

## MENTAL HEALTH CONSUMER EXPERIENCES AND STRATEGIES WHEN SEEKING PHYSICAL HEALTH CARE: A FOCUS GROUP STUDY

STEPHANIE B. EWART, JULIA BOCKING, BRENDA  
HAPPELL, CHRIS PLATANIA-PHUNG, AND ROBERT  
STANTON

### Bibliographic citation

Ewart, S. B., Bocking, J., Happell, B., Platania-Phung, C., & Stanton, R. (2016). Mental Health Consumer Experiences and Strategies When Seeking Physical Health Care: A Focus Group Study. *Global Qualitative Nursing Research*, 3, 233339361663167. <https://doi.org/10.1177/2333393616631679>

Link to Published Version: <https://doi.org/10.1177/2333393616631679>

If you believe that this work infringes copyright, please provide details by email to [acquire-staff@cqu.edu.au](mailto:acquire-staff@cqu.edu.au)


### aCQUIRe CQU repository

This is an open access article under [Creative Commons](#) license.

Downloaded on 29/7/2022

Please do not remove this page

# Mental Health Consumer Experiences and Strategies When Seeking Physical Health Care: A Focus Group Study

Global Qualitative Nursing Research  
Volume 3: 1–10  
© The Author(s) 2016  
Reprints and permissions:  
sagepub.com/journalsPermissions.nav  
DOI: 10.1177/2333393616631679  
gqn.sagepub.com  


Stephanie B. Ewart<sup>1</sup>, Julia Bocking<sup>1</sup>, Brenda Happell<sup>1</sup>,  
Chris Platania-Phung<sup>1</sup>, and Robert Stanton<sup>2</sup>

## Abstract

People with mental illness have higher rates of physical health problems and consequently live significantly shorter lives. This issue is not yet viewed as a national health priority and research about mental health consumer views on accessing physical health care is lacking. The aim of this study is to explore the experience of mental health consumers in utilizing health services for physical health needs. Qualitative exploratory design was utilized. Semistructured focus groups were held with 31 consumer participants. Thematic analysis revealed that three main themes emerged: scarcity of physical health care, with problems accessing diagnosis, advice or treatment for physical health problems; disempowerment due to scarcity of physical health care; and tenuous empowerment describing survival resistance strategies utilized. Mental health consumers were concerned about physical health and the nonresponsive health system. A specialist physical health nurse consultant within mental health services should potentially redress this gap in health care provision.

## Keywords

consumer participation, health care access, mental health nursing, mental health services, physical health, stigma

Received December 10, 2015; revised December 16, 2015; accepted December 28, 2015

## Introduction

It is firmly established that people with mental illness endure higher rates of physical illnesses and shorter lives attributable to those illnesses (Colton & Manderscheid, 2006; Laursen, 2011; Laursen, Nordentoft, & Mortensen, 2014). A recent inquiry into mental health service data by Lawrence, Hancock, and Kisely (2013) confirmed the increased prevalence of a multitude of physical health problems and the reduced life expectancy for mental health consumers across a number of mental illness diagnoses. Yet, while these inequalities in physical health would suggest a high commitment to accessible and quality health services for people with mental illnesses, there are continual reports of major gaps in mental health services, inpatient and community, with respect to prevention, management, and treatment of common physical health illnesses (De Hert, Correll, et al., 2011; Lawrence & Kisely, 2010; Mitchell, Delaffon, Vancampfort, Correll, & De Hert, 2012). For instance, a recent review found that, with the exception of hypertension, cardiovascular-related risk screening is unreliable and inadequate (Baller, McGinty, Azrin, Juliano-Bult, & Daumit, 2015). This observation is staggering given the use of atypical antipsychotic medications as a first option for psychotic disorders. Atypical

antipsychotics are known to cause adverse metabolic consequences, for instance, second-generation antipsychotic agents are associated with greater occurrence of metabolic health problems (American Diabetes Association, 2004; Viron, Baggett, Hill, & Freudenreich, 2012).

## *Research on Mental Health Consumer Perspectives on Physical Health Care Services*

The views of health professionals, such as nurses, General Practitioners (GPs), and psychiatrists indicates the neglect or suboptimal quality care of the physical health of people with mental illness (Ehrlich et al., 2014; Hyland, Judd, Davidson, Jolley, & Hocking, 2003; Shefer, Henderson, Howard,

<sup>1</sup>Synergy: Nursing and Midwifery Research Centre, University of Canberra and ACT Health, Canberra, Australia

<sup>2</sup>Central Queensland University, Rockhampton, Queensland, Australia

### Corresponding Author:

Brenda Happell, Professor of Nursing, and Executive Director, Synergy, Nursing and Midwifery Research Centre, Faculty of Health, University of Canberra and ACT Health, Building 6, Level 3, Canberra Hospital, P.O. Box 11 WODEN 2606, Australia.  
Email: [brenda.happell@canberra.edu.au](mailto:brenda.happell@canberra.edu.au)



Murray, & Thornicroft, 2014; Wheeler et al., 2010). However, when it comes to the most important group in this health care context—mental health consumers—little research is available. Happell et al. (2012b) synthesized findings from the small number of studies which examined consumer perspectives on physical health care (in conjunction with literature on providers' views) to delineate what barriers consumers have experienced in accessing physical health services. The review showed that at all steps in care, mental health consumers faced multiple difficulties, including the trivialization of consumer questions about their physical health when it was known that they had a diagnosis of mental illness. These findings indicate more inquiry on consumer views is urgently required. There is a dearth of in-depth research which incorporates consumer perspectives.

Given the marked divergence between the established higher rates of physical health problems reported in population and health service studies, and the limited research attention to consumer perspectives on physical health, it is clear there is great need for further qualitative studies on consumer views on their physical health and related health services. These data are imperative to generate strategies for improvement. Qualitative research approaches provide an opportunity for detailed exploration of opinions and experiences, as opposed to responding to predetermined questions, and is the best option when little is known about a phenomenon. Furthermore, consumer views on how to work toward more accessible and effective physical health care system would meet the principles of inclusion, recovery, and consumer-oriented services, which is the mainstay of all mental health policy statements (Commonwealth of Australia, 2009, 2013; World Health Organization, 2013).

### *Study Background, Aims, and Questions*

The research with consumers in the Australian Capital Territory (ACT), Australia was undertaken to enhance our understanding of the experience of physical health care from a consumer perspective and to address the identified paucity. The aim was to present the findings drawn from consumer experiences with physical health care systems. There was an emphasis on the actual interpersonal interactions between consumers and providers.

## **Method**

### *Design*

An exploratory qualitative design to the research was adopted to be open to the diverse perspectives of mental health consumers. Qualitative exploratory research is particularly valuable for areas where the research is limited (Stebbins, 2001). The focus group format to data collection was chosen to identify areas of importance and concern for mental health consumers in relation to physical health care.

### *Participants and Setting*

The ACT Mental Health Consumers Network (ACTMHCN) is the consumer peak body and systemic advocacy organization in the ACT. The ACTMHCN furthers the rights of mental health consumers, in line with human rights and social justice principles, in a range of fora (including policy). The ACTMHCN was ideally placed to assist with this study in two ways; the aim was congruent with their purpose and had access to a membership list to invite as participants.

The ACTMHCN agreed to assist in the recruitment process by way of an advertisement in the weekly bulletin for members, as well as offer an accessible venue suitable for conducting the four planned focus group sessions. This location was ideal as member knowledge of it was high and was relatively convenient to access, both in terms of public transport and physical accessibility.

Interested people were asked to contact the ACTMHCN and were sent a Participant Information Form, providing an overview of the research, and consent form as well as four choices of focus group times. The ACTMHCN maintained records of participants for each focus group and sent final details of the date, time and location of focus groups for interviews to each participant.

The ACTMHCN specifies that members who take part in research are reimbursed in a fair manner to recognize consumer expertise, and this was honored in this study. The approved rate of Aus\$70 was paid to those who attended the focus group.

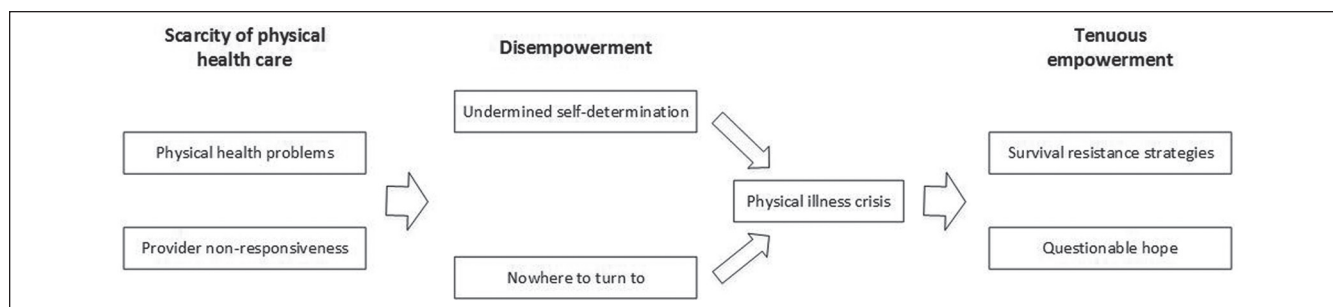
### *Ethical Considerations*

Approval for the conduct of the present study was granted by the University Human Research Ethics Committee. All participants were informed of the voluntary nature of the research and their participation (or nonparticipation) would not affect their health services. All participants provided written consent to participate prior to data collection.

The consumer sector in the ACT is relatively small, proportionate to the size of the jurisdiction. To maximize confidentiality, no names or other identifiers were recorded in the audio file or on the interview transcripts. The interviewers introduced the study in person and asked participants whether they had any questions. The importance of maintaining confidentiality of other participants, by not sharing their views outside of the focus group setting, was expressed at the commencement of the interview.

### *Data Collection*

The focus groups took place in June 2015. Focus group size varied from seven to nine participants. In total, there were 31 participants. Focus group duration ranged from 90 to 150 minutes. Interviews were audiotaped with consent of the participants. Participants were asked for their thoughts on their



**Figure 1.** Thematic structure of research findings.

Note. The main themes are scarcity of physical health care, disempowerment, and tenuous empowerment. Subthemes are presented below each heading.

physical health and their perspective of seeking, using, and forming relationships with related services. The interviewers allowed fluid and open discussion during the sessions.

Two experienced interviewers, both holding postgraduate qualifications in research, were involved in all four focus groups: One was a mental health nursing senior academic and the other a consumer researcher with a strong commitment to physical health advocacy for consumers of mental health services. This design demonstrates commitment to an authentic coproduced research process, as well as facilitating a more open discussion during focus groups. Consumers may feel more comfortable expressing their views and experiences in the presence of a consumer researcher, rather than to a health professional alone.

The research questions guiding the focus group component were as follows:

**Research Question 1:** What sorts of experiences do mental health consumers have interpersonally with providers, such as primary care and mental health services?

**Research Question 2:** How do consumers think about and relate to the services?

**Research Question 3:** How well do services meet consumer needs regarding physical health care, such as assessment and advice?

**Research Question 4:** Do mental health consumers find physical health care providers helpful in addressing physical needs?

Data saturation was evident in the third interview, in which no new themes were emerging. The scheduled fourth focus group was conducted to enhance the depth of the information collected.

### Data Analysis

The data were transcribed by an independent service. It was then thematically analyzed, consistent with the approach articulated by Braun and Clarke (2006). Transcripts were repeatedly read and coded in detail by one of the interviewers. Coding was then conducted using NVivo10. Common

sets of coding derived from inductive analysis were then condensed into a thematic framework. These themes were then discussed by three members of the research team and refined to ensure accuracy and reflect the consensus view. All researchers then discussed differences in interpretation which led to slight revisions to the thematic structure.

### Findings

This section describes the mental health consumer perspective of interpersonal interactions with physical health care providers. The experiences were primarily negative. Figure 1 presents the main themes, subthemes, and overall thematic structure regarding immediate consumer–provider relationships. In summary, there was *scarcity of physical health care*, characterized by *physical health problems* and *provider non-responsiveness* to those problems. For consumers, scarcity led to *disempowerment* that included the *undermining of consumer self-determination*, a sense of *nowhere to turn to*, and over time, *worsening physical illness* and *worsening mental illness* that could, and did, translate into *physical health crises*.

In response, many consumers adopted what may be described as *tenuous empowerment*, wherein *survival strategies* were developed and instigated despite ongoing negative interactions with service providers. In reflecting on prior negative encounters and the future, participants were hopeful of better quality health care, including respectful, holistic, and trust-building partnerships with providers. That said, participants wondered whether positive developments would materialize, given they had been let down by health care systems over an extended time frame. This theme will be described as *questionable hope*. In the following sections, the themes are further explored and referenced by focus group number (e.g., FG3). The thematic structure is presented in Figure 1.

### Scarcity of Physical Health Care

The first main theme was perceived scarcity of physical health care. This was characterized by a divide between the

consumer's normative physical health needs and a marked shortage of responsive physical health care services.

### *Physical Health Problems*

Participants described multiple physical health problems. For example, a participant in his early 30s reflected on his state of health and the challenges that lay ahead, in terms of both the power to bring about change through self-agency, and for support in the changes:

Now put on this weight . . . I get so paranoid . . . about heart conditions at 31 . . . I'm sorry, but I'm screwed, my body is broken and it will take a significant amount of bloody [sic] willpower to get me back to a point where I'm not sick, fat and nearly dead . . . [second participant joining discussion] the trouble is that it will need more than just your willpower, that's what we're talking about, we need a lot of support . . . (FG4)

### *Provider Nonresponsiveness*

Participants raised major systemic problems with the interface between mental health and physical health services. Troubling stories of the lengths that consumers go to for barely minimal standard physical health care were shared. Participants recounted that on the fortuitous instances where access to physical health services was gained, the diagnosis of "mental illness" was a major barrier to providers. This was particularly evident in the providers' communication with consumers about physical health issues, particularly in domains requiring self-monitoring, such as health education. Mental health issues appeared to occlude any notion that consumers may need diagnosis, support, and treatment regarding their physical health. A clinical diagnosis of mental illness is highly likely to adversely affect how the provider related to the consumer. Conversely, some physical health providers attempted to focus the consultation on delivering mental health treatment. Consumers sought a holistic approach to address both physical and mental health aspects, with a view to improving their overall health.

If you present not as a mental health consumer with observable, I suppose, physical issues that will be looked at first . . . We need to get you on a diet . . . We need to get you on that plan and come back next week and we'll talk about it further. But as a mental health consumer it's first—"how's your mental health? Are you okay? Stick to these drugs, you'll be fine. We'll put it up a little bit; you'll feel better about yourself." Except for the fact that your health is deteriorating and especially physically, making it harder and harder to do what you want to do, whatever that may be. (FG2)

### *Disempowerment*

A common experience for consumers was disempowerment. This arose from negative experiences of help seeking, such as their physical health concerns being dismissed.

### *Undermined Self-Determination*

Undermined agency was described in several forms, such as reduced physical and mental health aspects that are a source of personal power and self-determination.

. . . you go to a dietician, you say what will really help my mental health and physical health is to become a vegan—they start helping you with that. Next appointment they say, well, we received your medical records. We see that you have a history of an eating disorder. We have now decided that you don't know what you want and in fact you are trying to undermine your own recovery by becoming a vegan or whatever. And it just all goes backwards from there. They refer you back to mental health and say—or they'll something like would you like to be referred to the eating disorders unit at . . . ? No. Actually, I'm here because I have made an informed choice, involving self-determination that I know will benefit both my mental and physical health and you've just told me that it won't. That's so disheartening. That's so disempowering . . . (FG2)

While being open to the specialized knowledge of experts, it was pointed out that ultimately the person is the most knowledgeable about themselves. The balance of power between consumer and provider in the health care interaction ideally should reflect this:

. . . I feel like there needs to be a shift in power. So instead of me going to the expert and being told what to do, and me thinking that's going to cure myself. I want to be—I know myself better than anyone does . . . (FG1)

### *Nowhere to Turn to*

These types of adverse experiences created an associated sense of "nowhere to turn to." This was not restricted to the traditional aspects of a physical health care consultation, such as getting one's heart checked. It was also critically important on issues where there appeared to be no general pathways for support and advice, such as health promotion:

. . . if you imagine there's been a food group that you've been avoiding your whole life that will eventually have an effect on your overall health, which may well express as mental health. I have nowhere to go with that at the moment. (FG2)

Some also shared an experience of a dawning realization that one was truly isolated, literally and figuratively, and thus "really on one's own":

I reached a point where I was like, there is no one else looking out for me right now, except me. (FG1)

The consumer sense of extreme isolation was strongly connected with a range of negative feelings and distress. Anger, fear, frustration, hopelessness, and "being upset" were reported as negative emotions experienced as a direct result of interpersonal interactions with providers.



When I think about the situation a year ago, I feel I can cry still. How badly I was treated. (FG3)

There were also expressions of a sense of hopelessness:

... if I had bad GP and bad psychiatrist I am not good. They're really bad because they bring you to the brink, yes. You feel hopelessness; you don't know what to do. (FG3)

### **Worse Mental Health**

A worsening in mental health symptoms was viewed as one outcome of nowhere to turn to and undermined self-determination. The lack of access to basic physical health services resulted in the continuation of physical health problems, which in turn affected the mental state:

... definitely medical issues can become mental health issues, particularly if it goes untreated. (FG2)

In some cases, the unsuccessful attempts to get direction on addressing and/or preventing physical health issues was itself a source of harm to one's mental well-being:

... one of the things I have PTSD from is slander and trying to get decent, f\*\*\*\*ng medical advice. (FG2)

### **Worse Physical Health**

Some participants anticipated declines in physical health related to two factors: first, as a result of not gaining the needed physical health care services, and second, mental health services themselves taking clinical approaches that had physical health implications, such as use of certain medications (e.g., atypical antipsychotics). For instance, a participant experiencing weight gain after being treated with antipsychotic medication considered the gloomy future which lay ahead, with respect to accumulating physical health and other health problems:

... my physical health, that if it's not put in check, if we times this by 10 years, and aggravated effects, I'll be in a very interesting spot where I've got my mental health going on and I've also got drastic physical and wellbeing issues. (FG2)

There were also numerous occasions when experiences of having physical health symptoms disregarded unsurprisingly led to not seeking further physical health care. As a result, consumers expressed concerns about this leading to declines in physical health due to not receiving the treatment needed. The following participant recounted being highly selective of a GP after not getting help in a hospital emergency department for flu-related breathing problems after a practitioner had cited medical records of being previously diagnosed with depression:

Yeah, when that happened to me at the hospital ... I got worse after that, but I wouldn't go back there, I waited to go to my GP because ... I didn't want to get put—classified as a psych patient and be denied—I was denied medical treatment to help me breathe and it was really a serious situation. (FG4)

### **Physical Illness Crises**

Deterioration of mental and physical health was also described as leading to crises of physical illness. Some participants commented that declines in their physical health status led to a crisis point, and it was only in this circumstance that responsiveness from physical health care providers would emerge.

... reaching a crisis point [laughs] that's how it works. It works backwards. You go to the crisis, and then you get the help. And you don't get the help if you present without a crisis. (FG1)

One participant argued that this was due to the particular approach that health care organizations take, where interventions would only be provided if the physical health problems were perceived as serious:

And this is the whole how the system can actually make things worse for people with—around physical health because they don't respond because they ... won't come out to you unless they think you've reached a certain threshold that's visible to them. (FG4)

### **Tenuous Empowerment**

While health care services should embrace the self-determination of consumers, actions by consumers suggest self-determination was not supported and often were to counter, nonresponsiveness of providers and the broader scarcity of physical health care. This is described here as the theme of "tenuous empowerment," where consumers actively sought to improve their health, but this act became a negative experience due to these initiatives not only being unsupported by health care providers but actually misconstrued as a symptom of mental illness:

... with nutrition it's something you can study yourself ... you can, and I have done ... But if you then try and incorporate your knowledge into yourself care you'll say, oh, no, you're crazy and they'll actually use your efforts towards care as indication of greater illness. (FG2)

Identifying an individual provider who would listen, or at least provide reasonable follow up with a diagnosis, screening or further discussion was imperative. If successful in the search for such a provider (given the barriers to accessing physical health care), the provider was seen as a precious relationship to never let go of and as one to be quite fortunate to have:

... they need to believe the client. You're not making things up and they can check for themselves and see, you know. If I find a good doctor, I hang onto them. (FG3)

### *Survival Strategies*

Consumers were forced to use numerous survival strategies to improve their health care access and subsequent clinical outcomes, despite significant provider nonresponsiveness. These were deliberate actions to receive services from a seemingly impenetrable system. For some, this was an exhaustive process to see what worked best:

I've tried every different tactic. (FG2)

Survival strategies including considerable preparation for the interpersonal interaction with providers through prior information-seeking:

I actually Google symptoms. So I have the right language to use when with the doctor. That's one the strategies that I use. (FG1)

Consumers revised how they spoke to health care providers, being mindful there was a tight time frame during clinical encounters. The following quote illustrates how this revision was a major undertaking, especially as the consumer acted in total isolation:

... they've got this 10-minute window where they can see you in bulk-billing capacity, therefore ... you've got to condense everything down into that period of time, and then they've got to write down whatever, and give you a script, and send you on your merry way. But having a doctor actually sit and listen to you and say, "Okay. Well, all right I'll check your blood pressure," or, "I'll check your stomach," and whatever parts of your body that are causing problems, and actually be more interested in your actual health. So it's taken me a long time to have the courage to say, "Well, hang on a minute. I need help with this. Can you refer me to these other services?" So having ... the knowledge of what's happening, and being able to convey that to the medical professionals, and say, "Well, this is what's helping, and this is what's not helping." So that's been a big challenge for me to do. I've had to learn that for myself. (FG1)

Such tactics are briefly touched on here. For example, given providers were taken to dismiss physical illness concerns when seeing the consumer as a mental health person it was therefore advisable to keep certain details to oneself:

You just don't tell them. (FG2)

Consumers regularly raised a "set" of strategies in which efforts would be on making a consultation as helpful as possible, despite the known barriers. If an attentive provider was found in the midst of a largely inaccessible physical health care system, consumers felt extremely fortunate:

I'm lucky just to have really good doctor and it's good. (FG3)

Questioning providers, in particular, General Practitioners, by not taking their decisions and instructions as "gospel" and being more assertive about what was needed were strategies that consumers regularly raised. This confrontation was seen as requiring both courage and interpersonal skills:

Well doctors aren't gods and you should question them and if you find a good doctor, hang on to them, and the other ones I think you should report them, report them ... Yeah, I reported them, there was an investigation. (FG3)

The development and trialing of strategies, particularly in relation to finding an appropriate health care provider, was viewed by consumers as a journey of empowerment:

... it comes back to empowerment—it's knowing the system, what's available and using the right words to get. (FG1)

The actual search for a suitable practitioner was a difficult process. When successful, it was described as an empowering experience.

... then some of the doctors—it's a very frustrating experience. So I had to learn how to choose to see another doctor, if I wasn't—so there's that sense of empowerment ... (FG1)

During the focus groups, where references to empowerment were being expressed, it was apparent that participants rarely had the opportunity to share their experiences of each other's experiences and interactions with the physical health care system. This led to consumers swapping names of good practitioners and willingly sharing knowledge of consumer-centric physical health services in the area.

### *Questionable Hope*

Participants expressed hope for a better physical health care context in the future but verbalized understandable pessimism given their negative experiences thus far. There was minimal expectation of improvement in the near future, despite the strong conviction of urgency that substantial physical health needs were not being addressed through the current orientation of health services. Participants instead contemplated positive change occurring over a longer period, such as a decade. Participants hoped future access would be more equitable through a more transparent responsive physical health care sector:

I think in 20 years' time it's going to be a different conversation, I hope. Which will make it a lot easier to ask for help, and be referred to help, and not feel like you desperately have to find the language and find the manipulation to see the doctors ... maybe it's the worst point now, maybe it's just going to get better. I don't know. (FG1)

This included discussion about having one role person who can provide clarity in communication and redressing the persistent diagnostic overshadowing that inhibited access:

It's just so that you can get somebody whose job it is to address the backlog of health issues that have built up and to get one concise opinion, and it isn't clouded by all the mental health nonsense that's following you around. (FG2)

Participants felt that the way forward to improve consumer health outcomes was the need to (re)build the traditional definition of community. The shared commonalities between people, including shared needs, must be revisited and may assist in countering the marginalization experienced by consumers. That is, there was hope of improved services as part of a larger picture where the broader society recognized commonalities across people, as opposed to immediately anthologizing them:

Yeah, that focus, so the general community goes, "Oh, they're living with that. They're decent people." Okay. And it's changing back to that community focus. We're all part of the community, we all live, eat, breathe, you know, the whole kit and caboodle, don't ostracise, reintegrate, which is what [other participant] was saying. That is what I think we need to become in the future. (FG1)

## Discussion

The physical health of mental health consumers is fundamental to the primary purpose of health services. Knowledge and understanding of consumer perspectives regarding service access and performance is vital, especially given the known service gaps within mental health and physical health services. In the present study, consumers expressed significant concerns regarding the number and severity of their physical health problems, a consensus which is echoed in the clinical and epidemiological literature reporting the poor physical health of people with mental illness (Colton & Manderscheid, 2006; Lawrence et al., 2013). Yet, instead of physical health problems being diagnosed and follow-up collaborative relations between provider and consumer ensuing, there were experiences of disempowerment and sense of isolation (nowhere to turn to) and sometimes (re)-traumatization from the health care system. These manifested in worsening mental health, ensuing physical health issues, and in some cases, physical health crises.

There was a scarcity of truly accessible physical health care. While difficulties in gaining physical health care is acknowledged in the research literature mainly around systemic barriers such as cost of care (De Hert, Cohen, et al., 2011; Happell, Scott, & Platania-Phung, 2012b) and are important to address, the current findings highlight how negative interpersonal experiences with providers are disempowering for mental health consumers and how many are forced to respond to this to seek basic physical health care services.

While participants mentioned some success in access to physical health care, it was always a challenge to find and sustain. This was primarily due to the difficulty attached to escaping inappropriate health provider judgments once a "mental health" diagnosis was noted by a provider. This adversely affected how the provider then related to consumers. These findings may be partly explained by the phenomenon called "diagnostic overshadowing." Diagnostic overshadowing has been defined as "a process by which physical symptoms are misattributed to mental illness" (Jones, Howard, & Thornicroft, 2008, p. 169).

Research on consumer and health professionals' views has found numerous cases of diagnostic overshadowing (Happell et al., 2012b; Shefer et al., 2014). The current findings confirm the occurrence of diagnostic overshadowing. It relates to what one participant put as "mental health nonsense following you around"; in this case, the "shadow" of diagnosis is what follows them. It should be noted here that this type of problem was never raised in any questions of the focus group interviewers, but emerged repeatedly in participant responses.

This article brings to light the major *impacts* of this problematic form of provider practice on mental health consumers' lives, not just in deteriorating mental and physical health but negative feelings and general disempowerment: ironically, empowerment in an effort for survival when the health care system is letting one down.

It must be noted that the ACT is one of two Australian jurisdictions with a Human Rights Act (Australian Capital Territory Government, 2004). The "right to health" is enshrined in this legislation. The difficulties articulated in this study may be considered a breach of the Act. The interpersonal aspect of the clinical encounter can negatively affect both the mental and physical health of mental health consumers. This is an important finding as it suggests that the harms of services is not restricted to the growing physical health problems that follow use of psychiatric drugs (Alvarez-Jimenez et al., 2008).

It was clear from many consumer stories that it was necessary to go to considerable lengths to gain help (captured by the theme of survival strategies). Providers who did listen and were action-focused (e.g., referrals, discussion of pathways to better health, good quality information and advice) were cherished, fortunate to have, and a rare experience of trust in an unwelcoming health care system. Consumers felt that they needed to tailor themselves to the health services to get physical health care and long journeys of finding that one provider who would treat them as a person. Although the search for effective physical health care and associated access barriers was mentioned previously (Chadwick, Street, McAndrew, & Deacon, 2012; Decoux, 2005; Schmutte et al., 2009), the current findings highlight the theme: "survival strategies." Consumers undertook exhaustive and diverse approaches to counter physical health care scarcity characterized by nonresponsiveness of individual providers.



Participants held questionable hope of gaining more accessible physical health services in the future, and that others will do so in the decades to come. There is a limited public profile of the high prevalence of physical health issues among the Australian mental health consumer population. Efforts to create corresponding strategies to redress the issue have historically been ad hoc, fragmented, and minimal (Happell et al., 2015). It is well founded that mental health consumers in this study held questionable hope for improvement in the future.

It is typically stated in mental health services literature that people with mental illness are difficult to engage, educate, and orient to be more concerned and more proactive with respect to their physical health. In contrast, literature on physical illness and mental illness indicates that consumers are greatly interested in their physical health and ways to protect and promote their well-being (Scott & Happell, 2011).

As is quite clear from the discussion thus far, the findings of this article also challenge common assumptions: Consumers were greatly concerned about physical health problems, and had to go to extraordinary (unreasonable and unjust) lengths to strategies how they interact with individual providers to be even taken seriously about their concerns. We reiterate that these consumer strategies were a matter of *survival*, as seeking health care was to address life-threatening physical health problems and countering provider reluctance to acknowledge them.

### Limitations

Given the small sample size of this study, and that participants were from the same, small jurisdiction, there are limitations to the generalizability of the findings. However, as noted earlier, the current findings are highly consistent with major barriers encountered by mental health consumers in other parts of the world (Borba et al., 2012; Lester, Tritter, & Sorohan, 2005; Miller, Lasser, & Becker, 2007).

Further research on consumer experiences and outcomes is needed to see whether the processes identified in the present study, such as disempowerment and tenuous empowerment, are evident in other settings. In addition, more in-depth case studies with individual mental health consumers may help illuminate whether the processes outlined in the thematic structure (Figure 1) may be a common consumer “journey.”

### Implications

The overall findings have major implications for the ongoing debates about how to improve health services. The stark inequalities between people with and without mental illness, in service access, quality, and overall health outcomes, must be at least partially addressed. Participants emphasized how much they valued and embraced strong partnerships with a

health provider that was responsive and helpful in an environment of scarcity of physical health services. This relationship was particularly coveted if it could support both their physical and mental health needs. The discipline of nursing greatly values ideals of holism, trust, and consumer-centered approaches (understanding consumer’s perspectives and life situations; Shanley, Jubb, & Latter, 2003).

Nurses, therefore, play a crucial role in providing the kinds of physical health services that consumers desperately seek. A specialist nursing role should be explored further to progress improved physical health care within mental health services (Brunero & Lamont, 2009; Happell, Stanton, & Scott, 2014; McKenna et al., 2014). The physical nurse consultant’s role could potentially facilitate collaborative physical health care for mental health consumers, including acting as a “go-to” person for providers, consumers, and carers on matters of physical health. This is not limited to assessment and referral, but can extend to other areas such as health education, and ensuring that treatments are implemented correctly (Happell, Scott, & Platania-Phung, 2012a).

The present study provides further evidence to demonstrate how such a nurse specialist role would be valuable. It could act as a conduit between mental health services and the primary health sector to address the significant nonresponsiveness of mental health services to mental health consumer physical health concerns and needs. This role could also take steps to ensure that diagnostic overshadowing is minimized through providing training and ongoing consultation services. Physical health nurse consultants embedded in public mental health services may play a crucial role in eliminating current health practice mistakes where physical health problems (and help seeking) are viewed as symptoms of mental illness.

### Conclusion

This article demonstrates that many of the major challenges faced by mental health consumers in terms of physical health access are due to nonresponsive health care providers. This issue can lead to disempowerment, worsening mental and physical illness, and concerted efforts by consumers to attain basic physical health care. The findings indicate that major changes are needed to how physical health care providers relate to consumers. Approaches to redress the disparity in access could include improved provider awareness, skill development, and related practices. A novel approach worthy of consideration is the exploration of nurses specialized in mental and physical health care integration in a collaborative care arrangement. New ideas are needed to progress toward more effective and equitable physical health care and subsequent health outcomes.

### Acknowledgments

The research team extends sincere thanks to the ACT Mental Health Consumer Network for facilitating this research through access to participants, organizing the focus groups, providing the venue and

fantastic catering, and for being generally wonderful. The authors also thank the participants for their generosity and openness in sharing their views.

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

### References

- Alvarez-Jimenez, M., Gonzalez-Blanch, C., Crespo-Facorro, B., Hetrick, S., Rodriguez-Sanchez, J. M., Perez-Iglesias, R., & Vazquez-Barquero, J. L. (2008). Antipsychotic-induced weight gain in chronic and first-episode psychotic disorders: A systematic critical reappraisal. *CNS Drugs*, 22, 547–562.
- American Diabetes Association. (2004). Consensus development conference on antipsychotic drugs and obesity and diabetes. *Diabetes Care*, 27, 596–601.
- Australian Capital Territory Government. (2004). *Human Rights Act*. Canberra: Author.
- Baller, J. B., McGinty, E. E., Azrin, S. T., Juliano-Bult, D., & Daumit, G. L. (2015). Screening for cardiovascular risk factors in adults with serious mental illness: A review of the evidence. *BMC Psychiatry*, 15, Article 55.
- Borba, C. P., DePadilla, L., McCarty, F. A., von Esenwein, S. A., Druss, B. G., & Sterk, C. E. (2012). A qualitative study examining the perceived barriers and facilitators to medical healthcare services among women with a serious mental illness. *Women's Health Issues*, 22, e217–e224. doi:10.1016/j.whi.2011.10.001
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101.
- Brunero, S., & Lamont, S. (2009). Systematic screening for metabolic syndrome in consumers with severe mental illness. *International Journal of Mental Health Nursing*, 18, 144–150.
- Chadwick, A., Street, C., McAndrew, S., & Deacon, M. (2012). Minding our own bodies: Reviewing the literature regarding the perceptions of service users diagnosed with serious mental illness on barriers to accessing physical health care. *International Journal of Mental Health Nursing*, 21, 211–219. doi:10.1111/j.1447-0349.2011.00807.x
- Colton, C., & Manderscheid, R. (2006). Congruencies in increased mortality rates, years of potential life lost, and causes of death among public mental health clients in eight states. *Preventing Chronic Disease*, 3(2), 1–14.
- Commonwealth of Australia. (2009). *Fourth National Mental Health Plan: An agenda for collaborative government action in mental health 2009-2014*. Canberra: Author.
- Commonwealth of Australia. (2013). *A national framework for recovery-oriented mental health services: Policy and theory*. Australian Health Ministers' Advisory Council. Canberra: Author.
- Decoux, M. (2005). Acute versus primary care: The health care decision making process for individuals with severe mental illness. *Issues in Mental Health Nursing*, 26, 935–951. doi:10.1080/01612840500248221
- De Hert, M., Cohen, D., Bobes, J., Cetkovich-Bakmas, M., Leucht, S., Ndeti, D. M., . . . Correll, C. U. (2011). Physical illness in patients with severe mental disorders. II. Barriers to care, monitoring and treatment guidelines, plus recommendations at the system and individual level. *World Psychiatry*, 10, 138–151.
- De Hert, M., Correll, C. U., Bobes, J., Cetkovich-Bakmas, M., Cohen, D., Asai, I., . . . Leucht, S. (2011). Physical illness in patients with severe mental disorders: I. Prevalence, impact of medications and disparities in health care. *World Psychiatry*, 10, 52–77.
- Ehrlich, C., Kendall, E., Frey, N., Kisely, S., Crowe, E., & Crompton, D. (2014). Improving the physical health of people with severe mental illness: Boundaries of care provision. *International Journal of Mental Health Nursing*, 23, 243–251. doi:10.1111/inm.12050
- Happell, B., Platania-Phung, C., Webster, S., McKenna, B., Millar, F., Stanton, R., . . . Scott, D. (2015). Applying the World Health Organization Mental Health Action Plan to evaluate policy on addressing co-occurrence of physical and mental illnesses in Australia. *Australian Health Review*, 39, 370–378. doi:10.1071/AH14098
- Happell, B., Scott, D., & Platania-Phung, C. (2012a). Nurse views on the cardiometabolic health nurse as an approach to improving the physical health of people with serious mental illness in Australia. *International Journal of Mental Health Nursing*, 22, 418–429. doi:10.1111/j.1447-0349.2012.00892.x
- Happell, B., Scott, D., & Platani-Phung, C. (2012b). Perceptions of barriers to physical health care for people with serious mental illness: A review of the international literature. *Issues in Mental Health Nursing*, 33, 752–761.
- Happell, B., Stanton, R., & Scott, D. (2014). Utilization of a cardiometabolic health nurse—A novel strategy to manage comorbid physical and mental illness. *Journal of Comorbidity*, 4, 22–28.
- Hyland, B., Judd, F., Davidson, S., Jolley, D., & Hocking, B. (2003). Case managers' attitudes to the physical health of their patients. *Australian and New Zealand Journal of Psychiatry*, 37, 710–714.
- Jones, S., Howard, L., & Thornicroft, G. (2008). "Diagnostic overshadowing": Worse physical health care for people with mental illness. *Acta Psychiatrica Scandinavica*, 118, 169–171. doi:10.1111/j.1600-0447.2008.01211.x
- Laursen, T. M. (2011). Life expectancy among persons with schizophrenia or bipolar affective disorder. *Schizophrenia Research*, 131, 101–104.
- Laursen, T. M., Nordentoft, M., & Mortensen, P. B. (2014). Excess early mortality in schizophrenia. *Annual Review of Clinical Psychology*, 10, 425–448. doi:10.1146/annurev-clinpsy-032813-153657
- Lawrence, D., Hancock, K. J., & Kisely, S. (2013). The gap in life expectancy from preventable physical illness in psychiatric patients in Western Australia: Retrospective analysis of population based registers. *British Medical Journal*, 346, Article 2539. doi:10.1136/bmj.f2539
- Lawrence, D., & Kisely, S. (2010). Review: Inequalities in health-care provision for people with severe mental illness. *Journal of Psychopharmacology*, 24(S4), 61–68.
- Lester, H., Tritter, J. Q., & Sorohan, H. (2005). Patients' and health professionals' views on primary care for people with serious mental illness: Focus group study. *British Medical Journal*, 330, Article 1122. doi:10.1136/bmj.38440.418426.8F

- McKenna, B., Furness, T., Wallace, E., Happell, B., Stanton, R., Platania-Phung, C., . . . Castle, D. (2014). The effectiveness of specialist roles in mental health metabolic monitoring: A retrospective cross-sectional comparison study. *BMC Psychiatry*, 14, Article 234.
- Miller, E., Lasser, K. E., & Becker, A. E. (2007). Breast and cervical cancer screening for women with mental illness: Patient and provider perspectives on improving linkages between primary care and mental health. *Archives of Women's Mental Health*, 10, 189–197. doi:10.1007/s00737-007-0198-4
- Mitchell, A. J., Delaffon, V., Vancampfort, D., Correll, C. U., & De Hert, M. (2012). Guideline concordant monitoring of metabolic risk in people treated with antipsychotic medication: Systematic review and meta-analysis of screening practices. *Psychological Medicine*, 42, 125–147. doi:10.1017/S003329171100105X
- Schmutte, T., Flanagan, E., Bedregal, L., Ridgway, P., Sells, D., Styron, T., & Davidson, L. (2009). Self-efficacy and self-care: Missing ingredients in health and healthcare among adults with serious mental illnesses. *Psychiatric Quarterly*, 80, 1–8.
- Scott, D., & Happell, B. (2011). The high prevalence of poor physical health and unhealthy lifestyle behaviours in individuals with severe mental illness. *Issues in Mental Health Nursing*, 32, 589–597. doi:10.3109/01612840.2011.569846
- Shanley, E., Jubb, M., & Latter, P. (2003). Partnership in coping: An Australian system of mental health nursing. *Journal of Psychiatric and Mental Health Nursing*, 10, 431–441.
- Shefer, G., Henderson, C., Howard, L. M., Murray, J., & Thornicroft, G. (2014). Diagnostic overshadowing and other challenges involved in the diagnostic process of patients with mental illness who present in emergency departments with physical symptoms—A qualitative study. *PLoS ONE*, 9(11), e111682. doi:10.1371/journal.pone.0111682
- Stebbins, R. (2001). *Exploratory research in the social sciences: Qualitative research methods* (Vol. 48). London: SAGE.
- Viron, M., Baggett, T., Hill, M., & Freudenreich, O. (2012). Schizophrenia for primary care providers: How to contribute to the care of a vulnerable patient population. *The American Journal of Medicine*, 125, 223–230. doi:10.1016/j.amjmed.2011.05.002
- Wheeler, A., Harrison, J., Mohini, P., Nardan, J., Tsai, A., & Tsai, E. (2010). Cardiovascular risk assessment and management in mental health clients: Whose role is it anyway? *Community Mental Health Journal*, 46, 531–539.
- World Health Organization. (2013). *Mental Health Action Plan 2013–2020* (Department of Mental Health and Substance Abuse, Ed.). Geneva: Author.

### Author Biographies

**Stephanie B. Ewart**, BSW (Hons), B.Bus, Grad Dip Adult Ed, is a mental health service user researcher and PhD candidate at the Synergy Nursing and Midwifery Research Centre, University of Canberra. She is based in Sydney, New South Wales, in Australia.

**Julia Bocking**, B Phil (Hons), is a Consumer Academic at the Synergy Nursing and Midwifery Research Centre, University of Canberra and ACT Health. She is currently completing a PhD (Public Health) examining Government mental health peer worker roles in Australia.

**Brenda Happell**, RN, BA (Hons), Dip Ed., PhD, is Professor of Nursing and Executive Director at Synergy Nursing and Midwifery Research Centre, University of Canberra and ACT Health

**Chris Platania-Phung**, PhD, is a research fellow at Synergy Nursing and Midwifery Research Centre, University of Canberra and ACT Health. He is based in Melbourne, Victoria, in Australia.

**Robert Stanton**, PhD, is an Adjunct Associate Professor with Synergy, Nursing and Midwifery Research Centre, Faculty of Health, University of Canberra, and Lecturer in Exercise and Sports Sciences, CQUniversity, Rockhampton, Australia.