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"The biggest barrier is to inclusion itself": the experience of citizenship for adults with mental health problems.
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Abstract

Background: Citizenship has been promoted within mental health for several decades however, its application in the field of mental health policy and practice is relatively novel. The voices of people who experience mental health problems (MHPs) are often absent in ongoing discourses about citizenship.

Aims: To explore how adults with experience of MHPs and other life disruptions identify potential barriers to citizenship.

Method: A community based participatory research approach was adopted with peer researchers. Six focus groups (N = 40) using semi-structured interviews were conducted, consisting of participants who had experience of MHPS and other life disruption(s) within the last 5 years. The focus groups were audio recorded, transcribed verbatim and analysed in NVIVO using a thematic approach.

Results: Three major themes associated with participants lived experiences of barriers to citizenship were identified: 'stigmatisation (internal & external) creates further divide'; 'being socially excluded leads to isolation'; and 'a sense of difference (as perceived by the self and others)'.

Conclusions: Those who have experienced major life disruption(s) face multi-level barriers to citizenship. An awareness of such barriers has important implications for mental health research, policy and practice. Citizenship-oriented implementation strategies that aim to address multi-level barriers merit further investigation.

Keywords: Mental health, Community Based Participatory Research, Peer researchers, Citizenship, Barriers, Stigma

Introduction

Citizenship has been promoted within mental health for several decades (Anonymous & Davidson, 2016), however, its application in the field of mental health policy and practice is relatively novel and under-explored (Morgan et al, 2020; Anonymous et al, 2019). Inclusion of the voices of people who experience mental health problems (MHPs) are often absent in ongoing discourses about citizenship (Vervliet et al, 2019). Traditionally, citizenship is understood as ‘membership’ within a particular nation or state (Janoski, 1998) or in terms of ‘rights’ and ‘obligations’ within a political or legal context (Lister, 2003). Marshall (1950) introduced the notion of social rights, whereby providing individuals with the resources they need to claim their civil and political rights, can lead to greater equality with individuals developing a shared sense of identity that can cut across class divisions (Lawy & Biesta, 2006). Social rights have been understood as basic human rights such as the right to shelter, the right to a job with decent working conditions and the right to subsistence (Hunt, 2017).

Anonymous et al (2017) emphasised the role that the community has to play in extending informed and non-discriminatory attitudes towards people who experience MHPs to promote their citizenship rights and inclusion. Citizenship can, therefore, be viewed as a construct that requires an intricate balance between individual rights and community interests with an acknowledgement of the resources required to support full participation (Anonymous et al, 2019; Ponce & Anonymous, 2018). Multi-disciplinary mental health services, have limited capacity to facilitate people’s transition from a position of marginalisation to full community participation (Anonymous & Davidson, 2016). Despite anti-stigma campaigns that aim to address the stigma and discrimination that people experiencing MHPs often face (Corrigan, 2018), they continue to experience

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4 barriers towards being fully included and participating as citizens (Hamer et al, 2019).
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6 The relationships that people have with their communities are instrumental to gaining a
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8 sense of belonging and having the status of ‘first-class’ citizen (Anonymous &
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10 Anonymous, 2019; Anonymous et al, 2019; Anonymous et al, 2001).
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14 Anonymous et al (2015) proposed a theoretical framework for understanding
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16 citizenship, drawing on the needs of people experiencing MHPs (Ponce et al, 2016).
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18 This is based on the 5 R’s of citizenship: rights, responsibilities, roles, resources, and
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20 relationships (Anonymous et al, 2015), with individual’s connectedness to the 5 R’s
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22 determining the extent to which they experience a sense of belonging (Anonymous et al,
23
24 2017). Anonymous and colleagues tested this through the implementation of
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26 citizenship-oriented interventions involving peer support (Bromage et al, 2017; Clayton
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28 et al, 2013; Pelletier et al, 2017; Anonymous et al, 2009; Anonymous & Pelletier,
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30 2012). Outcomes indicate that people's lived experiences of regaining a sense of
31
32 citizenship and of belonging to their local neighbourhoods and communities can help to
33
34 foster a sense of inclusion. Further research is needed to ascertain if such interventions
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36 can have an enduring impact (Pelletier et al, 2017). Given that this work has largely
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38 been conducted with the United States, there is a need for research incorporating the
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40 perspectives of people with MHPs who have experienced life disruptions, across a range
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42 of socio-cultural contexts (Eiroa-Orosa & Anonymous, 2017).
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50 **The current study**

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53 The current study is part of a larger multi-method, community based participatory study
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55 which sets out to develop a framework of citizenship within the Scottish context (see
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57 Anonymous et al, 2019). Here we report on an in-depth qualitative analysis of focus
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59 groups with participants with MHPs who had experienced major ‘life disruptions’. This
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4 is a useful way to explore how people who use mental health services can be considered
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6 as having experienced a period of off-centredness that may have taken them 'off course'
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8 for a lengthy period (Anonymous et al, 2019; Stanton & Revenson, 2006). We also
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10 recognise that there can often be strong co-morbidity with other major life disruptions
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12 such as chronic physical illness, addiction or other adverse circumstances (e.g.
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14 homelessness, incarceration) that lead to time spent away from mainstream society
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16 (Ponce & Anonymous, 2018; Anonymous et al, 2012)
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21 Consequently, such life disruptions often mean that people struggle to meet
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23 culturally and socially defined milestones and roles (Anonymous et al, 2019).
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25 Therefore, the current study sought to understand the ways in which people with MHPs
26
27 and other life disruptions, experience citizenship and how this may be shaped by their
28
29 unique personal circumstances. If citizenship has the potential to encourage inclusion
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31 (Hamer et al, 2019), it would, therefore, be plausible to assume that citizenship may be
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33 experienced differently by marginalised groups who have experienced exclusion (Ponce
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35 & Anonymous, 2018). Citizenship as a framework for inclusion has been largely
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37 researched in the United States (Anonymous & Pelletier, 2012). The current study is the
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39 first study, to date, to explore how people with MHPs and other life disruptions
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41 experience citizenship within the Scottish context.
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47 The current study was conducted during a period of significant political and
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49 social uncertainty; Scotland had recently gone through a referendum for independence
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51 and Brexit was imminent (Jarmin et al, 2020). Despite such uncertainty, Scotland can
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53 be considered as having a progressive policy environment particularly receptive to ideas
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55 of citizenship and inclusion for individuals and communities experiencing
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57 marginalisation (Anonymous et al, 2019). It has its own unique political landscape
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4 where public spending per head of population is greater than in England and Wales
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6 (O'Hagan et al, 2019; Wallace, 2019). There has been a strong shift towards health and
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8 social care integration to promote joint working and a holistic approach to care and
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10 service provision (Pearson & Watson, 2018). Yet, similar to many other Western
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12 countries, mental health systems in Scotland often take an highly individualised and
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14 medicalised approach that does not necessarily take account of the broader social,
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16 economic and cultural factors that impact on people's lived experiences of MHPs
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18 (Anonymous & Anonymous, 2019). Given that the voices of people that have used
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20 services are often absent from discourses on citizenship, the current study sought to
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22 explore, as a starting point, people's understandings of citizenship through asking "what
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24 does citizenship mean to you?". While understandings of citizenship were the starting
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26 point for the study, the aim was to identify potential barriers to citizenship by drawing
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28 on participants' personal accounts and experiences.
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36 **Method**

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38 A community based participatory research (CBPR) approach was adopted
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40 whereby participants had control over the research agenda, its process and actions
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42 (Anonymous et al, 2019). Peer researchers were involved in all stages of the research
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44 process including collecting and analysing data and reflecting on this to develop
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46 findings and draw conclusions from the research. This approach placed people with
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48 MHPs and life disruptions, at the forefront of the research process. Evidence suggests
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50 that peer or service user involvement in the co-production of knowledge makes the
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52 research process more sensitive to the needs of participants (Beresford, 2007, 2019;
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54 Carey, 2011; Damon et al, 2017; Smith et al, 2008; Anonymous et al, 2017).
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Participants

Purposive sampling was used whereby participants were eligible if they self-identified as having MHPs and to have experienced major life disruption(s) in the last 5 years (n=40). Participants were people with experience of receiving mental health services and/or addictions services, having chronic physical health conditions, having criminal justice charges, or having more than one of these life disruptions. Participant demographic information is detailed in table 1.

TABLE 1 HERE

Recruitment

Ethical approval was granted by the University Ethics Committee. Participants were recruited during the period of 2016 to 2018 via third sector health and social care organisations. Organisations were provided with inclusion/exclusion criteria and asked to provide potential participants with information about the study so they could decide whether or not they wished to take part. They were provided with a copy of an information leaflet about the study with a covering letter inviting them to take part. This was followed by a phone call approximately a week later asking if they were interested in participating in the study. Informed consent was sought from all of the participants. They were informed that they were free to withdraw from the study at any time and issues regarding confidentiality and the protection of their anonymity were discussed.

Procedure

All data was collected in the West of Scotland, in the premises of the organisations involved in recruitment or the University. Focus groups were used as we asserted that the interactive nature of focus groups would allow for the generation of discussion that might not have occurred from individual interviews (Namey et al, 2016).

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4 In determining the number of focus groups necessary in order to reach data saturation,
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6 we drew upon recent empirical work reporting that the majority of themes are identified
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8 within the first focus group, with nearly all themes being discoverable within the first
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10 three focus groups (Guest, Namey & McKenna, 2017). We recognised that the degree
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12 of heterogeneity within a focus group, the complexity of a topic, or the size of a focus
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14 group affect the saturation rate and the nature of the data generated, therefore opted to
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16 conduct six focus groups (Krueger & Casey, 2000) and recruited 40 participants (6-8
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18 participants per focus group). The focus groups were facilitated by the peer
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20 researchers with the experienced qualitative researcher providing support where
21
22 needed. We sought to establish a safe, open, and respectful environment where all
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24 participants felt comfortable sharing their experiences.
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30 Before each focus group, time was spent going through the participant
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32 information sheets and participants were given the opportunity to ask the researchers
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34 questions. Participants were also asked to sign a consent form and were reminded that
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36 they could withdraw consent or leave at any time during the data collection process. For
37
38 the purpose of this study, peer researchers were individuals with lived experience of
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40 MHPs and other major life disruptions (Anonymous et al, 2018). The duration of the
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42 focus groups was approximately 75 minutes ($M= 75.7$, $SD= 14.9$). Following
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44 engagement in the focus groups, participants were debriefed and thanked for their
45
46 participation. The audio recordings were later transcribed in full verbatim. The
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48 qualitative data stemming from the transcripts was managed with the software
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50 programme NVIVO (Richards, 1999), which facilitates the storage, analysis and
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52 retrieval of textual information.
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Analysis

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6 Thematic analysis (Braun & Clarke, 2006; 2018) was chosen as an appropriate
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8 method of data analysis. The first stage involved familiarisation with the data which
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10 was achieved by reading and re-reading each transcript. Next, meaningful aspects of the
11
12 data were identified and named in order to produce initial codes. These codes
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14 represented something important about participants' perceptions and experiences of
15
16 barriers to citizenship. Data was then organised into initial themes which were reviewed
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18 to ensure that they represented something meaningful about the data. All the data
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20 relevant to each theme were extracted and the 'journey' of defining and naming the
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22 initial themes commenced (Braun et al, 2019). Refinement of themes was carried out
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24 to ensure that each theme portrayed the meaningful aspects of the data. The final
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26 strategy adopted was through a process of triangulation, whereby themes developed by
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28 the lead researchers were cross-checked by the co-researchers (O'Brien et al, 2014;
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30 Nowell et al, 2017). Themes were discussed among researchers until a consensus had
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32 been met on the definitions of each theme. This approach is in line with quality criteria;
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34 reporting followed the Consolidated Criteria for Reporting Qualitative Research
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36 (COREQ; Tong, Sainsbury & Craig, 2007).
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45 Findings

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49 Evident in all of the participants accounts were barriers to how they experienced
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51 citizenship. Analysis revealed three main themes which illustrated how participants
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53 experienced such barriers: (1) stigmatisation (internal & external) creates further divide,
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55 (2) being socially excluded leads to isolation, and (3) a sense of difference (as perceived
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57 by the self and others).
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Stigmatisation (external & internal) creates further divide

In reflecting on their understandings and experiences of citizenship, participants emphasised their perceived sense of divide within society between “them and us” (James). They described how they experienced negative attitudes from others that made assumptions about them based on misconceptions surrounding the life disrupting events they had gone through (psychiatric hospitalisation, addiction, incarceration, homelessness). For example, they felt that they were viewed as being “less able” (David) members of society that ‘took more than (I’ve) gave back” (John). They also discussed feeling less valued, with Fiona having stated:

People don’t value people a lot who have mental health issues because they think that they don’t have anything valuable to say and that is just a stigma.

This divide was reinforced by the experience and perception of being “categorised” (Keith) which appeared to be unwavering; participants felt that once they had been “labelled” (Claire) it was extremely difficult to change this. This was particularly evident in the accounts of those who had experience of the criminal justice system and the stigma of incarceration affected participants long after they had been released from prison; as captured by Keith:

It’s more important how others perceive you, how they think of you, where they pigeon hole you, what box they fit you into. So you can think you’re a good

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4 citizen but other people because you did something 20 years ago still categorise
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6 you as dodgy (Keith).
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10 The experience of stigma resulted in participants feeling as though they were “less than
11 others” (Billy), as “second class citizen” (Margaret) and on a “different level” (David)
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13 to the rest of society, and that they did not have access to the same rights, resources or
14
15 opportunities. This again strengthened their perceived sense of divide between
16
17 themselves and the wider society. Further, the experience and perception of negative
18
19 attitudes from others appeared to contribute towards self-stigma whereby participants
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21 internalised the stigmatising views of others. This was illustrated by Michael who
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23 discussed his experience of identifying with the negative views of others:
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31 The media are telling you that you can't because you have mental health
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33 (problems), you will actually soon identify with it because you are told, and you
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35 get it from the media, Government and the general public and probably health
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37 professionals who will say 'you can't do that'.
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43 Participants discussed the internal stigma they felt about themselves and the
44
45 adverse impact this had on their mental health and wellbeing, with Kate remarking:
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50 You even have stigma towards yourself, it's not just stigma from other people, it
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52 comes from yourself as well. It brings you down, it can make you ill and feel
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54 bad about yourself.
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4 As a result, participants often felt that they did not want to discuss their MHPs and life
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6 disrupting experiences with others as it was considered to further “create stigma”
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8 (James). Participants described how they had internalised the negative views of others
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10 and in turn feared that they would be judged; as captured in Andrew’s account of
11
12 fearing disclosure of his MHPs to potential employers:
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17 I feel I am on the scrap heap, because of mental health. I feel as if when you are
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19 going to employers you don’t want to mention mental health because that is a
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21 nail in the coffin right away.
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26 *Being socially excluded leads to isolation*

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31 Participants discussed feeling excluded from society; this not only led to
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33 participants feeling socially isolated but also to them self-isolating as a means of
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35 avoiding situations and other people in response to feeling excluded. Mark described his
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37 experience of isolating himself as a means of avoiding others:
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42 I isolated myself from a lot of people, I try and stay out of people’s road. It’s not
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44 their fault, it’s my fault and if I happen to bump into someone I will say “hello, I
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46 need to go quick”, it’s me that has isolated myself. I just don’t want to talk about
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48 what I’ve been through, or why I’ve not been about.
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54 This self-isolation resulted in participants feeling “ostracised” (Alan).
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56 Participants discussed how living with MHPs “can strip away your identity” (Fiona),
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58 creating the feeling that “you’re not connected to anything anymore” (Fiona). It was
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4 also linked to how participants felt they were perceived by others; participants had a
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6 tendency to isolate themselves due to “embarrassment” (John) and “shame” (Lesley)
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8 about living with MHPs and having gone through life disrupting events. Participants
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10 discussed how negative reactions from others, as well as fear of receiving negative
11
12 reactions, exacerbated feelings of exclusion. Individuals then self-isolated themselves as
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14 “self-protection” (Billy) in order to avoid negative emotions, as captured by Kevin:
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20 You get a bit isolated. It’s not because you don’t want people round you, you
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22 feel ashamed. There’s guilt there and fearing what other’s think of you.
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27 *A sense of difference (as perceived by the self and others)*
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31 Participants emphasised how they had a sense of themselves as being “out(with)
32
33 the mainstream” (Scott). Participants had a perception of themselves as “not accepted”
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35 (Simon), creating the feeling that they don’t belong as citizens within their
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37 communities. This point was highlighted by Andrew who discussed the challenges of
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39 going to new groups in the community:
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46 It is hard at first when you go to these places as you feel like a misfit, because
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48 you have bipolar, Asperger’s and things, you know, and it is a big step to go
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50 somewhere.
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54 This sense of difference was reinforced by others, with participants discussing
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56 how they were made to feel different (in a negative sense). Scott emphasised the
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58 negative connotations which created a sense of difference:
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6 See people with mental health, makes other people think ‘uh he’s daft, he’s
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8 dangerous’ you know what I mean, people see different.
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11 However, this sense of difference also created a unique source of inclusion or
12 citizenship among participants with MHPs with experience of life disrupting events.
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14 This appeared to be closely linked to having shared experiences with others which
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16 worked to create a sense of inclusiveness. This inclusiveness among those with shared
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18 experiences was strengthened by participants feeling as though they were “not included
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20 in the normal citizenship” (Scott).
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28 **Discussion**

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32 Three themes concerning the barriers to citizenship experienced by participants
33 were identified: stigmatisation (internal & external) creates further divide, social
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35 exclusion leads to isolation, and a sense of difference (as perceived by the self and
36
37 others). These findings contribute to existing research on citizenship (Hamer et al, 2015;
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39 Ponce et al, 2018; Anonymous et al, 2015; Vervliet et al, 2019) by providing a rich
40
41 account of the barriers experienced by adults with MHPs and other life disruptions
42
43 within the Scottish context. Stigmatisation was found to be a significant barrier to
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45 citizenship. Similar to previous work (Ho et al, 2017; Keene, et al, 2018; Link et al,
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47 2015; Poremski et al, 2014; Anonymous et al, 2015; Wood et al, 2017), stigma was
48
49 found to restrict participants’ access to services, housing and employment.
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52 Stigmatisation (from the self and others) was found to negatively impact upon the self-
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54 perception of participants, resulting in them feeling less able to access the rights, roles,
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4 resources, relationships and responsibilities which are required to exercise full
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6 citizenship.

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8 Involvement in the community is important for establishing social inclusion
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10 (Crisp, 2010) and, therefore, citizenship (Anonymous et al, 2019). As such, social
11
12 exclusion may limit access to full citizenship (MacIntrye et al, 2019). Indeed, the
13
14 findings of this study highlight social exclusion and isolation as a specific barrier to
15
16 citizenship within the Scottish context. Participants described the negative internal
17
18 feelings they experienced in relation to the life disrupting events they had gone through,
19
20 as well as fear of receiving negative reactions and judgement from others. As found in
21
22 previous work (Carrara et al, 2018; Corrigan, 2006), participants described how they
23
24 often sought to self-isolate as a means of trying to avoid negative and stigmatising
25
26 reactions from others; this further exacerbated the MHPs they experienced.
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34 Similar to earlier research (Anonymous et al, 2019; Mezzina et al, 2006),
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36 participants emphasised how their sense of feeling different was a barrier to citizenship.
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38 The need for belonging which is cultivated through being accepted by those within
39
40 one's local communities (Naslund et al, 2016) is a central aspect of citizenship. It is
41
42 important to note, however, that local communities are not always welcoming of those
43
44 they perceive as different as highlighted by participants in the current study and
45
46 elsewhere (see for example, Anonymous et al, 2017). In addition, understandings of
47
48 community tend to shift over time and for many, communities of interest have replaced
49
50 local communities as a source of social support and networking, although more recently
51
52 there has been a resurgence of local community work as a response to national and
53
54 international problems (Henderson et al, 2018; Anonymous et al, 2017; Webber et al,
55
56 2015). Indeed, participants in the current study highlighted how being with those with
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4 similar experiences of MHPs and to have gone through life disruptions can create a
5
6 unique sense of citizenship. However, it is important to acknowledge that there can be
7
8 tension between being among others with shared experiences and also knowing that by
9
10 doing so, it can lead to further exclusion from others within mainstream society (Richter
11
12 & Hoffman, 2019). Whilst shared experiences are important for creating a sense of
13
14 belonging, the current research suggests that the development of a citizenship approach
15
16 in practice, for example, through citizenship projects (Bromage et al, 2017; Clayton et
17
18 al, 2013) and tools (Bellamy et al, 2017; O'Connell et al, 20) which aim to facilitate
19
20 inclusiveness for all, regardless of experiences, is an important consideration.
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24
25 There are limitations to this research. Firstly, it is important to note the
26
27 difficulties in defining the term "life disruption". Most people's lives do not follow a
28
29 perfect trajectory and so most people are likely to experience some element of life
30
31 disruption that may impact on their mental health at some point. As such, it is extremely
32
33 difficult to define what qualifies as a life disruption. While this study, in line with
34
35 previous work (Anonymous et al, 2015) focused on participants who had experienced
36
37 specific life disruptions with a particular focus on MHPs within the last 5 years, future
38
39 work could adopt a broader perspective (e.g. veterans transition from military to civilian
40
41 life). Given the qualitative nature of the current research, it is not possible to generalise
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43 from these findings, however, the themes have informed work we are engaged in
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45 utilising a multi-method approach, including people who do not identify as having
46
47 experienced life disruptions, to develop a framework of citizenship within the Scottish
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49 context (MacIntrye et al, 2019).
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55 Identifying barriers to citizenship can help us to understand the ways in which
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57 people with MHPs and life disruptions have had their access to citizenship
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59 compromised. The barriers identified in the current research all shared a common
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4 component in that participants consistently drew reference to a perceived social divide
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6 within the communities they lived. Understanding and challenging such social and
7
8 structural barriers could help to lessen the divide and find ways to promote social
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10 inclusion (Ponce et al, 2016). Only by acknowledging and understanding such barriers
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12 can researchers, policy-makers and health and social care professionals begin to identify
13
14 ways to confront them. A citizenship approach which facilitates social acceptance,
15
16 social inclusion, a sense of belonging and fair distribution of resources (Hamer et al,
17
18 2019; Morgan et al 2020; Anonymous et al, 2015), has the potential to reduce such
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20 barriers and increase access to full participation for those who have experienced
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22 marginalisation. Future work transferring principles and practices of citizenship to
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24 different professional contexts in the field of mental health would benefit from
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26 longitudinal evaluation and socio-cultural comparison.
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Declaration of interest

Nothing to declare

Ethical approval

The study was granted ethical approval from the School of Social Policy and Social Work Ethics Committee, University of Strathclyde

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Table 1. Demographic information (gender, age range, ethnicity) for participants in life disruption groups

Characteristic	Life Disruption Groups
Total	40
Gender	
Male	30
Female	10
Age Group	
16-24	1
25-34	4
35-44	11
45-54	16
55-64	6
65-74	1
74+	1
Ethnicity	
White Scottish	19
White British	19
White Irish	2
Other	0

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