Mental Health and Social Inclusion

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Compulsion and race: over-representation and time to act decisively

In October 2019, the latest Mental Health Act statistics were published (NHS Digital, 2019). Yet again, they make grim reading.

In 2018–2019 there were 49,988 new detentions under the Mental Health Act 1983 – with 15.5 per cent being detained more than once in the year – and 4,840 Community Treatment Orders issued but “[...] the overall national totals will be higher. Not all providers submitted data, and some completed incomplete data” (NHS digital, 2019, p. 2).

The 2018–2019 rate of Mental Health Act detentions represents a 2 per cent increase over 2017–2018 figures (NHS Digital, 2019). Indeed the figures have risen by at least 2 per cent each year from 2015–2016 (see NHS Digital, 2017, 2018). Direct comparisons of numbers prior to this are not possible because the way in which data are collected has changed, but what is absolutely clear is that the rate of detentions under the Mental Health Act has been rising inexorably:

Rates of compulsory detentions in psychiatric hospital have more than doubled since 1983, with the steepest rises in the last decade and late 1980s/early ‘90s. From 2005-06 to 2015-16, the reported number of uses of the Mental Health Act to detain people in hospital increased by 40%. (Independent Review of The Mental Health Act, 2018, p. 49)

These increasing detention rates strongly suggest that there is much work to be done to improve access to, acceptability of, and experience of mental health services for everyone who experiences a mental health crisis. Numerous initiatives have been aimed to extend the range of options available to people in crisis, including sanctuaries, safe havens, crisis houses and crisis cafes: The NHS England (2019) Long Term Plan commits to increasing the availability of such options and ensuring that people can get help when they are in crisis 24h per day. In 2014, the Department of Health set up local Crisis Care Concordats, designed to facilitate access to care before crisis point is reached, improve the quality of crisis care and treatment, and prevent future crisis. Yet despite this, the data tables associated with the NHS Digital (2019)[1] show that the number of uses of Sections 135 and 136 “Place of safety” orders has risen from 15,050 in 2016–2017 to 19,023 in 2018/2019. The situation remains similar to that described by the Care Quality Commission in 2015. They emphasise that, while pockets of good practice exist, the quality of support people receive in crisis depends on where you live and when you seek help:

[...] too many people in this situation are unable to access the help they need, when they need it, and are dissatisfied with the help they have been given. (Care Quality Commission, 2015, p. 2)

[...] our work has also shown that far too many people in crisis have poor experiences due to service responses that fail to meet their needs and lack basic respect, warmth and compassion. This is unsafe, unfair and completely unacceptable. (Care Quality Commission, 2015, p. 4)

Until everyone has somewhere accessible and acceptable to go when they are approaching a crisis – a place where they know they will be treated with understanding, compassion and dignity – it seems unlikely that the rising tide of compulsory detention and treatment can be stemmed.

However, behind these overall rates of detention, gross inequalities can be found.

Known detention rates for men (91.4 per 100,000) are higher than those for women (83.2 per 100,000) and men are more likely to be subject to Community Treatment Orders (11.2 per 100,000 compared to 6.1 per 100,000 for women). Detention rates for younger
people aged 18–34 are about one third higher than those for people aged 50–64 (128.9 per 100,000 compared to 89 per 100,000).

However, inequalities are most stark, and most worrying, in relation to ethnicity (NHS Digital, 2019). In 2018–2019, in relation to “white” people, those from “Black/Black British” communities are:

- over four times more likely to be detained in hospital under the Mental Health Act (306.8 per 100,000 compared to 72.9 per 100,000);
- more likely to be detained more than once during the year (18.8 per cent compared to 15.5 per cent);
- over eight times more likely to be subject to a Community Treatment Order (53.8 per 100,000 compared to 6.4 per 100,000); and
- twice as likely to be detained under a Section 136 “Place of Safety” order (56.6 per 100,000 compared to 28.4 per 100,000)[2].

Recognition of these differences is not new. Keating et al. (2002) described relationships between Black communities and mental health services are driven by a vicious circle of fear:

We have reached a point in the relationship between the Black communities and mental health services where there are truly Circles of Fear. Black people mistrust and often fear services, and staff are often wary of the Black community, fearing criticism and not knowing how to respond, and fearful of young Black men. The cycle is fuelled by prejudice, misunderstanding, misconceptions and sometimes racism. (Keating et al., 2002, p. 6)

The prevailing situation in which “[…] Black people are 40% more likely to access treatment through a police or criminal justice route, less likely to receive psychological therapies, more likely to be compulsorily admitted for treatment, more likely to be on a medium or high secure ward and more likely to be subject to seclusion or restraint […]” (Mind, 2019, p. 1) can only further fuel these Circles of Fear.

There was a perception that MH services replicate experiences of racism and discrimination of black people in wider society, particularly those instances where individuals have experienced the more controlling and restricting aspects of treatment […] the way services respond to them mirrors some of the controlling and oppressive dimensions of other institutions in their lives; for example, exclusion from school, or contact with police and the criminal justice system. (Keating and Robertson, 2004, p. 442)

The research conducted by Keating et al. (2002) concluded that:

- the Circles of Fear described above discourage Black people from engaging with services;
- mainstream mental health services are viewed as inhumane, unhelpful and inappropriate by Black service users who feel that they are not treated with respect and that their voices are not heard;
- as a consequence Black communities are reluctant to engage with services and Black people tend to come to services late – when they are already in crisis – thus reinforcing the Circles of Fear;
- there is a lack of community based crisis support and Primary Care involvement and acute mental health care is perceived negatively and not considered to aid recovery;
- there is a divergence of models and descriptions of “mental illness” between Black communities and mental health services, and different philosophies and world views are not recognised or understood;
- there is a lack of service user, family and carer involvement;
- conflict between professionals and service users is not always addressed in helpful or constructive ways;
- while the concept of “culture” has been invoked to address some of these issues, this can detract professionals from looking at individual histories, characteristics, values and wishes;
Black-led community initiatives are not valued: their funding is often insecure preventing long-term capacity building; and

stigma and social exclusion are important dimensions in the lives of Black service users.

On the basis of this research, the authors argue that “A wide ranging programme is needed to break the circles of fear addressed both to the statutory sector and to the Black communities” (Keating et al., 2002, p. 10). A number of recommendations for national and local action were made, although it is hard to argue that these were really heeded or fully implemented.

However, in 2005, a major five-year national programme – delivering race equality in mental health – was launched “[…] an action plan for achieving equality and tackling discrimination in mental health services in England for all people of Black and minority ethnic (BME) status […]” (Department of Health, 2014, p. 3). This programme was designed to create more appropriate and responsive services, improve community engagement (including the employment of 500 new Community Development Workers) and provide better information (via an annual “Count Me In” census). Among the specific aims of the programme was the ambition that, by 2010 there would be “less fear of mental health services among BME communities and service users” and “a reduction in the disproportionate rates of compulsory detention of BME service users in inpatient units” (Department of Health, 2014, p. 4).

The continuing over-representation of Black and Black British people among those compulsorily detained and forcibly treated under the Mental Health Act shows that these aims were not achieved. As the final report of the Independent Review of the Mental Health Act 1983 stated:

Profound inequalities exist for people from ethnic minority communities in accessing mental health treatment, their experience of care and their mental health outcomes. We know that people of black African and Caribbean heritage are more likely than white British people to come into contact with mental health services through the criminal justice system, rather than via their GP or referral to talking therapies. Adults of black African and Caribbean heritage are more likely than any other ethnic group to be detained under the Mental Health Act. (Wessely, 2018, p. 163)

This review was specifically charged with addressing these disparities and made a number of recommendations. Like delivering race equality in mental health it emphasised involving service users, carers and communities and made a series of recommendations (see Wessely, 2018, pp. 172/3):

- the implementation of a community-driven “Organisational Competence Framework” and “Patient and Carer (Service User) Experience Tool” across health and social care services building on work conducted by NHS England to develop the Patient and Carer Race Equality Framework;
- the Care Quality Commission and the Equality and Human Rights Commission should use their powers to support improvement in equality of access and outcomes and ensure organisations are complying with their public sector equality duty;
- the provision of culturally appropriate advocacy for people of all backgrounds and communities, especially for people of black African and Caribbean heritage;
- the creation of safeguards to ensure that people are able to continue religious or spiritual practices while they are in hospital;
- greater representation of people of black African and Caribbean heritage in all professions (especially psychology and occupational therapy) and at senior levels (especially psychiatry and psychiatric research, psychiatric nursing and management);
- the piloting and evaluation of behavioural interventions to combat implicit bias in decision making;
- the improvement of data and research on ethnicity and use of the Mental Health Act, with all decisions being recorded and reviewed consistently by organisations involved in the process (especially criminal justice organisations and Tribunals);
funding should be made available to support research into issues that lead to mental disorder in different communities (especially people of African and Caribbean heritage) and intervention that improve outcomes; and

research into early interventions for children of African and Caribbean heritage, especially those who are at risk of exclusion from school.

Will these succeed where other initiatives and recommendations have failed? Only time will tell.

There is certainly a case for arguing that some of the money currently being invested in crisis services should be targeted specifically to address reducing the over-representation of Black and Black British people among those detained. There is evidence that peer support workers may reduce readmission to acute care (Johnson et al., 2018): there is a strong case to argue that at least some of these should be people with lived experience of acute crisis and detention from Black and Black British Communities.

However, while changing attitudes, values and behaviours, and extending the range of possibilities available is undoubtedly important, has the time not now come to ensure that good intentions are realised in the form of accountable targets for improvement?

Is it not time to say that compulsory detention represents a failure to offer people help that is accessible, acceptable and effective both at times of crisis and to prevent crises occurring? Recognise that this failure disproportionately disadvantages people from Black communities (and indeed other oppressed groups such as Gypsies and Travellers), and start setting targets to both reduce the use of compulsory detention and reduce the over-representation of Black/Black British people among those forcibly detained and treated under the Mental Health Act.

How about setting all mental health services (working in conjunction with communities, service users and partner agencies) the target of achieving:

1. a year on year reduction in the use of compulsory detention;
2. a year on year decrease in the use of Community Treatment Orders and Section 135/136 “Place of Safety” orders; and
3. a year on year decrease in the over-representation of Black/Black British people among those detained and treated under the Mental Health Act.

Services could then be held accountable for achieving such year on year decreases by inspectorate bodies and “special measures” invoked if they fail to achieve these. Would it not be reasonable to argue that, in terms of their Care Quality Commission rating, no service that fails to achieve such decreases can ever be rated as “good” or “outstanding” – at best they could be considered as “requiring improvement”?

Notes

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Research watch: what really helps recovery in relation to severe mental health difficulties?

Sue Holttum

Abstract
Purpose – The purpose of this paper is to examine three recent papers on mental health services and how they support recovery following a diagnosis of a severe mental health condition.

Design/methodology/approach – A search was carried out for recent papers on mental health and recovery. The author selected three papers that seemed to advance understanding of not only whether, but also how recovery of a meaningful life may be best supported in mental health services.

Findings – One paper suggested how staff were able to support service users’ personal goals and focus on recovery in acute inpatient settings, and what got in the way. The author suggests practical ways to address the barriers. A second paper reported the testing of a new model for supporting staff in primary and secondary care to work together so that service users with a diagnosis of bipolar or schizophrenia were better supported to work towards valued goals. A third paper reviewed 40 studies of how people can experience positive change after a first diagnosis of psychosis, and how change happened.

Originality/value – By studying the issues in detail, all three papers show how improved support for recovery and inclusion can be implemented against the backdrop of many years of service shortcomings.

Keywords Mental health, Personalization, Social inclusion, Recovery

In this paper, I look at three recent articles about what works in terms of supporting recovery in the context of severe mental health difficulties. None of them pretend it is easy but they show what can happen. Coffey et al. (2019) point to differences between the English and Welsh mental health systems:

What helps recovery in inpatient mental health care?

Coffey et al. (2019) point to differences between the English and Welsh mental health systems: The Care Programme Approach in England entails guidance to include a focus on recovery and to take a personalised approach. This means not just reducing “symptoms” but also supporting service users to have a life that is meaningful and fulfilling to them. Personalisation means service users and those close to them having more control and being equal partners to professionals. In the Welsh system, care and treatment plans (CTPs) have similar aims but they also come with “legal obligations” (Coffey et al., 2019, p. 2) to include recovery and personalisation. Coffey et al. (2019) point to differences between the English and Welsh mental health systems: The Care Programme Approach in England entails guidance to include a focus on recovery and to take a personalised approach. This means not just reducing “symptoms” but also supporting service users to have a life that is meaningful and fulfilling to them. Personalisation means service users and those close to them having more control and being equal partners to professionals. In the Welsh system, care and treatment plans (CTPs) have similar aims but they also come with “legal obligations” (Coffey et al., 2019, p. 2) to include recovery and personalisation. Coffey et al. (2019) set out to examine what helps and hinders the application of a recovery focus and collaborative and personalised care in acute inpatient wards in England and Wales.

Research methods for studying wards

Coffey et al. (2019) included four English NHS trusts and two Welsh local health boards. There were 19 acute wards in a range of geographical locations from rural to urban and inner city. In a
specific ward in each of the six localities, interviews were carried out with service users, staff and family carers. Coffey et al. (2019) interviewed service users about their experience of care planning and being in hospital. They also used established questionnaires to capture the following:

1. service users’, staff members’ and carers’ views on the amount of focus on recovery, for example looking at life goals and offering choice;
2. service users’ and staff members’ views of the relationship between staff and service users;
3. service users’ views of how empowered they were, including how much they felt able to have control over their situation; and
4. how involved service users felt in ward rounds and care planning.

In their qualitative analysis, Coffey et al. (2019) specified some themes in advance, as they expected certain things to be important, such as the organisational context, care planning processes, recovery and personalisation. However, they also allowed for new themes to be found. Over the six locations, 301 service users, 290 staff and 28 carers filled in the questionnaires. Coffey et al. (2019) had hoped to include more carers but it proved difficult to recruit them. Interviewed were held with 31 staff, 36 service users and 9 carers.

Were there any differences between English and Welsh ward experiences?

For service users who filled in the questionnaires, their perceptions were similar across the six sites. However, staff differed between sites as to level of recovery focus and quality of therapeutic relationship with service users. Staff in two of the Welsh locations rated recovery focus statistically significantly lower than staff in two English locations. Staff in one Welsh location rated therapeutic relationships with service users better than did staff in another Welsh location.

Service users who felt their care was recovery focused also tended to rate themselves as having a voice in decision-making on their care, and to have a good therapeutic relationship with staff. Staff who rated care as more recovery focused also rated the therapeutic relationship as better. Overall, staff rated therapeutic relationships with service users as significantly better than service users rated relationships with staff.

What did staff and service users say in interviews?

In interviews, staff seemed to value including service users in their care planning. However, service users often stated that staff did not include them or they had not seen their care plan. Some staff suggested that service users could be reluctant to cooperate in planning, or that the electronic records system was not designed for acute wards. There were examples of good practice in terms of planning for discharge, and also staff sometimes found that service users were discharged before planning was completed.

Some service users, Coffey et al. (2019) report, found ward rounds daunting but some felt better able to say what they wanted, especially if they had received support in preparing for them. In the accounts of both staff and service users, discussion of risk was not always collaborative, with service users rarely included. Some staff felt there was too much focus on risk, and not enough on “strengths and positive risk-taking” (Coffey et al., 2019, p. 12). Some service users also felt that the ward was not safe due to insufficient staffing.

Both staff and service users struggled to see the relevance of recovery in the ward context, with staff sometimes strongly questioning the idea. Service users who mentioned recovery tended to talk about it only as symptom reduction. Not many service users or carers had heard of personalisation, say Coffey et al. (2019). Staff said they valued it but felt there was a lack of resources to implement it.

What would help wards to become more inclusive?

Coffey et al. (2019) suggest that staff might need more support in order to work collaboratively in wards. They also recommend that service users should have support to prepare for the ward
round, and that they receive a summary of the decisions made in it. They suggest that rather than the ward being a place where recovery is not relevant, a personal recovery focus is especially important there.

Coffey et al. (2019) point to one ward in which staff had invented a new document to help improve service user inclusion in care planning, but the need to complete all the other routine recording made it burdensome. Service users in Welsh wards seemed more aware of their goals being monitored, and Coffey et al. (2019) suggest that this may be because of the different system in Wales, where staff saw the CTP system as helpful to personalised and collaborative working. However, Coffey et al. (2019) suggest that staff need more training and support to discuss risk issues with service users in inpatient wards.

Working together to support service users with severe mental health difficulties in primary care

Baker et al. (2019) point to the poor physical health of service users with a diagnosis of schizophrenia or bipolar disorder. They also point out that many people with these diagnoses are cared for only by their general practitioner (GP). Even when mental health services are involved, there is often poor coordination between services. Furthermore, GP service staff rarely have the right training to best support people with severe mental health difficulties, Baker et al. (2019) suggest.

A model of collaborative care

Baker et al. (2019) describe a new model they have devised, called PARTNERS, to be tested in an upcoming randomised controlled trial. The study reported here is their preparation for that trial. Their model is partly based on an existing model for collaborative care (Wagner et al., 1996), but with the addition of the concept of personal recovery from a review of research studies (Leamy et al., 2011) of how service users talked about recovery. This has the five components known as CHIME:

1. Connection
2. Hope
3. Identity
4. Meaning
5. Empowerment

The new model, say Baker et al. (2019), also includes coaching. Coaching is a way that staff can work collaboratively with service users to help them move towards goals they choose for themselves. In planning for their controlled trial, Baker et al. (2019) say they are following guidelines for planning trials of complex interventions such as theirs (e.g. Craig et al., 2013). These guidelines recommend gathering initial qualitative data on the experiences of various stakeholders involved in testing out a new programme. The qualitative evaluation helps to improve the programme, and the understanding of how it works.

Baker et al. (2019) carried out this initial try-out of the programme in three places and they used three different sorts of qualitative data:

1. interviews with staff and service users;
2. recordings of coaching sessions; and
3. playing back clips of the recorded sessions to the service users and staff involved (separately) and asking them about what was going on at the time.

Baker et al. (2019) asked each of the three NHS trusts to allocate a mental health professional to the role of care partner, and a senior mental health worker to act as the supervisor. Six GP practices agreed to try the new service. Care partners met with service users regularly and started by building an alliance and agreeing goals that the service user wanted to pursue. A plan was to be devised to help in this, and the goals were to be monitored regularly along with mental
and physical wellbeing. The expectation was that care partners would communicate regularly with members of the GP practice. Supervision was to happen every two weeks, with a template to support it.

Service users were eligible if they had a diagnosis of schizophrenia or bipolar disorder. They could be only under GP care or be receiving secondary mental health care. The number of service users included was 38. The intended length of service was 8–10 months. At one site, the start was delayed by six months so less information was gathered from there. Baker et al. (2019) reported the numbers of participants as 16 service users, 5 family members, 3 care partners, 3 supervisors, 4 GPs and 6 other staff across primary and secondary care.

Several different researchers gathered the data, including two service users. The interview data were analysed and the themes identified were discussed with stakeholders including service users to ensure the quality of the analysis and to look at how the programme was working, Baker et al. (2019) report. This led to some changes being made to the manual and guides to be used in the full trial, and changes in the way staff would be supported. Further data were collected after the discussion with stakeholders, so that specific things might be focused on more to understand what was working well and less well.

**What worked and what did not?**

Baker et al. (2019) found that some aspects of the programme were not being delivered as expected. One care partner found it helpful when a GP practice manager made introductions to the team and allocated an administrator as a link person. Without this, liaising was difficult, and such difficulties were not always discussed in supervision. However, when a care partner went to the research team for more support, a researcher was able to help.

Coaching did not always go to plan, especially if neither the care partner nor the service user seemed to value it. Sometimes goals were seen as purely practical, rather than recognising that they could also be psychological. So, for example, the care partner would focus on supporting the service user rather than think with them about how they could have more support in their life outside health services. Some care partners also did not appear to apply their coaching training and instead focused on risk-management, say Baker et al. (2019). Some supervisors also did not appear to support coaching, as when a care partner recounted that the supervisor just told them to read the manual.

Supervisors sometimes felt overworked with other demands, and if the care partner was aware of this, they did not always use supervision fully, say Baker et al. (2019). When supervisors felt able to give time to following the model, they felt they came to understand and use it well to support the care partners. However, it was important that both parties were open to seeing how the care partner could change their practice.

**What was changed to make things work better?**

Baker et al. (2019) listed a number of changes to the programme as a result of what they learned, for example having a named link person within the GP practice, researchers taking a more hands-on role, the supervision guide to include looking at communication with the practice team, more examples of coaching in the manual, and more role-playing of it in training, and follow-up training for both care partners and their supervisors to use session recordings in supervision for learning purposes.

**How did service users experience the programme?**

In terms of outcomes, say Baker et al. (2019), three things seemed to work as planned. One was that GPs gained better understanding of service users’ needs due to the care partner’s communication. For example, one GP said that their focus had shifted away from anxiety about risk so that in one case, for example, it felt more possible to consider a physical problem with a service user’s shoulder. In turn, care partners became more aware of service users’ physical health, which could help if addressing this was among a service user’s goals. For example, one service user
talked about the care partner mentioning the need for “heart checks” (Baker et al., 2019, p. 13) in relation to their psychiatric medication, which empowered them to ask their GP for this.

Some service users felt that contact with the care partner had increased their hope, in keeping with the programme theory and its CHIME focus, mentioned earlier. They felt able to try new things, knowing there was a “safety net” (Baker et al., 2019, p. 13). In turn, making these small changes could lead to increased confidence, in a virtuous circle, as the programme theory had predicted.

What have the researchers learned?

The different sources of information gave Baker et al. (2019) a detailed picture of how the programme was working. They have made changes to their manual and training and to the initial negotiations with NHS trusts to try to ensure sustained staff time. However, service users may also come to the programme with higher or lower motivation, say Baker et al. (2019). They suggest, however, that with better training of care partners in the coaching model, service users may experience coaching as supporting them to become more motivated rather than as telling them what to do.

How do people bounce back from psychosis?

Jordan et al. (2018) point out that much of the research on psychosis focuses on the negative aspects. There is a need, they state, to look at “whether and how people experience positive changes after a first episode” (Jordan et al., 2018, p. 84). There had not been any reviews of research on positive change after psychosis, say Jordan et al. (2018), so their aim was to search for studies on positive change after a first diagnosis of psychosis, and to see if the research could provide clues as to what helped to bring about this change. Jordan et al. (2018) specifically avoided articles that only focused on symptom reduction or return to previous functioning because they wanted to capture change that went beyond these. There were 40 articles in all, of which all but three were entirely qualitative. Quantitative results were converted into words and coded qualitatively. Jordan et al. (2018) produced a summary of themes from all 40 papers.

The experiences of 715 service users, family and friends were represented in the 40 papers, with an average service user age of 24.8 years. Most studies were done in the UK, Australia and Canada, with one study each from a range of other countries in different continents. People across a range of ethnicities and socioeconomic status were included. Half of the studies specified a time of up to five years after psychosis or its treatment, and half did not specify. The studies were rated at different levels of quality, with 7 seen as low quality, 13 as medium and 20 as high.

Despite their focus on positive change, Jordan et al. (2018) felt it important to report that there was a strong theme of suffering in relation to psychosis. This included thinking difficulties, difficult emotions, and difficulty in accepting and making sense of the diagnosis. There could also be problems for service users and their family in getting any help or the right help. Losing control of one’s life was an issue, as was “loss of self” (Jordan et al., 2018, p. 94), and finding it hard to connect with other people. For some, there was loss of religion or spirituality as previous practices or observances became associated with difficult experiences. All of these things might hinder recovery, say Jordan et al. (2018).

Becoming a better person

Despite these difficulties, Jordan et al. (2018) suggest that people experienced positive changes in three areas: personal, social, and religious or spiritual. Almost all the studies described personal changes for the service user and/or those close to them, say Jordan et al. (2018). These included new ways of seeing oneself and one’s life, and finding new meaning, including positive meaning of psychotic experiences. New values included less materialism and substance use, and more valuing of other people.

Psychosis was seen as “transformative” for some (Jordan et al., 2018, p. 94), leading to a new identity and stronger sense of self. There was improved ability to cope with problems, say Jordan et al. (2018). Some service users changed their lives to make them simpler and more meaningful and took better care of their physical health and fitness, including sleep. Some found new job opportunities and creative interests.
Better relationships

Relationships within families were reported as improved, say Jordan et al. (2018). Families often improved their communication and mutual kindness, which in turn improved the family’s ability to cope with adversity. Relationships with friends or intimate partners that appeared to be unhelpful were sometimes ended, and better but sometimes neglected friendships were re-started or new friends made, say Jordan et al. (2018). People found new roles in society such as peer support workers. In a few studies, there was reporting of increased spirituality or participation in religious services, Jordan et al. (2018) report.

Personal effort

Jordan et al. (2018) state that there seemed to be four things that led to positive experiences: personal, social, religious/spiritual and mental health services. Being hopeful, finding meaning in psychosis, developing coping strategies and understanding others all seemed to be helpful, say Jordan et al. (2018). Motivation to move towards goals and to overcome obstacles also helped, as did increased maturity. Wanting to help others also seemed to motivate people. Service users employed various skills, such as self-care, drawing on existing abilities, and working towards educational or employment-related goals.

Being cared about and finding solace in religion or spirituality

It seemed to be helpful if people felt connected to a community, and if friends or family supported them. This could include questioning assumptions about mental health. Not many studies looked at religion or spirituality, but the few that did seemed to suggest that prayer, going to services and reading scriptures could be helpful, Jordan et al. (2018) report.

How mental health services helped

Although mental health services were the most prominent theme in the papers, it was specific kinds of support and therapies that were helpful, say Jordan et al. (2018). In particular, the papers reported the importance of services that enabled people to develop agency and participate in society. These services also focused on recovery and instilled hope, self-acceptance and coping, including through psychological therapies. They focused more on individual needs and wishes than on diagnosis, say Jordan et al. (2018).

The importance of maintaining hope and providing high quality services

Jordan et al. (2018) conclude that change following psychosis can be similar to change following other kinds of adversity. Moreover, some studies described improved ability to think and see things clearly, which Jordan et al. (2018) point out contrasts with a common story of persistent problems in thinking. Jordan et al.’s (2019) findings are consistent with those of Leamy et al. (2011), although they took a narrower focus, just on first episode psychosis and included a lot of new papers.

Jordan et al. (2018) point to the difficulty of disentangling what causes change from what is the change, as when hope and motivation help people to move towards their goals, but moving towards goals can then inspire more hope and motivation. It is also possible, they suggest, that many of the changes could be due to the young people’s natural development. However, Jordan et al. (2018) emphasise the importance of services fostering hope and offering therapies that can help people develop their coping and resilience.

Conclusions

I find these three recent papers encouraging. Coffey et al. (2019) have shown that although it can be difficult, it is possible for staff to take a recovery and personalised focus in acute wards, and to support people’s goals, choice and agency. The ways of improving things are not complicated but they do probably require leaders to listen to what gets in the way and work to fix things like unsuitable recording systems or lack of the right training and support for staff to do their best work.
Training, support and sufficient staffing requires funding, but it seems likely that being able to have these in place may help improve many service users’ longer-term prospects and ultimately reduce inpatient admissions. Baker et al. (2019) take us into the primary care setting, and show how staff working across primary and secondary care may be able to further support service users to move towards the kind of life they would like.

Jordan et al. (2018) provide a picture of what positive change can look like, specifically in relation to “first episode psychosis”. It is now over 25 years since Mary Boyle published the first edition of her book *Schizophrenia: A Scientific Delusion*? (Boyle, 1993), which pointed to serious problems with the diagnosis of schizophrenia. Indeed, the entire basis for mental health diagnosis is increasingly questioned (e.g. A Disorder For Everyone, 2019). To my mind, these three recent papers help to strengthen the argument for more of a focus on recovery, in terms of what this means for individual people and what they want out of life and what they can contribute. They show what can be achieved and how.

References


Further reading

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Maddi Faith and Jerome Carson

Abstract
Purpose – The purpose of this paper is to provide a profile of Maddi Faith.
Design/methodology/approach – In this single case study, Maddi gives a short background and the origins of her mental health issues and is then interviewed by Jerome.
Findings – Maddi tells the authors how her problems developed in her childhood and of the journey she has been on since.
Research limitations/implications – Single case studies provide a single perspective. Yet are they of any less value than a commentary by an academic? On the contrary, many offer unique insights into how the authors provide services for people with mental health problems, and of better ways to help them.
Practical implications – Maddi raises the issue of “falling between services”, with the result that the individual concerned does not receive the help they need.
Social implications – The persistent stigma of mental health problems is an issue that will need to be addressed for decades if it is to be overcome. Personal witness is vital in tackling this issue. Maddi has already done a lot to address this through her work at University.
Originality/value – The Trust the second author worked for, for many years used to have a staff “Made a Difference” award. Maddi surely deserves such an award for her own efforts to develop our understanding of the realities of mental health problems.
Keywords Stigma, Recovery, Support
Paper type Case study

Introduction
I have known Maddi for four years, but more closely in the final year of her studies. She has a passion for mental health, seen in her writing on the topic and also in her advocacy for people with mental health problems. This has led to her organising two mental health conferences and bringing people to Bolton like Peter Bullimore and Rufus May. Her passion has developed from her own lived experience. Anyway, let Maddi tell the story in her own words[...].

Brief biography of Maddi Faith
Born in Enniskillen, Northern Ireland, raised in Kent, England. I was born into a military family, with my father serving in the Army, leaving shortly after I was born. I grew up in a single-parent household, just me and my mother after my parents got divorced. As a child, I was very athletic, captain of a lot of the sports teams in primary school, but I was also very shy and reserved, and I found it extremely difficult fitting in. I went to several different primary schools and moved houses every couple of years growing up. Looking back, this probably had a lot more impact on my lack of ability to fit in with those around me and form relationships. I was extremely ill for a prolonged period where I was in and out of hospital around school, which I think made me withdrawn a lot from my peers. On top of this, I was heavily bullied throughout school with peers calling me fat, ugly and worthless, or pointing out my speech impediment at the time. The recurrent theme was that no one liked me, and I had no idea why. I remember being a very
happy, smiley child on the outside, always wanting to get involved, but on the inside, I hated myself and would always feel sadness.

I was extremely anxious and a constant over-thinker. I can say that now I have awareness of what these feelings are; but back then, I would just get angry. I would go from being this calm child, to being completely enraged, spiteful in an instant, all because I could not communicate what I was feeling internally, which essentially was so much hate. The bullying continued throughout secondary school, and I felt like I could never fit in with anyone. I could feel myself slipping deeper into a sadness like I had never felt before, it was not a case of having a few good days, a few bad; I just hated the fact that I had even woken up each morning. Over a period of six months, I had started losing my appetite, and restricting my food, even getting to a point where I did not eat for two weeks before I was taken to my GP to talk about what I was doing to my body by not eating. Just after this, I remember my mother phoning the school and telling them I would be having time off, but later that day, I told her I wanted to go to school. I did not intend to come home that night; I had packed a bag and was ready to run away. After a week of sofa-surfing at various houses, I was then taken by police to my GP. I was referred to CAMHS urgently and seen that morning. I had told the practitioner I was fine, and was not a safety risk. Later that evening, I took my first lethal overdose. I was in a general hospital for a week, then sectioned and sent to a Young Person’s Psychiatric Unit in Sevenoaks for five months from October 2009 to March 2010.

I remember saying I do not know why I feel the way I do, and a lot of people decided to put it down to attention seeking, rather than the fact that I genuinely did not know what was going on inside my head and was not at all good at articulating how I was feeling. I remember kicking down doors in hospital, I remember my father telling me I would be dead, pregnant, or in rehab by the time I was 16, I remember feeling like I had lost everyone around me. I know people cared for me, but every time I saw anyone, I would see pity, anger and hurt; relationships were never the same. Shortly after going back to school, it was decided that I would leave school and home school myself for the rest of my GCSEs due to my mental instability. Although my GP had talked to me about depression and bipolar at the age of 16, I did not get a mental health diagnosis until the age of 19 during my first year of university. I was initially diagnosed with Borderline Personality Disorder, but I have had many professionals arguing over BPD or bipolar. I have since been diagnosed with Obsessive-Compulsive Disorder, and Problematic Eating as comorbidities. As part of my disorders I have suffered with suicidal ideation daily, self-harm, hallucinations and delusions, and alcoholism, along with episodes of mania, and a brief period of psychosis a couple of years ago. Unfortunately, throughout the last 10 years, I have been one of the many unlucky ones who have fallen through the cracks of the NHS; either too complex, or too functional. Support has been something I have lacked and have been on both sides of the fight against the system.

Although my degree allows me to have professional accreditation, it is my experiences that allow me to be the best professional I can be; giving me that empathy, compassion and drive to do everything that I can to improve just one person’s quality of life and inspire hope. Throughout my degree, I have set up a student society, which has helped raise awareness of mental health, and illness, and inspire people to speak up, and help themselves and those around them; the biggest impact being through the “United We Are!” Mental Health conferences. I have also been able to support so many students through difficult times wherever I can. I have also set up my own organisation called Minds in Unity Ltd, which is an organisation designed to raise awareness and support, as well as writing my book called “It’s Okay!” talking about my personal experiences, as well using scientific research, and self-help guides and resources, for individuals, and peers. Yes, I have to take medication daily, along with awaiting psychological therapies. Yes, OCD makes my life a living hell. Yes, I have to work harder than most just to keep my mental well-being afloat. But I am more than my illness, and I truly believe that there is hope for us all, we just need to learn what that means for us as individuals. I may still struggle a lot with my own mental health, but I have found great comfort in using my story to inspire hope, the most recent of which being a YouTube interview on Self-Harm and Addiction.

Maddi in conversation with Jerome

Jerome: Maddi, you moved around a lot when you were younger. I just wondered, is there any place that feels like home to you?
Maddi: Honestly, no. I’ve never really felt at home anywhere, and when I get asked where I’m from, I never know what to say. Being in Bolton for four years for University is actually the longest I have ever been in one town, so at the moment I would say Bolton; but when I was younger, I did spend a lot of time at my Nan’s, in a small countryside village outside of Canterbury, and that is what I miss most about being in Bolton, is being in the heart of the countryside.

Jerome: You chose to study Psychology at University. Has the subject offered you any particular insights into your own personal situation?

Maddi: I think it has to an extent, or at least being at University has. I was always a very aware person, and I didn’t come to University to learn more about myself, I didn’t even need a degree to become a Mental Health Advocate, I just wanted a degree in Psychology to be able to give me the best knowledge I could possibly have, with no idea of where this would eventually end up leading me. I do however, think I gained more of an understanding as to why I may find it hard to articulate the way I’m feeling, and who I am as a person, and my degree has allowed me to feel a lot more involved in my own treatment plans because I am seen as a professional who knows about certain treatments and has a vast knowledge of the area.

Jerome: While you have been one of the pioneers in bringing student mental health issues into the open, not everyone wants to admit to having mental health issues. What made you decide to take the very brave decision to come out about your own mental health problems?

Maddi: In short, because no one else was. Although mental health is becoming more of a household term, there is still so much stigma surrounding mental health, and until someone starts speaking up, we can’t begin to normalise what people are going through. Mental illness is lonely, we are social animals and need connection. By speaking up, I have allowed people to form a new community and realise they are not alone, and someone is always there for them, even if that person is me.

Jerome: What does the concept of hope mean for you?

Maddi: For me, it’s the belief that something better is yet to come. Hope drives our motivation to create a better life for ourselves, and push through the hard times, to get to the good. It’s allowing people to believe in themselves, developing aspirations, and inspiring change. It’s the belief that the future is brighter as long as we continue to work on ourselves to flourish.

Jerome: What changes would you most like to see in mental health services?

Maddi: I think most importantly it would be this grey area of the NHS so many seem to be falling into, including myself. We have thousands of people who are being told they are too complex for Primary Care, but are too high-functioning for Secondary Care. The problem with this is the more people are pushed away, the worse their mental health will tend to get, which in turn makes Secondary Care even more over-stretched, or leads to suicide attempts and completions, all through lack of support.

Jerome: What are your views on the use of medication for mental health problems?

Maddi: Most mental health problems come with a combination of biological and environmental factors. As with any physical illness, sometimes medication is key to our recovery. Unfortunately, with mental health conditions, medications are far more temperamental and trial-and-error than with physical illnesses, so it makes it a lot more complicated. I think medication is a necessity in some cases, but in all cases should be coupled with Psychological Therapies to treat the external factors as well as the internal, and where possible, should only be used as a temporary measure on the road to recovery. Medication can affect everyone differently, it can be the make or break of someone’s recovery.

Jerome: How do you think mental health services can best help promote recovery, which is said to be the goal of many services?

Maddi: I think services need to promote that recovery is a process and not perfection. When recovery is being promoted, it is often seen as a step-by-step way to get better. Recovery needs to be promoted as honestly as possible, it is rarely a straightforward road, and it needs to be promoted that recovery is not the same for everyone, it is unique to an individual and their condition, what may be recovery for one person, may not be for another. I think the promotion of recovery also often falls flat at the stage of existing, we need to promote the art of living beyond mental illness.

Jerome: Have you been inspired by any mental health or healthcare professionals you have come across?

Maddi: Yes, a few. I remember a couple of nurses when I was in hospital, Lisa and Georgie, they were amazing, their approach was so person-centred to each individual, and they treated us as normal kids,
like a family, patients who not patients that needed to be monitored. It really made a difference, and you could see that in people’s attitudes. Whilst doing research a while back, I also came across a YouTuber called Kati Morton who is a Psychologist in America who uses her channel to talk openly about real issues regarding mental health, demystifying illness, and fighting stigma. More recently, I was helped through a difficult stage in my life by Christina Morris, a local Mental Health Worker. In a short period of time, she went above and beyond in her role to support me, she showed me that someone cared, and in a short period of time, she taught me that it is ok to talk, and that I have a lot to offer in this industry, and I aspire to one day be half the professional she has shown to be.

Jerome: In terms of people with lived experience of mental health problems, have any specific individuals impressed you?

Maddi: A couple come to mind. Marie Senechal and Pip Rudge are amazing YouTubers who share their mental health journeys, through the good and the bad, generating awareness of mental illness, and inspiring hope to all their followers. Doing Mental Health Conferences have also allowed me to come across inspiring individuals living with mental illnesses, such as Peter Bullimore, Rufus May, and Ben Robinson to name a few. I have also had a number of peers come up to me talking about their experiences of mental illness which I have true admiration for, and am honoured they have found trust in me and the courage to speak up.

Jerome: What challenges lie ahead for you? What do you most want to achieve in the future?

Maddi: Personally, or professionally? I think personally, my biggest challenge that lies ahead is continuing my sobriety and focusing on my own recovery journey and treatment plans. Professionally, my biggest upcoming challenge and goal I have set out is to complete my PhD researching into mental health interventions in Higher Education, and getting as much experience in the industry as possible. In terms of achievement, all I want to do is be the best professional I can be, and I want to me able to make an impact with my research and be able to use this to help as many people as I can. I want to keep doing what I’m doing, just bigger and better!

Jerome: What would you most like to be remembered for?

Maddi: My honesty and openness in the world of mental health, along with my compassion for those around me and my drive to help others. I don’t care about being famous and remembered by everyone, but I want to make an impact through my mental health campaigns, my story, and my research. Even if I only help a handful of people and leave an imprint on their lives, I will have done my job.

Conclusions

This series has brought me into contact with many remarkable people, all of whom have shared their own stories of recovery and growth. Each person has an impact on the wider world in a different way. I find myself thinking “What Maddi did next?” This paper has offered a snapshot of Maddi’s journey thus far. I believe she has so much still to offer the field of mental health as an educator, activist, advocate and in the future as a writer and maybe even as a clinician. What Maddi did next is sure to inform and inspire and I look forward to her further insights and achievements.

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Surviving sixth form: a story of mental health in adolescence

Carys J. Morley

Abstract

Purpose – The purpose of this paper is to share experiences of attending sixth form with mental health difficulties and provide tips to young people for coping. Its aim is to encourage empathy and understanding of young people suffering with mental illness. It is the second in a series of three papers exploring mental health at different stages of education.

Design/methodology/approach – A narrative, first-person approach is taken.

Findings – Advice and reflections for young people with mental health difficulties are provided.

Originality/value – The paper is one person’s experiences and is therefore unique. It contributes a voice to the much-needed discussion on teenagers and mental health, and promotes an understanding of mental health to both teenagers who maybe experiencing difficulties and those who know such teenagers.

Keywords Mental health, Adolescence, Sixth form, Borderline personality disorder, Education, Depression, Service user, Emotionally unstable personality disorder

Paper type Viewpoint

My story

After the traumatic five years spent at secondary school, sixth form was a chance for me to start anew. I spent the summer between secondary school and sixth form alone – I did not see anyone except my family. I spent my summer reading, sleeping and playing games. I did not attend my secondary school prom, and did not speak to anyone I attended school with. And the day I got my GCSE results, I knew I needed to put the whole horrible ordeal behind me.

Something new and interesting happened to me that day, however. I achieved far better grades in my GCSEs than I had been anticipating. I got into a grammar school sixth form, notorious for its exceptionally high achievement and privileged students. After years of being told and believing that I was worthless, something clicked. I finally had value: I could be smart. Smart Carys was an identity people might like! Smart Carys was useful and people respected her. Smart Carys was fashionable, nonchalant and effortless. She would make friends with the fancy and smart grammar school people.

I tried to imagine what a clever person looked like, and bought clothes accordingly. I bought stationery; notebooks; binders; a fancy diary; got a fancy new haircut and dyed my hair. I was ready to step into my new role as Studious Carys. I thought of all of the people who would want to be friends with me because I knew things. Once I had accrued some respect, I figured that I would be able to trap people into friendship – lure them in with smarts, and keep them with my new, nonchalant and painfully cool persona. It was a fool proof plan!

On my first day of sixth form, I was thrown aback. The first person I saw as I walked into my registration class for the first time was the boy who assaulted me when I was 15. His smug face would greet me every single morning, a cruel reminder of everything I had resolved to forget. He stared at me from across the room on my first day, and I welled up within the first 15 minutes. I heard him laugh and joke and tell everyone about his amazing summer; every word spoken in that
arrogant voice felt like a kick on the shin. I remained silent throughout the tutorial, despite my earlier resolve to make new friends. Not a great start, but I was there to be clever, and not to be popular – I had never been popular before, and I tried to convince myself that there was not any reason to start. I found a bit of comfort in that, but my intense longing for friends was not easily subdued.

Later that day, I had my first lesson: history. Great, I thought. I was good at history in school. This will be fine.

I quickly discovered that every single person in that class, bar one, had gotten an A* with ease, whereas I worked relatively hard to achieve my A grade. My fellow students were actively comforting the other girl who received an A grade, patronisingly suggesting that it was “still quite good”. The teacher discussed the syllabus with a class full of people vastly more knowledgeable than me, even laughing at an obscure Henry VIII-related joke that I did not understand. I had never felt more humiliated or stupid in my life. The teacher scanned the room, spotted me, and said “you. What did you study on your syllabus?”

Again, I was thrown. I stuttered for a few seconds and managed to utter “medicine. History of medicine”. She said “what else? That can’t be all. Come on, speak up. You’ll need to speak to do this course”.

She was terrifying.

Later, I had English Literature. English had been my favourite and best subject since I could remember; I had nothing to fear.

Wrong again.

The teacher immediately started discussing all of these classics that I should have heard of but just never had; he asked the one of the girls I had seen in my tutor class whether she enjoyed Lady Audley’s Secret over the summer. I did not know what that was. The last book I read was about a kitten and I really liked it.

That was the end of my first day.

I was heartbroken. Everyone that I met today was a thousand-fold better than me, and no one wanted to talk to me. So much for being clever. I decided that if I could make it through sixth form with a straight set of Ds and a shred of dignity that would be the best outcome I could possibly desire. I had a panic attack on the way home, and spent the evening bashing my head against the wall and howling.

I started the next day with English Language. The teacher was smiling and encouraging. She did not expect us to know what a noun phrase or relative clause was – she taught us. I found myself immediately understanding the material and helping the boy sat next to me – my first friend! The teacher asked to see me at the end of the lesson and officially welcomed me to the school, and said she had a feeling I would make a fine linguist.

The same feeling of warmth enveloped me as the day I received my GCSE results. I felt worth a penny instead of less than a piece of mouldy bread in the bottom of a bin. For a moment, I felt proud. I felt confident, like I had something to offer. The teacher clearly liked me – because I was good at English. The thought that she was just being a genuine, welcoming and friendly teacher was just not a good enough explanation. She liked me because I was good at English. Therefore, everyone will like me if I am good at everything.

I knew what I needed to do: study. Study everything. I needed that feeling. It was the sweetest feeling I had ever experienced.

And thus began two years of exceptionally intense studying. Worrying. Grade-chasing. Isolating myself to write extra essays. Obsessively researching exam techniques.

I improved – quickly. I bought oodles of classics, and devoured them – most of them I even enjoyed. I read up on Tudor history; watched documentaries on YouTube; bought some second-hand books from a charity shop. Incidentally, I still harbour a real passion for the Tudor period. I read ahead in English Language, finding linguistics essays online to read and cite in the class. By the end of November, I was making As in all three classes.
My fourth subject was economics. I chose economics because, well, because the boy who assaulted me was in psychology, which was my preferred subject. I dropped it as soon as I found out. Although I had managed to move registration classes to be away from him, economics was a painful reminder of what had happened with that boy. Every time I had a lesson, I thought about that incident. It made me more determined to succeed, as if I would “defeat” the boy by becoming the world’s finest economist. I did not become the world’s finest economist, but I did well in the class. It was the beginning of the healing from the assault.

By around early December, people in my classes had started chatting to me. I managed to integrate myself with a group of around 12 studious, friendly, close-knit, funny and yet relaxed people. They were dedicated to their studies and the majority of them were Oxbridge candidates, pressured to achieve from an incredibly young age. We became friends and I am still friends with some of them today.

I was paranoid whenever they spent time without me. I thought they had group chats without me, were passing notes in class about me. I would monitor and scrutinise every action, and felt betrayed and abandoned if they did not reply to my messages. I had never really had friends before, so I did not know how to act.

I knew why they liked me. It was because I was clever. There was nothing else likeable about me, so I knew it must be that. The logical conclusion was to work harder and get better grades so that they liked me more and invited me to things. If I felt that they were pulling away from me, I would tell them how I recently scored 20/20 in a test. That will do it, I thought – they cannot dislike me now!

I talked a lot about lessons and classes and grades. I did not really have any hobbies other than doing school work, so I did not have much else to talk about. I was doing extra essays just to get that shot of self-worth – the high of achieving. I needed it. It was addictive. I stayed behind after lessons hoping that teachers would talk to me and praise me. In total contrast to secondary school, I could not wait to go in every morning, because I knew I would get approval. My teachers approved of my dedication and actively encouraged me, and often implied that other students were not dedicated enough.

The thing is, I never thought that I was actually clever. I knew that grades and intelligence were not married concepts. I knew I was good at learning and regurgitating information. Not so deep down, I knew I was still worthless. I was just really good at pretending I was not worthless for a quick flash of approval and contentment.

My grades continued to rise. I was regularly achieving 100 per cent in assignments and exams. I expanded my knowledge in general – I became interested in politics and world affairs for the first time. I even decided to go to university, which had not been a particular goal or concern of mine before. I attended a summer school at my dream university, which I loved every second of – even though I still felt very behind and like a total idiot. Still, I was getting good at pretending to be smart.

Regardless of my façade, I would still panic that my essays were appalling, and that the teachers would give me a B and they would hate me and kick me out of my class and never want to speak to me again, and then my friends would hate me and then I would have nothing again. I had anxiety attacks almost every day leading up to my exams. I thought I would lose everything. I got angry at my family when they distracted me from writing essays or studying. The harder I studied, the more my new friends seemed to start to push away. “Why would they do that?” I wondered. Did they realise I was ugly and useless?

My sister suggested that I was upsetting other people by persistently chased grades. She told me that by having such high standards for myself, and being disappointed with an A−, I was upsetting people. I was offending people for thinking an A− was bad. Whenever I felt that my friends were pulling away, it was likely that the thing I had been using to try and get them to stay close to me was actually pushing them further away. I had always believed that this was their attitude and I was simply replicating it in order to fit in. They clearly valued intelligence, so why did not they value mine?
I was confused. The A’s were to supposed to mean that I was worth something to other people. They meant I had a redeeming quality. I did not care about anyone else’s grades: everyone else had likeable qualities and did not need to prove themselves. I was on a mission to prove myself. Any comparative behaviour had been me trying to fit into an inherently competitive system, in a school which promoted belittling the less fortunate. In the process, I had isolated the very people I was trying to impress. I had made myself more hateable. And to top it off, I got rejected from my first choice university after interviewing me. I was not smart. People did not like me. The university I have been dreaming of rejected me even though my grades are more than good enough. They saw through it when they met me. They knew I was awful.

I tried to kill myself when I realised this. I tied a noose and hung it on my bedroom door. It broke and I fell down. I just cried and starved for a few days instead.

I was reluctant to leave sixth form once my final exams were finished. I made friends, and although I messed a lot of those friendships up, I found two of my most enduring friends.

I cried on our last day. I cried at our prom. I cried on results day. I cried in the car on the way to university – I did not want to go. University was a regression, of sorts, but I will look at that in my next piece.

A few months later, I received my A-level grades: the highest in my cohort. I won two achievement awards. It felt strangely empty. I had achieved exactly what I had set out to achieve: friends, and good grades. Why did not it feel better?

Reflections

Despite the anxiety, the strange shift in my mental health from apathy and depression to mania, paranoia, and fear, I enjoyed sixth form. I enjoyed the subjects, and although I approached it unhealthily, I learned a lot. I learned a lot about the world and what I care about. I discovered that, yes, I am a critical thinker. I love to question and learn and improve. I love classics but I also love books that just make you feel nice and mushy inside. Learning the basics of economics was not something I thought I would ever enjoy, but I did, and I know that those studies have shaped me and encouraged me to be a more politically active and engaged person.

I learned a lot about myself and who I genuinely was, for the first time in my life. It was like an intense course in learning to be me.

Sixth form was an abyss of anxiety. I did not realise it until recently (circa March 2019), but I was beginning to exhibit signs of Borderline Personality Disorder:

- Instability in my relationships – I was paranoid, intense, even obsessed – but whenever I feared I was being abandoned by my new friends, I decided that they were horrible and I hated them.
- Fear of abandonment – having friends really illuminated the problems I have with abandonment. I assumed they hated me if they did not invite me to walk with them to the next lesson. I looked at their social media multiple times a day to see if they had done something without me. I lied to them a lot to keep them close or to get them on side. It has been one of the hardest parts of my life, coming to terms with the fact that I cannot control how people see me or react to me. You cannot force people to like you.
- Splitting, or black and white thinking – my self-loathing or self-confidence really stemmed from grades. I was either terrible or great, depending on my grades. I felt similarly about my friends – when I was with them, they were great, perfect people. If they decided to abandon me, they were evil. If someone showed me the smallest bit of kindness, they were my new best friend.
- Shifting or unstable identity – Studious Carys had a specific wardrobe. Cool Carys had a specific wardrobe to match her cool new friends. History Class Carys had a specific demeanour and attitude – calm, collected. English Class Carys was different again – talkative; engaged; excited; hyper. Tutorial Carys was different – a shy mouse. These were intentional switches. I also genuinely did not think that I had any good characteristics. Thus, grades became a physical
manifestation of the goodness I so desperately wanted have within. If people could tell me I was
great, maybe I was. Maybe the illusion was enough.

- Trouble regulating emotions – I tried to kill myself because I did not get into my first choice
university. Two days later, I was extremely hyper because I was able to write an essay on my
favourite book, Les Miserables. A day after that, I was furiously angry because one of my
socks went missing (culprit: the cat).

- Paranoia – I was constantly paranoid that my friends were conspiring against me in order to
shift me out of the friendship group, or more ominously, to hurt me intentionally, as if we were
living in a sort of bizarre combination of Game of Thrones and Mean Girls. I wrestle with
paranoia a lot today still. Sometimes it becomes hard to tell what is real or not.

I would not be diagnosed with BPD for several years more. Instead, I was left to wrestle with my
sadness, terror, anger and fear. When I was shipped off to university by my parents, my whole
world changed – and I was not ready for it.

Advice

It can be easy to develop and unhealthy focus on grades when you are in education, let alone
when you are suffering with mental health difficulties. For people with BPD, or similar conditions,
overachieving can be an escape or a medium through which symptoms may appear. I sought
validation through grades; this is not uncommon for someone with BPD. For others, the pressure
of getting into university or getting a certain job that they desire is enough to create an unhealthy
relationship with academic achievement.

The imperative for young people to succeed academically is crushing. The competitive nature
of university applications can lead to animosity between friends, and feelings of self-loathing or
failure at the age of 16. This is difficult for any young person. It is difficult to process this in a
healthy, constructive manner if you have mental health problems. I let my grades take over my
life. Moreover, I let them take over my identity. Sixth form colleges actively promote this attitude,
often belittling students who do not achieve the highest grades, and shaming students who do
not spend every spare second studying. This environment inherently creates problems, and
worsens existing ones in students like myself. The fact that my damaging behaviour was
rewarded is enough to suggest that the expectation on young people to achieve is unrealistic
and unfair.

I wish someone had told me that much of this rigour and stress was arbitrary. I am not sure that I
would have listened, as BPD is not a rational condition. But if I could talk to the younger me, I
would say to her:

- Grades are not an accurate measure of intelligence. Someone with an A* is not inherently
more intelligent than someone with a lower grade. They were better at taking an exam on the
day – which is something to be proud of. But grades do not assess you as a person, or your
unique and you have so much more to offer than that.

- Academic and financial success are measurable. But they are not all what is to life. Life is
passion, and love, and people. Never compromise yourself to get 100 when you have already
achieved 99. Go hiking with your new friends! Read more books! Be a teenager.

- When you are a student, it can feel like your whole world is grades and exams and essays and
learning. It is not. Life is much more – my lower-than-expected GCSE physics grade meant a
whole lot less when I was offered my first job in publishing – a life-long interest and goal of
mine. It will mean so much less when you fall in love and your life is filled with joy and comfort.
There is a whole world – a big, big world – outside of this.

- Identities are not constructed around a single trait. Being clever is not an identity, and even if it
were a valid identity, grades are not indicative of this.

- Be empathetic. You may think that your hard work and high marks will ensure people like you,
but you are isolating people. And you of all people knows how that feels. Do not do it to
other people.
I am so happy that you have finally found some things you are passionate about – including learning and researching and enquiring – but again, these are separable from grades. Not everything has to have some kind of validation associated with it.

Little did I know, I would learn all of this the very hard way.

The amount of pressure put on young people to achieve is tangible. Combine that pressure with the generic difficulties of being a teenager and the complications mental health brings, you have got a recipe for disaster. Perhaps if we focussed on young people becoming emotionally intelligent, well-rounded and healthy citizens, good grades and attainment may naturally follow.

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Future studies, mental health and the question of citizenship

Phil Morgan, Tula Brannelly and Sarah Eales

Abstract

Purpose – The purpose of this paper is to examine the value of utilising future studies to explore citizenship for people with mental health challenges.

Design/methodology/approach – This paper critiques the discipline of future studies and considers it in the context of the citizenship and mental health literature. It explores how future studies can be utilised to promote marginalised voices, such as those of people with mental health challenges.

Findings – Technology is leading to rapid change in society including what it means to be a citizen (Isin and Nielsen, 2008; Isin and Ruppert, 2015). Whilst citizenship has been promoted within mental health for a long time, change has been slow (Rowe and Davidson, 2016). In order to create inclusive opportunities for people with mental health challenges, any focus on citizenship in mental health needs to not only address the present time but to anticipate and influence future technological directions.

Originality/value – This paper is original in bringing together mental health and the future impact on society of new technologies. It stands to offer a new perspective to discussions on citizenship.

Keywords Futurology, Mental health, Citizenship, Future studies

Paper type Conceptual paper

Introduction

Digital technologies are impacting on every sphere of life, including employment, leisure, transport, relationships, health care and education. All are changing at a rapid pace (Chace, 2018; Harari, 2016). As digital technologies are changing everyday occurrences, they are influencing what it means to be a citizen. New practices of citizenships are emerging including digital citizenship (regular users of the internet who engages in politics and social movements via information technology), consumer citizens (people who define their citizenship through their purchasing choices), global citizens (people who define their citizenship through a sense of shared humanity and roles and responsibilities that transcend the nation state) (Isin and Nielsen, 2008; Isin and Ruppert, 2015).

Future Studies include disciplines such as sociology, media, cultural, technology and business studies, and make predictions on changes to society based on economics, climate, demographics, political theory and developments in information technology (Potts, 2018). Whilst predominantly used in business, planning and policy making, as an academic study there are opportunities to adopt critical sociological perspectives (Potts, 2018; Bergman et al., 2014). There is also a growing body of popular Future Studies literature that is exploring the likely changes of society due to technological advances and how this will impact on citizens (Chace, 2018; Harari, 2016).

In terms of civil and human rights, people with mental health challenges continue to be significantly excluded from participation in society and experience stigma and discrimination (Slade et al., 2017). This results in social exclusions that perpetuate and sustain inequalities. Recent enquiries into the causes of mental ill health have identified the role of structural inequalities which has led to a renewed call to examine citizenship so that people with mental
health challenges are able to access the same opportunities and enjoy the same rights as other citizens (Hamer and Finlayson, 2015; Hamer, 2012; Hamer et al., 2019; Harper et al., 2017; Rowe, 2015; Rowe and Davidson, 2016; Slade et al., 2017). It could be argued people with mental health challenges have a unique experience of citizenship, as their human rights are dependent on their health status, for example when detained under the Mental Health Act (Brannelly, 2018; Hamer and Finlayson, 2015; Vervliet et al., 2019). Due to these fundamental concerns, citizenship is often fought for, a contested concept and challenged within the survivor movement. Despite this the pace of change has been slow. Neither the de-institutionalisation in the 1980s and 1990s nor the Recovery movement have delivered the level of equalities required (Eiroa-Orosa and Rowe, 2017; Rowe and Davidson, 2016). Now, there is another ubiquitous issue that needs to be considered in this debate, and that is the role of technologies.

Due to the impacts of technology society is changing rapidly. This paper will argue that it is important that citizenship for people with mental health challenges is not just explored in the present but also to look at future impacts. Currently, the development of this tech-led future society is driven by industry (Potts, 2018), to the exclusion of other voices (Bergman et al., 2014). People with mental health challenges, as a marginalised population, are excluded from contributing and influencing the conversation about citizenship, rights, the use of technologies and the future. The technology industry focus is on people with higher levels of social connectivity and social capital to monetarise their social value, and these industries are less interested in marginalised populations (Skeggs and Yuill, 2016).

Bergman et al. (2014) argue that part of the Futures Studies approach is that there are opportunities for marginalised voices to play an active role in shaping futures, for example, feminist Future Studies approaches challenge existing power structures. It can also be a vehicle for expressing constructive hope when dealing with complex social issues such as climate change (Ojala, 2015). This paper explores literature relating to Future Studies, citizenship and mental health and poses the question do Future Studies have a role in promoting citizenship for people with mental health challenges?

Visions of the future

One consensus in the Future Studies literature is that over the next 20–40 years (2020–2040) there will be significant advances in technologies which will influence what it means to be a citizen (Chace, 2018; Harari, 2016; Potts, 2018). Typically, these tend to be dystopian or utopian predictions. Dystopian futures are characterised by increased social control and inequality where the privileged elite have access to the benefits of a technologically driven society or even a society where Artificial Intelligence (AI) itself takes control of society and dictates to humans (see for example Harari, 2016). Utopian futures are described as heralding a new age of democracy, equality and creativity due to technology (Bregman, 2017).

Calum Chace (2018), in his book *Surviving AI*, describes the following future scenario where a character called Julia describes a day in her life, summarised below:

> Julia wakes up refreshed having been supported by her digital assistant to monitor her sleep patterns. Her health is monitored and ensures she is healthy and well. Based on her morning health readings, the digital assistant provides advice on diet and what to eat for breakfast. Overnight a drone has delivered a new outfit for work [...] Whilst she commutes, her personal assistant helps her prepare for work and suggests news stories of interest. As the journey continues she relaxes by wearing a virtual reality (VR) headset allowing her to look at the journey as if it had been in the Victorian era [...]. At work, she uses the latest psychological evaluation algorithm to understand how best to communicate with the people in her virtual meeting. Using VR technology she communicates with people across the world. After dark, on the way home from work she has her personal assistant checking the street CCTV cameras to ascertain the safest way home.

Whilst this is a fictional account, it paints a picture of how technologies may impact on employment, housing, health, transport, leisure and security. Perkins and Morgan (2017) argue that if people with mental health challenges, in line with the social model of disability, had greater access to social supports or adjustments this could empower people to access the opportunities open to all in society. If technologies were harnessed to promote inclusivity they could provide...
some of this additional support. Many of these new technologies are already with us or are under
development. For example, digital innovations within mental health care include chatbot therapy,
smart phones being used to monitor relapse from psychosis, wearable technologies to monitor
physical and emotional health, diagnosis through the use of AI predictive technologies,
monitoring for suicidality on social media and remote stress or symptom monitoring. People with
mental health challenges are already interacting with technology to monitor and support mental
wellbeing. For example, people are using Alexa or Google Home to discuss their emotional
distress (Luxton et al., 2016; Miner et al., 2017; Poulin et al., 2016; Tal and Torous, 2017).

These developments, not just in healthcare but across wider society are raising new ethical
questions about the impact on citizens’ rights, in particular around surveillance, privacy, data
and algorithmic programming (Harari, 2016; Luxton et al., 2016; Poulin et al., 2016). This is particularly
important for marginalised groups, such as people with mental health challenges, who already
struggle to access their full rights as citizens. There is also evidence that people with mental health
challenges are disadvantaged by some of the algorithms programmed into social media (Skeggs
and Yuill, 2016). People with mental health problems are one of a number of groups who are
more likely to be digitally excluded (do not have access to or are unable to access the internet).
Therefore, they may not have the opportunity to engage in digital citizenship (Greer et al., 2019).

As well as ethical challenges these technologies have the potential to benefit the lives of
citizens. For example, work may become less important as AI takes on more traditional
employment roles and there may be a greater focus on happiness and wellbeing rather than
measuring a nation’s success on Gross Domestic Product (Bregman, 2017; Harari, 2016). This
is something that Slade et al. (2017) have advocated in regards to promoting the mental health
of the whole population.

Citizenship

In western society, citizenship has conventionally been the relationship between the individual
and the state and the balance between the rights and responsibilities of each (Ponce and Rowe,
2018.) This definition and balancing of rights and responsibilities are based on social norms and
favour some groups over others and can sustain oppression (Atterbury and Rowe, 2017; Vervliet
et al., 2017). In the UK in particular this tradition has grown out of the work of T.H. Marshall and
his seminal work from 1949 Citizenship and Social Class (Marshall, 1987) and the establishment
of the welfare state. He describes how people have civic, political and social rights. However, the
tradition has been criticised from a neoliberal perspective arguing the welfarist approach has
been replaced by individuals taking personal responsibility (Atterbury and Rowe, 2017). It has
also been criticised by feminists and post-colonialists for its gendered and ethnocentric stance
(Hamer et al., 2019). It was never intended to take into account the needs of people with
disabilities or mental health problems, it was designed to support the employed when not in
employment (Atterbury and Rowe, 2017).

Citizenship and people with mental health challenges

Ponce and Rowe (2018) argue that by critiquing citizenship and understanding who is included
and excluded, the concept of citizenship can be used as a vehicle for social change by exposing
the processes of exclusion and advocating for marginalised groups. There has been a
long-standing movement within mental health, and in particular the survivor movement to
promote citizenship and equal rights. This can be traced back to the development of moral
treatment in the nineteenth century, through deinstitutionalisation in the twentieth, to the current
recovery movement (Rowe and Davidson, 2016). Despite this focus each of these approaches
has failed to deliver access to full citizenship for people with mental health challenges (Rowe
and Davidson, 2016; Slade et al., 2017). This is largely thought to be due to the dominance of the
combination of systematic injustices and the dominance of the abnormality approach to mental
health. People with mental health challenges disproportionately experience the injustices of
unemployment, forced treatment and compulsion, poverty and hardship (Brannelly, 2018). These
injustices do not stand alone; they intersect with other forms of discrimination and structural
inequalities relating to ageism, disablism, poverty, racism, sexism, homophobia and transphobia. When mental health is approached primarily from a clinical standpoint these problems become located in the individual rather than people’s psychological and social context (Faulkner, 2017; Rowe and Davidson, 2016).

Faulkner (2017) argues this long-standing view of locating the problem within the individual has been reinforced through the dominant ideology of neoliberalism. This, she argues, not only links to clinical understanding of recovery but also to those ideas of personal recovery leading to an over reliance on promoting personal responsibility to the exclusion of understanding the impact of the material conditions and context within which the person lives. This is happening despite the origins of the recovery approach being within the service-user survivor movement. There are claims these attempts to promote citizenship have been “colonised” by policy makers to harness the values of empowerment and mutual support to cut services and blame individuals for their problems (Eiroa-Orosa and Rowe, 2017). Faulkner (2017), Rowe and Davidson (2016) and Slade et al. (2017) state that in order to address these inequalities it is essential that approaches to citizenship and mental health have the voice and experience of people with mental health challenges at their centre and that solutions need to be led by or co-produced with people with mental health challenges and be linked to the wider disability struggle and identity politics.

Rowe and Davidson (2016) promote a citizenship framework to tackle these injustices. Their citizenship framework is defined by the 5 Rs of rights, responsibilities, roles, resources and relationships that a democratic society makes available to its members through public and social institutions, social networks and everyday social interactions. Rowe and Davidson argue that services should promote citizenship as the foundation of recovery from mental health challenges not the end point. They propose a twin focus for mental health services to support this agenda. First, by undertaking community development work and second, developing a citizenship education programme for people accessing such services.

They have also developed a measure and training programme which they are in the process of piloting. It evaluates both individual support towards citizenship and community change.

**Acts of citizenship and people with mental health challenges**

Hamer et al. (2019) and Brannelly (2018) take a different position on understanding and promoting citizenship within mental health services. Rather than looking at the 5 Rs as a citizenship framework they explore Isin’s work on *Acts of Citizenship* (Isin and Nielsen, 2008). Isin and Nielsen (2008) and Isin and Ruppert (2015) argue that citizenship should not be constituted as a single definition or even multiple definitions but instead should be understood as Acts of Citizenship. They critique traditional approaches to citizenship linked primarily to the relationship between the individual and the state, as reductionist, arguing people are citizens across multiple domains such as global citizens, consumer citizens and digital citizens. They suggest that it is more useful to explore acts of citizenship as a concept in its own right outside of the usual definitions of citizenship. *Acts of Citizenship* are described as the events through which people constitute themselves as citizens and this creates a pluralistic understanding. They claim that such acts involve both responsibility and answerability, but are irreducible to either. As Acts of Citizenship are either collective or individual deeds that rupture social-historical patterns, they are able to lead to positive change for marginalised groups. This provides opportunities for feminist and post-colonial critical perspectives. Therefore, they transform people from being passive subjects to political actors creating new ways of being as citizens (Hamer et al., 2019).

Hamer et al. (2019) used this framework to interview peer workers and professionals working within inpatient mental health services. They explore how mental health workers promote inclusion by subverting rules and organisational practices as existing practices and structures do not effectively support peoples’ access to full citizenship. Hamer et al. (2019) argue that by making these practices visible this can lead to organisational change. They argue a citizenship-based rights framework for mental health workers can embedded and prioritised to support inclusion and citizenship.
Brannelly (2018) through a study titled Acts of Citizenship explored the priorities of service user activists campaigning for change in mental health service provision. The service user activists from New Zealand and England – unequivocally their priorities for change were the removal of the use of force, compulsory treatment and detention. The study questions the ways in which people experience a lack of care within mental health services and question the lack of progress within service provision. The work explores which practices are just or not and how the marginalisation and subjugation of certain groups can be challenged through Acts of citizenship.

Whilst none of the research outlined here explores the impact on citizenship of future technologies, it does outline priorities to support people’s participation as full citizens. These are: rights and care in relation to compulsion, and alternatives to restrictive practices, access to relationships, employment, housing and leisure activities, freedom from discrimination and stigma. They also highlight the importance of understanding how these issues intersect across all protected characteristics.

As the pace of social change for people with mental health challenges is slow it could be argued that it is essential to explore both the impact of future technological advances and the changing multi-dimensional nature of citizenship. If there is not a future focus, the developments on citizenship within mental health could be misaligned with the direction of society or miss opportunities to contribute to these discussions. This is especially important as it is not just governments but also large corporations, in particular technology companies, such as Google or Facebook that are shaping the future (Potts, 2018) and in turn include and exclude the voices that contribute to those discussions (Bergman et al., 2014), and who gets access to data for research (Edwards and Brannelly, 2017).

Future studies and mental health

Whilst there are numerous studies looking at future developments in mental health (a search of Medline and CINAHL returns 100,000 articles), the utilisation of the academic approaches of Future Studies has only had limited application within mental health. These studies have focused on population changes in relation to dementia and not changes to society due to technology (Abramson and Halpain, 2002; Connolly, 2012). Whilst they do not focus on citizenship they do demonstrate the value of future thinking and planning in relation to dementia. They also show the limitations of the approach in the challenge of only being able to see things in the context of your own time and context, as the emphasis is on professional solutions rather than technological or community solutions. Connolly (2012) argues that in mental health Future Studies is under used and even there is a focus on the future it looks at immediate threats and consequences, not the medium to longer term future.

One exception to this, whilst not a research paper, is a Youtube video created by a service user activist O’Hagan (2013), who imagined a radio interview set in 2042 which describes the repeal of the Mental Health Act. This approach has a lot in common with the Future Studies approach of back casting (Davidson, 2017) and gives concrete examples of how current United Nations human rights documents can shape the future. As often with service user led research, rather than the focus being clinical it is on how society and the state responds to people in distress (Faulkner, 2017). Within the video there is very little on the use of technology and how this could impact on restrictive practices within mental health services. However, this is a good example of how future thinking approaches can contribute to discussions on citizenship and human rights in both the present and the future. Within the Future Studies literature itself mental health is very much explored through the lens of clinical recovery and the need to change peoples’ brains rather than the need to change society (Bregman, 2017; Chace, 2018; Harari, 2016).

The value of future studies

One of the key debates within Future Studies is the accuracy of prediction. Lee (2012) makes the claim that the future is knowable and that future studies should be considered a science. He argues that approaches that look for multiple perspectives are pessimistic and too concerned
with uncertainty. Potts (2018) counters Lee’s argument arguing that the evidence is not there to back up his claims and that people only really have the capacity to see things from the perspective of their own time, for example people expecting to have Jet Packs in the twenty-first century rather than predicting smart phones. Odeleye (2015) argues that Lee is overly optimistic about the ability of Future Studies to accurately predict the future and that Lee is too dismissive of post-modern approaches in being able to highlight complexities. They go on to argue that by treating Future Studies as predictive and not exploring the disadvantages Future Studies may bring, a full exploration is not undertaken for the benefits and threats across different sectors and therefore maintains the status quo. If Future Studies is not approached from a critical standpoint there is a danger that it may lead to self-fulfilling prophesies (Odeleye, 2015).

One of the challenges within the Future Studies literature is that it does not always explicitly articulate the political standpoint of the author especially those that take neoliberalism as a neutral standpoint. This maintains current political categories, choices and conflicts present in current power relations and gender dynamics (Bergman et al., 2014). Gunnarsson-Östling et al. (2012) state gender perspectives or perspectives of marginalised groups are rare within Future Studies and are often side tracked. Because of this it has been argued that Futures Studies does not have value for feminists. Bardzell (2018) and Bergman et al. (2014) counter the argument that future studies does not have value for marginalised groups by suggesting that if feminists do not explore future thinking, the possibility of bringing about more equal futures is diminished. They also argue that without embracing feminist methodologies Future Studies become monolithic and maintain existing power structures and that these feminist methodologies can lead to more critical and reflexive positions within Future Studies research and could radically change the dynamics of the field. Bardzell (2018) explicitly calls for feminist participative action in relation to the development of technologies.

It is important to note, that whilst feminism has not linked strongly with the academic discipline of Future Studies, future thinking has played a strong role in feminism in critiquing and challenging the status quo. Perhaps no more so than in Donna Haraway’s seminal book, from 1985, the Cyborg Manifesto (Haraway, 1994). In the Cyborg Manifesto, using blasphemy and irony, she breaks down the ideas of division between humans, machines and animals by exploring inter-species and technological kinship and how this challenges existing power structures and categorisations (e.g. between machine/living organism). Latimer (2017) describes how Haraway rages at technoscience, that whilst it has scope for inclusion, it is at the heart of division. Through the metaphor of the cyborg Haraway critiques traditional conceptualisations of gender, sexuality, humanity, nature and technology. Both Sofoulis (2015) and Latimer (2017) argue that revisiting these ideas from the context of the twenty-first century provides a new perspective on the work. Sofoulis (2015) highlights the importance of having values-based rather than positivist approaches to science and technology. Latimer (2017) calls for direct challenge of current divisions with more inclusive and collaborative visions for the future.

As well as Future Studies, in regards to mental health, it may be worth learning from other approaches to future thinking from groups who experience marginalisation. Capers (2019) puts forward a similar argument, to that of Bergman et al. (2014), for Afrofuturism. Afrofuturism is a unique discipline and is described as the intersection between black culture, technology, liberation, imagination and mysticism which can bridge the future and the past. As well as an academic discipline it is expressed through literature, art, music and film. It thereby helps reimagine the experience of people of colour providing an opportunity for black communities and African diaspora to engage in potential, real and imagined futures that can rupture the status quo, providing a link between the past, present and future (Womack, 2013). It could be argued that similar themes are important when advocating for equality for people with mental health challenges. Both Afrofuturism and Haraway’s Cyborg Manifesto show the importance of creativity in imagining futures and breaking down taken for granted power structures.

Bergman et al. (2014) propose that the purpose of utilising future studies with feminist methodologies is not to create a singular unified vision for feminist futures but rather to open new ways of thinking and innovative approaches. They suggest there are multiple ways of exploring feminist futures. These could be: imaging what the future could look like; describing preferred scenarios; working as “alarm clocks” [sic] if the future is not wanted or as a way of showing things are on the right track. Future Studies can encourage students to express constructive hope
about controversial social problems such as climate change rather than denying them or feeling passive (Ojala, 2015). There are specific teaching techniques within future studies such as discussion, role play and back casting (identifying a potential desirable future and then working backwards to identify the steps required to reach it) (Davidson, 2017). Gunnarsson-Östling et al. (2012) argue that participatory research methods are best suited to developing alternative futures, thus there is a commonality between Future Studies and participatory research methods. Both seek to transition students or research participants from knowledge consumers to knowledge creators (Davidson, 2017).

Discussion

It is clear there is a need for further research into citizenship for people with mental health challenges. There are a range of voices articulating that an increased focus on citizenship is required to challenge and change people’s experience within both mental health services and society in general (Eiroa-Orosa and Rowe, 2017; Faulkner, 2017; Hamer et al., 2019; Rowe and Davidson, 2016; Slade et al., 2017). It could be argued that the needs of people with mental health challenges in the present are so acute that exploring the future is a privileged indulgence which will be of limited immediate benefit and that all research should focus on promoting citizenship in the here and now. This focus on citizenship in the here and now should include ethical considerations in relation to technology particularly in relation to surveillance, privacy and algorithmic programming.

It is not proposed that Future Studies should be the only focus of citizenship research in mental health but rather it may complement existing directions. In both feminist Future Studies and Afrofuturism it is argued exploring the future it is possible to impact positively on the present (Capers, 2019; Bardzell, 2018). In addition, it is important to note that technologies are not the only impact on citizenship. Rowe and Davidson (2016) describe the importance of paying attention to the material, social, cultural and political environment in which recovery and citizenship can be impeded or nurtured. On-going austerity, climate crisis and demographic changes are also significant and may be more or equally important issues for people with mental health challenges to explore.

Digital technologies are changing society and what it means to be a citizen across multiple domains and these changes are taking place rapidly. Technological companies and policy makers already utilise Future Studies or future thinking approaches to ensure they anticipate challenges and set the direction for their own developments. If the same approaches are not explored for their validity within mental health this could lead to the rights and needs of people being left even further behind. Whilst there are very few studies in both gender studies and mental health research, there are indications that Future Studies could have value in supporting conversations around future societal change and engage and amplify diverse voices that are currently missing from conversation about the future (Bergman et al., 2014). In particular it is crucial that those who experience the greatest exclusions and rights violations due their mental health status are included, in particular those from the Black and Minority Ethnic community or LGBTQI community and those involved in the wider disability struggle (Slade et al., 2017). With the development of “Mad Studies” (Faulkner, 2017) lessons could be drawn from Afro-futurism to develop “mad-futurism” led by people with mental health challenges. Drawing learning from feminist future thinking participatory methods may be beneficial in developing research in this area. It would also suggest with the critiques of neoliberalism in the development of citizenship for people with mental health challenges feminist and post-colonial approaches would provide useful critical perspectives.

As technologies are impacting on what it means to be a citizen and are being delivered in healthcare it is more important than ever that people who experience mental health challenges are included and have the opportunity to lead these developments. This is not just in the testing of the technology but in the ethical considerations and the setting of agendas within the development of digital technologies within mental health. This means not just seeking engagement and partnership with mental health services and policy makers but also digital technology companies. At present within the literature there has not been a comprehensive review of the level of involvement of people with lived experience in the development of digital mental health products. It is evident one of the key priorities for citizenship for people who
experience mental health challenges is around coercion and unforced treatment (O’Hagan, 2013; Wilson et al., 2016). Therefore, it may be important to explore ethical technological solutions to promoting citizenship in this area. Also it will be important to include technology (and future technologies) in any proposed citizenship frameworks for people experiencing mental health challenges (Hamer et al., 2019; Rowe and Davidson, 2016).

As described above citizenship is a complex and contested concept. In order to discuss the future technological impacts on citizenship it is important to conceptualise citizenship which is flexible to change and provides a framework for challenge for people from marginalised communities. It could be argued Isin’s Acts of Citizenship has clear advantages over the other approaches to citizenship outlined. First, it has a broader definition of citizenship and incorporates broader forms of citizenship such as digital and consumer citizens. Second, it positions the individual as a political actor and defines acts of citizenship as acts that rupture the status quo rather than the individual experiencing citizenship as tension between the state and individual. It could be argued that participating in Future Studies research and contributing to generating new knowledge is an Act of Citizenship in itself.

As well as exploring the notion of citizenship, in order to explore future citizenship it may be worth exploring the following questions:

■ What are the likely technological impacts on citizenship?
■ Whose voices are being heard in the development of technology?
■ What threats and opportunities do technological changes present for people with mental health challenges?
■ How do each of these threats and discrimination intersect with other forms of discrimination and oppression?
■ What would desirable future citizenship look like?
■ What steps would need to be taken to achieve this?
■ What would be the “alarms” that it is off track and what can be the responses?

Conclusion

Does Future Studies have a role in promoting citizenship for people with mental health challenges? This was the question posed in the Introduction. This paper argues that it does, particularly as society is changing quickly and changes for citizenship for people with mental health challenges have been slow. Future studies can provide a framework to prepare for these changes, express constructive hope and be a way of sounding alarms. It is important to acknowledge the limitations of Future Studies; that it is not predictive and people can only see things from the context of their own time, nevertheless it can be useful to explore and critique power dynamics and create opportunities for marginalised communities. It is important not just to look at the future, many of the technologies are already under development or are being applied within mental health care. It is essential to understand what extent are people with mental health challenges are involved in setting the agenda for new innovations and then the extent to which they are co-developed. It is recommended a scoping literature review is undertaken to explore this. It is also important to continue to be aware of the digital exclusion of people with mental health challenges and the reasons for and consequences of this. The other key consideration both now and in the future is the ethical implications of digital technology and big data in relation to all citizens but in particular those from marginalised groups such as people with mental health challenges.

It is vital people with mental health challenges are able to lead and contribute to discussions that shape future citizenship. Participating in these discussions could be considered as an Acts of Citizenship as they have the potential to expose inequality and contribute to discussions on social change. In relation to digital technologies it is also important within this to explore engagement with technology companies and how these conversations can be shared and promoted across all stakeholders, including mental health professionals, family members and the wider community.
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A peer mentoring initiative across medical residency programs

Marie Fournier and Leon Tourian

Abstract

Purpose – Several studies have shown benefits of peer mentoring on wellness among medical students and health care professionals. Peer mentorship has also been pointed as having interesting potential for International Medical Graduates. However, the literature on peer mentoring at the residency level is very limited. The purpose of this paper is to assess the benefits of a resident-led pilot peer-mentoring initiative at McGill University.

Design/methodology/approach – Over 2 years, 17 residents from various residency programs were put in contact with a volunteer peer mentor by e-mail. The structure of the mentorship was flexible. A survey using Likert scale and free text responses was sent to all the participants.

Findings – There were response rates of 65 percent for mentees and 59 percent for mentors. The majority of mentees thought the service was either moderately helpful (18 percent) or helpful (36 percent). Several residents noted that communication by e-mails and lack of in-person contacts were a limitation in the mentorship experience. The most frequent challenge that led to consult the service was immigration or arrival from another province.

Originality/value – The results show that the program can be helpful to medical residents, is cost-effective, flexible and could be adapted and replicated elsewhere. In the future, the program will adjust to tend toward a more structured frame, highlighting the importance of in-person contacts. The small sample size of participants and the recall bias are some limitations of our study.

Keywords Wellness, Peer mentoring, Mentorship, Smart technologies, Postgraduate medical education

Paper type Case study

Introduction

High rates of burnout and diminished wellness among medical residents have been well studied and documented in the past decades (Dyrbye and Shanafelt, 2016; Dyrbye et al., 2014; Holmes et al., 2017; Markwell and Wainer, 2009; Soares and Chan, 2016). In addition to the pressure inherent in medical training, residents (postgraduate physician learners training to become family physicians or specialists) are asked to perform in administrative positions, as teachers, and in research. Some residents have the additional challenges of parenting or adjusting to a new culture away from their family and support networks. Given these demands, peer support becomes important to preserve wellness while going through residency training.

Peer support in mental health services has gained interest over the years (Perkins and Repper, 2019). In these models, peer workers are integrated into clinical services where they share their lived experience within the mental health system with patients in ways that mental health providers cannot. Despite some evidence for peer support in the literature (Bellamy et al., 2017; Repper and Carter, 2011), its underpinning mechanisms are not fully understood due to heterogeneity in the peer support literature (Watson, 2017).

Similarly, peer mentoring, another form of peer support, is not clearly defined, though generally understood to be a model in which groups with similar professional profiles and experiences engage in a mentorship relationship. The concept of mentoring itself has numerous definitions (Berk et al., 2005; Chen et al., 2016; Dawson, 2014; Jacobi, 1991) and it has been studied in various fields as presented below.
Several studies have shown the value of peer mentoring on wellness among graduate students (Bowman et al., 1990; Grant-Vallone and Ensher, 2000; Murdock et al., 2013). In the Counselling and Personnel Services section (CPS) of the School of Education at Purdue University in Indiana, graduate students who faced multiple or challenging transitions rated a new peer-mentoring program’s value highly and felt their peer mentor, a more experienced graduate student in the CPS program, had made a difference (Bowman et al., 1990). In a similar program at a mid-sized western US university, a co-mentorship scheme was developed where doctoral students were paired with master students. Both mentees and mentors reported that the program had helped them foster their professional identity (Murdock et al., 2013). Those results are similar to others obtained in a peer-mentoring program in the psychology department of a private graduate school in the USA where first-year graduate students enrolled in the program received psychosocial and instrumental support from their peer mentor (Grant-Vallone and Ensher, 2000).

In the health science field, peer mentoring has been well described in nursing (Ford, 2015; Gilmour et al., 2007; Rohatinsky et al., 2017), for medical students (Akinla et al., 2018; Altonji et al., 2019; Andre et al., 2017; Taylor et al., 2013) and medical faculty (Fox et al., 1998; Lord et al., 2012). Peer mentoring has also been identified as having interesting potential for international medical graduates (IMGs) (Warwick, 2014). However, the benefits of peer mentoring for medical residents has not been well established because literature on the matter is limited to very few studies. In a mentoring program where 21 first-year residents in obstetrics and gynaecology were paired with senior peers, 93 percent of mentees reported it had been helpful and 75 percent responded they had encountered work-related or training difficulties in the first 6 months of the mentoring program (Cowan and Flint, 2012). Similarly, in a small-sized pilot program among surgical residents, all six mentees reported that the peer-mentoring scheme was a good addition to their training (Vulliamy and Junaid, 2012). Finally, in a peer-mentoring program in pediatrics (Eisen et al., 2014), nearly all mentees (17/18) and all mentors (18/18) found the program useful.

The aim of this study is to assess the perceived benefits and explore the experiences of residents who participated as mentors and mentees in a pilot peer mentoring initiative at McGill University called Doc-to-Doc. The intent of the program was to provide a service through which residents could reach out to a peer resident to receive psychosocial support and practical/professional guidance in the context of the demanding reality of residency training. To our knowledge, Doc-to-Doc was the first peer-mentoring program to cross training levels and residency programs. We have not found any articles describing a similar scheme addressed to a population of medical residents.

**Methods**

The peer-to-peer mentoring program was set up in collaboration with The WELL Office and the Committee on Resident Wellness (part of the Association of Residents of McGill). Residents from PGY-1 to PGY-5 were recruited either to volunteer as a mentor or to participate as a mentee. The program did not require any funding. E-mailed advertisements were sent every few months and during wellness presentations to different residency programs. Residents who wanted to participate were invited to contact their program administrators through a designated e-mail address. Interested mentors were sent a document explaining the mentor’s role and listing pertinent wellness and mental health resources at the university and in the community. They were then asked to answer basic demographic questions and invited to specify if they had special strengths that might be relevant. The names of enrolled and available mentors were added to a list that was continuously updated. Residents who requested a match were asked similar demographic questions along with others that guided the selection of a mentor: preferred sex and language, and if they preferred a mentor in or outside their program, etc. Although it was not mandatory, mentees were encouraged to specify their reason for participating in the program: adjustment to new culture, stress, burnout, pregnancy during residency, career, academic guidance, etc. A list of available wellness and mental health resources was sent to all residents contacting the service. After receiving a request, program administrators chose a mentor from the list and checked his or her current availability. After verification of availability, a “matching e-mail” was sent, putting the pair of residents in contact.
The e-mail specified that the frequency of contact and mode of discussion (telephone, skype, in person, etc.) were left to their discretion and that they could contact the program administrators with any questions or issues. Within the first year of the program’s launch, a session was offered for mentors to exchange, reflect and provide feedback on their experiences.

A questionnaire using a five-point Likert scale assessing the perceived helpfulness of the program, satisfaction with the frequency and quality of contact with the mentor, and satisfaction with the mode of communication used (in-person, e-mails, text messages, etc.) was developed for mentees. Options for free text responses were also included to best capture how mentees experienced the program. A very similar questionnaire was addressed to the mentors. Participants received those surveys by e-mail in August 2018. Questionnaires were answered anonymously via Survey Monkey. As was the case in similar peer-mentoring schemes, the small sample size of participants limited statistical analysis of quantitative data.

Results

Of the 34 residents (17 pairs of mentors–mentees) who participated in the program, we received a response rate of 65 percent for mentees and 59 percent for mentors. Demographic information and characteristics on participants are described in Table I. The majority of mentees thought the service was either moderately helpful (18 percent) or helpful (36 percent). The majority of mentees (64 percent) and half of mentors were either satisfied or very satisfied with the quality of contacts with their matched resident. An important factor that seemed to influence the benefit gained from the program was the method of communication used by the pair. When the method of communication studied was limited to only mentor/mentee pairs who used in-person contact, the service was more helpful (see Figure 1). Characteristics of the

<table>
<thead>
<tr>
<th>Table I Sample characteristics</th>
<th>Total sample n = 21 (%)</th>
<th>Mentees n = 11 (%)</th>
<th>Mentors n = 10 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>8 (38)</td>
<td>5 (45)</td>
<td>3 (30)</td>
</tr>
<tr>
<td>Female</td>
<td>13 (62)</td>
<td>6 (55)</td>
<td>7 (70)</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26–35</td>
<td>17 (81)</td>
<td>9 (82)</td>
<td>8 (80)</td>
</tr>
<tr>
<td>36–49</td>
<td>4 (19)</td>
<td>2 (18)</td>
<td>2 (20)</td>
</tr>
<tr>
<td><strong>Civil status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>11 (52)</td>
<td>6 (55)</td>
<td>5 (50)</td>
</tr>
<tr>
<td>Married or DP</td>
<td>9 (43)</td>
<td>4 (36)</td>
<td>5 (50)</td>
</tr>
<tr>
<td>Separated or divorced</td>
<td>1 (5)</td>
<td>1 (9)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Education history</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MD in Canada</td>
<td>14 (67)</td>
<td>6 (55)</td>
<td>8 (80)</td>
</tr>
<tr>
<td>MTL</td>
<td>7 (33)</td>
<td>4 (36)</td>
<td>3 (30)</td>
</tr>
<tr>
<td>Province of QC</td>
<td>11 (52)</td>
<td>5 (45)</td>
<td>6 (60)</td>
</tr>
<tr>
<td>Data missing</td>
<td>2 (10)</td>
<td>0 (0)</td>
<td>2 (20)</td>
</tr>
<tr>
<td>IMG</td>
<td>7 (33)</td>
<td>5 (45)</td>
<td>2 (20)</td>
</tr>
<tr>
<td><strong>Residency program</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family medicine</td>
<td>5 (24)</td>
<td>3 (27)</td>
<td>2 (20)</td>
</tr>
<tr>
<td>Medical specialties</td>
<td>11 (52)</td>
<td>6 (55)</td>
<td>5 (50)</td>
</tr>
<tr>
<td>Surgical specialties</td>
<td>1 (5)</td>
<td>0 (0)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>Data missing</td>
<td>4 (19)</td>
<td>2 (18)</td>
<td>2 (20)</td>
</tr>
<tr>
<td><strong>Current employment status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resident</td>
<td>14 (67)</td>
<td>10 (91)</td>
<td>4 (40)</td>
</tr>
<tr>
<td>Fellow</td>
<td>2 (10)</td>
<td>0 (0)</td>
<td>2 (20)</td>
</tr>
<tr>
<td>Attending</td>
<td>5 (24)</td>
<td>1 (9)</td>
<td>4 (40)</td>
</tr>
</tbody>
</table>

Notes: DP, Domestic partnership; IMG, International medical graduate. Data are displayed as n (%).
mentoring experience are presented in Table II. In the comment section, several residents specified they met only once and exchanged few e-mails with their matched resident afterward. Most residents described a mentoring experience lasting less than a few months, and about half of residents had an experience lasting less than a single month. The majority (55 percent) of mentees were satisfied with the frequency of meetings with their mentor. The majority of mentees (55 percent) were referred to at least one other resource or resource person in the form of staff, another resident, a counsellor at McGill, a psychologist, etc. Reasons for consulting the service are shown in Figure 2.

In the comments section, a theme developed indicating a lack of structure and understanding of the program. For example, one mentee proposed “an actual outline of how many meetings, points of discussion” and another said she would have liked to “match with someone close to you[...] that knows exactly what you are asking.” This comment was echoed by a mentor:

I think it would be good if the mentors know exactly what are the needs of the mentee before getting in touch with him/her[...] I think it would help by ensuring the needs/questions/concerns are better understood and fully addressed. It’s a great initiative.

Table II  Characteristics of the mentorship experience

<table>
<thead>
<tr>
<th></th>
<th>Total sample n = 21 (%)</th>
<th>Mentees n = 11 (%)</th>
<th>Mentors n = 10 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Choice of communication method</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In person</td>
<td>8 (38)</td>
<td>5 (45)</td>
<td>3 (30)</td>
</tr>
<tr>
<td>Telephone or Skype</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>E-mail or text messages</td>
<td>13 (62)</td>
<td>6 (55)</td>
<td>7 (70)</td>
</tr>
<tr>
<td><strong>Length of mentoring</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than a month</td>
<td>11 (52)</td>
<td>6 (55)</td>
<td>5 (50)</td>
</tr>
<tr>
<td>1–3 months</td>
<td>2 (10)</td>
<td>1 (9)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>3–6 months</td>
<td>3 (14)</td>
<td>1 (9)</td>
<td>2 (20)</td>
</tr>
<tr>
<td>More than 6 months</td>
<td>1 (5)</td>
<td>0 (0)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>More than a year</td>
<td>1 (5)</td>
<td>1 (9)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>No data</td>
<td>3 (14)</td>
<td>2 (18)</td>
<td>1 (10)</td>
</tr>
<tr>
<td><strong>Reference to resources</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No reference</td>
<td>9 (43)</td>
<td>5 (45)</td>
<td>4 (40)</td>
</tr>
<tr>
<td>Reference to another service</td>
<td>12 (57)</td>
<td>6 (55)</td>
<td>6 (60)</td>
</tr>
</tbody>
</table>
This recommendation was, indeed, not always met, as mentees could choose to check or not clusters of reasons for accessing the program when sending in a request. This was intended to make the process more flexible. Another theme that arose in the comments was that some in-person contact should occur – that contact should not be made solely through e-mails or text messages. Indeed, unfortunately in some cases, some pairs never met in person and the mentoring experience was limited to a few e-mails or text messages. It was also common for pairs to meet only once with few e-mails exchanged afterward. Interestingly, it seems that for some residents, even a single in-person meeting was enough to provide help, as highlighted below:

[The mentor] provided excellent peer support. Listened actively. Normalized (in a compassionate way) some of my struggles and was extremely empathic. Offered insightful comments, as well as some humor and appropriate advice. Left the door open for further follow-up if needed which was reassuring even if not pursued.

Discussion

To our knowledge, Doc-to-Doc was the first peer-mentoring scheme developed for medical residents that crossed training levels and residency programs. It has now been running for more than 2 years during which time it has matched 34 residents (17 pairs). Limitations of this pilot study include the relatively small sample size that prevents us from conducting an advanced statistical analysis, the recall bias related to surveys and the fact that questionnaires were not validated. However, the results seem to highlight some trends that will help in improving the program.

The program has several strengths that include no required funding and little administrative time, support and human resources. For the participating residents, the commitment required is relatively small, the structure is flexible and the scheme is simple enough that it can be easily replicated elsewhere. Another important advantage is that, by allowing matches between residents in different programs, mentees could be matched with mentors whose description best suited the reason for consultation. For example, some mentors specified that they would be a good match for IMG mentees as they had gone through that process themselves. This might be particularly relevant in a multicultural university (such as McGill), given that the most common reason reported for consulting the program was to receive help adapting to a new environment due to immigration or arrival from another province. This finding is aligned with the literature highlighting the additional challenges that IMGs face (Slowther et al., 2012; Warwick, 2014; Zulla et al., 2008).
The results are aligned with the few previous studies evaluating peer-mentoring schemes among medical residents (Cowan and Flint, 2012; Eisen et al., 2014; Vulliamy and Junaid, 2012). However, comparisons and analogies with those programs should be made with caution as this scheme, in being a peer-mentoring service crossing residency programs, is different. It is still worthwhile to mention that participants’ perceptions of the helpfulness of the service varied more from one resident to another compared to previous studies. A first factor that could have contributed to this difference is that several residents communicated mostly by e-mail or text messages within their mentoring experience. However, when we included only the answers of residents who reported in-person contact as the main mode of communication, a marked increase in results for perceived helpfulness was noted. Another factor that likely played a role is that in many cases pairs did not formally schedule an appointment after their initial meeting. As already described in previous studies, the absence of protected time, busy schedules and difficulties organizing meetings may have played a role in this factor (Eisen et al., 2014; Vulliamy and Junaid, 2012). However, the absence of a clear frame likely played the biggest role in mentor–mentee satisfaction levels. In a systematic review of mentoring programs in Academic Medicine for Practicing Physicians, Kashiwagi et al. (2013) suggest the value of using mission statements and signed agreements to promote accountability in mentorship relationships, the inclusion of which might have limited some of our challenges. Finally, the lack of training for our mentors may have been a weakness of the program. It was thought that a general technique of support as learned in medicine might be sufficient, especially as the program was initially thought to be short term and an entry point to other resources and services. It is possible that providing workshops or mentoring handbooks to mentors would have resulted in improved outcomes.

In conclusion, this pilot peer-mentoring scheme can be helpful to medical residents, costs very little and provides flexibility. In the future, the program will make adjustments in line with feedback received from participants, including the importance of scheduling in-person contact, at least at the beginning of the mentorship experience. We will also consider incorporating a training day or preparing a mentoring handbook for mentors to better prepare them for their mentoring role. In a society that sells us social media and technology as the means to happiness, it is good to be reminded that there is nothing like human contact when it comes to wellness. More studies with standardized and ecologically validated assessment tools are needed to better target what are important factors in the success of peer-mentoring schemes for medical residents and how viable programs can be maintained in the long term.

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Mental distress and “self-stigma” in the context of support provision: exploring attributions of self-stigma as sanism

Victoria Armstrong and Toby Brandon

Abstract

Purpose – The purpose of this paper is to discuss the findings from a detailed qualitative PhD study exploring experiences of stigma and discrimination in the lives of people in receipt of “mental health support” at two voluntary sector organisations in the North East of England.

Design/methodology/approach – Empirical material was collected during two periods of three-month long ethnographic periods of fieldwork from July to December of 2013 at two organisations providing support to their members who experience or have experienced mental distress. Along with field notes taken during and after periods of participant observation, the empirical material also included 30 interviews with staff (n = 10) and members (n = 20) across both organisations, along with a series of three focus groups at each organisation.

Findings – Staff at the organisations did not demonstrate obvious stigmatising or discriminatory attitudes or behaviours. However, they did attribute “self-stigma” to particular attitudes and behaviours of some of the members they support, referring to how they “made excuses”, “did not try” and/or “avoided situations”.

Originality/value – This paper argues that these attributions resulted from the misrecognition of members’ reactions to experiences of discrimination. The empirical material also suggests that these attributions of self-stigma may be indicative of the material limitations of the support environment, the consequent frustrations of well-intentioned staff, and, overall, as symptoms of neoliberalism. Drawing upon a Mad Studies approach and focusing on self-stigma and its attribution in contemporary mental health support, this paper provides a new perspective, which considers how stigma is linked to discrimination by rethinking what is thought of as “self-stigma”.

Keywords Discrimination, Stigma, Self-stigma, Sanism, Mad Studies

Paper type Research paper

Introduction

Existing literature relating to mental health stigma, which relies on medical and/or psychiatric models of mental distress, indicates a distinction, but also a relationship, between “public stigma” and “self-stigma” (e.g., Corrigan and Watson, 2002a, b; Rusch et al., 2005). In summary, public stigma is considered to encompass reactions of the general public towards a group based on stigma about that group and/or predicated upon stereotypes, whilst “self-stigma” refers to individuals turning the discriminatory attitudes of stigmatisers against themselves. Corrigan et al. (2009) explain that self-stigma arises when people are aware of a stereotype, agree with it, and apply it to themselves which results in a “why try?” attitude manifesting itself in the individual concerned. However, Corrigan et al. (2006, 2009) also suggest that this attitude may be ameliorated by services, which can empower people and develop their personal identity (Watson et al., 2007, p. 1317). Previous research has explored the negative effect of self-stigma on the self-esteem of people experiencing mental distress, which often leads to individuals feeling reluctant to pursue work or other opportunities; not because of illness, but because of “self-discrimination” (Rusch et al., 2005, p. 531). Thus, tackling self-stigma and feelings of shame...
about experiencing “mental health problems” has become a cornerstone of support services promoting an individual therapeutic approach (e.g. Morrison et al., 2016) and public campaigns to reduce stigma (See Me, 2019; Time to Change, 2019). The harmful effects of self-stigma have been acknowledged (Stewart, 2019), specifically in relation to how arts-based initiatives can reduce incidences of self-stigma (Stewart et al., 2019). However, there has been little work both exploring and questioning the concept of “self-stigma” in detail.

Exploring self-stigma from a Mad Studies perspective enables us to consider self-stigma using a more structural and less individualistic approach. This paper uses empirical material to suggest how professional conceptions of self-stigma have the capacity to conflict with the interpretations of those in receipt of support. As a result, we consider whether professionals attributing “self-stigma” in the way they do reflects an individualisation, which can be potentially harmful and stigmatising in the support environment. In doing so we also highlight the cost of self-management techniques in relation to notions of self-stigma, and suggest that self-stigma is better recognised within the context of discrimination, or more specifically, sanism.

Method

The overall aim of the PhD study was to explore and examine the support context with particular focus on experiences of stigma and discrimination. Empirical material was collected during two periods of during a six month period of ethnography in 2013 at two voluntary sector organisations in the North East of England providing support to their members who experience or have experienced mental distress. All participants and the two organisations were given pseudonyms. Both organisations, “Bright Futures” and “Creative Mindz”, are city-centre based and registered charities. They were selected from a database of mental health organisations and approached with a research proposal. Durham University granted ethical approval to conduct the research. Along with field notes taken during and after periods of participant observation (three days at each organisation each week for three months), the empirical material also included a total of 30 interviews with staff \( (n=10) \) and members \( (n=20) \) across both organisations who self-selected to be involved, along with a series of three focus groups at each organisation. The recordings of the interviews and focus groups were transcribed for analysis. “Self-stigma” emerged as a compelling phenomenon during the process of thematic analysis and systematic coding using the computer software package NVivo. It should be noted that discussion around self-stigma arose because both staff and member participants regularly used the term unprompted. Taking an iterative approach to the project, in later interviews, discussion was incorporated into the interview guide.

Findings

Self-stigma as a “self-fulfilling prophecy”

The empirical material unequivocally suggested the majority of staff members believe “self-stigma” to be a significant barrier to members receiving support and “moving on” with their lives following experiences of mental distress. When staff members reflected on this notion of self-stigma, they identified that it manifested in both the attitudes and behaviour of members. For example, members were blameful of society for their predicament and/or felt powerless to change their circumstances and them avoiding situations or shying away from opportunity. It also seemed that many staff members considered self-stigma to be a “choice”. As Dave (staff, int., Bright Futures) illustrated:

Some people sort of go around looking for it, they look for the stigma as something to blame, blame society, “well it’s not me, I’ve got a mental health problem, it’s not my fault I can’t do it, they’re not letting us do it.” So, although stigma, if you asked them are you being stigmatised, they’ll say, “oh no no”, but they’re kind of self-stigmatising […] And I think it’s a self-fulfilling prophecy, that’s how I would sort of define it, because you can only be stigmatised if you let it […] .

The idea of using a “mental health problem” or diagnosis as an “excuse” for not seeking out or taking opportunities for things like work, education, socialising, etc. was common amongst staff.
Not behaving in line with the support rules or rules of the organisation and “bad behaviour”, was also considered by many staff participants as a facet of “self-stigma”. As Faye (staff, int., Bright Futures) described:

“They see themselves differently or use it as an excuse […] We had a gentleman who, I don’t know what his diagnosis was because I never really worked with him, he was a nice enough, very polite man but you always knew, you always felt as though he was going to kick off […] He was always I suppose a bit intense and you got that feeling that you would tread a little bit carefully around him and he did kick off this one day, someone had said “you know there’s no need to shout and scream and swear at people”, <raises voice> “I’m allowed, I’ve got a mental health problem and it’s your job to deal with it”.

Faye described a situation in which she believed the member behaved badly and used his mental health “problem” as an “excuse”. She attributed this to his “attitude” but there were no other understandings or versions of events offered to explain why the member behaved in this way.

Particular staff members seemed to place a lot of emphasis on choice and self-determination. For example, Nicola (staff, int., Creative Mindz) described a member who she considers to be “self-stigmatising” and “self-pitying” because the member believes she is unable to work as a result of her mental health:

“I think she’s just very self-pitying, like she feels sorry for herself […] Sometimes I do want to sit her down and be like, you know what I mean like, everything is a decision […] I think she’s too keen to play the victim, of like everything’s hard […] she could get a job, she could work […]”

In most cases, staff members continued to attribute self-stigma to members who do not try and other associated behaviours and “negative attitudes” with “self-stigma”.

Part of the common narrative of staff members with experience of mental distress involved talking about how they had actively “overcome” self-stigma or resisted the urge to self-stigmatise. For example, Daniel (staff, int., Creative Mindz) recognised he had stigmatised himself but had “overcome” it:

“I love my job here, but sometimes it’s so frustrating because mental health people are just so resistant against change, even if that change is going to help them […] obviously in my own personal experience, erm, I think a lot of stigma is inward, I think a lot of stigma comes from within.

**Self-stigma as self-censorship and avoiding contexts where discrimination has occurred**

Members, like staff, were keen to discuss “self-stigma” but they considered it differently to staff. In this section we suggest that the behaviours members associate with self-stigma could be better conceived of as responses to experiences of discrimination, and self-management techniques members have learned as a result of stigmatising or discriminatory experiences. Stevie (member, int., Creative Mindz) described “self-stigma” via an articulation of her own experiences relating to a time she felt excluded from a group:

“When you stigmatise yourself you’re afraid to go out, “oh I’ll not go out, I’ll not bother, I won’t go in that pub full of normal people”, but it’s not because you are stigmatising yourself, it’s because you don’t want to be in a situation where society has separated you as somebody not normal […] There’s been groups I won’t go to and groups I have stopped going to because of that, and you feel well they’re all normal and I’m not, they may be nice people, nice with each other, I’m welcome to go there and do the task, but if one invites the other, “oh there’s a film on in the cinema, isn’t it to do with superman or something”, and I say, “oh I like superman as well” says the one who’s not normal, and then another one says, “oh I like superman, oh are you going to come along and see it with me at the cinema”, and I say “any chance I can come”, and it’s “sorry no” […] because if you were normal they would have been happy about you going along with them and very often it’s the one who isn’t quite normal who doesn’t get included in conversation at breaks, they talk about something and you talk about something relevant to the conversation and they don’t look at you and they treat you as though they haven’t heard what you said.

When asked about “self-stigma” most members said that they did stigmatise themselves to some degree. When asked what made them think that they did self-stigmatise, the behaviours they described were self-censorship, i.e. thinking carefully about what details about their mental distress they disclose, and to whom, and avoidance of certain situations where they have
experience of being discriminated against or where they think they will be stigmatised or discriminated against. Both staff and members link feelings of self-stigma to previous experiences of exclusion. However, there is a nuanced distinction between staff and member perspectives, which is important for thinking about how self-stigma links to discrimination.

Comments from staff members suggested that self-stigma was attributed when members accentuate or exaggerate their difference from others, which can often manifest itself in “excuse making” or “avoiding situations”, in the eyes of staff. Yet here we see members working to reduce or minimise their “difference” from others, demonstrating the work they do in order to try to fit in and participate in society.

Conversations with participants indicated that often they did not like to tell people outside of the organisation that they attended a place associated with “mental health”. Felicity (member, int., Creative Mindz) initially came to volunteer at the organisation but was advised to become a member instead, highlights this point:

If I say to someone, I am coming here, it depends on the people if I am going to continue saying what it is about, and or, I don’t say it’s a charity for mentally ill.

However, Linda (member, int., Bright Futures) said:

I would rather tell people I go to XXXX or here and then they can make up their own mind as to what’s wrong.

Whilst members may reach different conclusions, as in the examples of Felicity and Linda, they are decisions which are negotiated and members seem to think quite carefully about how they manage that information. Thus, there is evidence of “hidden labour” (Scully, 2010) which staff members do not seem to acknowledge when they attribute “self-stigma”.

Discussion

Whilst staff acknowledge members’ individual histories, including bullying, abuse, negative experiences with psychiatric services, welfare benefit entitlement, employment, etc., it is still “self-stigma” that is seen by the majority of staff as being more “difficult” to “deal with” in their day to day work supporting members. The empirical evidence in this study suggests that via compliance with what is on offer in the support context and other help available such as psychiatry, a member can become less “self-stigmatising” or display the right kind of attitude which is then construed by staff as less self-stigmatising. Thus, we see support in this context potentially augmenting the medical/psychiatric model of support (Fabris, 2013). Self-management techniques, such as secrecy/concealing information are referred to by Link et al. (1989) as “coping orientations”. Secrecy, selective disclosure and “cost benefit” analyses are frequently reported as ways in which individuals cope with social and self-stigma (Holmes and River, 1999). Individuals may develop a disposition to see the world in a certain way resulting in a strong sense of “felt stigma” and a predisposition to secrecy and concealment (Scambler and Hopkins, 1986). This also relates to the concept of “passing” yourself as non-disabled in public (Goffman, 1963/1990; Brune, 2013).

Scholars such as Ritsher et al. (2003, p. 47) refer to the notion of “internalized stigma” which goes beyond the effects of direct discrimination and is more about internal perceptions, beliefs and emotions of the stigmatised person (Ritsher and Phelan, 2004). Corrigan (1998) concurs and believes “internalised stigma” relates to devaluation, shame, secrecy and withdrawal triggered by applying negative stereotypes to yourself. That said the literature still considers there to be some distinction between “self” and “public” stigma and discrimination. Conversely, the empirical material indicates that self-stigma and discriminatory experiences are so closely linked by those who experience it that to conceptually create a dichotomy, particularly in the way staff members seem to do, is misleading.

It also seems that when members do not take advantage of, or conform to, what support has to offer and other help available (psychiatry, talking therapies, back to work/skills training) they are labelled by staff as “self-stigmatising”. A critique commonly levelled at psychiatry is that support assists to regulate those who disrupt hegemonic social relations and institutional
processes (Diamond, 2013, p. 74) and it appears this may be going on to some degree in contemporary voluntary sector support environments. As a result, it seems that the way staff attribute self-stigma may be part of the wider “stigma problem” and, as Corrigan and Fong (2014, p. 112) suggest:

[…] focusing on how people might eradicate their personal struggle with self-stigma may unintentionally perpetuate the notion that stigma is their problem, that it is another sequelae of the illness for which they must be treated.

Thinking about the distinction between staff and member interpretations of self-stigma, it seems staff primarily relate member passivity to attributions of self-stigma, i.e. staff attribute self-stigma to members with the attitude of, and behaviours associated with, “there’s little point trying because the world is against me”. However, members’ comments demonstrate how members are active agents managing some of the socio-political realities they encounter. There are two important issues to consider here, first acknowledging the “work” members do on themselves to fit in and negotiate their social world (including “passing”), and second highlighting the role of mental health policy and the socio-political climate.

Furthermore, members’ comments also highlight how stigma can operate subtly at the micro level of social interaction, and so members were left feeling there was little anti-discrimination laws, policies and practices can do; and stigma can lead to some people hiding a problem or condition, or reducing its significance. Going further, the examples provided by the members demonstrate the considerable “cost” of coping strategies and self-management techniques, and their impact on psycho-emotional well-being, and thus, may be better understood in the context of discrimination or disablism. Thomas (2007, p. 73) extended the social model of disability to encapsulate this type of private social oppression:

Disablism is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being.

Reeve (2014) talks about how “direct psycho-emotional disablism” occurs as a result of interactions, often without malice, which serve to invalidate disabled people as people (Hughes, 1999) by undermining their self-confidence and self-esteem because of the negative messages they receive about their self-worth. Whilst members may not necessarily experience obvious structural barriers or barriers which overtly prevent them from talking about themselves openly or being present in certain social situations, the “psycho-emotional disablism” operating on a private level, and understood as self-stigma, seems to create a barrier to “being” for some of the members. As Mason (1992) suggests, “internalised oppression” as a form of psycho-emotional disablism can often arise as a result of the relationship a disabled person has with themselves. For the members involved in this study, any “self-stigma” seems to come about as a result of invalidating interactions and public perceptions of what a person who has experienced, or experiencing, mental distress is thought to be.

In a similar vein to Disability Studies scholars (Goodley, 2011) and activists (Spandler et al., 2015; Russo and Sweeney, 2016), proponents of Mad Studies employ the term “sanism”. Sanism is considered “a form of systemic discrimination similar to sexism or racism, which targets psychiatric survivors” (Perlin, 1991, p. 92). It has also been described by Poole and Ward (2013, pp. 96-7) as being:

[…] a devastating form of oppression, often leading to negative stereotyping, discrimination, or arguments that Mad individuals are not fit for professional practice or, indeed, for life […] sanism also allows for a binary that separates people into a power-up group and a power-down group. The power-up group is assumed to be normal, healthy, and capable. The power-down group is assumed to be sick, disabled, unreliable, and, possibly violent. This factional splitting ensures a lower standard of service for the power-down group and allows the power-up group to judge, reframe, and belittle the power-down group in pathological terms […].

It seems that staff attribution of self-stigma is a predominantly oppressive act and it is sanist to do so, this is because such an attribution constitutes professional narrative overriding personal experience of oppression and discrimination of the “power down” group. Furthermore, what the findings in this study can be said to demonstrate empirically is how “stigma power” may operate
through the stigmatised person (Link and Phelan, 2014), yet how that power operates is nuanced and complicated. Perhaps the power differential between staff and members inhibits the ability of staff to recognise the experiences and the social location of the member, or that their place of privilege denies them the capacity to recognise members’ situations differently.

This attribution of “self-stigma” tends to ignore, or at least simplify, and perhaps professionalise, the struggle and conflict which members experience. Attributing self-stigma to those people who staff consider not to be responding positively to the support on offer in the support environment and/or are perhaps seen as “passive”, has the potential to feed into the stigma cycle and may be potentially stigmatising, sanist, discriminatory and/or excluding. When it comes to overcoming “self-stigma”, staff members did display sensitivity and were somewhat understanding of external influences. Despite this understanding, staff tend to continue to believe some members not to be “trying” or that they are “making up excuses”, simply because they do not “fit in” with what is on offer in the support environment. It must be said, that from our own experiences and engagement with the case study organisations, none of the staff were malicious or overtly discriminatory in their attitude, and there was a genuine belief that the support they were providing could overcome “self-stigma” in most cases. However, it seems that if you do not “try” or “comply” in a prescribed way, members run the risk of being indicted for being “self-stigmatising” and set apart from members who did try or comply.

“Self-stigma” is not something people do individually and in isolation of their social environment and instead it may be more appropriately considered a form of self-management shaped by wider socio-political contexts, particularly “welfare reform”. These self-management techniques can often be misrecognised by staff members who attribute “self-stigma”. Self-stigma seems to be an oxymoronic or paradoxical concept because what some of the existing literature, staff and members define as “self-stigma” is predominantly resultant from negative and discriminatory experiences or the attitudes of others.

Whilst it may not be staff members’ intention to contribute to a stigma cycle, when taking into account empirical material and the existing literature on stigma, labelling behaviours as self-stigmatising does not challenge the notion or existence of stigmatised identities. In the case of the support environments, attributing self-stigma could be said to serve staff members and neoliberal mental health policies by absolving them of responsibility when the support, or policies behind support provision, do not seem to be effective in the ways that those in more powerful positions think they ought to be.

**Conclusion**

It is clear that “self-stigma” is described and understood by members and staff differently. Exploring “self-stigma” from a member perspective led us to understand that what members describe as “self-stigma” always occurs as a result of actual experiences or perceived reactions of others based upon experience. As a result, members seem to employ methods of information management/self-censorship and/or avoiding certain situations. We have suggested that the empirical material supports the idea that staff members’ attributions of self-stigma may be better conceptualised as staff misrecognising members’ reactions to stigma and/or discrimination. Furthermore, it is conceptually inaccurate, sanist and paradoxical for “self-stigma” to be considered synonymous with self-management techniques formed as a result of negative or discriminatory experiences because such classification locates the “problem” within the individual. Both staff and member perspectives on self-stigma see members contributing to their social condition, yet staff seem to see members’ contribution to their own situation as blameful in some way, or at least assume more personal responsibility or agency on behalf of a member, whilst members do not. Thus, members are not self-stigmatising but self-manage in a way which is sometimes misconstrued and prevented by staff as self-stigma. Whilst passing and covering might be understandable, it places demands on members and perhaps support environments could think more about the ways members contribute to their social condition without blame.

For example, setting the attribution of self-stigma in the context of discrimination or sanism, not only highlights the cost of self-management techniques for those of us who experience mental distress, but can also provide an alternative perspective on how we think about self-stigma.
From a practical perspective, staff members may benefit from a more formalised and facilitated outlet to talk about how they negotiate their role. This may reduce the potential for individualising problems in the form of self-stigma given that such attributions seem to be born of staff frustration and their own personal experiences. Furthermore, staff attributions of self-stigma are often based on a staff view of members being “passive” and not “wanting to change”. Thus, building staff awareness of micro-power and emphasising that reactions to stigma are not a “choice” is integral to disrupting the stigma cycle. Responses to discrimination shouldn’t be misrecognised as “self-stigma” and ultimately, individualised. Thus, briefings and staff training for policy makers and practitioners which couch attributions of self-stigma in the context of discrimination are integral to increase understanding of how these attributions fit within a stigma cycle.

Finally, the notion of “self-stigma” removes us from any understandings of a social model of madness and distress. It could be suggested that this individualised way of labelling information management or avoidance of situations as “self-stigma” or attributable to the “illness” itself, moves in the opposite direction of social models of disability, madness and distress. Attributions of self-stigma appear to place responsibility on individuals who have experienced mental distress to help themselves more, and focusses on their ability to “fit in”, which seems unjust from a member or service-user perspective if it is born of negative experiences or attitudes. Placing responsibility for overcoming self-stigma on the person concerned is a sanist practice, which distorts systemic and individual discrimination.

References


Further reading


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Social support, depressive symptoms, and online gaming network communication

Tyler Prochnow, Megan S. Patterson and Logan Hartnell

Abstract

Purpose – The increase of videogame use has raised concerns regarding mental health of gamers (e.g. social isolation, depression); however, online gaming may offer the benefit of social connectivity. Many games provide ways for people to meet and interact, providing social opportunities difficult to come by for some young adults. One way to investigate social connection is through social network analysis, which explores the influence of connections on behaviors. The purpose of this paper is to analyze factors related to social connections within an online gaming community, with an emphasis on the influence of social support and depressive symptoms on network ties.

Design/methodology/approach – All members of an online gaming site were asked to report demographics, site use, depressive symptoms, “in-real-life” (IRL) social support, and online social support. Members were also asked to nominate those in their gaming network with whom they spoke to about important life matters. Moran’s I determined the spatial autocorrelation of depressive symptoms and IRL support within the network. Exponential random graph modeling determined factors significantly associated with tie presence between members.

Findings – Members (n = 37) were significantly more likely to speak to other members about important life matters if they reported more site hours, more depressive symptoms, and less IRL support. Depressive symptoms and IRL support were not significantly spatially autocorrelated within this network.

Originality/value – Results suggest members may be filling an IRL social support deficit with friends they have met online. Additionally, members who reported more depressive symptoms may be seeking help from informal online connections through online gaming.

Keywords Social support, Social network analysis, Depressive symptoms, Help seeking, Online gaming

Paper type Research paper

Introduction

According to an industry report from the Entertainment Software Association (2019), over 65 percent of Americans play some form of video game daily (Entertainment Software Association, 2019). The same report stated the video game industry accounted for a reported $43.4bn in 2018 (Entertainment Software Association, 2019). The rise in popularity of online gaming has been met with many concerns over its potential negative health effects, including risk for isolation (Orleans and Laney, 2000), addiction (Grüsser et al., 2006), increased aggressive behavior (Grüsser et al., 2006), increased risk for depressive symptoms (Wei et al., 2012) and reduced real life social involvement (Kraut et al., 1998). Overall, greater internet usage has also been associated with increased risk for depressive symptoms and anxiety (Bernardi and Pallanti, 2009; Christakis et al., 2011). Meanwhile, increased video game use has been associated with higher BMI and lower physical activity among undergraduate males (Ballard et al., 2009).

Despite these preliminary concerns, a growing body of literature supports these games, identifying cognitive, emotional and social benefits to game participation (Granic et al., 2014). Uttal et al. (2013) found that cognitive improvements to spatial skills resulting from playing video games may be comparable to improvements from formal courses on spatial reasoning and skills. Video game use is also associated with improved creativity in children (Jackson et al., 2012).
Additionally, casual video game use (defined as 30 min three times per week), was linked to a reduction in depressive symptoms in a sample of adults with clinical depression (Russonello et al., 2013). Players have reported playing games as a form of relaxation and enjoyment (Olson, 2010; Reinecke, 2009), as well as turning to these games as an outlet or a coping mechanism for real life stress or conflict (Olson, 2010; Reinecke, 2009).

While there has been concern related to social isolation due to excessive gaming (Orleans and Laney, 2000), some games provide the opportunity for social connectivity through cooperative play and chat functions. An industry report indicated 63 percent of adult gamers reported gaming with others through online and local gameplay (Entertainment Software Association, 2019). Further, respondents indicated they played with others online and in person for an average of 4.8 h and 3.5 h per week, respectively (Entertainment Software Association, 2019). In addition to cooperative play, many games also provide a chat function for players to extend real life relationships and make new online friendships (Trepte et al., 2012). These games can be a comfort zone and form a vital “third place” (place outside work and home where an individual feels comfortable) for individuals to connect and share with others (Steinkuehler and Williams, 2006). In one study, coping through gaming was important for those who reported less “real life” social support (Reinecke, 2009). Similarly, a longitudinal study on psychosocial causes and consequences of gaming concluded young adults may use online games to compensate for pre-existing in-person social difficulties (Kowert et al., 2015).

One way to investigate social connections present online is through social network analysis (SNA). SNA is a set of theories and methods which allow researchers to investigate connections between individuals and analyze the social structure of groups (Borgatti et al., 2018). In sociocentric, or whole network studies, the researcher must determine a group with a defined boundary and subsequently survey connections within the group (Borgatti et al., 2018). In this case, participants only report their connections to members of a specified network, creating a census of connections present within the bounded group. Thus, the data includes attributes of all network members, as well as the larger structure by which the members have organized themselves (Borgatti et al., 2018). Additionally, sociocentric data collection and analysis allows the investigation of individual, group, and network level measures that would not be possible in other designs (Borgatti et al., 2018). SNA has been used to analyze many health concerns such as body dissatisfaction among sorority members (Prochnow et al., 2019), physical activity in children (Salway et al., 2018) and spread of infectious diseases (Verdery et al., 2017).

Network theory suggests social relationships and position within networks are important sources of social capital for individuals, serving as a mechanism for health and quality of life (Perry and Pescosolido, 2015). Studies have also shown the negative impacts of social isolation, including risk of depression and suicide (Cacioppo et al., 2010). Based on literature suggesting the possible positive impacts of online relationship building within gaming environments, particularly for those who experience greater social isolation in real life, it is important to understand factors related to the formation of social ties online. Thus, this study aims to use SNA to investigate the social structure of an online gaming site. More specifically, we will examine how factors such as social support and depressive symptoms influence the odds of whether members choose to connect with other gamers in their network, and how those factors are distributed across the online gaming network.

Methods

This study uses a specific online gaming website as a bounded network, with a clear member list, in order to perform sociocentric network analysis. The site is a football simulation game in which members take on the role of managing a team and compete with other members in football games. Members can communicate on site via forums, a chat function, and direct messaging. At the time of the study, the site had 101 active members, defined by the site as having logged in at least once in the previous two weeks. All active members over the age of 18 were invited to participate in an online survey by a posting in the main forum. All study procedures were approved by the Institutional Review Board prior to the start of the study.
Measures

Members were asked to report on various demographics such as age, sex, race, ethnicity, employment and marital status. They were also asked how many hours they spent per week on the site, as well as how many hours they spent playing other video games per week.

Depressive symptoms. Depressive symptoms were measured using the nine-item patient health questionnaire (PHQ-9) (Kroenke et al., 2001). Members were asked to rate how often they had been bothered with certain problems over the last two weeks, including having little interest or pleasure in doing things, feeling tired or having little energy, and feeling down, depressed, or hopeless. The scale provides response options of “not at all,” “several days,” “more than half the days” and “nearly every day” which are scored from 0 to 3, respectively. Responses are summed to create a total scale score ranging from 0 to 27. This scale has been previously validated and has excellent internal and test-retest reliability (Kroenke et al., 2001). This scale exhibited good internal reliability within our sample (α = 0.87).

Appraisal social support. Appraisal social support, or a perceived availability to talk to someone about one’s problems, was measured by adapting a subscale of the interpersonal support evaluation list (ISEL-12) (Cohen et al., 1985). The original scale included belonging and tangible subscales as well. In order to normalize the scale across online and “in-real-life” (IRL) connections, the appraisal subscale was used to denote social support from having someone to speak to about life issues. For this study, participants were asked to think of people in their life (IRL) and then think of only people with whom they speak to on the site, and then were asked three questions based on the support they felt from each group separately (e.g. “I feel that there is someone I can share my most private worries and fears with”; “There is someone I can turn to for advice about handling problems with my family”). Participants were asked if they strongly disagree, disagree, agree, or strongly agree with each statement scored 1 to 4. Scores for online and “IRL” items were averaged separately to generate scale scores for each setting. In our sample both online and “IRL” scales displayed fair to good internal reliability (α = 0.85, 0.74, respectively).

Social network data. Members were given a list of all active members on the site and asked to select any and all members with whom they had spoken to about important life matters. Members could select as many other members (alters) as they would like by checking a box for each person. Direction of connection was maintained in order to determine parameters for sending and receiving network ties separately (i.e. Member A speaks to Member B is represented differently than Member B speaking to Member A). Additionally, members were also asked to report up to five individuals they spoke to about important life matters “IRL.”

Data analysis

Summary statistics including mean, standard deviation, and frequencies were calculated for member demographics and network measures. Calculation of means, standard deviations and t-tests were conducted using SPSS v. 25 (IBM, 2018). A spatial auto-correlation model was used to generate Moran’s I to understand the dispersion of depressive symptoms across the network (Ord, 1975; Moran, 1950). This statistic determines whether depressive symptom scores were significantly clustered within the network. Moran’s I was calculated using the ape package in R Studio (Paradis and Schliep, 2018). Exponential random graph modeling (ERGM) was used to determine attributes associated with the presence of within-network social connections (members speaking to other members about important life matters) and network structure (Lusher et al., 2013). ERGM was performed using the ERGM and statnet packages in R Studio (Hunter et al., 2008).

Results

Sample characteristics

Members who responded to the survey (n = 37; 37 percent of total active membership) were on average 24.76 years old (SD = 6.55). Respondents all identified as male and 89.2 percent
identified as white. Members reported they spent, on average, 12.57 h (SD = 8.60) on the site per week. In this sample the average PHQ score was 6.92 (SD = 5.86). When asked to nominate other members with whom they spoke to about important life matters, members reported an average of 6.11 (SD = 5.74) other network members. When asked to list “IRL” connections with whom they speak to about important life matters, members listed on average 4.38 people (SD = 1.11). Members reported significantly more support from their “IRL” network (M = 3.49; SD = 0.57), when compared to the support they reported from their online network (M = 2.81; SD = 0.84; t(36) = 4.53, p < 0.001). See Table I for complete sample characteristics.

Network spatial autocorrelation

The Moran’s I calculated in this sample suggested no significant network spatial autocorrelation in how depressive symptom scores were distributed across the network (I = −0.03, p = 0.98). This was also the case with online (I = −0.013, p = 0.51) and “IRL” support (I = 0.01, p = 0.79).

Exponential random graph modeling

ERGM was used to determine factors which may influence members to talk to other members online regarding important life matters. Table II contains parameters included in the ERGM as well as the related estimates and standard errors. Interpretations are given next to these statistics for clarity.

Discussion

This study aimed to understand the social structure of an online gaming site, as well as how appraisal social support and depressive symptoms impact the presence of speaking to other

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<th>Table I</th>
<th>Sample characteristics</th>
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<tr>
<td>Race</td>
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<td>Age</td>
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<td>Site hours</td>
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</tr>
<tr>
<td>Other Online gaming hours</td>
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<tr>
<td>PHQ-9</td>
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</tr>
<tr>
<td>“In-real-life” support</td>
<td>3.49</td>
</tr>
<tr>
<td>“In-real-life” connections</td>
<td>4.38</td>
</tr>
<tr>
<td>Online support</td>
<td>2.81</td>
</tr>
<tr>
<td>Online connections</td>
<td>6.11</td>
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</table>
members about important life matters. Depressive symptoms were not significantly spatially correlated within this network. This means members reporting similar depressive scores were not clustered together in a significant way. One might hypothesize individuals with more depressive symptoms may cluster together based on homophily (Rosenblatt and Greenberg, 1991), or connecting to another person based on similarity (McPherson et al., 2001). However, this was not the case within this sample. Previous research has suggested “misery does not love company” as individuals with depression may withdraw from their network and not form ties altogether (Schaefer et al., 2011).

Members in this sample exhibited a significant propensity to reciprocate communication ties (i.e. If Member A reported connecting with Member B, then Member B would most likely report connecting with Member A). In addition, communication ties were significantly more likely to be reciprocated in this network (Reciprocity). Transitive communication patterns are common in both online and offline social networks (Filiposka et al., 2017). Keijzer et al. (2018) hypothesized the importance of transitivity in online social networks by showing an increase in isolation and discontinuity in culture change when there is a lack of transitive relationships among network members. Members of a network without transitive relationships may not receive vital feedback from the network on culture change and appropriate behavior, which can lead to isolation (Keijzer et al., 2018). Reciprocal relationships are also noted to provide more social support and be more effective at buffering negative effects of stress (Lu, 1997). Further, reciprocated relationships are associated to reduced depressive symptoms among middle-aged men (Takizawa et al., 2006). This connection to reduction in depressive symptoms is vital as online gaming connections showed a propensity for reciprocity.

Members of this site were more likely to report speaking to other members if they also reported spending more time on the site. This is unsurprising, as members who spend more time on the site would have more time to talk to and get to know other members. Since these results are only associative and not causal, it could be that those speaking to more people on this site results in spending more time on the site. While we did not specifically aim to measure gaming addiction or internet addiction, individuals who spend more hours online and more hours gaming have a higher risk of addiction and dependency, which has been linked to an increased risk of depression (Banjanin et al., 2015; McDougall et al., 2016). Thus, while increased social connection might be a positive aspect of an online gaming

<table>
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<tr>
<th>Table II</th>
<th>Model parameter estimates and standard errors for predicting the odds of members forming connections online</th>
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<tbody>
<tr>
<td>Parameter</td>
<td>Estimate</td>
</tr>
<tr>
<td>Edges</td>
<td>−4.38*</td>
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<tr>
<td>Reciprocity</td>
<td>2.22*</td>
</tr>
<tr>
<td>Transitivitya</td>
<td>0.42*</td>
</tr>
<tr>
<td>Demographics</td>
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<td>Marital status</td>
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<td>Age</td>
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<tr>
<td>Covariates of sending ties</td>
<td></td>
</tr>
<tr>
<td>Site hours</td>
<td>0.03*</td>
</tr>
<tr>
<td>PHQ</td>
<td>0.08*</td>
</tr>
<tr>
<td>“In-real-life” support</td>
<td>−0.68*</td>
</tr>
<tr>
<td>Notes:</td>
<td>Transitivity was modeled using geometrically weighted edgewise shared partner distribution with a decay of 0.4. *Parameter estimate is greater than two times the standard error which indicates a significant effect</td>
</tr>
</tbody>
</table>
community, it might also encourage increased use that could lead to problematic outcomes such as addiction and dependency.

In our sample, members who felt less “IRL” support were significantly more likely to report speaking to other site members. We hypothesize individuals who feel a lack of support from their “IRL” social circles may be looking to supplement the deficit with their online network. This result was echoed in a recent study among college students where social media served as an important source of support for students who reported less in-person support (Cole et al., 2017). Students in this study viewed online support and in-person support as non-overlapping forms of support that each had unique value (Cole et al., 2017).

Lastly, members of this site were more likely to report speaking to others online about important life matters if they also reported more depressive symptoms. This can be seen visually in Figure 1, as the larger nodes (sized based on PHQ-9 score) tend to have more ties compared to smaller nodes. The increased propensity of online connections is in direct opposition to literature suggesting social isolation and loneliness as predecessors and consequences of depression (Cacioppo et al., 2010). This may mean that individuals with more depressive symptoms felt more comfortable reaching out to others online about life matters. In a study on specific subsets of depressed individuals, participants with suicidal thoughts were less likely than participants without suicidal thoughts to seek help from all sources except for online forums (Harris et al., 2014). In another study, seeking help from informal online sources such as anonymous forums were shown to be an important source of support for those with depression and improved psychosocial wellbeing (Heerde and Hemphill, 2018). Therefore, the online gaming community could be a safe environment for people to cope and connect that might not be afforded to them within their “real life” social circles. Future research should measure whether online social connection developed through gaming sites decreases depression over time.

**Figure 1** Sociogram of site members and connections between them

*Note: Nodes are sized according to PHQ-9 scores (larger size = more depressive symptoms)*
**Limitations**

Because this study is cross sectional, results are limited to associative interpretations. Researchers may wish to utilize a longitudinal study design in future projects to track how network structure may change in respect to depressive symptoms and feelings of support. Further, the wide array of depressive symptoms combined in the PHQ-9 scale may also complicate the autocorrelation results. Some researchers are now advocating analysis of mental health at the symptom level, instead of using a combined, self-report score (Fried and Nesse, 2015).

The sample size and demographics are a clear limitation to the generalizability of the study. This study provides a pilot and preliminary approach to analyzing online social connections generated through online gaming. As with many network studies, generalizability to other networks should be cautioned, as the analysis is specific to the network specified here (Borgatti et al., 2018). As such, researchers may wish to replicate this study using other online game genres (e.g. role-playing game, first-person shooter) and platforms (e.g. mobile, web based, console), as each game has unique social components affecting the difficulty and impact of socialization. One assumption to consider when developing a whole network study is every member should have the possibility to come in contact or create a tie with any other member (Borgatti et al., 2018), which may not be the case in certain larger systems with multiple divided servers. In this case, researchers may need to replicate this study multiple times in each server and then using a controlling variable or parameter for the different segments.

Finally, only 37 percent of the whole network participated in data collection. Missing data are a notorious issue for sociocentric network designs (De La Haye et al., 2017), and the absence of important connections could change the structure of the entire network (Costenbader and Valente, 2003). There is no way to know if there were systematic similarities across those missing or if they were missing at random, and the potential influence those people have on the entire network is unknown. Future research using sociocentric designs should consider strategies to improve response rate (e.g. follow-up invitations for participation, incentives) whenever feasible.

**Implications**

Given these limitations, this study did benefit from using sociocentric network analysis procedures, which revealed important network and health-related factors related to the creation of social ties within the online gaming site. This pilot study supports taking a similar approach to study other online gaming networks. This paper adds to the literature surrounding online gaming structure and communication specifically from the lens of depressive symptoms and “IRL” support. The novel use of ERGMs and spatial analysis within a gaming community has not been reported on before, to our knowledge. Further research may wish to build on these findings to examine dynamics within other online and/or gaming networks.

This study offered a glimpse into the social networks of online gamers, and how those who report depressive symptoms were more likely to connect with other gamers. While future studies are needed to confirm this relationship, this information could be useful for future mental health efforts. Using online forums related to gaming as a means to connect people, especially young people, might help reduce social isolation. Further, services such as telehealth could be an effective clinical alternative for people experiencing depression that might prefer an online connection vs a real-life connection. While the online gaming community could provide otherwise isolated people a place to network and connect, it is also important to note that in-person support was still more important than online support. Creating mechanisms for gamers to meet in person might be a useful approach to bridging online and in-person support.

**Conclusions**

While members of an online gaming site did not significantly cluster based on depressive symptoms, there were many parameters that significantly impacted the social structure of the
site, including less “in real life” support and greater depression scores. Understanding the complex nature of online gaming socialization may help bridge the gap between the negative side effects originally attributed to gaming and the positive aspects of enjoyment and connection that can be possible through the online gaming experience.

References


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Chronicles of one woman’s journey towards well-being: acceptance

Jo Mullen

Abstract
Purpose – The purpose of this paper is to share the experiences and reflections of one woman’s journey towards well-being.
Design/methodology/approach – A narrative approach has been taken to structure reflections based on lived experience.
Findings – Reflections are offered based on a personal journey towards well-being.
Originality/value – This paper adds to the accounts of the lived experience of the journey towards well-being, and as such, contributes to the understanding of the process of rebuilding a life.
Keywords Validation, Approval, Self-acceptance

The concept of acceptance, I have discovered, can be quite a tricky notion to pin down. Difficult to define tightly, it is a state dependent on that to which it refers. It could, for example, relate to acceptance of self, acceptance of others, or acceptance by others, all of which require us to navigate and incorporate a range of associated emotions, opinions and actions.

Looking back at the early part of my life, I can say that I was something of an expert when it came to one type of acceptance in particular; I was a passive receptacle for everything that those around me did, and I obediently held that position without question or protest. As such, I now realise, I was never the central character in my own script. This pattern, the power of which had been firmly established during those formative years, continued to reign for a very long time; feelings were suppressed and rules set by others were automatically adhered to in the absence of any sense of my own agency.

In the context of my own life then, it comes as no surprise that I have been much more accepting of others than I have been of myself. This alone would have been enough of an obstacle on the path to attaining a healthy level of self-esteem. However, this trend was accompanied by a tendency to look outwards towards other people, in a desperate search for evidence that I was both accepted and acceptable. Put more bluntly, I needed proof that I had a right to exist. So, driven to pursue whichever route would lead to recognition and praise, I pushed myself to achieve ever higher and more challenging goals. The flaw in this strategy, however, has recently become clear to me; not only is it exhausting on all levels, but the much hoped-for endpoint can never be reached. The sense of well-being I experienced each time a personal action or accomplishment attracted favourable judgement from others could be described as the oft-cited feeling of walking on air. But, in line with the nature of all things, it was a temporary state, and as the memory of such moments inevitably faded, I would find myself back on the same track, seeking my next source of validation.

I am fully aware of how stubborn I can be when it comes to following my preferred course of action. Indeed, it often takes me more time than most to abandon a plan to which I have made an earnest commitment and worked hard to develop, even in the face of unlikely success. I have surprised even myself though (I am actually tempted to say impressed!) when I consider the length of time I have stayed loyal bound to a policy that does not – and never did – serve me.
Another lesson then, on the overall theme of acceptance, concerns my willingness, or rather, my unwillingness, to accept when things are simply not working.

I look back now with some amusement at my 10 year old self as I grappled with a particular question on the day I sat the eleven plus exam. There was a frog who wished to travel from one place to another, a certain distance away – let’s say say 10 metres. The task was to work out how many hops the frog would need to reach his destination, given that he moved forward 2 metres with his first hop, but with each subsequent hop the distance covered would be half of that achieved by the one before. I set about this challenge with the utmost confidence, looking forward to demonstrating my mastery of arithmetic! As I carefully calculated the distance gained after each hop, and then added that to what had been achieved by previous hops, I remember silently cheering the frog on, completely dedicated to helping him reach the finishing line. My page was full of workings out, division sum after division sum. This single-minded and determined approach, however, prevented me from considering the possibility that our friend would never ever reach his goal under the current rules. I did not in fact progress beyond this question – I was still scribbling furiously when the bell rang to signal the end of the test. I can only assume that I had performed well enough in the preceding questions because I was later notified that I had passed. Had I been presented with the frog’s dilemma at the very beginning of the exam, however, the next phase of my school career may well have taken me on a different course.

Moving back to the present, I am delighted to say that at long last I have abandoned the pattern of actively seeking the positive regard and acceptance of others. It would take far too long to describe the process that I recently underwent to arrive at this place, but it did eventually dawn on me that, like the frog, I too was on a path that would always fail to deliver what I wanted. Yes, a truly impossible venture – a trick, if you like – but one which I now suspect the magician was secretly willing me to figure out. It is likely that things went wrong at the start, when I made the incorrect assumption that I had to be something different, or do something different in order to feel that I deserved my spot in this world. I was making everything far too complicated when it is actually very simple. I now know that I could stand in one position till the end of time, never thinking another thought, nor uttering another word, nor moving in another direction, and I would be good enough exactly as I am. The need for external approval is gone.

In accordance with logic then, in future when I am faced with other people’s opinions of me, I should expect my response to be analogous to water off a frog’s back!

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