



REVIEW ARTICLE

A PERSPECTIVE ON MENTAL HEALTH RECOVERY: THE CATALYZING EFFECT OF PUBLIC DISCLOSURE BY PEOPLE LIVING WITH MENTAL ILLNESS AND CAREGIVERS THROUGH ADVOCACY EVENT

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ABSTRACT

Ensuring mental well-being has become an important target for community wholeness. Despite our growing knowledge and scientific discovery, the core challenges such as mental health stigma remain a sad deterrent in progressive society. The work of advocacy began in the 1990s to encourage social integration and support mental health recovery. However, it is still unclear how such advocacy work would produce favorable outcome. Locally in Malaysia, a mental health advocacy event was conducted in a tertiary university hospital with collaborative efforts from mental health providers and multidisciplinary units of care. The highlights of the event were three public disclosure and sharing sessions; two by individuals with lived experience of mental illness and another by a psychiatric caregiver. The event ended with a showcase of patients' various artworks done in the psychiatric rehabilitation unit. The impact of this advocacy work was experiential from the initial stage of planning to the delivery of content during the event, and thereafter as a catalyst to further improve in functional recovery. The therapeutic work and alliance were shared by different roles through guided reflection of the patients' and caregiver's journey in the content for sharing. The successful delivery of the advocacy event also foresees further empowerment of people with lived experience of psychiatric illness to step up as a critical role of voice to enhance community connections and encourage social integration. Furthermore, the importance and value of advocacy can be included in psychiatry training clinical settings, self-help organizations, and peer-led communities in efforts to promote mental health recovery.

KEYWORDS

Mental health, recovery, mental illness, lived-experience, advocacy, public sharing

1. INTRODUCTION

Mental health advocacy work began in the 1990s (Thomas and Bracken, 1999; Stocking, 1991; Heller et al., 1996; Executive, 1997). The greatest impact in mental health advocacy work is peer advocacy and self-advocacy, where self-advocacy is the ultimate goal of peer advocacy, when people are able to speak out for themselves (Executive, 1997). The presence of peer advocates promotes inclusion, empowerment, and the critical role of voice (Storey, 2011). The powerful messages delivered through advocacy work to both the people who call on them and the people from the services who encounter them would encourage the cultural shift in attitude and ethos needed, of doing things with people instead of to them or for them (Executive, 1997). Advocacy work promotes empowerment, which is the realization of the internal power and strength within each person (Storey, 2007) whereas self-stigma is the opposite of empowerment (Lucksted et al., 2011; Rüsch et al., 2014). Self-stigma results from internalized negative public stereotypes and attitudes that can lead to demoralization, helplessness, and hopelessness (Marino et al., 2016). Such experiences lead to social isolation, avoidance of mental health care, and missed social opportunities which further delay the journey of recovery and pursuance of life goals (Marino et al., 2016).

Self-advocacy work in the form of self-disclosure can be a key method for challenging stigma and promoting empowerment and recovery (Marino et al., 2016). The knowledge shared across interpersonal contacts can result in improvement in attitudes toward mental health issues through experiential knowledge (An and McDermott, 2014). Corbiere et al., (2012) in their work identified six differently grouped strategies to combat stigma toward people living with mental illness (PLMI), namely education, protestation, contact, person-centered, working on recovery and social inclusion, and reflexive consciousness. Social contact refers to strategies related to sharing or encouraging disclosure and meeting or coming close to PLMI, of which appears to emerge as an important strategy with significant improvements in attitude, in the concept of self-disclosure of mental illness (Corbiere et al., 2012). These changes in attitudes were maintained through time and are related to changes in behavior (Corrigan and Matthews, 2003). Interventions based on the culturally appropriate principle of social contact have been shown to be the most effective anti-stigma method globally (Thornicroft et al., 2022).

In advocacy work, many studies have shown that engaging people with lived experience of mental illness through physical participation can empower them in the recovery process (Cheng and Smith, 2009; Arblaster et al., 2023). Psychiatry has moved away from a negative 'antipsychiatry' perspective of advocacy to a more constructive engagement. This will eventually bring benefits to the whole mental healthcare system (Cheng

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and Smith, 2009; Vojtila et al., 2021). PLMI may step up as advocates themselves and lead the peer support group in their own community. Peers' role in promoting recovery is helpful and encouraging, although not definitive, within the continuum of care for PLMI, including delivering the curricula by peers (Chinman et al., 2014). The effects of peer support services are extensive and can be a transformation from patients to peer support providers (Shalaby and Agyapong, 2020). Engaging families of PLMI can also empower them to support PLMI in the recovery process (Wyder et al., 2022; Waller et al., 2019).

Despite the growing support for advocacy work in the field of mental health, there are still limited publications on how best to engage PLMI and their families. The meaningful engagement of PLMI was limited by various factors including knowledge, resources, organizational needs, and stigma (Rio et al., 2020; Ewalds Mulliez et al., 2018). People living with mental illness said that the most devastating impact on their lives came not from the illness itself but from the way others began to treat them (Kirby and Keon, 2006). Nearly half of the population of PLMI has kept their mental illness discreet from their family and only half would tell their friends or colleagues if a member of their family was diagnosed with mental illness, compared to other physical illnesses (Pokorny, 1988). Several factors may contribute to the adoption of self-disclosure of PLMI in any self-advocacy public event. What would the experience be for PLMI who have disclosed their mental condition? What added value would it bring to their recovery? Any disadvantages or loss in any form?

This case description gives a preliminary idea of the conduct of self-advocacy event through public disclosure and sharing of PLMI and caregivers, and its impact on mental health recovery.

2. COORDINATING A PUBLIC MENTAL HEALTH ADVOCACY EVENT FOCUSING ON PLMI AND CAREGIVERS

A mental health advocacy event was planned in conjunction with World Mental Health Day. The design of the self-advocacy event centered on the engagement with PLMI and their families, with collaborative efforts from mental health providers, frontliners, and multidisciplinary units of care. The objective of the event is 1) to promote self-advocacy among PLMI and their families, 2) to engage and enhance the recovery journey for PLMI and their families with the community, and 3) to reduce stigma and encourage help-seeking among communities with mental health issues.

The process of advocacy work started from the initial stage of planning itself. The self-advocacy event involved two PLMI and another caregiver of a loved one with psychiatric illness. These three individuals would share their personal lived experiences with the audience. The selection of these three individuals was based on several factors, namely for the PLMI 1) they are in a clinically stable condition with no active symptoms; 2) given their consent to share their lived experience in the event; 3) can communicate in English or Malay language and; 4) committed to sessions of being guided in their lived experience sharing. The selection for caregiver was based on 1) the suitability of sharing their caregiver experience with given consent by their loved ones living with mental illness; 2) their consent to share their lived experience as caregiver; 3) their ability to communicate in English or Malay language and; 4) their commitment to sessions of being guided in their lived experience sharing. Participants for the event were selected based on their role (direct or indirect) in the journey of recovery for PLMI.

The setting of the event was set up thoughtfully, taking into account 1) the number of audiences suitable for such self-advocacy event and 2) the platform or stage from which the PLMI and caregiver could deliver their lived-experienced sharing, for a balance of ceremonious versus community-like event. The content of the lived-experience was guided throughout the preparation for the self-advocacy event by mental health providers individualized to the needs of PLMI and caregiver. Guided reflective questions were given to PLMI and caregiver to facilitate their preparation (Figure 1).

Figure 1: Guided Reflective Questions

1. How would you want to introduce yourself?
2. How would you share about being a client to our services?
3. How would you want to share or highlight your journey of recovery and what is meaningful for you? (may include the challenges faced if you would like to)
4. How would you want to share your wishes and hope for the journey ahead?

3. CONDUCT OF PUBLIC DISCLOSURE BY PLMI AND CAREGIVERS IN MENTAL HEALTH ADVOCACY EVENT

The preparation of the content of lived experience sharing involved the collaborative work between PLMI and caregiver (presenters) with their primary psychiatrists and/or psychiatric postgraduate trainees with counsellors (facilitators). The contents of delivery were drafted by the presenters and revisions of the drafts were performed with respective facilitators on safe sharing and delivery of messages for such personal lived experiences. The facilitators would also rehearse the scripts and narratives with the presenters to build their confidence in delivering their messages. The sessions with the facilitators were approximately 3-4 sessions depending on the needs of each individual. Prior to and on the day of the event, the facilitators would prepare the presenters on the setting as well as go through relaxation techniques with them, where needed.

The self-advocacy event was conducted in September 2022 in a controlled and conducive open space area within a clinical education building in a university hospital in the central region of Kuala Lumpur, Malaysia. There were 50 participants for the event who were psychiatrists, psychiatric trainees, mental health workers and staff including occupational therapists, social workers, psychologists and counsellors, frontliners and clinicians including from emergency department and safety and security unit, medical students, mental health advocates and stakeholders of administrative authorities of the university hospital. It was a 3-hour event. The event was officiated by a local senator championing the rights of people with disabilities, followed by a public awareness educational talk. The presenters then took their place on stage after being introduced by their facilitators. Each presenter shared their lived experience for approximately 15 minutes. The session was moderated by a psychiatrist to ensure the safe delivery of conduct of the event. There was a psychiatric postgraduate trainee made available for psychological debriefing should anyone require it. The self-advocacy event ended with a walk-through visit to the displayed art and creative works section by PLMI.

4. DISCUSSION

Illness is a biographically disruptive event that forces people to re-evaluate their lives, values, and behavior (Bury, 1982). One way to find meaning in illness is to become storytellers and recover the voices that illness and its treatment often take away (Frank, 1995). Personal accounts and stories have the potential to support recovery and self-empowerment (Jones and Pietilä, 2020). In this event, public disclosure of personal accounts on mental health recovery was witnessed by various stakeholders. Following their experience, PLMI's personal perspectives on the involvement process and their narrations of becoming experts by experience would enable stakeholders to explore the opportunities and tensions associated with becoming involved, and how such a process can influence the accounts of experts of experience shared with health services (Dent and Pahor, 2015). There is growing prominence in a number of countries placing personal or lived experiences as the center of service development (Dent and Pahor, 2015). Patient involvement can come in different initiatives: as trainers, co-planners and coproducers alongside health professionals (Dent and Pahor, 2015). Personal disclosure and stories about living with illness or caring for an ill family member can be used to guide best practices, health policy, and research.

However, cautious attention needs to be taken in the conduct and delivery of content for public disclosure. A story that conveys a desirable level of vulnerability and resonates with listeners on an emotional level yet is conveyed in a manner that demonstrates personal control was suggested (Näslund et al., 2020). Our presenters in this event were trained and guided on this by their primary psychiatrists and/or facilitators. This was also advocated by Jones et al in 2020 in their study participants of the importance of distancing themselves from the personal emotions and constructing a clear, coherent account of their lived illness and caring experiences. The construction of a structured account can provide coherence to past events and help to build a positive sense of self, with the narrators themselves agreeing with this factor (Lysaker et al., 2010).

The construct of the contents for public disclosure by our PLMI and caregiver was facilitated by mental health providers. This process itself is a catalyze for initial and long-term engagement with their psychiatrists who took the responsibility of guiding the two PLMI and the caregiver on preparing an effective narrative of their personal lived experience. As our PLMI had battled with their debilitating illnesses and experienced multiple crises and relapses before their recovery journey unfolded, it took a few sessions to highlight and summarize the content following the guided reflective questions (Figure 1) for public disclosure. The benefits of such advocacy event extended beyond the conduct of the event itself.

Processing and constructing an account of past experiences may influence how past experiences are articulated and this process is itself therapeutic for the narrator. It also forms a reflection as well for PLMI and the caregiver on their journey of recovery in mental health. The meaningful engagement between the narrators and mental health providers also encouraged the development of therapeutic and professional relationships. The growth brought about by sharing their lived experience and their personal conviction as PLMI or caregiver in a public event catalyzed further progress in recovery by improving their self-confidence and thereafter, sought to have meaningful functioning. One of our PLMI took the momentum and motivation after the advocacy event to find employment and successfully engaged as a regular in a non-governmental organization that supported PLMI. Through this example, it is also possible to see PLMI stepping up as the critical role of voice and finding the support to lead local community peer support and recovery groups. This will promote leadership in social integration work for PLMI.

Through advocacy work, the community can establish a collective appreciation of recovery through radical redistribution of responsibility (Storey, 2011). There will be more opportunities for voice and inclusion to support recovery leadership. In the long term, the values brought about through advocacy work can be realigned into the healthcare system through review of service planning and execution (Storey, 2011).

Establishing strong therapeutic and professional relationships through the planning and execution of such public advocacy event can also foster additional advocacy values within clinical settings. The study of the use of crisis cards for psychiatric emergencies has been conducted even in the 1990s (Sutherby et al., 2007; Sutherby and Szmukler, 1998). Crisis cards offer choices for patients to entail their treatment preferences in anticipation of an emergency when they may be rendered incapable of making informed decisions. Hence, patients were engaged in their stable phase to discuss on advanced directives or crisis care when the need arises. They would inform the type of help he or she wants to receive when unwell or during a crisis, emergency contact person, and the type of medication to be given or not to be given. The practice of psychiatric advance directives is an effective tool for reducing coercive interventions (Swanson et al., 2008). However, such practice has not yet been explored at the local level. A crisis card is the simplest form of self-advocacy, offering PLMI adequate autonomy in their clinical care. Advancing advocacy work extending from the therapeutic engagement built upon by mental health providers and PLMI before, during, and after the advocacy event also foresees an opportunity to continuously engage PLMI for such psychiatric advance directives work. The sessions between mental health providers and PLMI would encourage discussion on the impact and motivation of recovery, relapse prevention, and future directions in management plans. Crisis card interventions would form part of the plans to sustain advocacy work and self-empowerment for PLMI.

Apart from the clinical setting, it is also equally important to consider the need for advocacy teaching in postgraduate psychiatry training (Kennedy and Vance, 2018). Different psychiatry residency programs in universities worldwide have included various experiential work such as legislative projects and community work (Kennedy and Vance, 2018). Tertiary education has an important role in equipping students with an understanding of mental health recovery (Happell et al., 2014). Gaining insights from real-world interactions and direct engagement, as well as learning from people with lived experiences of mental illness are powerful for such understanding (Brand et al., 2021; Chester et al., 2016; Horgan et al., 2020). The unique nature of our advocacy event allows our postgraduate trainees to shape the narrative of PLMI and caregivers, including conducting rehearsals with them before the actual event. Such involvement in advocacy efforts can be recorded in their logbooks as an integral aspect of their training and education. The local psychiatry postgraduate curriculum can be reviewed to promote direct patient involvement, such as providing step-by-step guidance for PLMI to organize events, aiding in their self-advocacy efforts, or acting as a mediator between patients and other agencies or stakeholders.

Health and industry policy has included the contribution of people with lived experience at all levels of health curriculum review, such as by Australia Association of Social Workers, Occupational Therapy Council of Australia Ltd including their accreditation standards for Australian entry-level occupational therapy education programs as well as the Australian Nursing and Midwifery Accreditation Council on their registered nurse accreditation standards 2019 (Australia Association of Social Workers, 2015; Occupational Therapy Council of Australia Ltd, 2019; Australian Nursing and Midwifery Accreditation Council, 2019). Moreover, the codesign of teaching resources with people with lived experience was proven to be beneficial both to PLMI and the students in improving their recovery-oriented capabilities and practices (Arblaster et al., 2023; Bell et

al., 2021). Advocates require a significant set of skills to undertake the role effectively, with a need for ongoing training and regular supervision to maximize effectiveness. Testimony or self-disclosure and stigma are highly correlated: the more people talk about mental illness, the less mental illness will be stigmatized, and the more people will talk about them.

The limitation of this advocacy work is that it represented and involved only a limited sample of population due to various factors, such as the medium of language used, suitability of set-up and stage, socio-academic background of the audience, patients' and caregiver's commitment and readiness, personalized needs of each narrator, and lack of familiarity with such events. The strength of this advocacy event is that it can be implemented in a resource-limited, low-middle-income country. The benefits span across different roles in such advocacy work, including but not limited to mental health practitioners or care professionals, the PLMI, caregivers, and audiences from multidisciplinary units as well as hospital stakeholders and community leaders. The experiential journey for PLMI in their mental health recovery is shared and witnessed through such advocacy event.

5. CONCLUSION

In the course of growing knowledge and scientific discovery, psychiatry progress is made at stages. Sometimes advances can occur in quantum leap, but the core challenges such as mental health stigma remain a sad deterrent in progressive societies. Advocacy event based on the principle of social contact through public disclosure, involving personal accounts and the lived experience of PLMI, and caregivers have the potential to reduce stigma and catalyze improvement and therapeutic management for mental health recovery. The importance and value of advocacy can be included in self-advocacy work, clinical implementation services, psychiatry training, self-help organizations, peer-led communities, and mental health and industry policy. Eventually, advocacy at the individual level must be complemented by advocacy at the institutional level. Further translational research can provide systematic evidence for the impact of such advocacy work.

CONFLICT OF INTEREST

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

AUTHOR CONTRIBUTIONS

Jane Tze Yn Lim and Lai Fong Chan contributed to the conception and design of the work, preparation of subjects and conduct of the work. Jane Tze Yn Lim drafted the work, which Zi Bin Teoh contributed to the revision, and all authors approved the submitted version.

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