“Coming from a different place”:

Partnerships between consumers and health services for system change

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Abstract

Aims and Objectives: The aim of the current study is to explore whether and how the expectations of consumers to be 'representative' influences consumers' ability to contribute to health services partnerships.

Background: Health standards call for services to partner with consumers in service development and governance. While existing research criticises the assumption that individual mental health consumers working with mental health services must be representative of consumers more broadly, research has yet to explore whether this requirement exists for consumers of other health services. Requiring individual consumers to be representative of consumers more broadly marginalises and limits consumer involvement.

Design: A qualitative, exploratory design was employed.

Methods: Consumers (n=6), clinicians (n=7), and health managers (n=5) were interviewed about consumer participation in health services. Data analysis was conducted through the lens of social exchange theory, and informed by discursive psychological principles.

Results: The current study extends existing literature within mental health, finding that consumers of other health services are also held responsible for representing broader communities. Data also suggested that a requirement to be representative would marginalise consumers with a passion to bring about change in health systems.

Conclusions: The findings suggest that organisations might need a culture change so that individual consumers are not expected to be representative of consumers more broadly, and that participation be made more accessible for diverse groups of consumers.

Relevance to clinical practice: Given the role that nurses might play as allies to consumers within health services, the findings of this study contribute to knowledge about the expectations placed on consumers and the ways that nurses might advocate for better partnerships.

Introduction

Contemporary health standards highlight that partnering with consumers is essential in service design, delivery, evaluation, and governance (for example, see Australian Commission on Safety and Quality in Health Care, 2017). Partnerships between consumers and health services can take place on an individual level (where consumers are partners in their own treatment decisions), at an organisational level (in which consumers collaborate on overall design of services or programs), and at a system level (including partnerships in decision-making about policy, funding, and governance) (Carman et al., 2013). While policy requires partnerships with consumers at all levels (Australian Commission on Safety and Quality in Health Care, 2017), the current study is concerned with partnerships at the organisational and system levels given the particular barriers and power disparities within partnerships in these contexts (O'Hagan, 2009).

Background

Much of the research on partnerships between health services and consumers has been conducted in the USA, Canada, Australia, and the UK (Simpson & House, 2003). However, such partnerships appear to have been gaining support in Latin America (Torri, 2012), intermittently applied in Africa (Rifkin, 2014) and have recently been implemented in Asia (Ng et al., 2013). Within Australia, the practice of consumer partnerships has been developing, with the requirement that health organisations partner with consumers for service planning, implementation, and evaluation (Australian Commission on Safety and Quality in Health Care, 2017)..

Research on partnerships between consumers and health providers is still emerging, but a recent literature review has synthesised information about some of the steps that organisations are taking to emphasise the importance of collaborating with consumers (Health Issues Centre, 2015). Several jurisdictions have mandated collaborations in policy drawing on the Convention on the Rights of Persons with Disabilities, which aims to ensure participation in public affairs (Degener, 2017). At the local level, this has led to several initiatives such as training for consumers involved in advocacy, consumer involvement in development of policy, advice, and standards of practice, and some services have established formal mechanisms for consumer representation (Health Issues Centre, 2015).

Despite more policies and awareness about collaborating with consumers, there still seem to be several barriers to widespread authentic, symbiotic partnerships with consumers. For example, as collaborative work between consumers and health organisations is still evolving, consumer partnership initiatives have been criticised as tokenistic (Happell &

Roper, 2006; Ocloo & Matthews, 2016) poorly resourced, and limited due to resistance from health professionals (Author, 2017a).

Within the mental health literature, it has been suggested that individual consumers' views are silenced by the requirement that they represent the views of consumers more broadly (Author, 2017b). Research has yet to explore whether the requirements for consumer partners to be representative of consumers more broadly also impacts on partnerships in health disciplines outside of mental health. Consumers with capacity to systemically engage in health services tend to be those perceived as doing 'well' in comparison with others (Freeman et al., 2016). Previous research has debated whether these 'high functioning' consumers are able to be representative (Armstrong, Herbert, Aveling, Dixon-Woods, & Martin, 2013; O'Shea, Chambers, & Boaz, 2017) with mixed opinions. Nevertheless, it is notable that other health professionals are not held to the same homogenous standards to be representative when they are selected to participate in organisational initiatives (Happell & Roper, 2006).

Ironically, even after consumers involved in systemic activity have established their legitimacy, the more experienced and confident consumers become, the more likely they are to no longer be considered "typical" of their constituents (Nathan, Braithwaite, & Stephenson, 2014). Further, it seems that demanding consumer partners to be more broadly representative constrains their contributions (Martin, Carter, & Dent, 2018), which is a concern given the value consumers bring to partnerships and the potential value being lost if these contributions are limited. Representativeness, therefore, is a complex concept, understood differently by different stakeholders, and thus requires further investigation.

Emerging theory in the field suggests expecting individual consumers to be representative perpetuates a power imbalance and further marginalises consumers, thus limiting the value that can be brought to organisations (Author, 2018). Further, it has been suggested that the onus to gain a broad consumer perspective be placed on organisations, rather than individuals, and should be sought by engaging with a diverse range of consumers rather than expecting one individual to represent all (Author, 2017b)

Theoretical Framework

According to social exchange, partnerships can be understood, at least partially, mathematically, whereby each side attempts to minimise costs and maximise benefits for themselves (Cropanzano & Mitchell, 2005). Parties are, therefore, interdependent on one another through exchange (Wasko & Faraj, 2005). To receive benefits within a partnership, any given party needs to exchange benefits with others.

As far as partnerships between consumers and health organisations are concerned, power imbalances favour organisational goals over consumer goals. The dominance of medical expertise over consumer experience is engrained, with consumers often thought unable to be able to function as well as non-consumers (Kopera et al., 2015). In terms of social exchange theory, then, the perceived benefits received by organisations through partnership with consumers may not be considered worth the costs of the partnership.

Aim and Objectives

The aim of this study was to explore how the expectation that consumers be representative in partnerships with health services influences the perspectives of consumers and other health service providers involved in this type of work. To achieve this aim, there are three specific objectives:

1. To conduct interviews with consumers, clinicians, and managers of health services and to collect their perspectives on systemic representation;
2. To explore participants' understandings of representation in relation to social exchange theory; and
3. To analyse ways in which participants' understandings about the need to be representative limited the exchange between consumers and organisations, and to better understand ways in which these exchanges could be improved for all stakeholders.

Methods

Design

An exploratory qualitative approach was undertaken to conduct this research as recommended by Stebbins (2001) for research in areas of emerging knowledge. Semi-structured interviews were conducted to facilitate exploration of a range of issues salient to participants.

Data Collection

The research was conducted at a tertiary referral hospital in [city hidden for review] in Australia. The hospital provides a broad range of specialist services to people within the immediate metropolitan region and surrounding regional area, servicing a total population of more than 500,000. Several areas across the hospital had formalised relationships with the local peak body for consumer advocacy, which links hospital staff and committees with consumers who want to participate in health services.

Managers (n=5), clinicians (n=7), and consumers (n=6) associated with the health service were recruited. Managers were defined as staff of the hospital overseeing a clinical

area or service and without a direct clinical role. Clinicians were staff in a role that provided clinical care, including doctors, nurses and allied health services. Consumers were former or current users of the service.

Manager and Clinician participants were nominated by the hospital's Patient Experience Manager using a convenience sampling method which targeted members of committees tasked with addressing the national healthcare standard of "partnering with consumers". Both managers and clinicians were from a broad range of areas within the hospital including in women and child health, Indigenous health, cancer care, surgical clinic, and intensive care. Consumers were recruited through a health consumer advocacy body associated with the hospital and through the hospital's volunteer services. Consumer participants had been involved in various areas of the hospital system.

Interviews were conducted by an independent research assistant with an Honours degree in a health discipline and with experience in qualitative research methodology. The participants were contacted by the interviewer to discuss the aims of the project, and to set up a schedule for a 1-on-1 interview at a location convenient to participants (most on the hospital campus). The interview duration was approximately one hour. Participants were asked a series of questions about their experiences with partnership, both successful and not successful and how this was measured, barriers and enablers to partnership, and how they thought partnership might be facilitated. They were asked to describe what partnership meant to them and the signs of partnership and what a health system based upon partnership might look like. Questions included "what have you done to enable partnerships with consumers?", "what are some of the partnerships that you have been involved in?", and "what do you see as the main factors that influence effective partnerships?". Follow-up questions were asked to elicit details about individual participants' responses.

Ethics approval was obtained from the [ethics committee hidden for review]. Participants were informed of the voluntary nature of participation and that they might withdraw at any time. Written consent was obtained to record and transcribe all interviews.

Analysis

Interviews were recorded and professionally transcribed verbatim to allow in-depth analysis. The entire data corpus was iteratively read and coded by three of the authors following the thematic analytic approach detailed by Braun and Clarke (2006). These codes were then grouped together into potential themes. The authors met to compare and discuss these potential themes. Following this discussion, overarching superordinate themes were listed – one of which was about representation.

A discursive approach was taken to analysis. This approach is concerned with how talk is a means through which individuals construct versions of their attitudes, feelings, and subjectivities (Wiggins, 2016). It therefore informed our analysis of the way that participants reproduce or challenge understandings of mental health concerns and mental health service access through their discourse; we treated participants' talk as a site of action. The analysis has particular focus on three key characteristics of discursive approaches to analysis (Potter, 2012). First, analysis is informed by the principle that discourse has an action orientation, meaning that action takes place within discourse itself (Potter, 2012). A relevant example of this would be whether someone refers to themselves as a 'victim' of ill health, a 'survivor' of the health system, or to not refer to themselves in relation to ill health at all. Each way of referring to oneself functions to create certain identities for the self, and to construct (ill) health in particular ways. Using the word 'victim', for instance, positions the individual as powerless. In contrast, someone might use the word 'survivor' to construct themselves as powerful and experienced, and to suggest that they are no longer experiencing ill health. Thus, this analysis is concerned with what is achieved through discursive actions.

The second key principle of discursive approaches is that discourse is situated sequentially in conversation – meaning that discursive actions unfold in sequence and thus actors are orienting to what has been said and building up to what they will say next – and situated rhetorically – meaning that actors orient to particular discourses and thus counter actual or potential alternatives (Potter, 2012). An example of this might be if someone was to tell of their experiences of depression, saying, for instance “my partner left me. I became a victim of my illness”. In terms of the sequential situation of the narrative, it can be implied that the narrator believes that their partner leaving them was related to their ill health. In terms of the rhetorical situation of the narrative, it can be implied that the narrator believes their ill health was more likely influenced by their partner leaving them than by potential alternatives, or that their illness precipitated their partner leaving them.

Last, discursive approaches posit that discourse is constructed – built on conversational repertoires and conversational practices – and constructive – actors use it to build descriptions (Potter, 2012). For instance, if someone talks about depressive symptoms, saying “nobody valued my perspectives. I felt a bit blue”, their experiences are constructed as potentially relatively minor, especially in contrast with someone who says “nobody valued my perspectives. I fell into a deep depression”. While both of these examples draw on common repertoires to explain the narrators' experiences, the latter constructs the experience as having a greater negative impact on them than the former.

Results

There were key discursive repertoires available to participants regarding their representativeness. The results focus on two of the key constructions of these repertoires. The first of these ('marginalising or valuing consumers through representation') examines the way that consumers are often required to be 'representative'. We present examples of representation discourses that marginalise and serve to silence consumers' perspectives, as well as examples of discourses that construct consumers' representation as valuable. The second key construction ('consumers that need to be valued') presented in this section examines the way that current conceptualisations of representation are too narrow.

Marginalising or valuing consumers through representation

Managers and clinicians had clear expectations that consumers partnering with health organisations should be representative, regardless of the particular health discipline with which they were engaging, as can be seen in Extract 1, from an interview with a clinician working in intensive care.

Extract 1

I think again you need to be very careful that people haven't got a particular agenda or that they were upset by a particular individual and that's why they need to improve things. But equally that goes for everyone around the table that you, are you representing your own agenda or are you representing the views of others?

In suggesting that care needs to be taken that consumers do not have "a particular agenda" or have not been "upset by a particular individual", the experience of these potential consumer representatives is called into question. Indeed, having a "particular agenda" is constructed as a detriment to representation. By referring to "everyone around the table", this participant also orients to the health service providers and managers that are part of working processes. The question of whether it is their "own agenda" or the "views of others" being represented is left unanswered. However, the implication is that everyone involved – consumers and non-consumers – draw on their own experiences as well as the views of others in their work. This view that clinicians or managers might also have their own agendas was not common in the data, yet it seems evident that individuals (be they clinicians, managers, or

consumers) are more motivated to participate in activities where they may bring particular interests or agendas into their work.

Consumers noted that valuing their perspectives because of the unique experiences they have had enabled effective participation in health services. Extract 2, quoting a consumer who has been a representative on family health care committees, provides an example of how this value could be demonstrated.

Extract 2

[One enabler is] understanding that a consumer representative on a committee is an equal member of that committee, that their views may come from a different place but they're just as valid. An enabler is a person within a committee or person or people who make efforts to ensure that that voice is heard because that person is coming from a different place to everybody else who is an employee, who kind of set an example of respect and leadership, and giving the person space, and encouraging their contribution, and ensuring that it isn't a token contribution, and the things that they say are minuted and that they're investigated in the same way that any other person around the table would be.

The participant in Extract 2 refers to the “different place” from which consumers’ perspectives come, which is likely to include their unique experiences that “an employee” or non-consumer have not had. Although Extract 1 discussed the importance of avoiding that consumers have particular agendas, Extract 2 instead suggests that consumers’ agendas be “minuted and...investigated” and given the same respect as those of any other non-consumer sitting on committees or in meetings. It was not only consumers who noted the validity of consumers’ unique experience. The following extract, from an interview with a clinician, presents the view that consumers’ unique perspectives should be seen as a positive influence that consumers can bring to organisations.

Extract 3

They usually are very driven by their own experiences. And that can be really positive. I can think of a brain injury group where someone’s wife died, and that person formed a brain injury

support group. Wonderful, really fantastic outcomes. But completely driven by the fact that yes, this has been a very personal experience. And that is the case for most situations. Most people become passionate about or want to be involved in, they either love the area, or they've had some significant impact for them. Somebody who has no interest isn't going to go and join something.

While there is a common narrative that consumer partners are only motivated to pursue their own needs, and are biased because of their previous experience (Happell & Roper, 2006), Extract 3 provides an alternative view that consumers' previous experiences can instead lead to "really fantastic outcomes". This constructs consumers' bias as positive, noting that experience can lead to being "passionate about [being] involved in" partnerships with health service providers. Stating that "somebody who has no interest isn't going to" participate provides a telling counterpoint to the dominant narrative that individual consumers should represent all consumers, in that basing their approach on their personal experiences should be valued.

Consumers that need to be valued

Previous research on the onus placed on mental health service consumers to be representative of consumers more broadly has criticised such requirements, suggesting instead that organisations need to be responsible for including the voices of individuals from socially marginalised groups (Author, 2017b). The findings of the current study extend this to other health disciplines, such as in the following extract, in which a clinician discusses their experience on a hospital committee.

Extract 4

Then I realised that it was quite a narrow spectrum, so these were obviously women. Obviously because they had babies and were not at work, they were obviously wealthier so they could afford not to go to work yet. They were Caucasian and so the young mums, the other cultures were missing, and fathers were missing. So I tried to engage them by setting up a chat room where if we couldn't come to a conclusion or had an issue, let's say do we

want an expressing room or do we just want to build the facility
so every mother can express at the bedside?

The participant in Extract 4 notes that it is “wealthier”, “Caucasian” women who were participating in their chat room. This extract refers to the “narrow spectrum” of consumers who are likely to be involved in health service participation. People who have fewer resources to support them experience additional barriers and have limited capacity to participate. Other participants echoed the concern that “if there could be some Asians [and] some Muslims” involved, the population demographics would be better represented. Some provided practical ways to make participation more possible for consumers from diverse backgrounds, such as by taking into account when particular groups are “going to be praying” or those who cannot do particular activities “on a Friday...or Sunday” because of religious or cultural reasons, for example. Another participant stated that “if you haven’t walked in a different person’s skin...or whether you’re wearing a hijab, or whether you’ve got black skin, you really don’t get it” and then went on to say that health services “need to have people that are in those groups, that understand what it is” involved as partners. Together, these views underscore the importance of health services working to include diverse groups of consumers in their processes.

Participants recounted their experiences with organisational committees that had attempted to forge consumer partnerships, with varying degrees of success. The inclusion of consumer perspectives required adjustments to the organisation of work. Some committees achieved a partnership only in the figurative sense, as their work proved inaccessible to consumers. Extract 5, from a health service manager, highlights the adjustment that needs to occur for successful inclusion of diverse, and previously excluded perspectives:

Extract 5

The contrast is a quality and safety meeting within one particular division and you happen to have a consumer rep there who comes in and they sit there and there’s an agenda item that says consumer perspective. They’re actually not a consumer of that particular part of the health system, so they don’t know the ins and outs. They sit there, there’s a whole lot of acronyms, jargon, the business, because it’s a – and I’m not saying that people are not well-intentioned, it just - - -

Extract 5 suggests that not only do health services need to take responsibility for partnering with consumers from diverse groups, they also need to take responsibility for making their material accessible to consumers. It appears that some health managers are aware that when committees use “acronyms” and “jargon”, they exclude many consumers from decision-making processes. One of the concerns noted in this extract is that some consumers may be included in committees even when “they’re actually not a consumer of that particular part of the health system”. If some health services are engaging with consumers out of convenience rather than seeking out opportunities to partner with consumers who have an interest in or experience with their specific area of health, this could be interpreted as tokenistic on the part of the health service.

Extract 5 also refers to a common finding of this study about having an “agenda item” within meetings for the “consumer perspective”. Some participants suggested that in such meetings the consumer partner would “sit there” other than during the agenda item specifically included for the consumer perspective. It was common for health service providers to suggest that consumers would have no interest or input into some organisational discussions such as conversations about occupational health and safety, for instance. Such discourse serves to restrict consumer input only to the “consumer perspective”. This language constructs the limits of the decision-making that consumer partners could be involved in, rather than integrating experiential knowledge throughout the partnership.

Discussion

The findings of the current study highlight ways in which consumers are held responsible for representing their particular consumer groups. Previous research has discussed how mental health service consumers are held responsible in this way (Author, 2017b; Happell & Roper, 2006) and highlights a lack of clarity about what is meant by ‘representativeness’ in collaborative projects (Armstrong et al., 2013). The current study extends these findings to consumers of other health services more broadly. Further, the findings demonstrate the value that consumers bring to partnerships with organisations, and that consumers who are perceived as less representative because of their “particular agenda” (Extract 2) might, in fact, bring greater value to organisations. This might seem like common sense – that people who are more interested will want to participate more – but the dominant discourse still questions the motives and legitimacy of such consumers’ participation. Last,

the findings also highlight gaps which health services must address to strengthen consumer partnerships. Specifically, the lack of authentic partnerships with diverse consumer groups was identified as an issue, and organisations need to work to make participation (and resources for participation) accessible to a broader range of consumers.

Social exchange theory posits that exchange within a partnership is facilitated by the inter-dependence of parties (Cropanzano & Mitchell, 2005). The relationship between parties is reciprocal, therefore receiving benefits from a partner is contingent on giving benefits to said partner (Wasko & Faraj, 2005). This theory provides a useful lens in which to view our findings with particular practical implications to improve meaningful consumer involvement and foster strong partnerships.

First, the dominant discourse across health disciplines positions consumer partners as participating only if they have personal agendas, and in turn positions such participation as problematic. Health service providers need to work to challenge this dominant discourse given findings that suggest that consumers with agendas participate more and add value to health services. In social exchange theory terms, providing consumers with the respect that their agendas deserve (rather than using their personal experiences to silence them) will allow organisations to better listen to consumers' perspectives and potentially benefit from the value that their desire for change can bring.

Second, the current study findings suggest that although some consumer partnership is happening across a range of areas in health, these consumers tend to be from socially powerful groups (ethnic majority groups or those with more resources). Given that further marginalised groups may have further value to add in terms of improving health services for people of colour and people with fewer resources, for example, organisations will better benefit from diverse consumer input if they adopt an inclusive approach and adjust the workload accordingly. Engagement strategies will vary, and should be dependent on the need of the particular consumer groups. They might include, as suggested by a participant, being mindful of religious commitments in the scheduling of meetings. They could also include clarifying the language used in committee meetings to make the content more accessible.

Last, health services should rethink the way that consumers are able to participate in discussions, and whether current practice fosters authentic partnership. The current study found that it was common across health areas to have a standing agenda item specifically for consumer perspectives to be expressed. In some instances it might be useful to leave a standing item to ensure that consumers' perspectives are sought. However, in terms of social exchange theory, it seems that a single agenda item for consumers could subtly exclude

consumers from participating in other parts of the meeting to which they might add significant value. Committee chairs and secretariats should critically examine meeting agendas and ensure they provide consumers multiple opportunities to participate. In turn, the organisation will benefit by being able to incorporate input from consumers on a wider range of issues and backgrounds.

A potential limitation of this study is that participants all come from one city in Australia. Therefore, those from other organisations in other jurisdictions may have different ways of partnering with consumers not reflected in our findings. Nonetheless, the findings do align with existing research about the stigma held by health professionals towards consumers (Kopera et al., 2015). Therefore, it is likely that health services beyond this Australian city are facing similar issues in their partnerships with consumers.

Conclusion

Establishing strong partnerships with consumers is a complex yet necessary goal for contemporary health services. The introduction of systemic consumer participation is relatively recent and presents emerging challenges, largely stemming from discrepancies about the scope and credentials of involved consumers. Consumers' who draw on their personal experiences are often viewed with suspicion by health professionals, but organisations should emphasise the value that they contribute.

Social exchange theory is a useful framework through which to examine the dynamics of consumer engagement more closely. This lens posits that a mutually respectful interdependence is necessary for an authentic partnership. Health services, therefore, must critically examine participation strategies to ensure a broad range of perspectives are heard. Given that the organisations – not the individuals – hold the power in these relationships, they must take the responsibility to be more inclusive of and to not silence consumers. This will help to push organisations towards authentic consumer participation which is vital to progress health reform and create cost-effective, high quality public health services.

Relevance to Clinical Practice

Nurses are particularly well positioned within healthcare to be advocates for and allies to consumers – particularly where the perspectives of consumers have been silenced by institutional power imbalances (Happell & Scholz, 2018). The findings of this study contribute to knowledge about the expectations placed on consumers. Nurses – particularly more senior nurses with greater influence within organisations – can use their relatively

powerful positions to challenge current practices. Specifically, they might be able to advocate for more meaningful, less tokenistic consumer participation on committees and projects, and to challenge the requirement that consumers have to be 'representative'.

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

- Health policies around the world now require greater inclusion of consumers in meaningful, less tokenistic ways.
- The findings of the current study highlight that the requirement to be representative is used to limit the meaningful inclusion of consumers in health care partnerships.
- As potential allies to consumers, nurses and other health professionals may be able to challenge the requirement that consumers be representative and advocate for more meaningful inclusion, thereby improving the way in which services meet policy requirements.

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