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**FILLING THE GAPS AND FINDING OUR WAY: FAMILY CARERS NAVIGATING THE HEALTH CARE SYSTEM TO ACCESS PHYSICAL HEALTH SERVICES FOR THE PEOPLE THEY CARE FOR**

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**FILLING THE GAPS AND FINDING OUR WAY: FAMILY CARERS NAVIGATING THE HEALTH CARE SYSTEM TO ACCESS PHYSICAL HEALTH SERVICES FOR THE PEOPLE THEY CARE FOR**

**ABSTRACT**

**Aims and Objectives:** To elicit the *perspectives of carers of people with mental illness regarding access to, and experience with, physical health care services for mental health consumers.*

**Background:** People diagnosed with mental illness have increased risks of physical illness and earlier death, problems able to be addressed through better physical health services. Carers of people with mental illness play a significant role in the mental health care system yet research examining their views is lacking.

**Design:** Qualitative exploratory

**Methods:** Indepth interviews were conducted with 13 mental health carers. They were asked to describe their views and experiences pertaining to the physical health and availability of physical health care for of the people they care for. Data were analysed using the framework of Braun and Clarke.

**Results:** Analysis of carer responses identified two important themes: responsiveness and access, and a shortage of care co-ordination. Carers felt alienated from physical health care providers and were compelled to fill gaps in available care through persistence in ensuring access to physical health care services.

**Conclusions:** The findings identify carers as key stakeholders in the physical health care of the people they care for. Their involvement in accessing and co-ordinating care provides vital perspective on health service capacity which requires further consideration in the practice and research domains.

**Relevance to clinical practice:** Carers of people diagnosed with mental illness are crucial to the effective delivery of mental health services. Their perspectives must be central to their research agenda and contribute to the development of initiatives to improve clinical practice and promote improved physical health care.

**Keywords:**

Carers

Health services

Mental health

Mental health nursing

Mental illness,

Physical health

**What does this paper contribute to the wider global clinical community?**

- Articulation of carer views and experiences regarding the physical health of people with mental illness that they care for. There is currently extremely limited research undertaken from the carer perspective.
- Highlights the importance of involving carers in enhancing understanding of the issues associated with physical health of people with mental illness, and in contributing to potential solutions
- Identifies responsiveness and access, and a shortage of care co-ordination as major barriers to ensuring appropriate physical health care for people with mental illness. Carers frequently take on the coordination role in the absence of a more structured approach.

## **Introduction**

A major challenge confronting health care systems is the significantly lower life expectancy and worse physical health of people with mental illness, such as schizophrenia, bipolar disorder and major depression (McCloughen *et al.* 2012, McDaid & Smyth 2015). A meta-analysis by Walker *et al.* (2015) found a median 10 years of potential life lost for people with mental illness. To a large extent, this disparity in life expectancy can be addressed since the major contributor to early mortality is preventable or treatable physical illnesses such as cardiovascular and respiratory diseases (Hayes *et al.* 2015, Lawrence *et al.* 2013, Olfson *et al.* 2015).

Contributing factors to worse physical health of people with mental illness include lifestyle practices such as physical inactivity, poor diet and smoking (Bartlem *et al.* 2015). Inequalities in physical health can also be attributed to the stigma demonstrated by health professionals toward people with mental illness, gaps in the quality of **physical and mental** health care co-ordination, and side-effects of medications (Lawrence & Kisely 2010). The literature on inequalities in physical health care for people with mental illness discusses physical health and mental illness in the context of health care

services, and in particular, government-funded health care (De Hert *et al.* 2011, Smith *et al.* 2013).

Carers (some-times referred to as Family Carers to emphasis care provided on an unpaid basis) of people with mental illness, defined as those who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail-aged also have a crucial role to play in informing on the physical and mental health care performance of the health care system (Carers Australia 2015). However, until recently a standardised way to capture carer involvement has not been available (Kelly *et al.* 2011) As a result, their insights into physical health care do not feature in the peer-reviewed literature. This is in spite of carer involvement being seen as central to international contemporary mental health policy (World Health Organisation 2013). This paper is in response to the discourse between policy recommendations and the absence of carers view in the literature, and focuses on carers' perspectives regarding access to, and experience with, physical health care services for mental health consumers.

## **Background**

In response to concerns about mental health services from a range of stakeholder groups, a three-year review of mental health care across Australia was conducted, culminating in a 1,008 page report known as 'Not For Service' (Mental Health Council of Australia 2005). Importantly, submissions from, and forums with, carers were an important component of this review. Carer voices conveyed in the 'Not For Service' report reflected their perspective of the Australian health care system as highly disjointed, with a lack of communication between primary care and mental health care services. The physical health needs of mental health consumers was a prominent theme. Carers described limited access to general practitioners

(GPs), other primary care services, and discounting physical health problems by health professionals, as particular concerns. These findings are consistent with health service research reporting the tendency of mental health services to prioritise mental health treatment, rather than embrace a holistic approach to **both physical and mental health** care (Hyland *et al.* 2003). The literature also points to poor rates of assessments and screening for physical health problems such as cardiometabolic disorders (Lambert & Newcomer 2009), and general difficulties accessing a GP for physical health advice (Happell *et al.* 2013).

Ten years since the *Not For Service* report, granting consideration to carers' views on the physical health needs of consumers with mental illness is essential, especially in light of the emphasis on the neglect of physical health raised in that report. However, research on carer perspectives is particularly scarce, in comparison to research examining the perspectives of health care providers (Ehrlich *et al.* 2014, Hyland *et al.* 2003), mental health consumers (Schmutte *et al.* 2009) and policy-makers (Henderson & Battams 2011).

Mental health policy (Council of Australian Governments 2012, World Health Organisation 2013) and the academic literature (Lee *et al.* 2013) recognise carers as centrally important to collaborative care, where carer viewpoints and expertise are actively drawn on to ensure services are accessible, of high standard and effective. **These views are seen internationally as central to contemporary mental health policy (World Health Organisation 2013), yet are poorly defined and implemented (Pollard *et al.* 2014). Significant efforts are in place to acknowledge the contribution of carers, with, for example, the recently revise. 'Triangle of Care' showcasing examples of how carer can be better supported and included in decision-making for mental health consumers (Bisconer & Harte 2010). However, in terms of research, there is only one published study that includes carers as participants on the topic of physical ill-health of people with mental illness**

conducted in the UK (Dean *et al.* 2001). Carers expressed concern about a range of shortfalls in service provision, such as a predominant biomedical approach to health, lack of response by providers to mental health consumers' physical health issues.

In the absence of a strong literature base, the *Not for Service* report has been regarded as the main repository for carers views and opinions (Mental Health Council of Australia 2005). Whether these views of carers regarding the accessibility, suitability and responsiveness to physical health care reported more than a decade ago remain, is unclear. In Australia, and internationally, carers are recognised for their valuable role in consumer support (British Medical Association 2014, Commonwealth of Australia 2009, Lee *et al.* 2013). However, the effect of policy change and increased awareness of physical health care inequities on carers remains an untold story. In response to this significant gap in the literature, the present paper reports on a qualitative exploratory study of carers in the Australian Capital Territory of Australia. In this study, carers were provided the opportunity to share their experiences of physical health care of the people with mental illness they care for.

## **Method**

### ***Design***

Due to the paucity of research describing carers' views and opinions on the topic of interest, a qualitative exploratory approach was utilised (Stebbens 2001). Qualitative exploratory research provides the scope for in-depth exploration of a specific issue and enhances comprehensive examination of specific issues, as perceived by those well-placed to be informative (Stebbens 2001).

## Setting and *sample*

The research was conducted in the Australian Capital Territory (ACT). Carers ACT, the peak body for carers in the region, endorsed the project and provided their full support. Carers ACT sent information about the study to carers of people with mental illness via a mailing list, and an advertisement in their weekly newsletter, and further promoted the research through a community radio program requesting those interested in participation to contact Carers ACT and register their interest. A participant information sheet and consent form was sent to all carers who expressed an interest, and an interview time was booked for those willing to participate. Thirteen carers participated in one of two focus groups. One individual interview was organised for a carer who was not available for either interview time. Carers ACT provided a \$50 gift voucher to acknowledge the contribution carers made and thank them for their involvement.

## Procedure

Data were collected in 2015 via focus group interviews. Focus groups were selected as the most appropriate method due to benefits identified in the literature, including facilitating participation from a larger number of participants, encouraging a conversational approach and allowing participants to respond to the views and opinions of others (Zhang *et al.* 2015). This approach proved effective with lively discussion and active participation, with rich data provided.

Interviews were conducted at the premises of Carers ACT. This venue had specific advantages including its familiarity to most of the participants, and evidence that Carers ACT was supportive of the research. The interviews were conducted in a quiet room and were run jointly by an experienced mental health nursing researcher and a mental health carer with research

experience. The interviews were of approximately one and a half hours duration.

The two researchers introduced themselves at the beginning of each interview. Both provided a brief overview of their background as a mental health nurse and as carer, and their experience in mental health research. The carer researcher was considered an essential part of the team, particularly given the intention to be inclusive of carer perspective. Additionally, the research team believed the inclusion of a carer researcher may put participants at greater ease, knowing their experiences and perspectives would be understood through first-hand experience.

The mental health nursing researcher and carer researcher collaborated on the development of the interview guide. The questions were broad and open-ended to encourage participants to describe the issues of greatest relevance to them. They were encouraged not to be limited to questions specifically but to also express their opinions, thoughts and experiences.

The interview guide consisted of the following questions:

1. Please describe how important physical health is to the person you care for?
2. How well do you believe the physical health concerns and needs of the person you care for have been addressed?
3. Please describe your experience of how physical concerns been responded to:
  - a. Within mental health services?
  - b. By general practitioners or other community based clinicians?
4. How much emphasis has been placed by service providers on diet, physical activity, smoking status, sleep and other health promotion

- activities for the person you care for? (this could also include yoga etc)
5. Please describe any actions or factors that have assisted with physical health issues for the person you care for (including consumer and service directed)
  6. Please describe any actions or factors that have been a barrier to addressing physical health issues for the person you care for?
  7. A specialist nursing position has been suggested to improve coordination of physical health care, do you feel such a position could have advantages in promoting physical health for consumers, in what way?
  8. Can you describe ways the current system could be changed to improve physical health care the person you care for?
  9. Please describe your observations of the relationship and interactions between physical health and mental health services.

#### *Ethical issues*

The project was approved by the institutional Human Ethics Review Committee. Participants were provided with an information sheet outlining the purpose of the research, and the risks and benefits associated with participation. All participants provide written informed consent including consent for audio recording of the focus groups. At the beginning of the interview, the purpose of the research was discussed, and participants were encouraged to seek clarification and ask questions if necessary. Participants were assured their information would remain private and that confidentiality would be maintained, and no names or other information that might identify them would be published in any form. Interviews were audio-taped and professionally transcribed to provide an accurate account of the interviews. Any names of people or places were removed in the transcripts.

## Data analysis

The interview transcripts were analysed by **two** members of the research team **to ensure themes were identified independently and to reduce the chances of bias**. Braun and Clarke's framework (2006) was adopted as the approach to analysis, **the two researchers followed this approach carefully**. There are five stages to the framework:

- Stage 1 – each transcript is read several times to allow the researchers to gain familiarity with the data and the primary issues raised.
- Stage 2 – specific areas of content are identified and coded manually. Each identified area was screened for its relevance and areas with some similarity in content were grouped together.
- Stage 3 – the development of provisional themes for the grouped areas. Descriptive titles were assigned to each.
- Stage 4 – a conceptual map of tentative themes was created.
- Stage 5 – each theme was revised for accuracy and a final reading of transcripts was undertaken to ensure all relevant information had been identified and included. The conceptual map and major themes were reviewed by the research team and modified until consensus was reached.

Two major themes to emerge from the analysis were lack of service access and responsiveness; and, lack of **physical and mental health** care co-ordination. These themes will be presented in this paper

## Trustworthiness

**Several steps were taken to ensure the trustworthiness of the research and its findings. Interviews were conducted by an experienced mental health**

researcher, with expertise in focus groups from both methodological and practical perspectives. The focus groups were co-facilitated by an experienced carer researcher, which assisted in putting participants at ease with the knowledge that their experiences were understood. The interview guide was developed by the two interviewers with additional input from the research team. Regular meetings of all members were held throughout the project to oversee all aspects of the study. As stated under data analysis, interview transcripts were reviewed independently by two team members and differences were discussed and negotiated to the point of consensus.

## Results

### ***Lack of service access and responsiveness***

The carer participants in this study were active participants in coordinating services, both physical and mental, and advocating for appropriate care and treatment for the person they cared for. However, the views expressed by carers suggested that service systems (mental and physical health) did not operate in a systematic, coordinated way, and access and being listened to remains a significant issue. *There was lively discussion about these issues among participants, the quotes presented are representative of this discussion and were widely agreed upon by all participants.*

*In particular, participants had found it difficult to find a GP who was responsive to the needs of, and the person for whom they cared, as willing to engage with, but when this did happen, outcomes were positive.*

*For my son I found finding a GP that was good and that he liked was one of the best things but it's not easy (Focus Group 1).*

For others, availability of GPs and possible reluctance to take on the care of someone with a mental illness were issues, **reflecting apparent stigma towards them. Participants** were also concerned that the people they cared for often cycled through GPs.

We tried to get him into other places but a lot of GPs closed their books and a lot of them won't take people with psychosocial disability. They don't say that because – but you kind of know that they're not – they're saying they've closed the books but they won't take people with mental illness **(Individual interview)**.

For other participants, the lack of connection between GPs and psychiatrists resulted in **the fragmentation of treatment**, lack of communication and negative experiences. **These problems were exacerbated by frequent changing of GPs.**

My daughter's psychiatrist and GP don't really connect and if you change GPs, you have to start all over again and sort of ascertain whether how much support there's going to be from both ends **(Focus Group 2)**.

**Participants provided numerous examples where the** person they cared for was not listened to by service providers about physical health concerns, **which resulted in physical illness not being diagnosed and treated, for example:**

She also has symptoms including pathology symptoms of increased white cell count for many years which we've tried to investigate or been to the GP. It's hard to find a GP that will listen to someone with her mental illness diagnosis **(Focus Group 1)**.

Participants recounted many examples of physical health complaints being interpreted as symptoms of mental illness, also resulting in a failure to diagnosis and treat, and placing the onus back on carers and those they care for to identify their own solutions:

I think the time factor in trying to find out what is wrong, finding a GP that will listen and won't brush off and say, "It's just a symptom of the medication or the illness." Without really stating why or exactly why that is, and there's an awful lot of research that you have to do, both my daughter and myself trying to find out why is this occurring (Focus Group 2).

Some carers had similar experiences of not being listened to by primary health care providers when expressing concerns about the physical and mental health of the person they cared for.

They don't give the whole picture and if you say anything and they're not prepared to listen to it, you're talking to a brick wall. It's not like you're allowed to even say things that they're not prepared to listen to. That's what I find fascinating, they're not open to what you're saying (Focus Group 1).

Other participants kept detailed medical records to show services and sometimes needed to take extreme measures because they were only listened to if they were at breaking point.

...and if you have a bit of a wobbly and get dramatic, they might listen too. I find that I sometimes have to come to tears before anyone will listen, and that's really depressing. Why do you have to go to that? Why can't you just speak to someone? They fob you off all the time (Focus Group 1).

### **Lack of *physical health* care co-ordination**

An issue of great concern expressed by all carer participants was the lack of co-ordination of physical health care within the mental health sector. Discussion of this topic was animated, with wide agreement between participants for each point raised. For example there was no specific role dedicated to managing the physical health needs of the person they cared for, as a result of competing demands and no clearly identified role, physical health care often fell through the cracks:

I mean certainly the [mental health] case managers don't take it on. They've got too many people anyway, so I don't really blame them. The psychiatrists don't see it as their role, the physical health ... (Focus Group 1).

As a result of no clear role for physical health care, participants often took on the role of coordinating services, particularly between mental health services and primary care, ensuring that each provider was aware of the person's history and that follow up services occurred.

There's no communication. It's the carer does all the communication and the coordinating (Individual Interview).

Participants described problems occurring when the person they cared for moved between various components of the health care system as their condition changed over time, and the need for carers to maintain communication between these components to ensure all health care needs are addressed:

I felt like I had to do all the coordinating because she [daughter] went into the detox unit at one point ... she's been in and out of [services] so much ... but I had to make sure ... she was then going to the rehab that it was dove tailed [detoxification and rehabilitation services] otherwise you've lost her again then she has to go through the whole thing (Focus Group 1).

Lack of discharge planning and appropriate follow up services was also mentioned by some carers as problematic, particularly on weekends, as connections were not made between hospitals, GPs, psychiatrists, and support for carers.

We've been sent home from hospital twice after suicide attempts, told that she's okay.... and ... to me, who has no psychiatry skills to keep her alive (Focus Group 2).

Taking a holistic approach to the mental and physical health care of a person was considered by study participants to be essential to improving wellbeing, and coordination was essential in securing effective communication between different components of the health care system:

So as part of seeing a psychiatrist, they [consumers] should either be referred or they should work with [primary care providers] ...so the physical health plan [can work effectively], because they're based in the community health setting anyway (Focus Group 2).

A couple of participants spoke about long-term residential services for people with severe mental health and/or addiction problems that were very effective in treating people as whole beings, with coordination being central rather than leaving that role to carers, for example:

They consider the whole family, the whole person. Mental, emotional, spiritual; everything, the whole person and follow through and case worker afterwards (Focus Group 1).

A suggestion was made for an automatic system response when someone is diagnosed with a mental health condition, similar to when someone is diagnosed with a chronic health condition or has a heart attack. Monitoring of physical health, would be included in the treatment plan for that person, rather than placing the burden on carers to ensure this care is provided:

And I think what's important is there needs to be a system in place, an automatic system as there is in other....chronic illnesses.... So if there's an automatic system in place and when someone visits a psychiatrist ... from there, you have someone there linked in with to do with the physical and any other possibilities with medication, that checks pathology, et cetera, et cetera (Focus Group 2).

## Discussion

Carers' accounts provide in this research, suggest that from their experience, health service responsiveness, co-ordination and comprehensiveness of the physical health care available to people with mental illness has not improved, that is, since the physical health neglect of people diagnosed with mental illness was described in the *Not for Service* report (Mental Health Council of Australia 2005) and that is also observed outside of Australia (British Medical Association 2014, McDaid & Smyth 2015). Carer voices are rarely heard in the academic literature on the physical health of people with mental illness. However, the experiences of inadequate physical health care expressed by carers have similarities with the experiences of consumers (Zeber *et al.* 2009) and health care providers (Kristiansen *et al.* 2015).

Carers describe seeking support from health care services to have physical illnesses identified and diagnosed, and receiving advice, referral and treatment provided as needed. Carers identified a clear lack of access to physical health services and system responsiveness to carer and consumer efforts to access physical health care. Difficulties accessing GPs and other primary care were particularly noted. This was also a key finding of the 'Not for Service' national inquiry (Mental Health Council of Australia 2005). One recommendation from that report was for the improvement of primary care services for people with mental illness. Unfortunately, based on the view of carers, this recommendation does not seem to have been heeded. **This finding also resonates with other studies of informal carer views on mental services and other health services, where providers are characterised as distant, in contrast to carers' wishes for partnership-focused relationships and informed decision-making (Cree *et al.* 2015, Morton *et al.* 2010, Rowe 2013).**

In the 'Not for Service' report, and peer-reviewed literature, stigma and discrimination was proposed as the main reason for inadequate response to physical health issues (Olson *et al.* 2015); views which are reflected in the comments by carers in the current study. In addition to, or perhaps an aspect of mental health stigma, carers considered the competencies and professional skills of clinicians as **a major barrier to access and a source of non-responsiveness, including a failure of the provider to actively listen to consumers and carers.**

**Necessary for gaining access to needed services is correct diagnosis of physical health problems, which includes active listening by clinicians (Happell *et al.* 2013).** Diagnostic overshadowing is defined in the literature as the misattribution of symptoms of physical illness due to mental illness diagnosis (Jones *et al.* 2008), **is reported in the international literature (Chadwick *et al.* 2012).** Carers provided clear examples of diagnostic overshadowing, although they did not use this term specifically. Efforts to

reduce the occurrence of diagnostic overshadowing has only been a recent development **that is evident in the UK** (Shefer *et al.* 2014). It is quite clear that in Australia, what is strongly needed is research which seeks a greater understanding of diagnostic overshadowing with the aim of developing strategies to overcome it or at least to lessen its impact.

The other major problem, representing the second main theme, was a lack of **physical and mental health** care co-ordination. Rather than being included in collaborative care and partnerships centred on the mental health consumers well-being, carers, in the main, felt left out, such as solely taking on the task of connecting the person with the needed services, and a general sense of being ignored by the system. These findings echo views of mental health consumers and health care providers voiced via academic research (Hyland *et al.* 2003, Shor & Shalev 2013) that the inadequate co-ordination does not allow an adequate quality of physical health care. **It also is similar to findings of the views of informal carers of people with physical illnesses in that care co-ordination is a significant problem in health services (McPherson *et al.* 2014, Røthing *et al.* 2015).**

In the absence of **physical and mental health care** co-ordination, carer participants generally took on this role. However, health care systems can be difficult to navigate in the absence of expert knowledge and experience (Kelly *et al.* 2014). **With respect to this issue, it is noted that** Integrating physical and mental health services has been identified as **a key** strategy to reducing inequalities in physical health for people with mental illness (Ehrlich *et al.* 2015, Lawrence & Kisely 2010). An integrated approach **includes** mental health services as the focal point for increasing access to physical health care, including assessments, health care advice and primary care specialists and programs promoting healthy diet, physical activity and smoking cessation (Baller *et al.* 2015, British Medical Association 2014).

One strategy identified as potentially effective in both increasing access to physical health services and enhancing the level of co-ordination is the Physical Health Nurse Consultant (PHNC). A PHNC is a nurse specialist role within mental health services designed to improve the coordination and delivery of physical health care. The role of the PHNC is similar to that of the Cardiometabolic Health Nurse (Happell *et al.* 2014b). Activities include making sure that baseline physical health assessments are conducted, referrals to appropriate services are facilitated and information and education is provided to consumers and carers on the range of local services available. In Australia, although some health care provider roles, such as case workers and mental health nurses, include some of these activities, they tend to be either marginal to health practice or undertaken in an ad hoc way (Happell *et al.* 2013, Hyland *et al.* 2003). Evaluations of specialist nurse roles to enable more systematic and comprehensive care, such as nurse-facilitated co-ordination, have demonstrated positive outcomes on clinical measures and quality of life (Happell *et al.* 2014a, McKenna *et al.* 2014). The PHNC has potential to lessen the burden on carers, particularly in relation to coordination, and significantly address the issue of stigma and diagnostic overshadowing discussed above, by decisively ensuring mental health consumers and their carer concerns about physical health are listened to and appropriate physical health care provided in response. Further research is required to determine its effectiveness and carers need to be recognised as key stakeholders in this research.

### **Limitations**

This research was conducted with a small number of participants from one Australian city. The extent to which they can be considered typical of broader carer views is a matter of conjecture. There is also an implicit limitation in advertising as people who respond generally have strong opinions about the issue in question. Individual views are also influenced by

experiences of specific health services they have accessed or attempted to access. Additional research with a larger sample of carers from a range of geographical settings in Australia and internationally should be prioritised.

## Conclusions

Carers are key stakeholders in the mental health service system in Australia and internationally. To date their perspectives have played little part in the research data. Carers have considerable experience in assisting consumers to find quality physical health care and can therefore make a significant contribution to strategies designed to address the problem. Improving physical and mental health care coordination by implementing PHCN's is one such strategy with a flow-on benefit of reducing carer burden. The current study is one of the few research studies undertaken specifically and exclusively with carers to examine the issue of physical health needs of people with mental illness and the health services response to identified needs. Governments and carer advocacy groups have been more effective in capturing carer perspectives than academic researchers (e.g. Carers UK 2015), despite the emphasis on carers as key stakeholders within mental health policy (e.g. Commonwealth of Australia 2009, 2013).

## Implications for clinical practice

The findings of this research clearly emphasise the important role carers play in facilitating physical health care for people with mental illness. The insights gained from their experience is valuable and should be reflected in the development and implementation of strategies to improve clinical practice, enhance physical health care and reduce the unacceptable life expectancy gap for people with mental illness. Adoption of the PHCN role will be an important first step this address this physical health care inequity.

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