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145 Editorial

149 Research Watch: mental health services supporting social inclusion
  Sue Holtum

156 Remarkable Lives: John McManus in conversation with Jerome Carson
  John McManus and Jerome Carson

162 Surviving secondary school: a story of mental health in adolescence
  Carys J. Morley

166 Recovery colleges and dementia courses – a scoping survey
  Christine Lowen, Linda Birt and Juniper West

173 Mental health recovery narratives: their impact on service users and other
  stakeholder groups
  Myra Piat, Jessica Spagnolo, Suzanne Thibodeau-Gervais, Catherine Deschamps
  and Yves Gosselin

185 Regression and labyrinthine diagnosis – a case report
  Jing Ling Tay, Alias Lijo, Bixue Wen, Susan Zachariah and Manu Lai

189 Chronicles of one woman’s journey towards well-being: re-membering
  Jo Mullen
Growing the availability of evidence based supported employment

The majority of people with mental health challenges want to have a job (Rinaldi and Hill, 2000; Secker et al., 2001) yet, among people using secondary mental health services, only 8 per cent are in employment (see IPS Grow, 2018). It does not have to be this way. We know that there are effective ways of supporting people with more serious mental health challenges to get and keep real jobs in open employment. Developed in the 1990s in the USA (Becker and Drake, 1993; Drake and Becker, 1996), at least 16 randomised controlled trials in different countries have demonstrated that Individual Placement and Support (IPS) evidence based supported employment is effective in enabling between 40 and 60 per cent of people with serious mental health challenges to gain and sustain employment (see Bond et al., 2008). As a result the 2015 NICE quality standards for psychosis and schizophrenia[1] clearly indicate that this evidence based supported employment support should be provided for everyone who wishes to find or return to work. There is also increasing evidence that IPS is equally effective for people experiencing what have been described as “common” mental health challenges like anxiety and depression (Te Pou, 2014; Reme et al., 2018).

Despite the strong evidence base and NICE guidance the reality is that most people who wish to work do not have access to the support they need to do so. Although the first IPS service in the UK was established in 1999/2000 such services are available to very few people. The 2018 National Service User Survey in England (CQC, 2018) showed that only 23 per cent said they had definitely received support to find or keep work – a significant fall from 27 per cent in the previous year. At the same time, 47 per cent said they would have liked help but did not get it – a rise from 43 per cent in 2017.

But things are changing.

The Five Year Forward View Implementation Plan (NHS England, 2016) requires a doubling of access to IPS from 10,000 people per year in 2017 to 20,000 in 2021 and additional (time limited) funding has been provided to facilitate this. The NHS long term plan (2019) makes it clear that this increase must continue:

> Through increasing access to IPS, the NHS will support an additional 35,000 people with severe mental illnesses where this is a personal goal to find and retain employment by 2023/24, a total of 55,000 people per year. This investment will support people to get back into or gain access to employment. It will improve outcomes and recovery for people, meaning they spend less time in hospital and live healthier, happier lives. By 2028/29, we aim to extend this to 50% of the eligible population to benefit up to 115,000 people. (NHS England, 2019, p. 117)

It should be noted that this is not about forcing people into work with threats of withdrawal of welfare benefits but ensuring that those whose “personal goal is to find and retain employment” have access to the evidence based support they need to do so.

Across England many IPS services are being established all of which are based on 8 core, evidence based, principles[2]:

1. It aims to get people into open competitive employment “real jobs”.
2. It is open to all those who want to work […] with no exclusions based on diagnosis, health condition or benefits claim.
3. It tries to find jobs consistent with people’s preferences.

4. It works quickly […] job search starts within four weeks, even if a client has been off work for years.

5. It brings employment specialists into clinical teams […] so that employment becomes a core part of mental health treatment and recovery.

6. Employment specialists develop relationships with employers based on a person’s work preferences […] not based on who happens to have jobs going.

7. It provides ongoing, individualised support for the person and their employer […] helping people to keep their jobs at difficult times.

8. Benefits counselling is included […] so no one is made worse off by participating.

Some of the developing IPS services are provided by health services, others are commissioned from voluntary and a few private sector providers working within mental health teams. In some areas, existing IPS services are being expanded, in others, completely new services are being established, and on occasions, organisations who have hitherto provided other types of non-evidence based vocational support are converting to an IPS model.

In order to support providers and commissioners of these emerging services, NHS England and DWP has funded “IPS Grow”[3]. A national lead and seven regional leads[4] – all experts in IPS and establishing IPS Services – can provide implementation support (including communities of practice and networking events) workforce development (including workshops, training and e-learning opportunities) data tools and fidelity reviews. A website provides a range free materials, information and guidance for providers, commissioners, people who are wanting assistance to gain employment and people wanting to work in IPS services.

This support for implementation is important. The rapid expansion in process is extremely positive, and indeed overdue given that it is 20 years since the effectiveness of IPS has been demonstrated in randomised controlled trials. However, any expansion of this magnitude is fraught with problems. Already we are seeing problems with finding, training and developing the workforce of skilled Employment Specialists who provide employment support within IPS. If not more important is the challenge of finding team leaders with experience and expertise in IPS to lead the many emerging teams and supervise the Employment Specialist workforce.

There is also a danger that in efforts to increase the quantity of IPS provision, quality may be compromised. Fidelity scales and review methodologies[5] have been developed for IPS and these are important. Research shows that effectiveness in relation to employment outcomes, and cost effectiveness, are strongly related to fidelity (Bond, 2004; Grieg et al., 2014; Lockett et al., 2016). It is imperative that services adhere to all eight of the underpinning principles of IPS and it is not uncommon for a service to say they “mostly” do IPS and miss out one or other of the key principles on which it is founded. It appears that services sometimes struggle with “employer engagement” – developing relationships with employers – and integrating employment support and clinical treatment – ensuring that Employment Specialists are core members of the team. Without these, the effectiveness of IPS is reduced and employment outcomes compromised. The development of effective mechanisms for reviewing and improving fidelity of IPS service provision is critical.

The current expansion of the availability of IPS focusses on the number of people who can access IPS services. This is important, but it risks focussing IPS teas attention on how many people use the service rather than the number of people who gain employment. For example, there may be a risk of “cherry picking” (selectively directing resources towards those who are deemed more “employable” in contravention of the second principle of IPS outlined above) or that caseloads will creep up and intensity/duration of support reduced in order to achieve the necessary service usage numbers. The essence of IPS is a focus on enabling people to access open employment and this must remain the core focus of IPS services and the way in which their success is evaluated. Many mature services have found it useful to set targets for individual workers. In their initial discussions, the IPS Grow team have suggested that in a mature IPS service each full time Employment Specialist might be expected to work with a minimum of 45 people per year and
achieve a minimum of 24 employment outcomes. However, in a mature service, the caseload of an Employment Specialist will be balanced and comprise some people who require a lot of support to gain employment and others who have gained work and require a lower level of support to maintain their employment. In a new service, all those supported by the Employment Specialist will be at the often more intensive job searching stage of their journey and it takes time to provide information and develop the relationships necessary to provide an effective, integrated service. Therefore in the first year of the operation of the service, it may be more realistic to expect an Employment Specialist to work with a minimum of 35 clients and achieve a minimum of 17 employment outcomes.

However, there may also be two more fundamental issues to be addressed.

First, IPS was developed within secondary, specialist, mental health services and it is assumed that people will remain in those services for long periods of time and receive ongoing employment support from the Employment Specialists within those teams. However, models of mental health support are changing. It is increasingly assumed that people with more serious, ongoing, mental health challenges will leave specialist mental health services when their mental health problems have stabilised and receive ongoing clinical care within primary care services (returning to secondary services only if their mental health problems deteriorate). However, while they may no longer need specialist mental health clinical treatment, people often continue to need employment support. It is not uncommon for an Employment Specialist to begin supporting someone to get and keep a job when they are in secondary mental health services but have to stop working with them when their treatment is transferred back to primary care.

One of the core principles of IPS is that ongoing support can be provided to both the individual and their employer for as long as is necessary. Some people will need continuous support, for others this may not be necessary, but as mental health conditions often fluctuate, it is important that a person can quickly and easily access support if they have problems. If we are to develop high quality IPS services it is critical that they span the primary/secondary care divide and provide the ongoing access to employment support that people may need if there are to sustain and prosper in employment.

Second, IPS services were initially developed to help people who were unemployed to first gain, and then sustain their employment; they have not been directed towards enabling people towards “job retention” – enabling people to keep their employment when they develop mental health problems and come into mental health services. In the UK, a substantial proportion of people are in employment (often on “sick leave”) when they first develop mental health problems and come to primary or secondary care services. Helping people to retain and prosper in employment after getting a job has always been a core part of IPS, but it is important also to help those who are in work to retain their existing employment, or retain their place in the labour market by moving to another job if this is more appropriate to their needs and wishes. It is absurd for an Employment Specialist in a mental health team to say that they cannot provide employment support until the person has lost their job! It is important that the roll out of IPS includes the possibility of helping those who come into secondary mental health services who already have a job to retain their employment. Successful UK IPS services have shown themselves to be as effective in helping people to retain and return to existing employment as they are in helping those who are unemployed to gain (Rinaldi et al., 2010).

Finally, perhaps the most important risk to the expansion of access to IPS services is that, hitherto, the new monies for developing services provided within the Five Year Forward View are time limited. Those who have received funding have made undertakings to continue to fund the services after the additional monies finish […] but with all the pressures on resources within mental health will these promises be fulfilled? It seems to us that there is a significant risk that, when the short term additional funding ceases IPS services will be cut. The real challenge will be to maintain the investment over the longer term and ensure that IPS becomes a core part of mental health services. We will only know that we have succeeded when an Employment Specialist is accepted as an integral part of a clinical mental health team (whether in primary or secondary care) – as integral and indispensable member of the team as the occupational therapist, psychologist, pharmacist, nurse or doctor.
Notes

1. www.nice.org.uk/guidance/qs80/chapter/Quality-statement-5-Supported-employment-programmes
3. IPS Grow website: http://ipsgrow.org.uk/
5. www.centreformentalhealth.org.uk/ips-fidelity-scale

References

Research Watch: mental health services supporting social inclusion

Sue Holttum

Abstract
Purpose – The purpose of this paper is to examine three recent papers on mental health services and social inclusion.
Design/methodology/approach – A search was carried out for recent papers on mental health and social inclusion. The author selected three papers that each spoke to a similar theme, from slightly different angles, and that seemed to advance understanding of how social inclusion might be supported to a greater degree in mental health services.
Findings – One paper vividly describes some of the blocks to social inclusion, and what that can feel like from a service user perspective, and also points to ways for peer workers to support service users’ social inclusion. A second paper illustrates how mental health professionals and peer workers can choose to stand up for people’s human rights despite lack of organisational support for such actions. The third paper describes pioneering co-designed work to build dedicated support for social inclusion alongside mental health services.
Originality/value – All three papers highlight the ongoing need for better support for social inclusion in mental health services across different countries. They also show how such support can be implemented and even made more mainstream. This raises hope for wider progress in mental health services becoming real enablers of social inclusion.
Keywords Mental health, Social inclusion, Human rights, Co-design

In this paper, I wanted to focus on how mental health services can support people’s inclusion in the kind of ordinary life that many take for granted, things that are the focus of this journal: such as having a job we want to get out of bed for; having friends we can help out and who can help us in times of need, or just to do things we enjoy with; access to transport to go where we want or need to go, when we want to; and having a voice about things important to us and having that voice heard. I discuss three recently published papers that speak to this topic. Stewart (2019) writes in this journal about her experience as a mental health service user and peer support worker in Quebec, Canada, and describes the lack of support for real inclusion. Hamer et al. (2019, p. 303) describe how mental health professionals and peer workers in Connecticut, USA can “buck the system” in order to uphold service users’ human rights, because it is “the right thing to do” (p. 297). Finally, Bertram (2019) describes gradually building co-designed services in London, England, to supplement deficiencies in standard mental health care that is not designed to support social inclusion.

Being “ghettoized”

Stewart (2019, p. 53) uses the term “ghettoized” to explain her experience in Quebec when she was a mental health service user and then a peer worker with a community treatment team. She, and then other service users she worked with as a peer worker, was offered only a few activities for occupational health: “art workshops, cooking and computer classes” (Stewart, 2019, p. 55), and these were only with other service users. Whilst Stewart recognises that service users can draw strength from each other, there seemed to be almost no thinking within the mental health system about how to support people to make a broader range of connections or to engage in other activities of ordinary life that they might find fulfilling.
In the end, Stewart (2019) found her own ways to make connections with others who shared her interests outside the mental health system, but she wondered why staff with whom she came into contact did not seem to prioritise this (Stewart, 2019). She recounts how service users she worked with as a peer worker had similar complaints, with one saying she felt “cooped up” (Stewart, 2019, p. 55) in a drop-in centre. Another echoed her feeling about being “lumped in a group” (p. 55) with other service users. It felt as if people were “not good enough” (p. 54) to be in ordinary mainstream settings. Staff may unintentionally reinforce this feeling by believing that people cannot manage anything else, Stewart (2019) suggests.

**Building bridges**

Stewart (2019) describes how, as a peer support worker, she was able to work with service users to find ways to support them to do other things. Together they found ways to tackle some very real obstacles. For example, lack of money is often an issue, so Stewart sought low-cost activities open to members of the public. There were many women’s centres around Quebec that any woman could attend, and which ran activities that the women themselves suggested. Stewart (2019) found a gym that offered a discount for people with disabilities. Stewart (2019) also highlights that there are some websites that support members of the public to find others who share an interest, so that groups in specific localities in different countries can form and arrange to do things together around their interests, at low or no cost.

Stewart’s role as a peer support worker enabled her to do things like going with a service user to public places such as the local swimming pool. This could form a bridge so that eventually the person could go alone. However, Stewart (2019) wonders why there is not a more fully developed system for supporting such activities, and also funding to help with the cost of transport. Whilst Stewart (2019, p. 54) suggests that “safe spaces” might be important due to prejudice, and because being together with other service users can help people to campaign for change, she also suggests a need for mental health services to work harder to support social inclusion.

**Being insider activists**

Hamer et al. (2019) use the concept of citizenship as a framework for thinking about social inclusion in mental health. Hamer et al. (2019) describe what staff do in supporting social inclusion as “acts of citizenship” (p. 209), referring to Isin’s (2008) theory of citizenship. This refers to making a special effort to support the human rights of marginalised people. Thinking of a broader arena than mental health services, Hamer et al. (2019) discuss how the organisational context of commercial companies in which people work can limit their choices. However, employers and their workers can espouse citizenship by respecting each other and their customers, and building mutual trust. Hamer et al. (2019) apply this framework to mental health care, suggesting that managers can support the rights and citizenship of staff, and in turn this enables them to support those of service users. However, Hamer et al. (2019) also point to obstacles to this in the mental health system, in that there is a bias towards restriction and often coercion, and a view that it can be risky to allow service users much choice and autonomy.

Acts that subvert the organisational culture in order to uphold service users’ rights are, say Hamer et al. (2019, p. 298), “acts of citizenship” and constitute political action. Hamer et al. (2019) tell us that this idea has so far been applied in relation to refugees more than in mental health care. However, they draw parallels between the marginalised groups in these different fields, and the way in which, by siding with those who are marginalised, it is possible to promote their rights to citizenship and inclusion.

**Recognising human rights**

Hamer et al. (2019) point to the tendency of the dominant narrowly biological view of mental distress to equate people with their diagnosis and to take a view that people need to be restricted rather than enabled to exercise choice and agency. Hamer et al. (2019) also refer to an account by a service user (Lampshire, 2018) in which she describes how staff broke the rules in order to
enable her to feel accepted and connected. Hamer et al. (2019) refer to the reality that stigma and discrimination occur within as well as outside the mental health system, and suggest that when staff promote service users’ inclusion and citizenship, they are acting in accordance with the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006).

**Mental health workers’ understanding of inclusion**

Hamer et al. (2019) interviewed seven mental health professionals and five peer workers in Connecticut, USA. They analysed the data to identify themes and produced two main themes: “breaking the rules”, and “the right thing to do” (Hamer et al., 2019, p. 299). However, they also reported on workers’ understanding of inclusion. Workers talked about feeling “like an equal, feeling connected, being similar rather than different” (Hamer et al., 2019, p. 299). In the community, one could feel togetherness when affected by common adversities such as storms, and in the workplace, one could feel it when working towards common goals and feeling connected with service users. Sharing creative interests in the community also helped people to feel included, as did mutual greeting on entering the workplace.

**Breaking the rules**

In terms of Hamer et al.’s (2019, p. 300) first theme, “breaking the rules”, some peer support workers seemed to be following the example of professionals, who would “game the system” (p. 300). An example was changing the appointments diary to fit in an urgent case. One peer worker took a service user out to a café and noted how a relatively small act like this could make a huge difference to someone who no longer felt accepted in such ordinary spaces. Arguably this kind of thing might have been part of the support worker’s role (this was unclear), but it did not appear to be built into the wider system, in which there was a feeling that such action was questionable.

**Political action**

In another example of acting to uphold the rights of a service user, Hamer et al. (2019) present a story of a mental health professional whose training included more emphasis than usual on social justice. She was therefore more aware of the effects of discrimination on service users than the rest of the clinical team. She learned to talk in such a way that other clinicians could hear her, while at the same time introducing a new approach. She felt that it would be helpful to a service user to accept his offer of getting her a coffee, but it was necessary to persuade the clinical team that this would be “therapeutic” (p. 300) by talking about it in clinical terms. By this means, she got it built into his rehabilitation plan, and he was thereby able to enact the role of a valued citizen. The team also became more interested in this new way of thinking.

**Doing the right thing**

In another story relating to their second main theme, “doing the right thing”, Hamer et al. (2019, p. 301) describe a clinician spending 15 minutes finding out how a service user could get a bus pass. This felt like doing something that was beyond his role, but it also felt like “the right thing to do” (Hamer et al., 2019, p. 301), and it seemed likely to do more good than other aspects of care, and therefore to be morally defensible. A peer support worker spoke about feeling invalidated when you have a diagnostic label because you are no longer seen or heard. For one professional, validating a service user could include accepting a small gift when offered as an expression of thanks. It enables a sense of equality in the relationship and allows the service user to have agency (Hamer et al., 2019). However, there was also a sense that staff may feel it was not their role to uphold people’s rights because there was someone with that as their designated role. Other staff pointed to fears among staff that giving service users more agency would increase risk. This even applied to registering them to vote, even though the organisation appeared to support it.

Another problem that Hamer et al. (2019) highlight is the way that people have to identify as disabled in order to carry on receiving welfare benefits. It means that recovery of a meaningful life is linked with losing out financially when this can have serious detrimental effects. Some mental
health professionals could feel that their efforts to uphold people’s rights were hampered by this. However, Hamer et al. (2019) do not comment on the deficits of a welfare system that requires one to be either ill or well and that pulls the rug from under people as soon as they are considered to cross the threshold between the two.

**The need for service users’ rights and citizenship to be central in mental health care**

Hamer et al. (2019) suggest, on the basis of their participants’ comments, that clinical supervision should routinely incorporate asking professionals about their actions to support service users’ social inclusion, and whether they had done anything to change stigmatising ways of talking about people. There was also a recommendation for regular training for both staff and service users about citizens’ rights.

Hamer et al. (2019) provide a different take on the increasing UK interest in moving from asking “What’s wrong with you?” to “What’s happened to you?” (Longden, 2013). They suggest asking, “What matters to you?” (p. 302). This, Hamer et al. (2019) suggest, will bring back the clinician’s role of working in genuine partnership with service users. They argue that the acts of upholding service users’ rights should not have to be hidden or feel subversive. Staff should be able to feel that this is mainstream and part of their job.

**Making social inclusion happen**

Bertram (2019) discusses the lack of literature describing vocational support in mental health services, despite some research suggesting it can be helpful. He sets out to describe what has been happening in one National Health Service mental health trust in London, England, over the past few years. He mentions the Individual Placement and Support (IPS) system of support for employment, reviewed in a previous Research Watch (Holttum, 2011). Bertram (2019) suggests that this system is difficult for some service users if they do not feel ready for employment, and suggests a need to support a wider range of activities. He also highlights that UK Government policy calling for support for people to find education and employment does not state how this should happen or whether it should be built into mental health services or outside them.

**Listening to service users**

Bertram (2019) also points to a lack of consultation with service users, which is where he and his team began in 2006. He cites three papers he wrote and co-wrote on this issue (Bertram, 2008; Bourne et al., 2007; Josefsberg and Bertram, 2012). Bertram (2019) presents some key service user perspectives from these consultations:

- the need for person-centred support (being heard, encouragement);
- real opportunities;
- one-stop shop to get the right information;
- support tailored to individual needs, not the service need;
- not just employment, but also training and volunteering opportunities;
- advice on welfare benefits;
- tackling stigma to support self-esteem; and
- prioritising people’s vocational aspirations (always making it part of the care plan).

Service users wanted a better deal out of life, especially as they often recognised the role that adversity, trauma and discrimination had played in causing their mental distress, consistent with Longden (2013). An initial examination of 278 care plans found that 96 per cent of service users were unemployed but only 8 per cent of the plans included support for their occupational goals (Bertram, 2019). There was also no local strategic plan to address this in 2006, says Bertram (2019).
Small beginnings

Bertram’s team started with some small pilot projects, for example one with two occupational therapists and a benefits advisor (Bertram, 2019). This small team assessed people individually and gave them support to move towards their goals. As reported by Bourne et al. (2007), 22 of the 55 people assessed found activities in just a few weeks, with a further 11 engaging with continued support, and 22 unable to stay engaged.

The service director was supportive of further innovations, and a social services day centre made an office available for user-led information provision, one voluntary-sector IPS worker, and a work training and volunteering project that brought income. There was also a time bank for people to make their skills available on a mutual exchange basis. With 170 service users supported, this provided persuasive evidence for asking for service commissioner support to do more work.

Co-design and expansion

The next stage was co-designed between staff and service users. The services included individual vocational assessments, supporting people’s goals, enabling choice from a range of opportunities (not just mainstream employment and including leisure activities), and working with employers, job centres and colleges. In addition some ways of measuring outcome were agreed, such as whether people got into employment or supported employment, or were involved in any of the other activities (Bertram, 2019).

A project board was also set up, comprising a range of stakeholders to keep things growing and improving access to service users. This led to a substantial increase in posts in the various projects, a dedicated resource centre from 2009, and a change to the mental health service computerised record system so that there was a box for staff to record employment.

Bertram (2019) presents some outcomes for 470 people seen between 2009 and 2010. According to the numbers he presents, the percentage who gained employment and came off benefits was small ($n = 41$, 9 per cent), but a further 19 per cent started voluntary work, 19 per cent started mainstream education and 17 per cent started other activities. This leaves 37 per cent unaccounted for, but it is clear that the majority (63 per cent) of people were able to engage with new activities. Bertram (2019) reports additional benefits such as improved wellbeing and reduced service use, greater confidence and hope, gaining new skills and improvements in relationships.

Ditching the box-ticking

Bertram (2019) emphasises how effective the service user-led information and support was. It was made part of secondary mental health care. The service user manager of the vocational support service talked about tackling obstacles one by one, and also ditching the assessment form because it got in the way of building a relationship with the service user. I feel a need to comment on this, because many mental health workers would love to ditch forms and box-ticking. Yet there is a well-worn argument that ticking boxes demonstrates accountability. Indeed, the creation of a new box in the data recording system for recording vocational assessment seems a milestone. I have heard mental health workers talking about the impossibility of changing the IT system so that they can make something that is important to service users easier to record. They recognise that if there is no box for something, the organisation does not value it, and they have the feeling that you should not be doing it because you are not paid to do it and you are not given any time to do it. So to my mind, having that extra box was no small thing. It meant that asking about people’s vocational goals and aspirations had finally been officially recognised.

All that said, I would argue that box-ticking in mental health to confirm that certain things have been discussed or assessed is a bit different from box-ticking in a medical consultation when a fatal disease is suspected, and covering certain things might determine getting life-saving treatment or not. In most mental health consultations, the main need is that the service user feels respected, heard and understood. Anything that takes away from this, including the need to tick boxes, may obstruct the thing that is the main therapeutic force, that is, connection with another human being who cares and shows empathy.
To return to the service user manager of the vocational support service (Bertram, 2019), there were often very practical obstacles in people’s lives that made it difficult for them to pursue their goals. This included housing, debt and immigration issues, so information was given about help lines and organisations that specialise in supporting people with such things. Pressing practical needs must be addressed before vocational issues can become the focus. Listening to service users and working in partnership gave them validation and spurred them to do their bit and enabled them to grow in confidence (Williams, 2012, cited in Bertram, 2019).

**Financial realities and leadership**

The centre, unlike usual mental health services, had no glass partitions or door locks. Essential work (decoration and cleaning) was done by two work training projects, which saved a lot of money. One training project obtained a commercial contract to clean local authority venues, bringing valuable income. The advent of austerity was a threat, with the local authority budget reduced by 56 per cent (Bertram, 2019), and NHS budgets also stretched. However, the new services were maintained, although not able to expand further.

Bertram (2019) suggests that he needed good communication skills to engage with many stakeholder groups and to keep promoting a clear vision and holding onto hope. However, he sees challenges for the future. There is still no clarity from policy makers about how vocational support should be addressed, and it may be under threat from cuts. Most mental health care training also tends not to see service users as experts on what can help them to move towards their goals, says Bertram (2019).

**Warning**

Bertram (2019) warns that continued failure of services to address the social causes of mental distress (mainly difficult life events, exclusion and invalidation) will lead to more and more demand. One thing that he suggests might help policy and services to shift their emphasis is to have a demonstration of how much money is saved by offering vocational support. He also suggests a need for the benefits system to change, since it tends to be shaming and all too often adds to people’s distress rather than helping them achieve their goals.

**Conclusions**

These three articles coalesce around a common theme of how mental health service users’ social inclusion can be supported. All of them highlight the continued lack of priority given to this in mental health services. Stewart (2019), in her role as a peer support worker, found ways to use her role to support people to find ways to pursue their goals of taking part in everyday activities. Hamer et al. (2019) demonstrate how both mental health workers and peer workers can be covert activists to subvert a system that fails to acknowledge people’s rights to citizenship. This is reminiscent of the insider activism espoused by mental health professionals who also had experience as mental health service users, and also peer workers in Richards et al. (2016). However, political action could also be more open, suggest Hamer et al. (2019), for example when a mental health worker with particular training experience that placed emphasis on social justice was able to bring some of the ways of talking from that training into discussions in the mental health team, and thereby influence thinking.

Bertram seems to take things to a whole new level, where he was able to drive significant change and build parallel and integrated services that would support service users’ goals for social participation in a range of ways that were right for each individual in their recovery journey. He drew on the power of co-design to harness the expertise by experience of service users themselves. The additional achievement of changing the IT recording system to include a box for recording assessment of vocational goals, whilst raising the whole issue of how box-ticking may get in the way of real relating, also illustrates that “it can be done”. Things that matter to service users can be built into systems that can appear so big and remotely controlled that nothing can be done. Wider political uncertainties notwithstanding, this raises hope for real and sustained change.
References


Corresponding author

Sue Holttum can be contacted at: sue.holttum@canterbury.ac.uk

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Remarkable Lives: John McManus in conversation with Jerome Carson

John McManus and Jerome Carson

John McManus and Jerome Carson are both based at the Department of Psychology, University of Bolton, Bolton, UK.

Abstract

Purpose – The purpose of this paper is to provide a profile of John McManus.
Design/methodology/approach – John provides a short life history and is then interviewed by Jerome.
Findings – John tells us about the insidious development of his illness and how for many years it was masked by substance abuse.
Research limitations/implications – As Patricia Deegan has stated, “Each person’s journey of recovery is unique” (Deegan, 1996). That is why we can learn so much from case studies like John’s.
Practical implications – John’s account shows the value of Early Intervention Teams. The service he received from his local team was “second to none”.
Social implications – John talks about the value of volunteering and how it helped him believe that he could once more play a constructive role in life.
Originality/value – There is no doubt that John benefitted from support from professionals, experts by experience and his family. Equally he was also open to all these sources of support.
Keywords Volunteering, Hearing voices, Early intervention teams, Experts by experience
Paper type Case study

Introduction

Looking back it is hard to say what first captured my attention about John. He asked to see me on his own to discuss assignments and it was during these sessions that I came to learn about his mental health problems. He told me he was a voice hearer. One of the first people in this series of Remarkable Lives was Peter Bullimore, also a voice hearer. Naturally, I shared with John the story of Peter and his achievements. John was already aware of Peter and also that other great pioneer, Ron Coleman (readers can see talks by each on YouTube). John is of course on his own unique journey. Let us hear about it in his own words […]

Brief biography of John McManus

Where to begin? Well! My name is John (McManus) McEwan born and bred in Glasgow, Scotland. Having six younger sisters growing up was not the greatest, but both my parents tried to make the best out of a very bad situation. As a result, I am not going to be selfish and reflect on it negatively as it made us stronger as a family and stronger as individuals. I have managed to produce three sons and three daughters, who have at this time made me a grandad to two grandsons. I live with auditory, tactile, olfactory and visual hallucinations and have done for almost 30 years, if my memory serves me correctly; however, I never noticed them as being anything other than normal. Unfortunately though, through what I would deem a series of unfortunate life events and turbulent relationships 14 years ago, they became somewhat of a hindrance and I started having not only a negative experience but an extremely debilitating disabling experience.

I was living with a family member and I remember waking up one day and looking out the window at my uncle, who was chatting with neighbours and a group of voices came and called him a “beast”. Now in Glasgow that can mean anything from a paedophile to a rapist and if your name
is tarnished by this, it can be very, very, very harmful and have a detrimental effect on your life. However, I did not realise I was hearing voices. I thought this was a neighbour and thought about confronting them. Instead I had a chat with my uncle and made him aware of this. However, in the following few months my life was set to change dramatically.

I started suffering from other experiences; however, these were aimed at me. I would listen to my loved one screaming; however, due to the nature of one of my experiences I interpreted these as being things I had done. I started ringing the family members in question asking them if I had ever done anything? They reassured me but the voices were relentless. I was self-medicating (or self-overdosing) on cannabis, cocaine, amphetamine and alcohol and my life was beginning to spiral out of control. As a result, my symptoms were accusatory and imitated the people I loved. I was not convinced I was hearing voices, and I believed initially that these were the actual people talking to me. My family thought they had no reason to fear me or I them, but why would they be saying such horrible things to me or why would they not tell me what was going on? Within a short period, my suffering had spiralled out of control and I was arrested for the first, second, third and fourth times in my life and went to prison briefly for the first time as a result of symptoms manifesting from drunken stupidity. I “fled” the law and I decided to go to Blackpool where my mum and dad had lived for the past 17 years to seek support.

Blackpool had a positive and negative effect. I soon realised that I had a drinking problem. My symptoms were still apparent, however, due to them imitating my immediate family. Within a short period of time I was convinced they were trying to kill me. Listening to something out of a serial killer documentary of a room being “duct taped” and covered with plastic to hide the evidence of my body, I had entered the scariest stage of my illness. I was petrified, the most traumatic experience of my life to date, and growing up in Glasgow throws a lot of them your way as an individual! Not realising at the time I had entered the “startling phase” of a diagnosis of alcohol and drug-induced psychosis, I realise why it is called the “startling phase” now. Within a short time I was rearrested for being drunken and disorderly and escorted to Glasgow to face my crimes. Thankfully, the judge took into consideration that I had briefly hit a very hard time in my life and gave me two years’ probation and 240 hours of community service with a condition that I attended Alcohol and Drug Services in Blackpool. This was to prove a turning point in my recovery. Although I was still struggling with my symptoms, I realised I had to start eradicating the known causes of my symptoms and rather than go back to prison I grasped at the chance of support. I started working at Blackpool pleasure beach as a cook and also in customer services. I sold flasks for soft drinks to make money. I was still suffering very badly from my symptoms, which had cost me my life with my children, my family in Scotland and now my job. I explained to my supervisor what was happening and he said I should have some time off and go to my GP.

Initially, this was a bad experience as in the GP’s words (although he only documented it) I was more preoccupied with getting a sick note than anything. He said “I think work is the best thing for you Mr McEwan”. Angrily realising it had taken me quite some time to even get there. I said, “What? You can stick the f***ing sick note up your a**el”.

I changed doctors and was started on antidepressants, yet knowing that I was not depressed, I did not take them. This time was also a turning point in my life with regards to my symptoms. I was in a shop with both my sisters and a lady appeared to say, “You have AIDS”. I responded to my sisters’ dismay by replying, “I do not have f***ing AIDS”. My sisters convinced me I was hearing voices. I became extremely paranoid. As I had met a new woman and was sexually active, I decided to go and get checked out and explain to the staff at the hospital that I was hearing voices and what they were saying seemed very normal. However, to curb my paranoia I spent the night at Blackpool Victoria Hospital probably to sober up. Fortunately for me this was one of the few nights I spent in hospital due to my mental health problems. The girl I met fell pregnant and supported me the best she could and the baby. We decided to leave Blackpool and moved to Leigh eight years ago.

My son was born, and I was being supported by a new GP who referred me to the Early Intervention Team (EIT). This was the ultimate turning point in my life, and I cannot thank the team enough for the help and support they have given me. I had numerous CPNs and support workers and all were very helpful and supportive. However, there are a few who stick in my mind. The first was Ann Johnson (CPN). She really kick-started my recovery with an introduction to some
self-help groups and local activities. I felt a burden of living in a town were the only people I knew and socialised with were my son’s family. This was great until the relationship with my son’s mum went sour and on one Friday at 4 p.m. I became homeless. This is where I have special thanks for the EIT and Ann Johnson. Knowing I had no one and nowhere to go she came to see me and within an hour I had a temporary flat. Now I do not know if the conversations we had been having about the relationship had prompted this lady to do some work in advance, however, I have been homeless in Glasgow before and know that you do not get a furnished flat in 1 hour! I needed benefits. I was on £50 a week as a result of sanctions and could not concentrate enough to even do the Maths and English assessment. The medication I was on was making me extremely drowsy. I could not stay awake at appointments in the Jobcentre and I looked more like a heroin addict than a mental health sufferer. However, the EIT had taken a lot of my psychosocial problems away. I needed to socialise with peers so they provided social inclusion groups, like the hearing voices group. I needed money. They helped me get my benefits and in collaboration with my GP, I was put on Employment Support Allowance and Disabled Living Allowance. Now my money worries were gone. I met support worker Charlie Leonard. He took me to football (as I said I liked football) and I was now attending a local football group as well as going to see my boyhood heroes Chelsea (in the Wigan End of course) and the Scottish National team players Sean Maloney and James McCarthy, who played for Wigan at the time. I rang Charlie when I had a water leak, as at the time I could not remember how to turn the water off. He told me what to do. For me, EIT is a service that was invaluable to my recovery. They rarely let me down and on numerous occasions went beyond the normal job role to help me. I was on five different types of medication during my time in the services. Olanzapine, Aripiprazole, Quetiapine, Risperidone and Zopiclone, none of which had an impact on the symptoms, and yet I was on maximum doses of each of these. My last hope was Clozapine. I had been having numerous side-effects from the other medications, fidgeting legs, severe drowsiness, dizzy spells and blackouts, so my psychiatrist asked me would I like to try Clozapine? I was given a leaflet and video to help me think about it. I would have to spend two weeks in hospital. I thought that would not be too bad so did not mind it, however, the side-effects were irritating. I just knew that I was having all the other symptoms and after watching the DVD I decided a non-medicinal route would be better for me and it is a decision I am glad I made. I live with my voices. However, due to therapeutic interventions and peer support within the services I am back to a fully functional existence no longer categorised as disabled via debilitating symptoms.

For the past eight years I have been a volunteer for the National Health Service Inclusion Team, as an expert by experience. I was able to both lead and co-facilitate peer support groups in the community and on hospital wards. During this time we have won awards and I was nominated for the Harry Blackman award for my work as a volunteer for the NHS. For the past three years I have been working on the NHS nursing bank and this was a huge step for me, as all I ever wanted was to get back into work. I am now providing for myself and am proud of where I came from and where I am going to with regards to my life. I loved my voluntary work and always found it very rewarding to help people like myself. Doing it for nothing always got a special response from people as they knew I did not have to do it and was not doing it for money, I was doing as so many did in the founding years of the NHS. I was, however, learning from them and they from me, which was very therapeutic.

Academia has helped me immensely throughout my struggles. I started Wigan College after failing to complete the simple online assessment a few years previously as a result of visual hallucinations. I persevered and read, read and read and continually told the voices to go away (in impolite Glaswegian terms) until the symptoms were no longer dominant. I had gained control over the situation and I have never looked back. In Glasgow I had GCSEs to get to college before. However, now I had to start from basic level Maths and English. I am now in my last year at University. I feel a great sense of pride in my achievements so far. Not only have I challenged the illness I have embraced it and as a result of academia I found a constructive coping strategy that will benefit not only myself, but service users and carers in my line of work in the future.

John in conversation with Jerome

Jerome: How old were you when you first started hearing voices?
John: I cannot be 100% sure. When I was a child I had auditory hallucinations or unexplainable experiences, however, between the age 24 and 25 they became hostile towards me and my family.

Jerome: Are the voices you hear these days different?

John: I barely notice them nowadays, but they remain the same in derogatory content. The only thing is the anxieties they have produced and certain words that people say make me anxious or experiences people talk about.

Jerome: What do you see the role of the Hearing Voices Movement as being?

John: The Hearing Voices Movement is a massively expanding therapeutic avenue, which is crucial to peers and professionals in understanding the detrimental effect the symptoms can have on an individual. It also allows us to understand the ways in which these symptoms can inspire individuals and in a more positive outlook shape a more functional, productive life and successful career.

Jerome: You come from a large family. Have your family always been understanding about your mental health problems?

John: My family are very understanding and empathetic. Naturally, when I became ill that is where I went for support. I am fortunate to have them. If it was not for that support God only knows where my struggles would have led as I negotiated the startling phase of my illness.

Jerome: You have done a lot of volunteering work. This year you will graduate with a degree in Psychology. Do you see yourself as someone who might inspire others in the future through presentations of your experiences?

John: I have been a proud volunteer now since September 2013 and found it very rewarding and very therapeutic and in fact, I had the most rewarding experience as an Expert by Experience. I think if I was not to do something positive with it to help other people it would be a waste as I have found Pete Bullimore’s experience very inspirational and therapeutic. For me not to be doing something where my experience is helping others would be unthinkable and probably even selfish of me.

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

John: I am not sure, hope […] I hope I can keep doing what I am doing, I have a blueprint of my future and it is to help as many people as possible. If I can help motivate someone into academia to start learning or into the gym to help them deal with the stress of unwanted symptoms, then in my eyes I am creating a slight degree of hope in them. I read in an article in Psychology Today “The Power of Hope: as long as the patient, individual or victim has hope they can recover from anything and everything”. I believe in this mostly in that I had hoped that I would get better, and my symptoms would diminish, however, instead of hanging on to this hope, I adapted it and learned to live with the voices and embrace the other unwanted symptoms that manifest in their presence. Hope is a lifeline and without it I might have had nothing but thankfully hope is adaptive, inspiring and motivational and I have it in abundance.

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

John: I think in this country we are blessed with a fantastic empathetic and inclusive mental health service. Having experienced both sides of the service, I feel I am very fortunate. I have been part of the Psychosis recovery pathway which was looking at changing the way the NHS treated psychosis. However, I would make changes in how we manage the initial intervention. I think when an individual is aggressively ill the symptoms (especially in the startling phase) can take people right out of their normal characteristics and personality.

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

John: I think there are times and places for it, I think it must be researched more as I know that a lot of my symptoms were medication-related. For instance, an increase in agitation the next day from sleeping medication. If I had to take medication for consecutive nights that agitation would
increase and with that a massive increase in the symptoms and intolerance to the symptoms. However, the antipsychotics may not have helped with the auditory hallucinations but did help with managing my mood and coping with them. I believe anything that affects the natural biological process meets rejection of sorts from the body as the body tries to maintain homeostasis. When medication is given at the right time it helps, after that, I think the best way is to look at a more natural way of coping.

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

John: I think recently there has been a massive increase in peer-led organisations and groups within the community, a lot of whom are set up and funded by the NHS. I think more of this type of funding would be very beneficial to the promotion of mental health recovery.

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

John: Loads, absolutely loads. If I had listened to my voices, I would have hated them all. However, I rejected the voices and not the therapy. As a result I built up productive relationships instead. To name a few. Initially clinical psychologist Janine Coyne was a massive inspiration and source of knowledge. You could also say she inspired me to become a psychologist. My first CPN Anne Johnson helped with all aspects of my care and was ever-present. I was homeless she got me my house and sorted everything else. She was hardworking and very knowledgeable. A support worker called Charlie Leonard inspired me to get fit and train and supported me with football, gym and other sporting events. Bernadette Fitzpatrick and Dennis Dewar of the Inclusion Scheme. I could name loads but these are the ones who stick in my mind and ones I have a lot of respect for. They asked, I said, they did! Everything I am doing now was influenced by these and so many others in one way or another.

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

John: My late Grandfather for one. Not a lot of people knew he heard voices but one night when he was sipping on his whisky, he told me. He was a great man, very proud and hardworking. My friend Laura has heard voices since we were kids and they have always troubled her, but even in the face of adversity she would try and smile. However, more recently people like Ron Rotherham, Pete Bullimore and Ron Coleman. They have had similar experiences and managed to lead productive lives and help others, especially Ron Rotherham as we facilitated many groups together.

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

John: It looks as though my biggest challenge will be to obtain a job in psychology. However, I would like to start planning an increase in hearing voices and health and wellbeing groups as out of all the psychological, cognitive and biological interventions I have received, this was my main form of assistance.

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

John: I would like to be remembered for my contribution to mental health services but just to be remembered by my children, grandchildren and my family is good enough for me.

Conclusions

John’s is a remarkable story. He heard voices for years, but no one recognised what was happening to him. His family were a constant and reliable source of support. When the symptoms of his illness brought him into contact with the judicial system, it was a judge who recognised he needed help not punishment. When his illness manifested itself, he was helped by an incredible Early Intervention Service, who provided him with “somewhere to live and something to do”. It would appear that he has often found “someone to love”. When he graduates from his psychology degree, let us hope that he is able to continue playing a role in helping others.
Further reading

About the authors
John McManus is finishing his Psychology Degree at the University of Bolton.

Jerome Carson is Professor of Psychology in the Faculty of Professional Studies at the University of Bolton. Jerome Carson is the corresponding author and can be contacted at: J.Carson@bolton.ac.uk

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Surviving secondary school: a story of mental health in adolescence

Carys J. Morley

Abstract

Purpose – The purpose of this paper is to share experiences of attending a secondary school with mental health difficulties and provide tips for coping. It is the first 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 tips for both adolescents experiencing mental health difficulties and teachers are provided.

Originality/value – The paper is one person’s experiences and 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 may be experiencing difficulties and those who know such teenagers.

Keywords Adolescence, Mental health

Paper type Viewpoint

Although becoming increasingly acknowledged and understood, mental health issues in teenagers are often reduced to “phases”, “hormones” or “just part of growing up”. At least, this was my experience in school. I am 22, and I have been suffering from various mental illnesses for over a decade – including depression, anxiety, PTSD and Borderline Personality Disorder. I went through school, sixth form, and most of university, without any support. Secondary school was an avalanche of depression. Sixth form was a hurricane of anxiety. University was acceptance. Now I am learning to manage my illness.

This is the first in a series of three papers, exploring each level of education and the impact mental illness can have on both education and being a young person in general. This piece will begin the series with secondary school.

My story

I distinctly remember the first time I felt something akin to depression. I was six years old, and I had just gotten home from school. I sat inside and heard children outside, giggling amongst each other. It occurred to me that no one wanted to spend time with me outside of school. I concluded that I must be awful.

It did not improve. By the time I was 13, and far into secondary school, I was struggling. I was moody, defensive, easily angered, spoke bluntly (and therefore had very few friends), fell asleep during lessons, was fanatical about my hair and had regular panic attacks. I was all but convinced that I was the worst person in the world and that there was no reason to live. I threw my mum’s lovingly made packed lunches away more often than I ate them. I spent my evenings right through to very early mornings online – going into chat rooms, creating personas on games, trolling the forums – pretending to be anyone else except myself.

I was bullied mercilessly. I was an awkward-looking teenager, and my peers did not hesitate to point it out, branding me “rank”, a “proper minger” (see: 2009 slang for “ugly”). It did not upset me. I knew it was true, but I did not need reminding. I grew an absurdly long side fringe to cover my face. “Nice hair”, they would say, with a smile dripping in sarcasm.

Carys J. Morley is an Independent Writer based in Leeds, UK.
I was not a talented teenager, either. I did not really have any hobbies because I neither had energy, nor did my depression allow me to enjoy anything. Therefore, I was not good at sports, art, crafts, music – any of the cool things that teenagers often engage in. Given that I never, ever engaged in any form of sports other than in school, PE lessons were torturous. People audibly groaned when I got put in their teams. One girl even had the nerve to say to the teacher that it “wasn’t fair” to have “her” on their team. The teacher asked me to try “extra hard”. I sure did try – tried everything to get out of it, that is – faked illnesses, detention, forgot my kit (how many times can someone forget their kit, anyway?). It rarely worked, and for years, I spent 2 hours a week being laughed at callously whilst I tried my best to sprint or do a forward roll or kick a ball. Two boys once followed me home for two weeks consecutively, pushing me in the road when a car came close. As if being depressed was not enough, I was reminded of how awful I was – constantly.

One morning, I was walking to school. I was 14 years old and nearing the end of year 9. I started walking to school at 8:30 (10 minutes before school started), already exhausted and overwhelmed. It was especially windy. My hair blew around, meaning my meticulous styling fell out. I caught a glimpse of myself in a car window looking like, I thought, some kind of gremlin. Who knew what they would say to me when I got to school?

I could not stand any more comments, sniggering behind my back (real or imagined) or being full of self-loathing every second of every day. I snapped. I fell into the road, weeping, hoping a bus would hit me. Memories of the rest of the morning are patchy, but I ended up in the school counsellor’s office for most of the day. I saw her twice a week for the remainder of my school career. I told her I was sad, tired and angry all of the time. She told me being a teenager was hard. She listened to me cry and scream and rant, but she did not say much.

By the time I was 15, the vines of depression had firmly wrapped themselves round me, squeezing the life out of me. I barely ever woke up early enough to get to school on time. I was tired all of the time and routinely slept until 5 p.m. at the weekend. I hated myself more than I could ever express and did not want to be awake to live in that reality. I began to have episodes where I bashed my head against a wall whilst crying and howling – particularly on days before I had PE. I had what I would later understand to be panic attacks on a near daily basis. I cried myself to sleep more often than not. I feigned illness to avoid school because I physically did not have the energy to walk there and back – let alone face the day.

I tried desperately to fit in with every group in school – I had different outfits for different purposes – from gothic Lolita get-up to crop tops and skinny jeans. I finally found a few “friends”, who beat me down and told me I was weird. I learned to adapt and to act how they wanted me to act. They invited me to a party. One of them sexually assaulted me. When I told someone, the boy contacted me telling me I was “the worst person in the world” and I deserved it. I believed him. I tried to kill myself twice. I was a month away from doing my GCSEs.

I told my mother what had happened with the boy. After years of being afraid of my strange behaviour, she let me open up and she began to help. Luckily, this coincided with “independent study”, where year 11s study for their GCSEs at home and occasionally come to school for lessons. I called in sick for those lessons. I took my exams, and never looked back after leaving the school for the last time.

How I survived

Although things did not start truly improving for me until recently, secondary school was, without a doubt, the worst period of my life. I am beginning to appreciate how much I survived with little to no support. How did I do it? Well, with hindsight.

Passion

Even though I hated lessons and fell asleep in most of them, I still enjoyed English. I enjoyed reading as a very young child, and it is something that even when I am at my worst, I still find (varying levels of) joy in. It can be hard to pick up a book and get stuck in, but when I do, I am lost
in that world. I always enjoyed writing and analysing. Granted, I enjoyed it insofar as I did not hate it or feel apathetic, but when you feel low, a drop of water in a desert is as good as an oasis. Reading a book, entering a world, and then writing about that world and expanding it through analysis and thought, is a perfect escape. I ended up pursuing English as a degree subject, and reading continues to be one of my lifelines today.

Love

We adopted I cat when I was 14. As ridiculous as it sounds, the cat saved my life. Grumpy from the beginning, we were kindred spirits. She was, and still is, my little buddy. She sat with me when I cried, and licked my hand; she meowed at me and rubbed my face in the morning to wake me up. She also helped me out in sixth form, when I felt suicidal after being rejected from my first choice university. What is more is that she needed me – I fed her, played with her, loved her. She is a neurotic cat whose trust needs to be earned – and I am the only one in my house who took the time to build that relationship. I had to be there for her. Take whatever love and passion you feel, and embrace it.

Logic

I knew I could leave secondary school once I completed my GCSEs. Indeed, I set my sights on going to a grammar school for sixth form. The idea that all that stood between me and “happiness” was decent GCSE grades inspired me enough to work, and to survive. This was misguided and naïve, but I am still alive. Sometimes, whatever gets you through the day is enough. Sixth form presented its own challenges – but they were distinctly different.

Dear past me

It’s hard to recognise your own patterns and behaviour. I knew I was sad and understood the concept of depression. I suspected that diagnosis fit me (it would later turn out to be Borderline Personality Disorder), but I had no help or support. I did not know what to look for, who to turn to, or where to go. If I could tell past me anything, it would be that:

- You are right – what you are feeling is not average. Do not doubt what you know.
- Tell your mum about the bullying. Move school. Never accept bullying because you think you deserve it – no one deserves to be bullied.
- Tell someone how you feel. Tell your mother. Tell your English teacher. Just because one or two people brushed you off, it does not mean you should never open up ever again.
- See a doctor. The only person other than you qualified to comment on your thoughts and feelings is a trained professional who can help and provide the correct care if necessary.
- Avoid things that make you uncomfortable. You are not being dramatic.
- Insomnia is treatable. Please treat it. You should be sleeping for 8 hours a night.
- Equally, sleeping for 18 hours is not normal or healthy. See a doctor – you may be anaemic or severely depressed.
- There are people who love you. You are witty, and you are kind. You just do not know it yet.
- You do not need to be someone else; you need to accept who you are, and become the best version of you.

I often wonder how different my life would have been if someone had listened to me. Aside from the gross neglect I suffered when it came to bullying and the lack of action on behalf of the school, I told my counsellor and my teachers that I was not OK often. I understand that it is difficult to distinguish dramatic teenage tendencies from something more sinister. Teenagers, mentally ill or not, deserve a voice. Perhaps listening to them in general would yield a more productive school environment. A child who is constantly late for school, and clearly exhausted, requires attention. If they have to have a breakdown in order to be taken to see the school counsellor, it is no wonder
that teens feel ignored. When the child is taken into counselling and tells the counsellor how they feel – yet they are still ignored – we know it is time to actually listen.

Take the time to listen to your students. Run mental health awareness workshops for teachers. Include mental health education in science or PHSE. Ensure every student sees a counsellor at some point in their school career. If a kid falls asleep in your lesson, do not discipline them. Ask them if they are okay. Being a teenager is hard – but it is harder when you are ill.

Corresponding author
Carys J. Morley can be contacted at: carysjmorley@gmail.com
Recovery colleges and dementia courses – a scoping survey

Christine Lowen, Linda Birt and Juniper West

Abstract

Purpose – The purpose of this paper is to understand how dementia is represented within current UK Recovery College courses and how people with dementia are involved with such courses.

Design/methodology/approach – A scoping survey was developed with seven multiple choice questions. Information was collected to find out: How many Colleges are currently offering dementia courses; have previously offered courses or plan to start offering courses; how they have developed their courses; who delivers them; who can attend; and how long courses have been running. Individual Recovery Colleges could leave contact details if they were interested in collaborating on future research projects. UK Recovery Colleges were identified using a published list (Anfossi, 2017) supplemented with internet searching. 86 e-mail messages were sent to Recovery Colleges inviting Leads/Managers to complete the survey through an electronic link.

Findings – Of the 28 (32.6 per cent) Recovery Colleges who completed the survey, 11 reported to be currently offering dementia courses, while eight planned to start doing so. Six Recovery Colleges stated they were not currently offering dementia courses, have not done so previously and have no current plans to.

Research limitations/implications – The survey results indicate variability in provision of UK Recovery College courses for people with dementia, and raise further questions about the way the courses are used, their acceptability and usefulness.

Originality/value – This service evaluation highlights the variability in what is offered, which is an important step in understanding the current service provision.

Keywords Dementia, Recovery, Service evaluation, Recovery college

Paper type Research paper

Introduction

Improved diagnostic routes mean that people are increasingly being given a diagnosis of dementia at an earlier stage in the disease trajectory. The importance of living well with dementia has been highlighted within the UK National Dementia Strategy (DH, 2009), and it is increasingly recognised that supporting the involvement of people in positively managing their illness and their care can raise quality of life (Cheffey et al., 2013).

As the number of older people in the UK population rises, more people are likely to find dementia becoming part of their life: whether they are a person living with dementia, a family supporter or a health care professional working with people with dementia. The Recovery College Model may have the potential to meet some of the needs of people affected by dementia (Perkins et al., 2016). Yet it seems likely that the specific cognitive impairments associated with dementia such as difficulties with memory, changes in language and planning skills and changes in social behaviours may mean that stakeholders do not see dementia as a condition which fits with the language of personal recovery, or Recovery College delivery in mental health services. In this paper we first draw on literature to illustrate how the concept of personal recovery is highly relevant to people with dementia and how dementia fits within Recovery College ethos, before reporting on a scoping survey undertaken to understand if those affected by dementia can access support through the Recovery College Model across the UK.
Dementia and recovery

The social discourse on dementia as an incurable condition leading to a “living death” seems to be a juxtaposition to the idea of recovery. Yet recovery has been defined as “a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness” (Anthony, 1993, p. 15); a definition which clearly fits with the English Dementia Declaration (Dementia Action Alliance); that people living with dementia have the right to be recognised as partners in care, provided with education, support, services and training, enabling inclusion within personal communities and positive, proactive support in planning and making life decisions now and for the future.

Five key recovery processes identified by Leamy et al. (2011), are described through their conceptual CHIME framework for personal recovery in mental health; (connectedness; hope and optimism about the future; identity; meaning in life; empowerment) which is often used to support people in their recovery from mental health problems. The concept of recovery when considered within dementia care has similarities with Kitwood’s (1997) conceptual person centred approach in dementia care (South London and Maudsley NHS Foundation Trust and South West London and St George’s Mental Health NHS Trust, 2010; Hill et al., 2010; Irving and Lakeman, 2010), with both recovery and a person centred approach working towards constructive management of long term conditions in a humanistic way, sharing a common goal, and both focussing on the development of a positive sense of identity, social inclusion, co-working, self-care and management (Hill et al., 2010). Importantly, both the recovery approach and Kitwood’s person-centred approach move from highlighting a person’s deficits towards recognising personal strengths (Perkins et al., 2016). McKay et al. (2012) suggested that the underlying principles of recovery can be used to generate hope and fulfilment for older people with dementia and suggested that using a person-centred approach to care can also support the meaningful use of recovery principles.

In considering the applicability of recovery principles for people living with dementia, Hammond and Debney (2017) considered in turn the relevance of each of the five CHIME processes of recovery to people with dementia, summarising how concepts can be applied and examining existing literature in this area. For example, the authors highlighted how Daley et al. (2013) have reported that maintaining a sense of self is key for recovering life after receiving a diagnosis, a study which demonstrated the applicability of the CHIME process of “Identity” in people with dementia. Hammond and Debney demonstrated how the difficulties experienced by people with dementia are not unique to this condition and concluded that the concept of recovery can be applicable to all individuals regardless of diagnosis.

In an article exploring whether the concept of recovery is relevant to older people, Woods (2007) highlighted that decisions about the care of a person with dementia are often made quickly, whereas recovery work may need more time. Woods suggested that adopting a recovery approach might allow processes to slow down, giving people more choice and preventing a sense of being overwhelmed by difficulties.

Published evidence about supporting people with dementia by adopting the principles of a recovery model is limited. One research trial identified is reported by Jha et al. (2012), who described a small scale randomised controlled trial in which 34 participants completed post-intervention assessments. Jha et al. reported that people with dementia who received a recovery-orientated approach and post-diagnostic intervention had greater improvement in well-being compared to those who received treatment as usual.

Recovery colleges and people with dementia

The first Recovery College to be piloted in the UK was in London in 2009, growing to over 75 Recovery Colleges in existence by 2017 in the UK and abroad (Perkins et al., 2018). Meddings et al. (2015) summarised that all aspects of Recovery Colleges should encompass co-production, co-facilitation and co-learning. Recovery College courses are co-produced by those with lived experience and those with professional knowledge, varying across locations, with courses taking an educational approach rather than being therapy (Perkins et al., 2018).
In a study exploring whether the students of Sussex Recovery College reflected the demographics of the local and general population, Meddings et al. (2019) found the proportion of people aged over 60 accessing the College was lower than would be expected considering the number of people in this age group in the general population. They also reported less people over 70 were accessing the College compared to the proportion of people from this age group accessing mental health services, which they suggested demonstrated an under-representation of older people in Recovery Colleges.

Whilst the Recovery College audience has widened and has been described as including people with dementia (Perkins et al., 2018), extremely limited information exists in the literature on UK Recovery Colleges adopting a recovery approach for people with dementia and offering dementia courses. Whilst locally it is known that Norfolk and Suffolk NHS Foundation Trust (NSFT) Recovery College offer a “Living Well with Dementia” course, the situation in the rest of the UK is largely unknown. A search of the published literature provided information on only two other dementia courses offered through Recovery Colleges, indicating that whilst there may be more courses on offer in the UK, research and evaluation of these to-date is limited.

Perkins et al. (2016) suggested that for people with dementia, it has been helpful to offer co-produced and co-delivered courses, referring to four UK Recovery Colleges and providing links to their documents. None of these links are still functioning, and on further internet searches of the four individual Recovery Colleges' prospectuses, only one College appears to be currently offering a dementia course.

Cheffey et al. (2017) described the process of co-producing a dementia course for the Devon Recovery Learning Community, highlighting that “The words of the expert by experience were very powerful […] magnified hugely when we worked together to educate and teach” (p. 22), with “the concepts of recovery and personhood were central elements to the delivery of the course” (p. 23), and that “Recovery orientated practice and co-production can and does work in the context of dementia” (p. 24).

Duff's (2016) poster presentation focussed on how recovery principles and Recovery Colleges have been used in work with people with dementia in Lincolnshire. Duff suggested that taking a recovery approach can help to decrease the demands on services and enable people with dementia to have a better quality of life.

Given the limited information about dementia courses published to-date, further projects to understand, evaluate and disseminate information about those courses currently being delivered may develop and support clinical practice across the UK.

**Design**

**Aims**

A scoping survey was developed with the aim of understanding the current practice in UK Recovery Colleges in relation to dementia courses. The objectives were to find out if UK Recovery Colleges are offering dementia courses, and if so, how many do? How are these dementia courses developed, who is involved in this? How are the courses delivered, and who can attend? How long have Colleges been offering dementia courses?

**Method**

The survey. A brief scoping survey was developed to gain an understanding of current service delivery. There were eight questions: Does your Recovery College currently run any courses about dementia; Has your Recovery College previously run courses about dementia; Does your Recovery College plan to start running courses about dementia; Who is able to attend these dementia courses; How have you developed your dementia course content; Who are these courses delivered by; How long have these courses been running in your Recovery College? All questions had multiple choice options from which respondents could select all response options that were relevant, as well as space for additional responses to be entered for
questions 4, 5 and 6. Finally, respondents were invited to leave their contact details if they were interested in collaborating on future projects.

The survey was initially piloted by the local Recovery College Manager to check for coherence, acceptability and that the questions were answerable. At this stage, no further changes to the survey were necessary.

Identifying recovery colleges. The ImROC report “The current state of Recovery Colleges in the UK: Final report” (Anfossi, 2017) listed 85 UK Recovery Colleges in the appendix. An additional internet search identified a further 16 Recovery Colleges, resulting in a potential sample of 101 Colleges. However, internet searches to find Recovery College contact details indicated that some had either changed their name, were being run by different organisations or had closed, resulting in uncertainty about which details were current. Contact details were identified for 91 of the 101 Recovery Colleges. A standardised e-mail was sent inviting Recovery College Leads/Managers to complete the brief scoping survey. The survey was accessed through a Survey Monkey link embedded in the e-mail. The survey remained open to responses for one month.

Responses to the survey were provided anonymously, unless individual Recovery College Leads/Managers chose to enter their contact details, if they were interested in collaborating on future projects. All responses are reported here anonymously.

This project was classified and approved as a service evaluation by NSFT Trust Research and Development Department.

Findings

Of the 91 e-mails sent, messages to five Recovery Colleges were undeliverable. Therefore 86 survey invitations were successfully sent, with 28 responses to the survey received, a response rate of 32.6 per cent.

Of the 28 Recovery Colleges who responded, 11 (39.3 per cent of respondents) reported they are currently offering dementia courses, whilst 17 (60.7 per cent) are not. Of those 17 not currently running courses, three have previously run dementia courses and plan to do so again; two have previously run courses but do not have plans to do so again; five have never run dementia courses but have plans to start; six have never run dementia courses and do not have plans to do so; one response was incomplete.

In total, 11 Recovery Colleges were delivering dementia courses and these could be attended by people with dementia; family/friends supporting people with dementia; staff working at the NHS Trust; and staff working at another organisation. Additional responses to this question on who could attend were provided by seven respondents: four Recovery Colleges reported being open to anyone/anyone over 18; one to students on placement; one to Peer Support Workers/Volunteers, and one to anyone enrolled at the College.

When asked how they developed their dementia courses, the 11 Recovery Colleges currently delivering dementia courses responded that courses were developed in collaboration with a range of people, but eight included people living with dementia (see in Table I). In addition to our offered

<table>
<thead>
<tr>
<th>Table I</th>
<th>Responses to question 5: how have you developed your dementia course content?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Multiple choice response option</strong></td>
<td><strong>Number of recovery colleges selecting this response (%)</strong></td>
</tr>
<tr>
<td>In collaboration with academic staff</td>
<td>3 (27.3)</td>
</tr>
<tr>
<td>Adopting a course from another site</td>
<td>3 (27.3)</td>
</tr>
<tr>
<td>Using local or national guidelines</td>
<td>7 (63.6)</td>
</tr>
<tr>
<td>Using research publications</td>
<td>7 (63.6)</td>
</tr>
<tr>
<td>In collaboration with people with dementia</td>
<td>8 (72.7)</td>
</tr>
<tr>
<td>In collaboration with NHS staff</td>
<td>9 (81.8)</td>
</tr>
<tr>
<td>Using materials produced by dementia charities</td>
<td>9 (81.8)</td>
</tr>
<tr>
<td>In collaboration with family/friends supporting people with dementia</td>
<td>10 (90.9)</td>
</tr>
</tbody>
</table>
suggestions, four individual respondents stated they had developed courses in collaboration with partner agencies that specialise in this area; having a representative of the Alzheimer’s Society’s “Dementia Friends” network run the course; using a connected dementia support service; working with an author and service user.

The 11 Recovery Colleges currently delivering dementia courses all responded to question 6, asking who delivers the course. Only 4 of the 11 Colleges reported that people with dementia delivered the course (see Table II). In addition to our offered suggestions, five respondents gave additional responses to who delivers the courses: a Representative of “Dementia Friends”; Peer Support Worker; Peer Trainer; Volunteer from dementia-related charity.

Out of the 11 Recovery Colleges currently offering dementia courses, five reported these courses had been running for more than two years; four Colleges for one to two years, and two Colleges for less than a year.

Discussion

Research implications

This scoping survey has provided an important insight into the current provision of dementia courses in UK Recovery Colleges, with at least 11 (12.8 per cent of those contacted; 39.3 per cent of those who responded) offering dementia courses at the time of the survey (May 2019) and an additional eight Recovery Colleges planning to do so. While this suggests an increasing consideration of recovery principles in relation to the needs of people with dementia and that people with dementia are included as students of some UK Recovery Colleges, the survey results indicate that the numbers remain low. However, it is possible that some of the Recovery Colleges which did not respond to the survey may also be offering dementia courses and therefore the provision of dementia courses may be greater than reported here.

This evaluation has demonstrated the difficulty inherent in contacting all UK Recovery Colleges and establishing with complete accuracy, the current situation with regards to dementia courses. As with many mental health services, the provision of Recovery Colleges may be in a state of flux.

Importantly the survey results demonstrate variation in provision of Recovery College courses for people with dementia. In part this may be because the application of the recovery concept to people with dementia remains in its infancy, or is perhaps due to the perceived difficulties of co-producing or co-delivering courses alongside people with dementia.

The results of this scoping survey also raise questions about the acceptability and usefulness of dementia courses within Recovery Colleges. Are these courses different or complementary to what may be offered within NHS services? There are also questions about the applicability of dementia courses which are developed by people who do not have dementia.

Originality/value

This is the first study exploring the provision of dementia courses by UK Recovery Colleges. The results of this survey represent an important initial step in understanding the current service provision and highlighting the variability in what is currently offered. Further research is needed.
to gain a more developed understanding of the provision for people with dementia in Recovery Colleges, and importantly the role people with dementia have in the development and delivery of courses.

References


Perkins, R., Meddings, S., Williams, S. and Repper, J. (2018), Recovery Colleges 10 Years On, ImROC, Nottingham.


Further reading


Corresponding author

Christine Lowen can be contacted at: christine.lowen@nsft.nhs.uk
Mental health recovery narratives: their impact on service users and other stakeholder groups

Myra Piat, Jessica Spagnolo, Suzanne Thibodeau-Gervais, Catherine Deschamps and Yves Gosselin

Abstract

Purpose – The purpose of this paper is twofold: first, assess the effects of the peers’ recovery narratives on service users’ perceived mental health recovery; and second, explore various stakeholders’ perspectives on the program, specifically its facilitators and barriers.

Design/methodology/approach – The study used a convergent mixed-method design. First, a pre-test post-test design was used with service users to evaluate the peer recovery narrative program. They completed the Recovery Assessment Scale (RAS) and participated in qualitative interviews that explored perspectives on their mental health recovery before and after the program. Second, a cross-sectional design was used to explore stakeholder groups’ perspectives on the recovery narrative program immediately after listening to the narratives.

Findings – While findings show that there was no statistical difference between scores on the RAS before and after the peer narratives, thematic analysis revealed a change in service users’ understanding of recovery post-narratives. Other stakeholder groups confirmed this change. However, some healthcare professionals questioned the universal positive effects of the peer recovery narrative program on service users. Stakeholders agreed that beyond effects of the peer recovery narrative program on service users, there were also positive effects among the peers themselves.

Originality/value – To the authors’ knowledge, this is the first Canadian study, and one of the first studies to rely on mixed-methods and various stakeholder groups to evaluate the impact of peer recovery narratives on service users. The research, thus, fills a knowledge gap on peer recovery narratives.

Keywords Peer support, Mental health, Mixed methods, Recovery narratives

Paper type Research paper

Introduction

Peer support is defined as “people with similar experiences of mental health problems [who] share support with each other” (Burke et al., 2018, p. 1). Service users were the first to advocate for peer support as part of the service user movement (Deegan, 1996; Davidson et al., 2012). Their vision was to promote a more consumer-driven and recovery-oriented mental health system (Burke et al., 2018; Chinman et al., 2006), with interventions offered to people living with mental illness by consumers themselves (Anthony, 1993). Implementing peer support is a concrete example of how organizations have transformed to a recovery orientation (Cyr et al., 2016; Gagne et al., 2018).

Evidence on the benefits of peer support in mental health services has increased in recent years, supporting mental health system transformation (Farkas and Boevink, 2018; Burke et al., 2018). Studies show that peer support interventions have positive impacts on the more traditional mental health outcome measures. Peer support interventions reduce psychiatric symptoms (Cook et al., 2012), rates of days spent in inpatient facilities (Davidson et al., 2012; Sledge et al., 2011), alcohol use (Rowe et al., 2007) and readmission to acute care (Johnson et al., 2018; Sledge et al., 2011). Research also highlights the benefits of peer support with regards to mental health.
health recovery including increased: self-efficacy for people living with mental illness (Mahlke et al., 2017; Burke et al., 2018), service user hopefulness (Cook et al., 2012), empowerment (Burke et al., 2018) and service user engagement (Farkas and Boevink, 2018). Previous research also reports positive effects on peer support workers themselves. Being a peer support worker increases levels of self-esteem (Proudfoot et al., 2012).

Mental health recovery narratives, first-person mental health recovery accounts or recovery stories are increasingly being used in peer support work. Recovery narratives may be shared face-to-face, online, via video or audio, or in written form by trained peers (Cronise et al., 2016; Mancini, 2019; Rennick-Egglestone et al., 2019). Characteristics of recovery narratives include social, political and human rights factors, accounts of supports from both within and outside of mental health services, and less emphasis on illness (Llewellyn-Beardsley et al., 2019). Recovery stories or recovery narratives (as referred to throughout this paper) have been shown to instill hope in service users (Davidson et al., 2012), benefit the narrators motivated to send positive messages (Morelli et al., 2015), improve services (Kidd et al., 2014), further encourage consumer advocacy (Morrison, 2011), and improve attitudes toward mental illness (Corrigan et al., 2010).

Like many countries worldwide, Montreal, Canada, the setting of this research, is also working to further enhance peer support. In 2012, a mental health recovery narrative program was launched by two organizations: Maison Échelon and the Department of Social Services, Psychiatric Division, Notre-Dame Hospital. The aim of this initiative was to hire people with lived experience and train them on how to share their recovery stories with service users and mental health service providers. The training component consisted of ten sessions, totalling 40 h. A five-person Advisory Committee oversaw the implementation of the program and its evaluation. It included a Board Member, a person with lived experience, the coordinator of the peer narrative training program, and two managers of the participating organizations.

The overall objective of this research was to evaluate the recovery narrative program offered to service users. The paper’s specific objectives are to: assess the effects of the peer recovery narratives on service users’ perceived mental health recovery; and explore various stakeholder groups’ perspectives on the program, specifically its facilitators and barriers. These include perspectives from members of the Advisory Committee, those who trained the service users to tell their recovery stories (“trainers”), mental health service providers in contact with service users, peers telling their stories and service users. While there is an increased interest in recovery narratives in peer support work, little research has been conducted on the impact of recovery narratives (Rennick-Egglestone et al., 2019). This paper, therefore, aims to address this knowledge gap.

Methods

Setting

Three sites participated in this study: supervised apartments of Maison Échelon, transitional apartments of Maison Échelon and the Department of Social Services, Psychiatric Division, Notre-Dame Hospital. Maison Échelon, a not-for-profit organization, aims to assist people with serious mental illness obtain safe and affordable housing, psychosocial support and rehabilitation services. They operate three group homes on the island of Montreal housing 84 persons. They also operate 35 transitional housing units and 35 autonomous housing units. The Department of Social Services, Psychiatric Division, Notre-Dame Hospital provides mental health services for service users. These sites were selected based on their different geographic locations and the diverse socio-demographic profile of service users.

Ethics

The Board of Directors of Maison Échelon provided ethics approval for the research. Written consent was obtained from all participants.

Study design

The study used a convergent mixed-method design (Creswell and Plano Clark, 2018). This design relies on both quantitative and qualitative methodologies, with the intent of comparing and
combining the results from both methods to enhance understanding of a phenomenon. In our study, we aimed to further understand the effects of the recovery narrative program on the perceived mental health recovery of service users, and perspectives on the program through the lens of four stakeholder groups: the Advisory Committee, mental health service providers, trainers and peers sharing their recovery narratives:

1. A pre-test post-test design was used with service users who participated in the program. Service users attending the recovery narrative program completed the Recovery Assessment Scale (RAS), before and after. In addition, they participated in qualitative semi-structured interviews that explored perspectives on their mental health recovery.

2. A cross-sectional design was used to explore four other stakeholder groups’ perspectives on the recovery narrative program. Qualitative group interviews were conducted with members of the Advisory Committee, trainers, mental health service providers and peers sharing their recovery narratives after the program was implemented. Service users also completed a satisfaction questionnaire immediately after listening to the recovery narratives, to quantitatively assess their opinions of the program.

Figure 1 illustrates the convergent mixed-method design, and highlights when (and from whom) data were collected.

Figure 1  Convergent mixed-methods design and data collection

Notes: X, service users attend recovery narrative program; RAS, Recovery Assessment Scale
Study participants

Peers sharing their recovery narratives. In all, 18 people expressed an interest in becoming trained to share their recovery narratives. Recruitment pamphlets were distributed at the three sites. Interested persons were invited to an information session, at which details about the recovery narrative program was presented. Attendees were asked to write about their recovery journey and to explain their interest in the project. In all, 12 of the 18 people wrote about their recovery journey. Following the information session, the Advisory Committee selected six people for the training program based on their ability to: articulate their recovery journey, speak publicly and participate in the training. One peer withdrew during the training, resulting in a total of five people trained. All participants were compensated for their participation in the training and in person meetings where they shared their recovery stories.

Service users

In total, 32 service users participated in the recovery narrative program. They attended a 2 h in person session in which two trained peers presented their recovery narratives. This included: 13 service users from the Department of Social Services, Psychiatric Division, Notre-Dame Hospital, 11 from transitional apartments at Maison Échelon and 8 from supervised apartments at Maison Échelon. Service providers distributed recruitment pamphlets. Service users were given a small compensation to cover their transportation expenses.

Trainers

Two people provided the recovery narrative training. One was a staff person at Maison Échelon and the other was a peer support worker who was recruited from the community.

Data collection

Service users. Service users ($n = 32$) completed the RAS (Corrigan et al., 2004) just prior to attending the recovery narrative program and again immediately after listening to the recovery narratives. The RAS is a 22-item questionnaire that measures the perception of personal mental health recovery. It includes five domains: personal confidence and hope, willingness to ask for help, goal and success orientation, reliance on others and no domination by symptoms (Corrigan et al., 2004). The RAS is scored on a five-point Likert scale (1 – strongly disagree, and 5 – strongly agree). Service users ($n = 28$) also completed a satisfaction questionnaire immediately after hearing the recovery narratives. The questionnaire includes items on the program’s content and structure and was scored from 1 to 6 (1 – not at all in agreement, and 6 – absolutely in agreement). Service users also participated in qualitative group interviews: 32 participated prior to listening the recovery narratives and 28 again immediately after listening to the recovery narratives. These interviews explored service users’ perspectives on mental health recovery, what they appreciated about the peers’ stories/the program, and what could be improved. The interview guide was developed in consultation with the Advisory Committee. The first author (MP) and a research assistant conducted the group interviews which lasted between 60 and 90 min. Service users completed a short socio-demographic questionnaire that included questions on age, gender, country of origin, schooling (e.g. last completed academic year), employment, mental health diagnosis and sources of income.

Stakeholder groups

In all, five qualitative interviews were conducted with the four other stakeholder groups between June and October 2012. This included: one group interview with the peers sharing their recovery narratives, two interviews with mental health service providers, one group interview with the trainers and one group interview with the Advisory Committee. The interview guides were
developed in consultation with the Advisory Committee and included questions on clinical utility of the recovery narrative program, what they appreciated about the program, and what could be improved. Group interviews were conducted by the first author (MP) and a research assistant and lasted between 45 and 90 min.

Data analysis

Service users. Service users’ data were analyzed using SPSS version 25.0 (IMB Corp., 2017). Descriptive statistics were reported; group frequencies and percentages were reported for all variables as they are categorical. Specifically, categories of answers were regrouped, and their percentages were reported. The RAS was analyzed in two ways. First, mean scores on the RAS were computed per participant. The mean overall scores before and after the service users attended the peer recovery narratives were then computed. Second, frequencies (in percentage) of answers on individual questions were analyzed. Certain questions were reported using categories of “agree” ("strongly agree" and “agree”) and “disagree” ("strongly disagree" and “disagree”).

For all qualitative interviews a thematic analysis (Braun and Clarke, 2006) was used. First, the interview guide was used to identify preliminary themes, matching the specific questions. Second, all transcripts were read by the first and second authors, which allowed for the identification of key passages into identified in themes. The effect of the peer narratives on mental health recovery were regrouped into positive and negative effects and reported in the results section. Perceptions of the peer narratives on mental health recovery were regrouped into facilitators and barriers and reported in the result section.

Results

Service users

As shown in Table I, most service users were recruited from the Department of Social Services, Psychiatric Division, Notre-Dame Hospital (41 percent). An equal number of men and women participated in the study, and a majority were born in Canada. Service users’ primary diagnosis was psychosis (41 percent), but several listed mood disorders as their main diagnosis (22 percent). Of note, 31 percent of service users decided not to reveal their mental health diagnosis. At the time of the study, most service users were unemployed (78 percent) and on social assistance (75 percent). Close to a majority of service users completed high school (44 percent).

Peers

The average age of the peers was 55. A total of 60 percent were women, and the majority completed either high school or Cégep (two years of College for Québec students, prior to enrolling in university). A total of 60 percent were unemployed at the time of the study. Most peers were diagnosed with a serious mental illness and were on social assistance.

Trainers, healthcare service providers and the Advisory Committee

Both trainers had experience in training and recovery narratives. One was employed for over 15 years at Maison Échelon. The other had lived experience and was employed as a peer support worker in a hospital. Both participated in all training sessions. The average age of the service providers was 55 and the majority worked at the Department of Social Services, Psychiatric Division, Notre-Dame Hospital.

Recovery Assessment Scale

Prior to attending the peers’ narratives, 69 percent of the service users had never participated in such an activity. Despite this, there was no statistical difference between scores on the RAS questionnaire before and after the peer narratives (4.0 vs 4.1, $p > 0.05$).
Prior to attending the recovery narrative program, service users’ understanding of recovery was based on the biomedical model including concepts related to pathology, treatment through medication, dependence on services and the elimination of symptoms. For example, service users stressed the importance of medication and associated treatment by medication to a “good” recovery. Most (87 percent) service users agreed that they had supportive people in their lives. They also described the support from mental health services (mental health service providers working in healthcare settings, rather than family members and/or friends) as important in supporting their recovery. Some service users believed that recovery was associated with the absence of symptoms related to their mental illness:

For me, recovery is healing, it is not having any more symptoms. It is about all the activities that one does to recover, to heal. I believe that we can cure a mental illness, contrary to what doctors believe.

(Service User 1, Group Interview: Pre)

Table I  Socio-demographics of the mental health service users

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean, SD)</td>
<td>43 (11.55)</td>
</tr>
<tr>
<td>Sites</td>
<td>n (%)</td>
</tr>
<tr>
<td>Transition housing</td>
<td>11 (34)</td>
</tr>
<tr>
<td>Supervised apartments</td>
<td>8 (25)</td>
</tr>
<tr>
<td>External psychiatric clinic</td>
<td>13 (41)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>16 (50)</td>
</tr>
<tr>
<td>Male</td>
<td>16 (50)</td>
</tr>
<tr>
<td>Country of Birth</td>
<td></td>
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<tr>
<td>Canada</td>
<td>24 (75)</td>
</tr>
<tr>
<td>Haiti</td>
<td>5 (16)</td>
</tr>
<tr>
<td>Morocco</td>
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</tr>
<tr>
<td>Russia</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Psychosis (schizophrenia, schizoid-affective and paranoia)</td>
<td>13 (41)</td>
</tr>
<tr>
<td>Mood disorder</td>
<td>7 (22)</td>
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<td>Personality disorder</td>
<td>1 (3)</td>
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<td>Anxiety disorder</td>
<td>1 (3)</td>
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<tr>
<td>Last completed academic year</td>
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<tr>
<td>Elementary</td>
<td>6 (19)</td>
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<tr>
<td>High School</td>
<td>14 (44)</td>
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<td>CEGEP or Trade</td>
<td>5 (16)</td>
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<td>Bachelor or Masters</td>
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<td>Unknown</td>
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<tr>
<td>Employment</td>
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<td>No</td>
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<td>Sources of income</td>
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<td>Quebec Pension Board</td>
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</table>

Note: n = 32
There was a marked change in service users’ understanding of recovery after attending the peers’ recovery narratives. The majority no longer used terms such as “healing” and “eliminating symptoms” to define their recovery, but instead focused on hope for the future, despite the presence of symptoms and limits caused by mental illness (Anthony, 1993). Service users explained that listening to the recovery stories helped them identify with the peers’ struggles and generated hope for their future: “[The stories] taught me that […] we can have a certain quality of life, we can get better, and we can live. They brought me a lot of hope” (Service User 2, Group interview: Post). Hope for the future was also reflected on the RAS questionnaire. After attending the peers’ narratives, 82 percent of service users agreed that they had specific personnel objectives they wished to meet and 79 percent agreed that they could meet them. In addition, 85 percent of service users agreed that they were optimistic about their future. Service users spoke about identifying and respecting their limits, “taking small steps” to achieve goals, learning how to say “no,” finding a supportive entourage, and developing a personal routine. Listening to the peers’ lived experience was, according to service users, more effective to recovery than “formal” supports:

Someone who has been in pain, who lives alone, suddenly meets people who have had experiences like that, who are on this journey and who share it, I find it more helpful than a psychiatrist. (Service User 1, Group interview: Post)

Results from the satisfaction questionnaire completed by service users provide additional insight into service users’ experience. A total of 50 percent “absolutely agreed” that the narratives met their expectations, and 68 percent confirmed that the sessions were “very interesting” and “well organized.” Most service users were “very satisfied” with the structure of the stories, that is how peers articulated their recovery stories. Almost all service users appreciated the authenticity of the peers, the ease in which they conveyed their messages, and their enthusiasm. Service users also liked the diversity of the recovery stories: “I thought it was a very good idea to include various people […] there was psychosis, there was bipolarity, there were completely different personalities. So, it was very interesting” (Service User 3, Group interview: Post).

However, some service users had reservations about the peer narratives. These service users explained that some content was difficult to accept. For example, discussions on religious beliefs and living in extreme poverty made some service users uncomfortable and very emotional. Other service users did not feel represented in the peers’ stories. They would have liked more narratives on daily life in psychiatric hospitals and how to recover after psychotic episodes.

Service users’ recommendations to improve the program included: changes to the structure of the sessions, their content and the project’s continuity. They suggested modifying the structure to include an animator who would facilitate a question period; providing service users with a copy of the peers’ narratives and with documentation on mental health recovery in order to further promote service users’ recovery; and offering psychosocial support when peer stories were too difficult to hear. Service users described the importance of this project: they felt understood, cared for, and supported by peers and each other. They wanted the project to continue and they wanted the opportunity to listen to other peer narratives. Not only was this project instrumental to service users’ mental health recovery, it also resulted in the creation of an informal support group that encouraged positive exchange and dialogue around mental health recovery whilst service users participated in the project.

The three other stakeholder groups confirmed the positive impact of the peer recovery narrative program on service users. Advisory Committee members and service providers stated that service users’ participation in the program generated hope for the future. It helped them develop coping strategies and changed the way they understand mental illness. However, some service providers and peers questioned the positive effects on service users. They explained that certain service users did not feel inspired by the recovery stories and some were indifferent about the program. Peers also questioned the motivation of service users to participate in the program since they received financial compensation for their participation. Mental health service providers were not concerned about the influence of compensation for service users; in their opinion, service users are well versed in ways to make quick money through participation in diverse activities and thus participated by choice in the peer recovery narrative program.
Advisory Committee members, peer trainers, service providers and peers all described the clinical utility of the program. Peers were better able to structure their recovery narratives, were less shy, and had more confidence when speaking in public and during job interviews. Peers validated the opinions of the other stakeholder groups as they described how participating in the peer training helped them feel better about themselves: listening to other peers was therapeutic as they gained insight into different recovery journeys, and sharing their story made them feel useful to others by “giving back the help they had received.”

Advisory Committee members reported how the program influenced service providers’ interest in hiring peers at their respective organizations, and how they have come to better understand and appreciate peers’ work in mental health. This finding was also confirmed by the service providers:

What [the program] helped reinforce is the fact that I believe in peers and hope that one day they will be on [...] mental health teams. (Service Provider 1, Group interview: Post)

However, service providers remained cautious about including peers on their teams, as they did not understand what implication this would have on their own profession.

All stakeholder groups reported on the facilitators and challenges of the program. Peers, service providers and trainers described the program infrastructure as a strength. For example, compensating peers and service users for their participation was viewed as a good strategy to recruit and retain participants in the program. Advisory Committee members also highlighted the importance of including a person with lived experience on the Advisory Committee as it helped prospective peers feel comfortable during selection interviews, enabled the creation of a program that considered the realities of people living with mental illness, and inspired people to sign up to the program.

Service providers and peers reported that the program was appreciated for two main reasons. First, service users and peers acquired new knowledge and skills (e.g. how to adequately construct and publically deliver a peer recovery narrative), and second, there was an increase sense of community among service users and peers. Peers felt supported by trainers and other peers as they wrote their recovery stories and/or practiced their stories. However, they also suggested ways to improve the content and the program’s structure. Specifically, peers were unhappy with training occurring in the evenings, which made it difficult for most to concentrate; they were disappointed that they did not get a chance to share their narratives with psychiatrists and social workers; and they noticed that trainers focused primarily on “therapeutic” interventions (e.g. mindfulness) instead of skill-building at the beginning of training, which encouraged many to share that they would have liked more training sessions to improve their narratives.

Both Advisory Committee members and peers recommended that the program be offered in a different physical environment, one that is less noisy and better ventilated. Advisory Committee members and peers stated the need to address sustainability of the program prior to its implementation. They suggested including a knowledge dissemination session to ensure that peers obtained the feedback from service users about their recovery narratives. In addition, they recommended developing a plan for trained peers after their participation in the initial program. Peers also shared this concern; they were not sure what their role would be after their experience.

Discussion

This mixed-methods study aimed to evaluate a peer recovery narrative program by assessing the effects of peer narratives on service users’ mental health recovery and exploring various stakeholder groups’ perspectives on the program. Findings show that there was no statistical difference between scores on the RAS before and after the peer recovery narratives. However, thematic analysis revealed a marked change in service users’ understanding of recovery after attending the peer recovery narratives; most service users no longer used terms such as “healing” and “eliminating symptoms” to define recovery. Service users articulated that listening to peer recovery narratives helped them identify with peers’ struggles and generated hope for their future. Other stakeholder groups confirmed that service users’ participation in the program generated hope by helping them develop coping strategies and changing the way they understand mental illness. However, some service providers questioned the positive effects of
the recovery narrative program on service users; some service users did not feel inspired by the recovery stories, a finding that might help explain why we did not find a statistical difference between scores pre- and post-service users’ participation in the program. Stakeholders agreed that beyond effects of the program on service users, there were also positive effects among the peers themselves. After the program, peers were better able to structure their recovery stories, had more confidence, and felt more useful and connected.

This study provides three specific contributions to practice and research. We implemented an innovative peer support program using peer recovery narratives. While such programs are increasing, their impact is rarely assessed. A recent systematic review identified only five impact evaluations of peer recovery narrative programs (Rennick-Egglestone et al., 2019). Interestingly, our program’s findings, like these studies evaluating the impact of peer recovery narratives (Sheens et al., 2016; Williams et al., 2018), are promising as they highlight many of the recovery concepts identified in the evaluations of traditional peer support programs (Burke et al., 2018; Cook et al., 2012; Mahlke et al., 2017). These include generating hope for the future and changing service users’ understanding of mental illness. Thus, peer recovery narrative programs may be a promising innovation for organizations wanting to implement recovery-oriented services. However, more research such as the Narrative Experiences Online (NEON) project is needed. Currently, underway this randomized controlled trial aims to evaluate whether having access to recovery narratives can have an impact on personal recovery (www.researchintorecovery.com/research/neon/about-neon).

A second contribution of this study is its mixed-methods design. To our knowledge, a mixed-methods design has not been previously used to evaluate a peer recovery narrative program. Studies identified by Rennick-Egglestone and colleagues (2019) use either quantitative (pre-post designs) (Thomas et al., 2006) or qualitative methods (Nurser et al., 2018; Shaw and Homwood, 2015; Sheens et al., 2016; Williams et al., 2018). We used a mixed-method design to answer related questions: quantitative methods to measure outcomes (RAS and satisfaction with peer recovery narratives), whereas qualitative methods were used to describe different perspectives of the program including both facilitators and barriers (Palinkas et al., 2011).

The third contribution is the inclusion of different stakeholder groups evaluating the peer support program. Rennick-Egglestone et al. (2019) report that most studies rely on service users’ perspectives to assess the impact of peer recovery narratives. Our research adds to this by including an evaluative component of the program on peers themselves and exploring perceptions of the program by interviewing other stakeholder groups (i.e. mental health service providers, trainers and members of an Advisory Committee). Including these diverse perspectives allowed for the triangulation of findings on key themes, such as perceived effects of the program on service users’ mental health recovery and satisfaction with the program.

Our findings also contribute to how policy is being translated into practice. In most North American and European countries, there is political commitment to promoting a recovery-oriented mental health system: peer support is increasingly being recognized as an integral part of the mental health system (Cyr et al., 2016; Gagne et al., 2018; Gillard et al., 2013; O’Hagan et al., 2010). This recognition, however, requires the development and implementation of peer support training programs to enhance the credibility of peer support work and to promote recovery-oriented practice (Canadian Mental Health Association, 2019; Cyr et al., 2016; Mental Health America, 2019; Mind Australia, 2017; O’Hagan et al., 2010). Peer support work is a pillar of Québec’s Mental Health Action Plan (Québec Government, 2017). The implementation of our peer narrative recovery program is a concrete example of translating political commitment to peer support into practice.

Study limitations

There are several limitations to this study. First, this study relies on a pre-test post-test design. While random assignment to an intervention (i.e. the peer narrative program) and a control group was beyond the scope of this study, findings should be interpreted considering potential confounding variables influencing the results and threats to internal validity (Campbell et al., 1963). Second, the study’s aim was to assess the effects of peer narratives on mental health recovery from the perspective of a group of service users and to explore various stakeholder
groups’ perspectives on the specific program. Hence, we cannot generalize results to other study samples. Third, findings are based on self-reports and interviews. Therefore, results should be interpreted considering potential social desirability and with the understanding that self-reported responses may not be a true reflection of behaviors.

Conclusion

This study assessed the effects of the peer recovery narratives on service users’ perceived mental health recovery and explored various stakeholder groups’ perspectives on the program. Little research has been conducted on recovery narratives. The paper addresses this knowledge gap. Findings may be useful to inform other peer recovery narrative programs as they become increasingly integrated into mental health organizations.

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Corresponding author

Myra Piat can be contacted at: myra.piat@douglas.mcgill.ca
Regression and labyrinthine diagnosis – a case report

Jing Ling Tay, Alias Lijo, Bixue Wen, Susan Zachariah and Manu Lal

Abstract
Purpose – The purpose of this paper is to illustrate a lady with regression and disassociation with multiple psychiatric symptoms. This case highlights the limitations of descriptive psychopathology and the usefulness of psychodynamic psychopathology in explaining and managing the mental phenomena.

Design/methodology/approach – Case report: the patient R is a 29-year-old lady. She has been known to the mental health institution since 14 years old. Over the next 15 years, she was admitted 27 times. She had been diagnosed with schizophrenia, bipolar disorder, depression, mental retardation, autism spectrum disorder and dissociative identity disorder. She has been subjected to long-standing abuse by her mother.

Findings – Discussion: labyrinthine diagnosis – placing a diagnosis on R proves to be challenging. When R presents with psychosis like and depressive symptoms, she is labelled as having a primary psychotic disorder and mood disorder, respectively. When R regresses to the P or the non-verbal individual persona, she is deemed to have mental retardation and autism spectrum disorder. Furthermore, R’s intelligence quotient was tested to be 65 at 14 years old. However, the intelligence quotient test was not consistent with her level of functioning during her non regressed state and therefore not considered reliable. Explosive and emotional outbursts and a positive family history of bipolar disorder rendered her to be diagnosed with the same. The multiple personas seem classical of dissociative personality disorder. However, the personas seem to exist on a continuum and are not independent of each other. Upon regression, R seems to be fixated at the oral stage. R also reported amnesia of events especially her emotional outbursts, while she was displaying her third persona. Dissociation could have rendered her unable to remember these events.

Originality/value – While the use of descriptive psychopathology is pragmatic and has the obvious advantage of being free from the burden of seeking explanation of the psychopathological phenomenon in a theoretical construct such as the psychodynamic framework, not all patients can be awarded a meaningful diagnosis using such an approach. This case report exemplifies that psychiatric presentation in some patients refuses to be neatly subjected to a useful psychiatric diagnosis using descriptive psychopathology as the diagnostic tool resulting in a confusing array of diagnoses, with each diagnosis representing an isolated facet of the psychological world of the patient while ignoring the rest. Explanatory models of psychopathology such as psychodynamic psychopathology still remain relevant in such cases for both understanding and explanation of the mental phenomena, and devising appropriate intervention strategies.

Keywords Regression, Dissociation, Defence mechanism, Dissociative identity disorder

Paper type Case study

Introduction
Regression is an unconscious defence mechanism (Freud, 1989). It can be precipitated by anger, fear and insecurity. It helps individuals feel safe by allowing them to return to an earlier phase in their development. It has been described in patients with cancer (Straker, 1998) and case report (Tarazi, 1990).

Dissociation is a psychological defence mechanism, which usually results from trauma. Dissociation allows an individual to detach from reality and stay in a different world where the situation, thoughts and feelings are more bearable (Bromberg, 2003).

In this case report, we present a lady with a myriad of diagnosis that can be explained with regression and dissociation. This history comes from R, her brother and several professionals.
Case report

The patient R is a 29-year-old lady. She has been known to the mental health institution since she was 14 years old. Over the next 15 years, she was admitted 27 times. She had been diagnosed with schizophrenia, bipolar disorder, depression, mental retardation, autism spectrum disorder and dissociative identity disorder. She has been subjected to long-standing abuse by her mother.

Family situation

R’s parents divorced when she was less than three years old. R’s brother attributed the divorce to poor parental communication and their mother’s needs to control and treat their father like a young child. The father was uninvolved, whereas their mother was over-involved. Hence, R grew up without a father figure in her life. Her brother has bipolar disorder.

R experienced emotional and physical abuse, that was reported to a child protection officer when she was 12 years old. For the next six years, R moved to different foster homes. When R was being fostered, R’s mother would often visit and demand for her return. After six years, R was returned to mother. The abuse continued. R’s mother would lock R up in their house for months. She used vulgarities on R, and called her “idiot”. She would tie R up when she had outburst episodes. She gave R and her brother diarrhoea causing food but all the same gave them anti-diarrhoeal medications also.

Throughout the next decade of her life, R has been offered alternative placement. However, mother would fetch patient home shortly after. During periods while patient was at home with mother, mother was non-adherent to home visits by community partners and was abusive towards them. R feels that her mother is too controlling. However, rather than anger, R mainly feels a sense of ambivalent attachment towards mother. She also forgives her actions, “If my Ma beat me, if I die, I forgive her”. R feels that father is neglectful and does not care about her. R feels that everyone else will harm, betray or neglect her. R began to regress and disassociate to avoid the tension and conflicts evoked by circumstances at her present level of development.

Psychiatric history

R has three personas. The first is herself, who possesses normal intelligence and exhibits behaviours commensurate with her age. The second persona is a character called P, who is five years old. P will behave and speak like a five-year-old, who cannot count or write. The third persona is a non-communicative individual who will rock self, flap hands, suck thumb, eat rubbish and smear faeces. The third persona does not acknowledge anyone else around her and will also exhibit occasional outbursts where she tries to hurt herself by biting herself and banging her head against the wall. During these outbursts, she sometimes also hurts others near her.

R acknowledges that she is sometimes P, although she has no recollections of the outburst episodes that she demonstrates as the third persona. During her frequent admissions, she often presented as the non-communicative individual during the initial weeks. Thereafter, her persona will gradually shift until she adopts the P persona. Sometimes she adopts a persona in between both R and P. She will address herself as R, who is also P. This persona is not toilet trained and requires assistance in her activities of daily living.

During her admissions, R reports symptoms such as hearing voices telling her to kill her mother, reminiscent of psychosis. These were determined to be pseudo-hallucinations. She has culture-bound ideas about being bewitched. R also reports depressive symptoms and suicidal thoughts. R’s admissions were often triggered after conflicts with mother.

R’s commentary on the report

Upon completion of the report, R was regressed to five years old and presented as P. She needed the report to be read to her, as P could not read. Despite saying she was five years old, she had apparent deeper understanding of what was going on around her. She heard the article with blank eyes and a kind of detachment and with no emotional outbursts that was initially
expected. She asked in a child-like manner, “What is regression?”, “What is disassociation?”, and appeared to understand when it was explained to her in layman’s term. She would nod her head and replied, “Yes, that’s correct, I shout and throw tantrum but later I don’t remember”. She would ask inquisitively why she had the diagnosis “regression” rather than “bipolar disorder” – which she said her brother had. After her remarks, she proceeded to do colouring activities with fellow patients with no outburst episodes that day and the next.

Discussion: labyrinthine diagnosis

Placing a diagnosis on R proves to be challenging especially with cross-sectional examination. When R regresses to the P or the non-verbal individual persona, she is deemed to have mental retardation and autism spectrum disorder. Further evaluation was generally not conducted in view of the seemingly obvious diagnosis when R rocks back and forth, putting a teddy bear in her mouth. Attempts to assess R’s intelligence quotient failed as they were not consistent with her level of functioning during her non-regressed state and therefore not considered reliable.

When R presents with psychosis like and depressive symptoms, she is labelled as having a primary psychotic disorder and mood disorder, respectively. Explosive and emotional outbursts and a positive family history of bipolar disorder rendered her to be diagnosed with the same. During these periods, she was often treated with antipsychotic medications and mood stabilisers. Although they helped in reducing R’s outbursts episodes, the episodes remain unpredictable, without triggers.

Only upon longitudinal and deeper evaluation did we realise that R presents with multiple personas. This is made difficult with the corroborative history mother who often minimises symptoms and discharge R prematurely. The multiple personas seem classical of dissociative personality disorder. However, the personas seem to exist on a continuum and are not independent of each other, R and P both know of each other’s existence. Only the uncommunicative persona seemed to be out of both personas’ radar. Upon regression, R seems to be fixated at the oral stage. R also reported amnesia of events especially her emotional outbursts, while she was displaying her third persona. Dissociation could have rendered her unable to remember these events.

Research implications

Contemporary psychiatry depicts several challenges. Symptoms-based illness classifications have no basis on mechanisms and do not advice treatment. Genetic and neuro-scientific studies have yet to contribute significantly to the clinical area (Stephan et al., 2016). Psychiatric diagnosis is often made by history taking, and often, rather subjectively. Future genetic studies will shed some light and bring psychiatry to greater heights.

Additionally, regression is often described sporadically, as part of a more wholesome diagnosis. There is an overall paucity of research conducted on the topic. More research is required on the phenomenology, presentation and successful treatment of regression.

Conclusion

Diagnosis is often made cross-sectionally. Longitudinal history taking, multiple assessments and medical notes reviews are necessary to facilitate precise assessment and holistic management. Current diagnostic systems primarily make use of descriptive psychopathology as the basis of criteria for diagnosis of psychiatric conditions. While the use of descriptive psychopathology is pragmatic and has the obvious advantage of being free from the burden of seeking explanation of the psychopathological phenomenon in a theoretical construct such as the psychodynamic framework, not all patients can be awarded a meaningful diagnosis using such an approach. This case report exemplifies that psychiatric presentation in some patients refuses to be neatly subjected to a useful psychiatric diagnosis using descriptive psychopathology as the diagnostic tool resulting in a confusing array of diagnoses, with each diagnosis representing an isolated facet
of the psychological world of the patient while ignoring the rest. Explanatory models of psychopathology such as psychodynamic psychopathology still remain relevant in such cases for both understanding and explanation of the mental phenomena, and devising appropriate intervention strategies.

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Corresponding author

Jing Ling Tay can be contacted at: jing_ling_tay@imh.com.sg
Chronicles of one woman’s journey towards well-being: re-membering

Jo Mullen

Abstract

Purpose – The purpose of this paper is to share the experiences and reflections of one woman’s journey toward 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 toward well-being.

Originality/value – This paper adds to the accounts of the lived experience of the journey toward well-being, and as such, contributes to the understanding of the process of rebuilding a life.

Keywords Story, Authentic voice

The following allegory was gifted to me 20 years ago in 1999, the year I made my transition from London to Findhorn, a small coastal village in the North East of Scotland. It was my first experience of expressing something meaningful in words – this was my own story, spoken by My Authentic Voice. At several points along the way, I felt certain that I had reached the end point. I now realize, however, that this was, in fact, an illusion. Recent events have taught me that I was required to work with – and through – my story on many levels, with each one bringing me back to the beginning again. It is only in this present moment that I have finally arrived at my intended destination, ready and fully-equipped to create a New Story.

The story

Once upon a time there was a story. It was trying to live amongst the people who told stories freely to each other every day. But nobody wanted to tell this story. NOBODY.

The people slowly began to notice that this story had never been told. They would wonder about it, realising that it must be very different if no-one had told it. Then one day a little girl said:

"Perhaps it is something that we don’t want to hear. Perhaps it is so full of pain that it would certainly change us if we heard it."

After she had spoken, a man standing next to the girl felt cold, and the woman next to him started trembling, and a little boy clung to the woman as the sobs came. And this went on until all of the people were shaking and crying and screaming. Only the girl remained silent. At last, someone had invited pain and grief to stay awhile in the land of the storytellers.

The people turned to face the girl. Their fear became anger, and their anger hurled itself into rage.

"You must suffer for what you have done," said a man, and he grabbed a heavy iron chain. He dragged it toward the girl and clamped it tight around her right ankle, and the other end he wrapped around her story.

Then the seven strongest men in all the land struggled to lift the pain-filled story and carried it to the water’s edge. They placed it in a small wooden boat and they pushed and pushed so hard until the fear and the grief were gone.

Jo Mullen is based at Wot R U Like?, Elgin, UK.
The people stood and watched as the boat moved away from them. And they saw it travel onwards and come to rest in a distant land. They all felt so relieved that they could return to their joyful storytelling, and they turned their backs on the girl.

Many years had passed and new generations of storytellers were telling their stories freely to each other every day. They had no knowledge of The Distant Land; they looked across the sea and saw only what they believed to be a mirror of their own land reflected by the rays of The Great Sun in the water.

And nobody noticed the little girl who, in all this time, remained unchanged. She had sat by herself on a rock at the edge of the land. The people forgot about her because she was silent and had no stories to tell.

But as the years went by, the waters began to move. The story in The Distant Land was pushing the wooden boat with its feet as it cried for its voice. And after many months, the little waves reached the girl and began to dance around her chain. They flowed into each link, leaving their saltiness behind. The waves grew stronger and more persistent, grabbing at the chain and pulling hard. And the metal rubbed the girl’s ankle until she cried out in pain. Her sound came again and again, each time louder and deeper. It moved around her whole body and then pushed itself out and out and out until it reached the ears of the storytellers.

Their tongues stopped. Their stories – broken and unfinished – were held still in their breath. They saw and felt the strange sound in the air. They followed it and noticed for the first time, a little girl curled up tight into her body. She was shaking and shaking and shaking.

A wise woman stepped out from her people and placed her hand gently on the girl’s wound. Then she faced the storytellers and said:

- Why have we never heard this girl’s story?
- “We didn’t know she was here,” came one reply.
- “Maybe she can’t speak,” came another.
- Or perhaps she doesn’t have a story.
- “EVERYONE HAS A STORY,” said the woman angrily. Then she turned to the girl.
- “Child,” she whispered softly. “Where is your story?”

The girl shook and cried but very slowly she moved her fingers toward her ankle and let them rest on the chain that was biting into her skin.

The people, feeling the peaceful flow of their own tears for the very first time, saw that this was the beginning of her story. Not one of them trembled as they moved forward to hear more, each person reaching for a piece of her chain and gently – very gently – pulling it from the water. As one by one the links emerged from the sea, there was a new cry from the girl: the release of the deep pain which had kept her separate from the other storytellers.

She uncurled her body and looked into the loving eyes of the woman who, ever so lightly, held the girl’s head and turned her toward the sea. The little girl watched as the boat was bringing her story back home.

When the boat reached the shore, seven women approached the story. They carried it to the rock and placed it next to the girl’s ankle. The little girl picked it up and cradled in her arms. She invited it to speak and it began:

- Once upon a time there was a story. It was trying to live amongst the people who told stories freely to each other every day. But nobody wanted to tell this story. NOBODY.

The girl continued until, looking into the eyes of the storytellers, she saw that each one had remembered. Then, with her story held tightly against her chest, she rose and stood tall for the first time in many many years.

She gathered up her chain and stepped into the boat.
“Where are you going?” asked the woman. And the girl replied, “I am journeying with my story until I reach the Land of the Songwriters. I will stay with them until they can sing songs of pain and grief without feeling afraid. And I will stay with them until they remember.”

I now warmly invite you to ask yourself, “What is my story?”

Corresponding author
Jo Mullen can be contacted at: jomullen@btinternet.com
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Mental Health and Social Inclusion

Number 4

145 Editorial
149 Research Watch: mental health services supporting social inclusion
   Sue Holtum
156 Remarkable Lives: John McManus in conversation with Jerome Carson
   John McManus and Jerome Carson
162 Surviving secondary school: a story of mental health in adolescence
   Carys J. Morley
166 Recovery colleges and dementia courses – a scoping survey
   Christine Lowen, Linda Birt and Juniper West
173 Mental health recovery narratives: their impact on service users and other
   stakeholder groups
   Myra Piat, Jessica Spagnolo, Suzanne Thibodeau-Gervais, Catherine Deschamps
   and Yves Gosselin
185 Regression and labyrinthine diagnosis – a case report
   Jing Ling Tay, Alias Lijo, Bixue Wen, Susan Zachariah and Manu Lal
189 Chronicles of one woman’s journey towards well-being: re-membering
   Jo Mullen

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