insight than would be expected in the whole population of people diagnosed with schizophrenia and psychosis. Previous research reported rates of lack of insight between 30% and 80% (Lincoln et al., 2007; Mintz et al., 2003) in samples of people diagnosed with psychosis and schizophrenia. The researchers were also unable to verify the diagnoses given by participants due to the anonymous nature of the survey design.

The participants in this study predominantly identified as White and British. While this may be reflective of the demographic composition of Scotland [96% White as per 2011 census (National Records of Scotland, 2013)] it should be noted that this sample may not reflect the average or typical experience of people from minority groups who are diagnosed with psychosis and schizophrenia. The study conducted by the Schizophrenia Commission (2012) included a focus on minority ethnic groups and meeting the needs of the most marginalised service users. This study did not access the population required to address those areas, which is a limitation that may need to be considered when designing future research.

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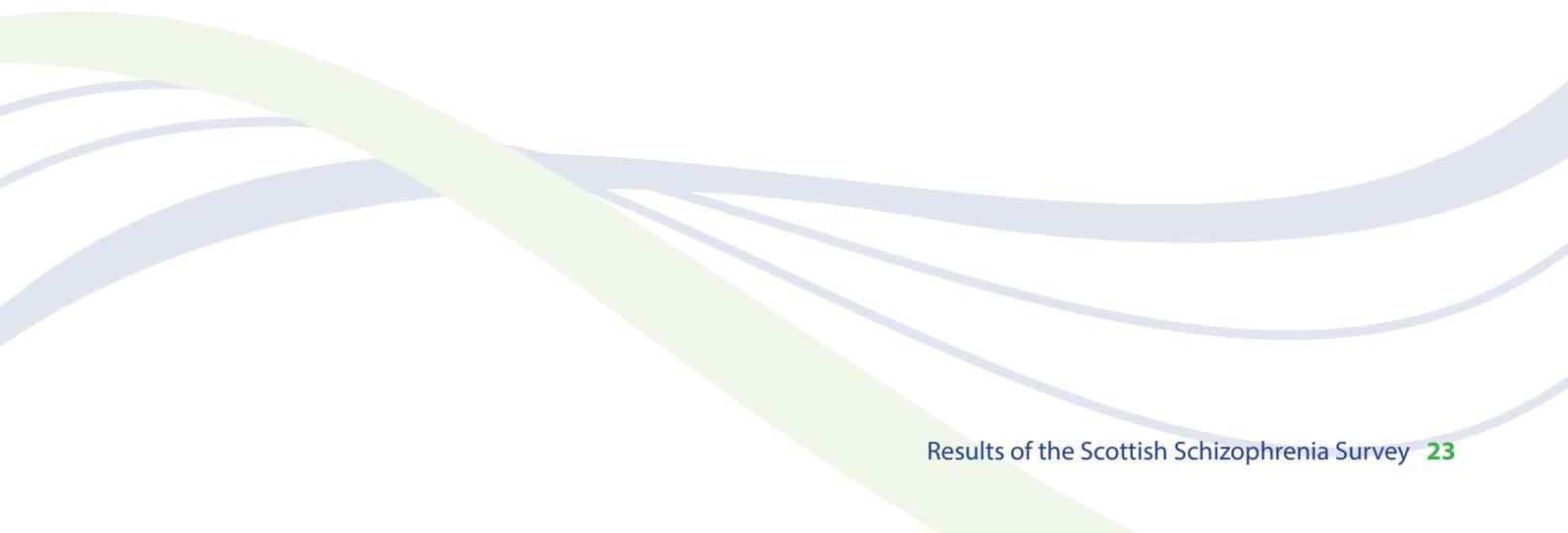
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