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ORIGINAL ARTICLE

Understanding advocacy practice in mental health: a multidimensional scalogram analysis of case records

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ABSTRACT

Background: Few studies have examined mental health consumers' motives for seeking advocacy assistance.

Aims: This study aimed to identify factors that influenced mental health consumers' use of advocacy services.

Methods: The analysis was based on 60 case records that were sourced from a community advocacy service. Each record was dichotomously coded across 11 variables to generate a series of categorical data profiles. The data set was then analysed using multidimensional scalogram analysis to reveal key relationships between subsets of variables.

Results: The results indicated that mental health consumers commonly reported a sense of fear, which motivated them to contact the advocacy service in the hope that advocates could intervene on their behalf through effective communication with health professionals. Advocates often undertook such intervention either through attending meetings between the consumer and health professionals or contacting health professionals outside of meetings, which was typically successful in terms of achieving mental health consumers' desired outcome. The resolution of most concerns suggests that they were often legitimate and not the result of a lack of insight or illness symptoms.

Conclusion: Health professionals might consider exploring how they respond when consumers or carers raise concerns about the delivery of mental health care.

Keywords

Advocacy, mental health, consumer participation, multidimensional scaling

History

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Introduction

Health consumers and advocacy

The National Mental Health Statement emphasised that mental health consumers have the right to “be considered capable of a making a decision by the service or person providing care” and “have their wishes respected and taken into account” (Commonwealth of Australia, 2012, p. 12). However, Australian mental health services tend to exhibit cultures that prioritise coercive treatment, either through inpatient detention or community treatment orders, in preference to collaborative recovery orientated care (National Mental Health Commission, 2014). Given this context, it is essential that the voices of mental health consumers are heard and acknowledged within the system of care. A number of factors, however, ensure that the consumer voice is weakened and often goes unheard.

Mental health consumers, for example, are often vulnerable and may therefore be reluctant to fully disclose their views (Dassori et al., 2003; Morrison et al., 2015a, 2016; Roe & Goldblatt, 2009). Moreover, case managers often have

a limited understanding of the lived experience of mental health consumers, which tends to result from poor communication on the behalf of case managers (Morrison et al., 2015b; Roe & Goldblatt, 2009). Formal advocacy then provides an essential service in ensuring that the experiences and views of mental health consumers are uncovered and received, and that their rights are maintained.

A recent systematic review of independent audits, conducted between 2006 and 2013, of the Australian mental health care sector identified the following main themes: inadequate access to services; inadequate cooperation between agencies; lack of continuity of care; human rights concerns; and lack of monitoring and surveillance (Griffiths et al., 2015). These issues mirrored the conclusions of the Burdekin Report in 1993, which presented the findings of a national enquiry into the human rights of people with mental illness (Human Rights and Equal Opportunity Commission, 1993). In addition, the replication in 2013 of a survey originally conducted in 2004 found no improvement in any area of mental health service delivery (Hickie et al., 2014). Of particular note was the “return to unacceptably high levels of seclusion and restraint in our acute care services and ongoing use of compulsory treatments in those returning to community-based care” (Hickie et al., 2014, p. 446).

The place of community treatment orders

Severe mental health conditions are typically treated within the community in Australia (National Mental Health Commission, 2014). Community treatment orders allow health professionals to enact involuntary treatment in community settings. The introduction of community orders was well-intentioned, since the rationale was that appropriate care could be provided in the least constrained setting (O'Donoghue et al., 2016). Nonetheless, the use of community treatment orders remains contentious since they restrain civil liberties, and systematic reviews have demonstrated that these orders deliver no improvement in mental health consumers' social functioning, quality of life, or use of services (Kisely & Campbell, 2015; Maughan et al., 2014).

Notwithstanding the lack of evidence, the use of community treatment orders in Australia has increasingly escalated over time and remains high in comparison to other developed countries (Light et al., 2012). The rate of community treatment order use differs between Australian jurisdictions, ranging between 30.2 per 100 000 in Tasmania and 98.8 per 100 000 in Victoria (Light et al., 2012). Several Australian jurisdictions have recognised the need to reduce the use of community treatment orders and have introduced legislation that substantially tighten the criteria for coercive treatment (Ryan et al., 2015). However, the impact of such legislation remains unclear as its introduction in one jurisdiction, along with the implementation of a recovery orientated model of care, counterintuitively resulted in a 10% increase in the use of community treatment orders (O'Donoghue et al., 2016).

The place of advocacy services

The establishment of the consumer movement in Australia began in the late 1960's (Epstein, 2013). An integral aspect of this movement was the development of mental health advocacy, which sought to foster consumer participation in the planning, implementation, and evaluation of mental health services (Funk et al., 2006). Mental health advocacy services are now commonplace in many countries, and in Australia there is a diverse range of advocacy organisations (Gee et al., 2016).

Relatively few international studies have evaluated advocacy services. Studies undertaken in UK have reported that advocacy was inaccessible for many mental health consumers, even though the right to advocacy was enshrined in law (CQC, 2010; Grant, 2004; Newbigging et al., 2015). In addition, most mental health consumers did not understand the purpose of advocacy or what the service could do for them, which further limited the uptake of advocacy (Newbigging et al., 2015). To some extent, this lack in understanding resulted from health professionals neglecting to advise consumers about the availability and potential uses of advocacy (CQC, 2014; Newbigging et al., 2007, 2012). The widespread inability to access advocacy is concerning because consumers who have made use of advocacy experience improvements in empowerment, self-efficacy, and wellbeing (Mind, 2006; Palmer et al., 2012). In particular, these improvements have been associated with advocates taking the initiative in reaching out to consumers and

maintaining regular in-person contact, which builds rapport and trust (Foley & Platzer, 2007; Newbigging et al., 2012).

Only two studies have explored mental health advocacy services in an Australian setting. Rosenman et al. (2000) examined whether a person-centred advocacy model, which involved negotiation at all points during treatment, was more beneficial than standard statutory advocacy that is undertaken only at the point of inpatient commitment. The results of that study demonstrated that the use of the person-centred advocacy approach led to mental health consumers experiencing higher levels of satisfaction with care while in detention, improved attendance at follow-up consultations, and fewer instances of subsequent involuntary inpatient admissions. Gee et al. (2016) reviewed the strategic focus of two advocacy organisations and reported several priorities: facilitation of consumer agency and recognition; influencing and enhancing mental health systems; promotion of effective collaboration and partnerships; and consolidation of organisational capacity.

In considering the extant literature, it is notable that no studies have examined the factors that influence mental health consumers' use of advocacy services. The present article addresses the literature gap through detailing how key issues affect the manner in which mental health consumers' use advocacy services.

Methods

The study was conducted in consultation with the Health Consumers Council (HCC) with the aim of understanding the experience of mental health consumers and carers who seek support from an advocacy service. A selection of advocacy case records were analyzed with the use multi-dimensional scalogram analysis (MSA), which is a nonmetric multivariate statistical procedure used to uncover possible relationships in qualitative data (Morrison & Lehane, 1995). The main purpose of MSA is to provide a visual representation of the relationships between a set of variables, which can be reviewed and interpreted. In the following method sections, we describe the manner in which the advocacy case record data was collected and coded, and then provide further technical details about the use of MSA in this study.

A sample of advocacy records

The data for this study was drawn from an advocacy databank held by the HCC. HCC is a not for profit health consumers' advocacy service operating in Western Australia. The databank contains data from ~320 mental health consumers who have contacted the HCC to seek support for a diverse range of issues in 2014–2015. Of these 60 case records were chosen for analysis. As part of routine practice advocates record detailed case notes for each interaction with a mental health consumer and store these records on an electronic database. A senior advocate for the HCC de-identified a sample of 60 records and made these available to the research team in a word processing format. These records were selected to capture key issues for which mental health consumers and carers typically seek the support of the HCC.

Coding

The set of 60 records was read several times by two members of the research team to identify a number of key variables that were refined over time. Each record was then coded accordingly with a string of 0s or 1s to generate a profile of categorical data for individual records. Three records were discarded as the information contained in these was lacking details about the episode that might be analysable. Ethics approval was provided by the Murdoch University Human Research Ethics Committee (Approval 2015/149). Eleven variables in total were used (Table 1). The gender of the person consulting with the advocacy service was not included in the final analysis as it did not provide additional information when examined alongside the other variables.

MSA analysis

The data set was submitted for analysis using MSA (Morrison & Lehane, 1995). In MSA, the data profiles are used to produce a visual plot that represents each record in geometric space according to how closely the record (profiles) resemble each other—records with similar profiles are plotted closer together, while records with dissimilar profiles are plotted further apart (Bradford & Wilson, 2013). The more records have in common, the closer together they will be in the visual plot which is created. All of the points plotted on the MSA output denote a specific record profile, some of which represent a number of non-unique record profiles. From the 57 records used here, 49 unique record profiles were identified.

The MSA program also produces a contiguity coefficient to assess how well the data are mapped onto a two dimensional space. A coefficient of contiguity of 0.90 is considered satisfactory in a two dimensional portrayal (Zvulun, 1978). A general overall plot with points representing records with unique profiles is produced as well as plots for each of the individual variables (item plots). These item

plots can be divided into contiguous regions in line with the codes allocated to each variable (Wilson & Lemanski, 2013). Patterns between these can be identified, described and interpreted.

Findings

Mental health consumers initiated most of the contacts with the advocacy service (80.7%). The consumers tended to be located in the community (60.7%) and consumers who initiated contact themselves or had issues raised on their behalf by carers typically were of voluntary status (72.2%). Medication was the most common concern (54.4%). Mental health consumers (and carers) frequently asked advocates to facilitate communication on their behalf with health professionals (57.9%), and also commonly requested assistance with legal support (35.1%). In many cases, the consumers reported a sense of fear that was associated with the issue for which they contacted the advocacy service (61.4%). Finally, the issue for which consumers sought support was resolved by the advocacy service in two thirds of the cases (66.7%).

The MSA produced an overall arrangement of the records (Figure 1) in a two-dimensional plot (coefficient of contiguity 0.98) and eleven separate variable plots. Plots that are partitioned in the same way are assumed to be related in some important respect. The individual variable plots can be overlapped, which results in the delineation of the relationships between the variables. While none of the plots divide the space in exactly the same manner, it is clear some do share a common direction and from these certain important similarities and differences have been identified. These are examined by reviewing some subsets of the eleven variables below.

The regions identified in Figures 2–5 are partitioned by vertical lines into similar regions. Superimposing Figure 4 (sense of fear) and Figure 3 (person making contact) demonstrated that it was mainly mental health consumers

Table 1. Variables used in the MSA.

| Variable | Categories | Codes | % of records |
|--|-------------|-------|--------------|
| 1. Consumer legal status | Voluntary | 0 | 72.2 |
| | Involuntary | 1 | 21.8 |
| 2. Setting | Inpatient | 0 | 39.3 |
| | Community | 1 | 60.7 |
| 3. Contact initiator | Consumer | 0 | 80.7 |
| | Carer | 1 | 19.3 |
| 4. Concern: medication | Absent | 0 | 45.6 |
| | Present | 1 | 54.4 |
| 5. Concern: detainment | Absent | 0 | 71.9 |
| | Present | 1 | 28.1 |
| 6. Concern: other issues (medical records, basic necessities, and change of care type) | Absent | 0 | 50.9 |
| | Present | 1 | 49.1 |
| 7. Request for advocate communication | Absent | 0 | 42.1 |
| | Present | 1 | 57.9 |
| 8. Request for legal support | Absent | 0 | 64.9 |
| | Present | 1 | 35.1 |
| 9. Reported fears | Absent | 0 | 38.6 |
| | Present | 1 | 61.4 |
| 10. Advocate facilitates communication | Absent | 0 | 49.1 |
| | Present | 1 | 50.9 |
| 11. Issue resolved | No | 0 | 33.3 |
| | Yes | 1 | 66.7 |

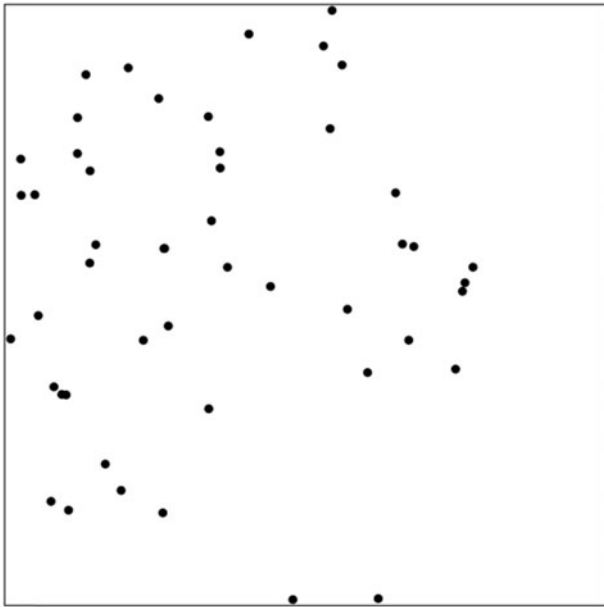


Figure 1. Overall MSA plot.

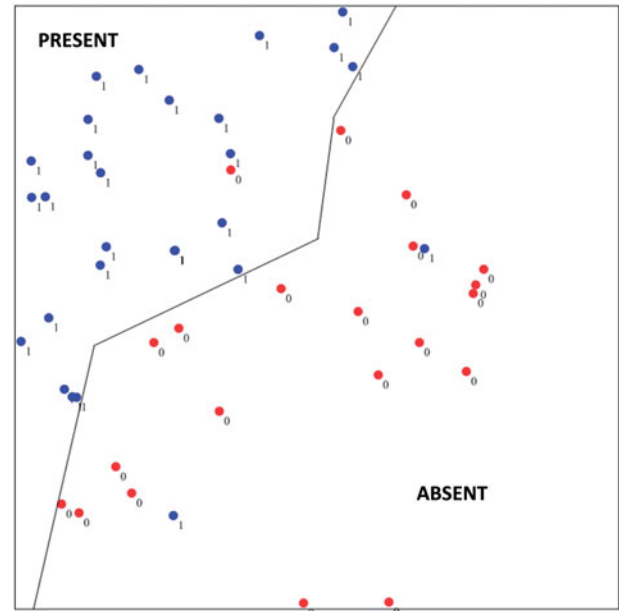


Figure 3. Advocate communication needed.

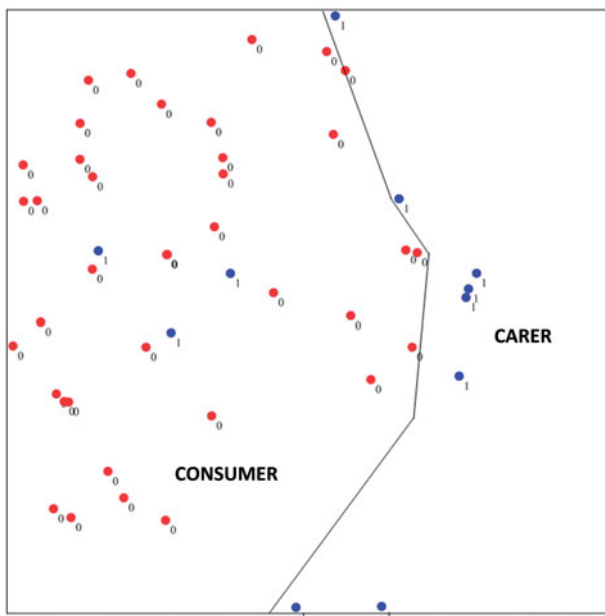


Figure 2. Contact initiator.

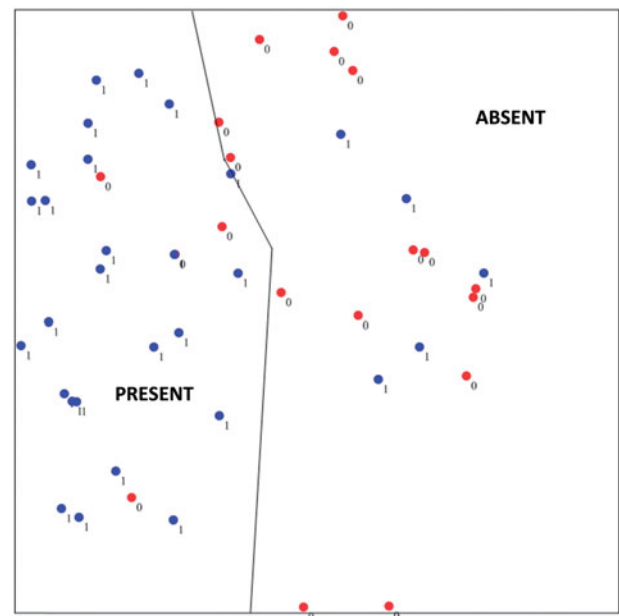


Figure 4. Reported fears.

who reported a sense of fear. Further superimposing Figure 3 (facilitate communication), and Figure 5 (advocate attend meeting/liase with health professionals) revealed that mental health consumers, who reported a sense of fear, typically wanted advocates to communicate on their behalf with health professionals, either through attending meetings between the consumer and health professionals or contacting health professionals outside of meetings. In essence, the sense of fear motivated consumers to contact the advocacy service in the hope that advocates could intervene on their behalf through effective communication with health professionals. Moreover, when Figure 6 (issue resolved) is superimposed over Figure 5 (advocate attend meeting/liase with health

professionals), it is evident that the intervention of the advocate was invariably successful in terms of achieving mental health consumers' desired outcome.

The superimposition of Figures 7 (consumer legal status), 8 (setting), 9 (request for legal support), and 4 (sense of fear) further delineates key relationships between these variables. Almost all of the inpatients that contacted the advocacy service were of voluntary status and reported a sense of fear. Interestingly, almost all of the mental health consumers who asked the advocates to assist with legal issues were located in the community and had an involuntary status. This relationship suggests that involuntary inpatients do not tend to contact advocacy services for legal support, and among those of

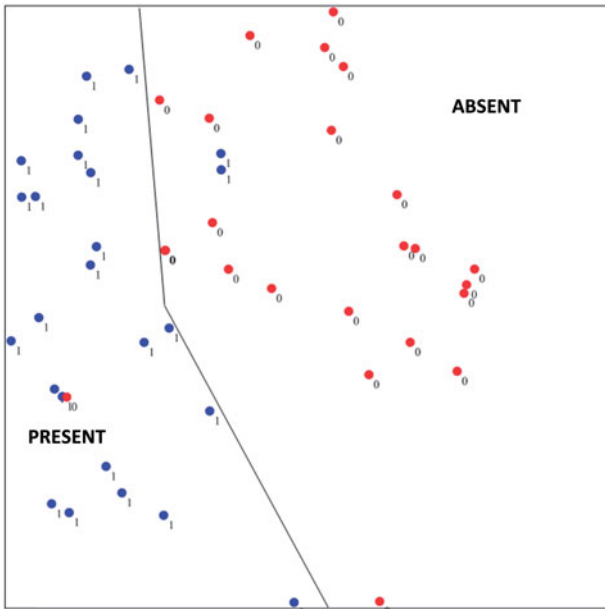


Figure 5. Advocate action needed.

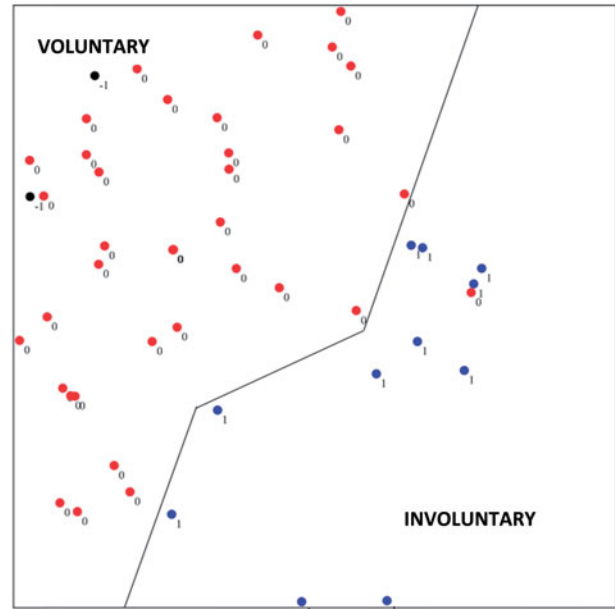


Figure 7. Consumer legal status.

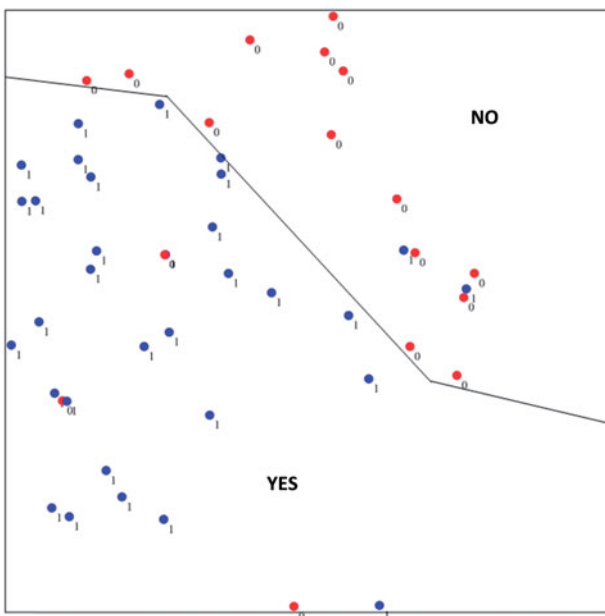


Figure 6. Issue resolved.

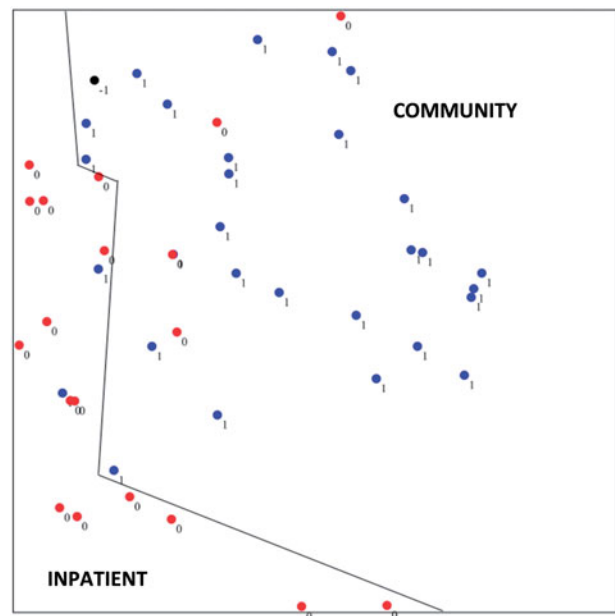


Figure 8. Setting.

involuntary status it tends to be only consumers subject to community treatment orders who contact advocates for assistance with legal issues.

Figures 10 (medication concern), 11 (detainment concern), and 12 (other issues concern) partitioned the space in a horizontal manner, producing another set of relationships. An inspection of these figures revealed that medication, detainment, and other issues (medical records, basic necessities, change of care) were all distinct concerns. In addition, superimposing the figures indicated that consumers with concerns about medication also tended to have concerns about other issues, but consumers with concerns about detainment were generally unconcerned about medication

and other issues. When Figure 6 (issue resolved) is superimposed on these three figures, it is clear that most of the concerns about medication and detainment were resolved while most of the concerns about other aspects of care remained unresolved. In essence, the concern about detainment is quite different from the concerns about medication and other facets of care, and the latter appears to be an area where resolution may be more difficult to achieve from the advocate's perspective.

Finally, the gender variable was not included in the MSA because when it was included no clear partitioning of the space resulted. Gender in the instance refers to the mental health consumer seeking advocacy themselves or the person

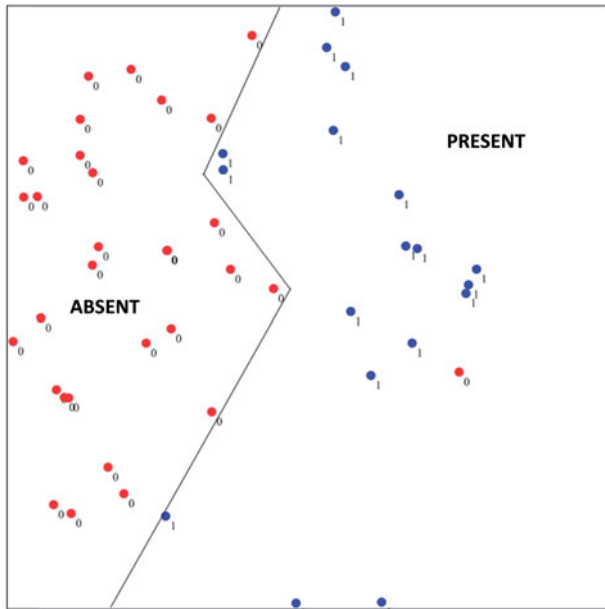


Figure 9. Request for legal support.

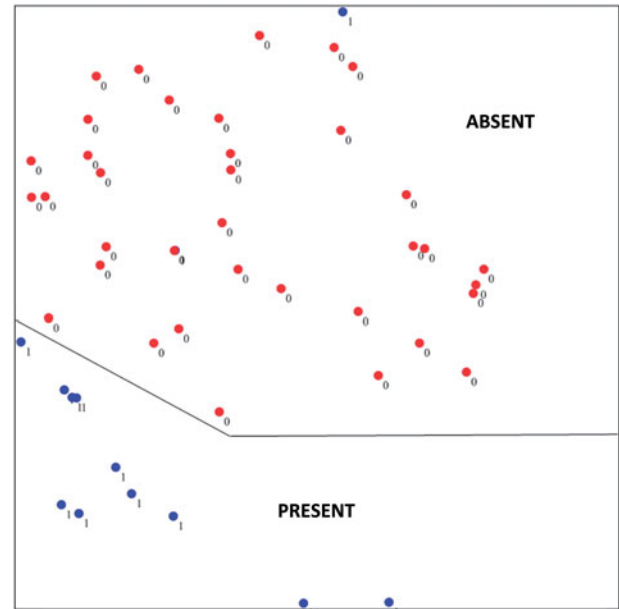


Figure 11. Concern: detention.

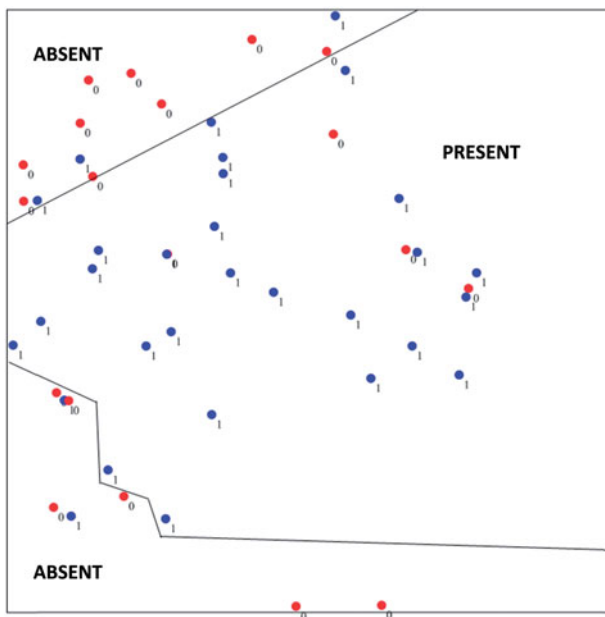


Figure 10. Concern: medication.

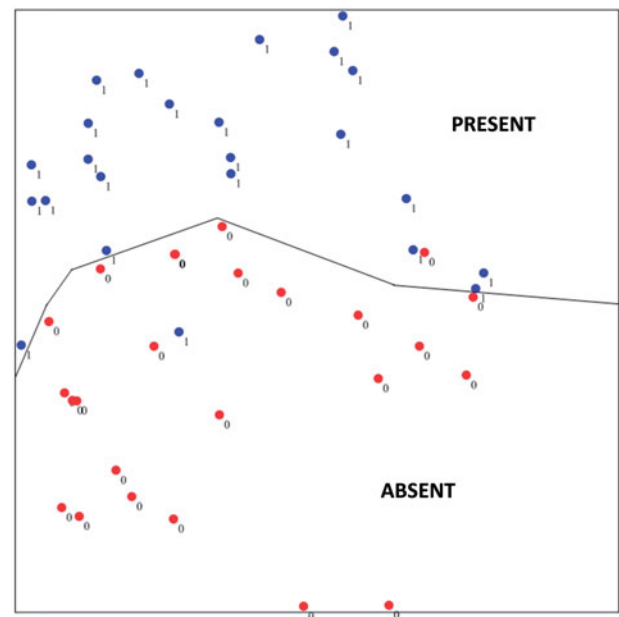


Figure 12. Concern: other issues.

for whom a carer is seeking advocacy. Of the 57 records used, 43 (75%) were female and 14 (25%) were male.

Discussion

The findings of this study extend prior research in several respects. Previous studies have found that mental health consumers' uptake of advocacy was influenced by factors that included knowledge of entitlement (Newbigging et al., 2007, 2012), health professionals explaining access to advocacy services (CQC, 2010, 2014), and the establishment of

partnerships between advocacy services and minority organisations (Rai-Atkins et al., 2002). Our findings build on those studies through demonstrating that one of the primary determinants of seeking advocacy support was a sense of fear, which led to mental health consumers asking advocates to contact health professionals on their behalf. Finding that one of the main roles of advocates was to facilitate communication between consumers and professionals was consistent with recent research in this field (McKeown et al., 2014). However, the results of this study augment prior research in establishing that advocates in liaising with health

professionals successfully resolved most of the complaints of mental health consumers. The typical resolution of concerns may to some extent explain the increase in empowerment and wellbeing mental health consumers have reported after using advocacy services (Mind, 2006; Palmer et al., 2012; Stomski et al., 2015).

A particularly troubling finding of the present study was the sense of fear that vulnerable consumers experienced within the healthcare system. Many consumers feel anxious and exposed as a result of their mental health problems. It might be expected that the healthcare system would provide a place of safety and support physically and emotionally. Clinicians might argue that the fear is almost entirely symptomatic. However, as our results have demonstrated, the intervention of the advocates usually resolved the issue that was evoking fear, which suggests that the actual provision of care was a contributing factor. This begs the question of how the issues that elicit fear could be better managed in clinical or community settings.

Our findings indicated that the sense of fear mental health consumers experienced was not related to any one particular concern, and neither was it associated with an involuntary or voluntary status. Especially surprising was the fact that voluntary consumers were fearful, since the nature of voluntary status means that consumers can withdraw from treatment at any point in time. The sense of fearfulness needs to be explored carefully—what exactly are the sources of fear that elicit this feeling in consumers and how can these be managed within the caring environment? A failure to address the fear issue is likely to impede the recovery process.

Another important concern identified in the results was that many mental health consumers located in the community, and of involuntary status, contacted the advocacy service for legal assistance. These findings highlight the fact that consumers in the community were drawing on the support of advocates in challenging community treatment orders. Such actions are unsurprising, given the high rate of use of community treatment orders in Australia (Light et al., 2012), the imposition on civil liberties (O'Donoghue et al., 2016), and the general lack of effectiveness of these orders in improving consumer outcomes (Kisely & Campbell, 2015; Maughan et al., 2014; Stroud et al., 2015). Considered together, these issues suggest that alternative approaches to care within the community need to be explored.

Of the three main areas of consumer concern highlighted in the records, the more general “other issues” of care was the most difficult area to resolve. The “other issues” variable captured concerns that included access to medical records, accuracy of medical records, availability of basic necessities, and change of treatment setting. Given the tendency for these concerns to remain unresolved, it may be valuable to examine the nature of these in more detail in the future, and explore avenues through which they might be addressed in clinical settings.

At face value these concerns may seem somewhat trivial when compared with the potentially distressing issues of medication and detainment. However even these “less serious” issues need to be attended to in clinical settings as they reflect respectful care. Not to do so can leave the consumer feeling diminished and unworthy of professional

care and unlikely to engage constructively in their care and decision-making (Stomski et al., 2015). Moreover, a failure to address these consumer concerns effectively may reflect a culture of an uncaring service. It would be beneficial therefore to systematically document the most effective approaches advocates use to resolve the concerns of consumers and carers to ensure these specific interventions are refined, practiced, and shared with others for training purposes.

Finally, the disproportionate number of females seeking advocacy in the sample of records used here was surprising as the distribution of males and female gender indicators for mental disorders presents quite a different picture (Australian Bureau of Statistics, 2013). This may be an artefact of the particular sample or simply reflect the people who seek advocacy.

Limitations

All records are limited to some extent; particularly, as the record taker's subjective views may influence the captured details and the nature of record taking typically requires that details are presented in a shorthand form. Reflexive skills, acquired through training and experience, can mitigate the influence of preconceptions on recorded details, but subjective views may still subtly shape the data. However, in the context of this study, the primary purpose of record taking is to highlight why advocacy was sought and what was done to address this need. Thus, the records should have captured these key details and provide useful material for careful analysis. Finally, our research team did not include mental health consumers and therefore it is unclear if the issues we identified and prioritised as important would be viewed in the same manner by consumers. As such, it would be beneficial to formally include consumers as co-researchers in further studies of mental health advocacy to ensure that the concerns investigated and the resulting narratives are in keeping with the needs and perspectives of consumers. Moreover, mental health policy in both Australia and other developed countries calls for the participation of consumers in research, which further highlights the importance of formally drawing on the perspectives of mental health consumers in developing study protocols and informing the interpretation of research findings (Commonwealth of Australia, 2009; Omeni et al., 2014).

Conclusion

An analysis of the official records of advocacy services provided to consumers can be a useful source of review to better understand the consumers' experiences within the mental health care system, and the nature and value of advocacy services to those consumers. The records revealed that advocates intervened effectively on behalf of mental health consumers in the majority of cases and helped to maintain the rights of individuals who are often vulnerable and marginalised and who may see themselves as lacking in personal agency. The fact that most consumer concerns were resolved after the intervention of advocates demonstrates that the concerns were often legitimate and not the result of a lack of insight or illness symptoms. Given this, health professionals might wish to consider exploring how they respond when consumers or carers raise genuine concerns or challenge

the views of the health care team when decisions about their care and treatment are reviewed.

Declaration of interest

No potential conflict of interest was reported by the authors.

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