Participative mental health consumer research for improving physical health care: An integrative review

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Abstract

People with mental illness have a significantly lower life expectancy and higher rates of chronic physical illnesses than the general population. Health care system reform to improve access and quality is greatly needed to address this inequity. The inclusion of consumers of mental health services as co-investigators in research is likely to enhance service reform. In light of this, the current paper reviews mental health consumer focussed research conducted to date, addressing the neglect of physical health in mental health care and initiatives with the aim of improving physical health care. The international literature on physical healthcare in the context of mental health services was searched for articles, including mental health consumers in research roles, via Medline, CINAHL and Google Scholar, in October 2015. Four studies where mental health consumers participated as researchers were identified. Three studies involved qualitative research on barriers and facilitators to physical health care access, and a fourth study on developing technologies for more effective communication between GPs and patients. This review found that participatory mental health consumer research in physical health care reform has only become visible in the academic literature in 2015. Heightened consideration of mental health consumer participation in research is required by health care providers and researchers. Mental health nurses can provide leadership in increasing mental health consumer research on integrated care directed towards reducing the health gap between people with and without mental illness.

Key words

Action research

Consumer participation

Mental health

Mental illness,

Physical illness

Research

Introduction

People with mental illness have the right to good health, and a life expectancy equal to the general population. Yet epidemiological data and the lived experiences of those affected by mental illness clearly demonstrate significant discrepancies (British Medical Association 2014; Meagher 2013; Walker *et al.* 2015). People diagnosed with mental illness have elevated risk of preventable chronic physical illnesses and reduced life expectancy of up to 30 years (Gladigau *et al.* 2014; Brown *et al.* 2010; Leeb *et al.* 2011; Lawrence *et al.* 2013; Vancampfort *et al.* 2015; Rosenbaum *et al.* 2015). Psychotropic medications typically prescribed in mental health services are identified as contributing to higher rates of physical illness, particularly cardiometabolic disorders (Saddichha *et al.* 2008; Sussman 2003; American Diabetes Association 2004). Co-occurring physical and mental illness are also found to vary with socio-economic deprivation such as low income or unemployment, and 'risk factor' behaviours such as alcohol misuse, smoking, high-sugar food consumption and physical inactivity (Wilton 2004; Scott & Happell 2011).

To reduce inequalities in physical illness between those with and without mental illness, and to close the life expectancy gap of up to 30 years, it is widely recognised that significant changes are required to health care systems (De Hert *et al.* 2011; Lawrence & Kisely 2010; Thornicroft 2011). Strategies to achieve this include greater integration of mental and physical health services, such as screening for cardiometabolic health problems,

informative consultation with medical specialists, effective referral pathways, health education and programs such as smoking cessation, diet and physical activity (British Medical Association 2014; Ministerial Advisory Committee on Mental Health 2011; Horvitz-Lennon *et al.* 2006; Mitchell & Lord 2010; Druss *et al.* 2010; Brown *et al.* 2011; Lawrence & Kisely 2010; White *et al.* 2011; Shuel *et al.* 2010).

A growing force in improving health care services, particularly with respect to embracing the perspectives, needs, rights and values of service users has been the mental health consumer movement (Salzer 1997; Schauer *et al.* 2007). Initiatives have included participation of consumers in evaluating services, training and education of health practitioners, and advocacy. In policy, mental health consumer participation is recognised as part of moving to recovery-orientated and highly responsive service delivery (Commonwealth of Australia 2013; World Health Organisation 2013; Browne & Hemsley 2008). Consumer participation is becoming increasingly valued for enabling better interpersonal engagement with a breaking down of power differentials and greater respect for individual knowledge and contribution (Linhorst & Eckert 2002; Schneider 2012). In practice though, the evolution of services and culture through consumer participation is challenging, as it confronts traditional arrangements in health care systems and the stigma of mental illness (Slade *et al.* 2008; Lammers & Happell 2003; McAllister & Walsh 2004; Borg *et al.* 2009).

A particularly important form of consumer participation for improving health services has been the inclusion of consumers as co-researchers (Happell & Roper 2007; Kidd *et al.* 2015). Exemplar forms of such research include “participatory action research” (Schneider 2012) and “service user research” (Fothergill *et al.* 2012). For consistency, we will use the term Participatory Mental Health Consumer Research (PMHCR).

Consumer participation ensures that consumer interests and needs are prioritised in research evaluation (Linhorst & Eckert 2002). PMHCRs are more likely to voice their real concerns and needs when interviewed by a peer (Rose *et al.* 2008; Callard *et al.* 2012). Furthermore, new knowledge gained is not constrained to academics and health providers, and can be more quickly applied to solve problems (Schneider 2012). However, the potential value of PMHCR in contributing to reforms to mental health services (Callard & Rose 2012) does not seem to have been realised in addressing physical health services. There is a rapidly expanding growth in research and policy on integrated care with very limited outcomes thus far in improving screening and assessment of physical health problems, supporting consumers via health education and health-behaviour change, and countering mental health stigma and diagnostic overshadowing (Verhaughe 2011).

Mental health consumer researchers, through their lived experience expertise, may help shape further research so that the needs, concerns and values of their consumer peers are not overlooked (Rose 2011). Given these

matters, ascertaining the contribution of PMHCR to physical health service provision for mental health consumers would be valuable to inform service providers and health professionals seeking to improve physical health service access and quality for mental health consumers. Moreover, the contributions of consumers can be seen as critical to shaping both policy and future research directions.

Thus, the purpose of the current review is two-fold. Firstly, this review aims to identify the occurrence of PMHCR in studies concerned with improving physical health care and physical health. Secondly, and building on the first aim, where PMHCR has occurred, to examine the nature of physical health problems, the scope of PMHCR across the research process and the outcomes of these studies.

METHOD

Preliminary searches of the literature on physical illness and physical health care for people with mental illness indicated a systematic review of PMHCR would not be feasible, given the wide-ranging literature and lack of consistency in approaches to research and service reform. Studies could not be systematically compared on a common variable such as a clinical outcome. In such situations, an integrative review is needed so that differences in methodologies of the target literature can be brought together

and analysed in order to advance evidence-based practice (Whittemore & Knafl 2005).

Search strategy

The search was of the peer-reviewed literature published between 2000 and November 2015. The review included studies on the topic of physical health care of people with mental illness where consumers were involved in a highly participatory way in at least one phase of the study as co-researchers. The review excluded publications not written in English, and publications reporting research that did not include the collection of primary data.

Literature searches were conducted in CINAHL and Medline. Google scholar is a comprehensive search engine equivalent to major searching systems (such as CINAHL) in outputs (Gehanno *et al.* 2013). Based on the evidence of the comparable coverage of the literature that Google scholar provides (Bramer *et al.* 2013; Shariff *et al.* 2013), it was also utilised for the current exploratory integrative review. Searches were based on combinations and adjusted wordings of the following "full text" search terms , in October 2015: "mental illness", "mental health consumer", "service user", "physical illness", "chronic disease", "health promotion", "physical healthcare", "participatory action research", and "user research". Relevant papers were also inspected for citation of studies that may meet the selection criteria.

Fifty seven papers were found where some form of consumer participation was reported (e.g. rating satisfaction of services, being interviewed for views on physical health services), and these were scanned for evidence of mental health consumer participation in the design and conduct of research (see Figure 1). Four publications met the inclusion criteria (Corrigan *et al.* 2015; Pelletier *et al.* 2015; Ross *et al.* 2015).

== Figure 1 here ==

Given the small number of studies, the current integrative review seeks to maximise what knowledge can be derived with respect to the current topic. Therefore the next section describes each of the studies in turn, with particular emphasis on the types of challenges with respect to physical health that researches were looking at, the actual approaches to PMHCR, and outcomes of the studies.

RESULTS

Table 1 presents a summary of the studies reviewed, the area where they took place, the type of research design, nature of PMHCR participation, and study outcomes.

== Table 1 here ==

Exploring physical health challenges and peer navigators as avenues to service access and integration

In Chicago, Corrigan et al. (2015) inquired into problems surrounding physical health care arrangements with respect to African Americans that had a diagnosis of mental illness and were homeless. Corrigan et al. (2015, p. 119) described the method as “community-based participatory research” (CBPR), where the members of the cohort that were the focus of the research participated in the design and conduct of the research itself. In exploring barriers to physical health care, community views were sought about including peer navigators as a potential path to improving access to quality physical health services. Peer navigators were defined as “... paraprofessionals who are African American, previously homeless and now in recovery that help others – homeless African Americans with mental illness – access health care clinics to address their health needs.” (p. 122). The navigator’s purpose is to strengthen relationships between people seeking health care and the health care providers.

In the study reported by Corrigan et al. (2015), African Americans who were in a homeless situation and experiencing a mental illness were research partners during all phases of the research. In this way, the lived experience of this group could contribute to research process and guide the direction of the research in defining and addressing problems, with the ultimate aim to draw on new knowledge to bring about local change.

African Americans classified as having both a mental illness and as homeless were invited to participate as members of the research team for up to 12 months. Eight were selected from the 49 who applied. Members from the community in the CBPR team would have travel costs reimbursed for the research work. One became a co-leader of the CBPR team. The CBPR first involved development of an interview schedule for focus group inquiry with local residents and decided on stakeholders to approach for the interviews. Focus groups took place with local residents, and, in a separate set of group interviews, with local health care providers.

PMHCRs engaged in thematic analysis of the interview data. Matters captured by themes included health problems experienced, difficulties accessing resources important to health care, and the accumulation of vulnerabilities during homelessness and the role of communities and governments in meeting needs. The findings also pointed to the community supports in greatest need, and towards the need for individual health management. Findings suggested peer navigators would be valuable and participants indicated what they thought would be essential competencies and orientations of people in these roles. Further research emanating from the CBPR project will contribute to establishing a peer navigator system as a strategy for more effective access to needed health services of African Americans with mental illness and in a situation of homelessness.

Consumer photograph-facilitated exploration of physical health care approaches

Cabassa et al. (Cabassa *et al.* 2013), reported on the “Health and Wellness Photovoice Project” underpinned by “Community-based participatory research” (p. 618), centred on the physical health of people with mental illness living in North Manhattan, New York. In this case, the partnership was between a government psychiatry institute, a multi-disciplinary research centre with a background in participatory research, and two housing support organisations. The partners recognised housing support services as mediating physical health services of the health care system and people with mental illness. The purpose of the participative research project was consumer-led shared dialogue on issues of physical health and “community-based knowledge” (p. 619) as the basis for the planning and design of physical health care approaches.

Photovoice is a visual representation and dialogical approach whereby participants share their experiences and views about life through the pictures themselves and their narratives with respect to those pictures (See also Balbale *et al.* 2015). The participative feature of Photovoice is the extension on means of participant expression, such as the range of mediums (choosing what to photograph, presenting images, open narratives); this is uncharacteristic of conventional research methods.

Sixteen housing tenants diagnosed with mental illness consented to take part in six once-a-week, 90 minute in-person sessions of Photovoice. The majority of participants were male and Latino background or African American background. Participants were given digital cameras for the course of the project and to keep at the end. The opening session was focused on familiarisation with the use of digital cameras and participants were asked to take shots "about what they did to stay healthy" (p. 621). Outside the sessions, participants chose what to photograph as they went about their daily lives. The interviews centred around the photographs and the meaning they conveying. Follow up sessions were group discussions of the photographs and participants sharing other aspects of their experiences. There was a debrief at the end of each of the follow up sessions and a vote on the thematic topic for photos before the next meeting. It was indicated that participants were not directly involved in the analysis of the data due to insufficient funding.

The major finding was participants wanted peers to be central to physical health supports. Participants expressed an interest in doing more physical activity for physical health and general well-being and were greatly concerned about the lack of physical activity opportunities. They also raised concerns about barriers to healthy eating food and an interest in learning practical steps to dietary change.

It was argued that these findings demonstrate new knowledge from Photovoice participatory research has capacity to translate to evidence-based approaches to health and interventions that suit the particular needs and preferences of the local community (Cabassa *et al.* 2013). More broadly the findings highlighted to the partnering agencies the importance of context in developing effective health care approaches that could be continued in the long-term. The authors emphasised that Photovoice should be adopted further in improving community health services, where people normally marginalised by the research process are genuinely included in the research and such co-development of knowledge may more effectively bridge science-practice divides.

Developing technology-based communication frameworks to enhance patient-GP communication

Pelletier *et al.* (2015) report a “participatory action research design.” Consumers diagnosed with schizophrenia participated as researchers in evaluating a strategy to increase primary care access of people with schizophrenia experiencing comorbid physical health problems. Lack of access to primary care in Montreal, at the point of the patient-GP relationship, and in particular, the occurrence of diagnostic overshadowing were noted as particular problems. Diagnostic overshadowing occurs when a clinician fails to acknowledge that symptoms may result from physical causes, often leading to under treatment of physical health problems (Jones

et al. 2008). A key strategy for reducing diagnostic overshadowing by Pelletier et al. (2015) was a tablet-based Interactive Guide for Medical Appointments (IGMA) to increase preparedness of the consumer for meeting with the GP, especially in terms of self-awareness of physical health problems. The IGMA involves the mental health consumer completing a questionnaire on various symptoms and signs of several physical health problems known to be more commonly occurring in people with schizophrenia.

The structure of the research group was reported in detail by Pelletier et al. (2015). Project co-ordinators included consumer-held research expertise from the International Program for Participatory-Action Research (IPPAR). Two “peer research assistants” contributed to the project. Health Practitioners from general practice, psychiatry, and nursing were members of an advisory board and “co-research team”. The overall project comprised multiple and international partnerships **between** carers, patients, health service providers and organisations (mental and primary care), a non-government organisation (IPPAR), as well as input from a representative of an Australia-based state government integrated care initiative, called Activate: Mind and Body.

Working with a partner with a health professional background, the consumer researchers developed 33 videos presenting symptoms of physical illnesses. Research and development also involved consumer researchers partnering with a GP in refining the language of the IGMA questionnaire to

ensure it was both consumer-centred and consistent with evidence-based medicine. These researchers then, in groups of five people, sought in-person feedback from participants in the study on the workability of the IGMA and videos shown on this device. During sessions, participants were provided with the questionnaire results and details on websites with reliable information on chronic physical diseases.

The effectiveness of consumer involvement in developing and evaluating new integrated care strategies as a valuable and feasible approach was a major finding of Pelletier et al. (2015). In addition, both 'groups' of consumers – researchers and study participants, benefited from the in-person interactions during the process of the study. Pelletier et al. (2015) concluded that the IGMA presents the results of the questionnaire in a comprehensive and simple way, and GPs viewing this become more mindful of physical health problems their patients are experiencing, reducing the risk of diagnostic overshadowing.

Qualitative research on primary care from the viewpoints of consumers and health care providers

In Ontario, Ross et al. (2015) engaged in PMHCR in a field study exploring the question: "What are the barriers and facilitators to primary health care for people living with mental health and/or substance use issues?". This research project was underpinned by cross-sector partnerships concerned with the

three-way division of services on primary care, substance use and mental illness. Eighty five mental health consumers were interviewed, as well as 17 health care providers, including nurses, social workers, physicians, and case managers, and primarily from hospitals and community health centres.

Mental health consumers, described as “service users” in Ross et al. (2015), contributed to steps in the research process, although it was not clear whether consumers took part in research in all stages of the study. Mental health consumers participated in providing feedback on the interview guide for the study, in the coding and analysis of interview data, and in discussing the revision of themes. It is also notable that as the overall research was conducted in close connection with the community. For example, in the early stages the lead investigators ensured that they did not follow particular language, such as “psychiatric disorder” in consideration of the preferences of the community and their arguments about why such language was considered inappropriate.

The qualitative research led to a detailed mapping of barriers to entering primary care stemming from institutional arrangements, consumer-level factors and social-economic issues. Difficulties in access to primary health services by people with mental illness were frequent and severe. The overall findings prompted further research into the educational needs of primary health care providers and closer co-operation amongst services.

DISCUSSION

The current review highlighted studies where mental health consumers have contributed as researchers in studies on problems and strategies relevant to mental health services and physical health care. It was found cases of PMHCR in this health service area are very recent. Although the number of included studies is small, each focused on a different aspect of the interface of physical and mental health care services. Together, they illustrate not only that the inclusion of mental health consumers as co-researchers is feasible, but this type of research contributes to more promising integrated care approaches. For instance, the Pelletier et al. (2015) research and development project in Canada developed an electronic-based platform to mediate patient-GP communication that would arguably be much less suitable to consumers if it had **been** developed exclusively by conventional designers (health professionals, researchers).

Given that each of the four publications represented employment of different research designs we were not in a position to directly compare study quality as would be possible when the literature is comprised of conventional approaches such as randomised controlled trials. Nonetheless, it is suggested here that – as the consumer perspective can enhance the external validity of research (Fothergill et al. 2012) and so potentially lead to approaches that effectively address barriers to physical health care – all

those seeking a PMHCR approach should consider the portability of research designs that were reviewed.

The generalizability of the studies reviewed to other regions is likely limited as it was the intention in each one to address physical health challenges particular to the local area. In addition, as three of the studies involved quite complex and unique cross-partnerships with different 'types' of stakeholder (esp. Pelletier *et al.* 2015; Ross *et al.* 2015), the generalizability to other partnerships in research is also questionable. A caveat to these evaluations, however, is that all the studies reviewed were exploratory and despite their complexity, were successfully completed with relatively good sample sizes for qualitative research (e.g. n=102 in Ross *et al.* 2015; n=146 in Pelletier *et al.* 2015). Overall, a conclusion of this review is that there is feasibility in studies based on PMHCR on tackling the major issue of physical health inequality between people with and without mental illness.

Integrated care approaches are being explored internationally (Druss & von Esenwein 2006; Baller *et al.* 2015). There is a great opportunity for health care providers and applied researchers to benefit from PMHCR to ensure forthcoming reforms meet mental health consumer physical health needs and preferences before new service arrangements are implemented. In seeking to innovative in research and health service practice, it is **beneficial** to have case examples and consider what lessons have been learned from other initiatives. It is important to note that three of the four

studies reported in the current review (Corrigan *et al.* 2015; Pelletier *et al.* 2015; Cabassa *et al.* 2013) provided great detail (and transparency) on the types of relationships formed during the research and how mental health consumers participated in research activities. Ross *et al.* (2015) did not provide as much detail on the nature of PMHCR, probably because of the wide range of stakeholders involved in the research project. At the present time, there is very little in the way of examples of PMHCR in the academic literature on the major public health issue of physical health inequalities between people with and without mental illness and in physical health service access and quality. Corrigan *et al.* (2015) and Pelletier *et al.* (2015) should currently be considered benchmarks for how PMHCR can be enacted on this issue.

It is notable that two of the four studies identified were from Canada (Pelletier *et al.* 2015; Ross *et al.* 2015) and the other two from the USA (Corrigan *et al.* 2015; Cabassa *et al.* 2013) suggesting active involvement of mental health consumers in research on improving physical health services is more developed in North America. Although it could not be ascertained why other parts of the world have not drawn on mental health consumers as health partners, we speculate that it does not reflect on the level of development of mental health consumer movements outside of North America. For instance, in Australia and the UK, there is a relatively strong presence of mental health consumer participation, as well as mental health consumer advocacy and interest groups (Bennetts *et al.* 2011; Rose 2011).

Whatever the reasons, stakeholders primarily responsible for reforming health services can benefit from this current review and the details contained in primary papers that were reviewed, in considering inclusion of mental health consumers as researchers in their efforts to lower health service inequities and improved overall health of consumers.

Mental health nurses can provide leadership in promoting PMHCR on physical health care inequalities and development and evaluation of new approaches to integrated care, such as through advocacy. The development of PMHCR, including consumer-led research and consumer academics has being successfully supported and facilitated by mental health nurses (Happell & Roper 2007). Mental health nursing researchers and practitioners may also contribute by articulating how the many elaborate practice frameworks and models for mental health consumer research on mental health services (e.g. Hancock *et al.* 2012; Fothergill *et al.* 2012) can be utilised for investigation of physical health services.

To ensure PMHCR is central to physical health care reform, strong partnerships are needed between consumer advocacy groups, health care systems, and researchers. Nurses and managers of health care organisations can draw on examples of such organisational supports of mental health consumer participation (Stewart *et al.* 2008; Boardman & Shepherd 2011), when endeavouring to include mental health consumers in physical health service reforms. It should be noted that genuine inclusion and recognition of

consumers is challenging as it destabilises long-running power asymmetries (Horsfall *et al.* 2007; Ochocka *et al.* 2002).

This review was limited to the literature from peer-reviewed journals published in English-language. A search of government policy and other sources may identify other forms of participatory consumer research taking place. It was beyond the scope of this review to include research by consumer advocacy groups and organisations that were not published in the academic literature or studies that were based on secondary data. A more comprehensive review may identify consumer-led research on physical health care integration that is not published in the peer-reviewed literature.

CONCLUSION

Health care reform to improve physical health and management of physical illness of people with mental illness is developing throughout the world. This review found that PMHCR as described in the peer-reviewed literature is a new phenomenon. Findings to date show PMHCR to be feasible, and to provide clarity and context to research investigating physical health care for people with mental illness. Nurses are well-placed to both facilitate inclusion of consumers on research teams, and to translate consumer-informed findings into practice. Stakeholders should pay much more attention to PMHCR, such as the studies highlighted in this review, in endeavours to improve physical health services in line with consumers' orientations and

needs, towards reduced inequities in service access, physical health and life expectancy.

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Table 1.

Summary of features of the studies reviewed: topic and authors, region, type of research, nature of mental health consumer involvement and outcomes.

Topic and authors	Region and country	Research participants	Type of research (as described by authors' of the study reviewed)	Nature of consumer involvement in the research	Outcomes
Problems of homelessness, mental illness and physical illness, and exploring Peer navigators as a physical health support strategy (Corrigan et al. 2015)	Chicago, USA	African Americans, in condition of homelessness, and classified as having mental illness (n = 42)	'community-based participatory research' (p. 119) Focus group interviews	All phases of the research over 12 months, e.g: -development of interview schedule, -decision to do focus groups - choice of stakeholders One co-leader in the research team	New understanding, based on 98 themes, of: -What competencies and approaches are needed by health navigators -Health problems experienced -Barriers to health care -Many pathways on how health care providers, government and local communities can meet physical health needs
Health and Wellness Photovoice Project (Cabassa et al. 2015)	New York, USA	Consumers with 'serious mental illness' (n = 16)	'community-based participatory research' (p. 618) Photovoice discussion group (qualitative).	Collaborative process of in-person discussion of physical health via Photovoice. No direct involvement in data analysis	Photovoice project demonstrated to be an effective means of conveying consumer viewpoints that respected consumer autonomy. New 'community based knowledge' (p. 619) on consumers' preferences and interests: -Prefer peers as major source of physical health support -Consumers want more practical advice and opportunities for physical activities and healthy eating.

Topic and authors	Region and country	Research subjects	Type of research (as described by authors' of the study reviewed)	Nature of consumer involvement in the research	Outcomes
Technology-supported Patient-GP communication on physical health matters (Pelletier et al. 2015)	Montreal, Canada	Consumers with 'serious mental illness' (n = 146)	'participatory action research design' Research and development groups. Questionnaire.	Oversight of research by Co-development of videos and questionnaire on physical illness and health. Peer-to-peer feedback on the new videos and questionnaire.	Establishment of a Consumer and GP friendly Interactive Guide for Medical Appointments (IGMA). IGMA a feasible and valuable platform for GP-consumer discussion of physical health issues. IGMA may potentially reduce diagnostic overshadowing by GPs.
Obstacles and facilitating processes to primary care access (Ross et al. 2015)	Ontario, Canada	Consumers with mental illness and/or substance use issue (n = 85) Health care providers (n = 17)	'qualitative, community-based participatory action research study' Semi-structured interviews.	Feedback on interview guide. Data analysis (coding data and revision of themes). Participation in other stages of study unclear.	New map of barriers to primary care: institutional arrangements, consumer-level factors and socio-economic issues. More depth of information on magnitude of barriers to primary health care. Better education of primary care providers on mental health and substance use.

Fig 1. Flow diagram of study selection process.

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