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How Do We Know It Works? Mental Health Service Evaluation, Recovery and Routine Outcome Measurement

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The introduction of standardised instruments to measure the outcomes of mental health services is now well advanced in Australia. At the same time, consumer participation in all aspects of mental health service delivery, including evaluation, is now firmly positioned with Australian mental health policy. However, considerable evidence now exists to support the view that consumers have not been active participants in the development and implementation of routine outcome measures, and that the instruments used do not necessarily reflect consumer priorities. The aim of this paper is to discuss consumer participation in the evaluation of services in relation to the introduction of routine outcome measurement. More specifically this discussion is set within the context of the recovery movement, and the inherent incompatibility between outcome measurement and the recovery movement is explored.

Keywords: Consumer participation, Evaluation, Outcome measurement, Recovery

Introduction

Few would disagree with the necessity and importance of evaluating mental health services in order to ensure they are successful in making a positive contribution to the health and well-being for the service users. However, the means for determining success or otherwise is highly controversial. In Australia the discussion seems to be deeply immersed in the apparent contradiction between the introduction of routine outcome measurement (ROM) involving little or no consumer participation, and the empowerment of consumers as active contributors to the evaluation process (Lakeman, 2004).

The apparent contradiction between ROM and consumer participation is not necessarily obvious. Indeed it may be assumed that ROM provide a opportunity for consumers to participate, particularly with the inclusion of the BASIS-32, the consumer-rated scale (Eisen, Dill, & Grob, 1994). However, the findings from two reports commissioned by the Victorian Government (Graham et al., 2001; Miller et al. 2003) suggested significant problems with the existing measures being used. Miller et al. (2003) agreed that the BASIS-32 included domains of interest to consumers but were extremely limited with the issues considered pertinent by consumers extending well beyond those captured by ROM. The recommendations of both reports included the development of one or more additional measures. These measure(s) should reflect a high level of consumer and carer involvement at each stage of the process to ensure that the interests of these groups were adequately covered by the instrument developed.

Despite having invested considerable resources in the commissioning of these two reports, the Victorian Government has not only failed to act on these recommendations, it has subsequently committed considerable funding to increasing the completion of ROM by facilitating consumer and clinician compliance with the existing measures, or in short by 'selling' ROM. Arguably this money could have been more appropriately expended by exploring more consumer-focused approaches to the measurement of outcome.

The development of consumer outcome measures has been a priority area for Commonwealth and State Governments for over a decade. Although valid and reliable measures have been developed, consumers have not had an integral part in this process. The aim of this paper is to consider the issue of ROM within the context of recovery and consumer participation in the evaluation of mental health services in order to encourage the debate to continue in order to work towards a more consumer focused mental health service delivery framework. This will include a discussion of consumer participation in the evaluation of mental health services, the concept of recovery and the extent to which ROM has supported the inherent underlying principles.

Consumer Participation in the Evaluation of Mental Health Services

Over the last two decades there has been an international movement towards the empowerment of consumers and their carers to become active participants in the provision of mental health services (Goodwin & Happell, 2006; Lammers & Happell, 2003; Lammers & Happell, 2004; Weinstein, 2006). Australian Government policy clearly articulates consumer participation as a priority area (Commonwealth of Australia 1992; 1997; 1998). Indeed, one of the 11 National Standards for Mental Health Services comprises a complete section devoted to the promotion and implementation of consumer and carer participation in mental health services. Among the requirements of services in this domain is the inclusion of consumers and carers at every level of Mental Health Services, including evaluation (Commonwealth of Australia, 1997).

It is interesting to note that despite espousing consumer participation as a paradigm, there has been a paucity of research to explore the extent to which the policy rhetoric has become reality. The findings of one qualitative study (Tobin, Chen and Leathley, 2002) suggested the consumer participants had been afforded only very limited opportunities to participate in mental health services at either the micro or macro level. Lammers and Happell (2003) found the experiences of consumers in relation to participation varied considerably. While some participants considered their views and opinions were generally respected and valued by health care providers, a number of others described barriers to genuine participation. The attitudes of mental health professionals in particular have been recognised as a major barrier to consumer participation.

In terms of evaluation more specifically, there is mixed evidence as to whether the rhetoric of greater consumer involvement has been matched with their active participation. The review of the literature suggests a degree of involvement is evident (Chapko, Borowsky, Fortney, Hedeon, Hoegle, Maciejewski, 2002; Eales, Callaghan, & Johnson, 2006; Howard & El-Mallakh, 2001; Poulton, 1999; Weinstein, 2006). In the Eales et al. (2002) evaluation of a liaison mental health service, for example, consumers (n = 17) were interviewed, along with professional stakeholders, about what aspects of the service were important to them. Howard and El-Mallakh (2001) described how former consumers were trained to collect data from consumers using a survey tool and face-to-face interviews. The researchers perceived that involving former consumers in the evaluation would increase the validity of the data because participants would be more likely to provide open and honest feedback than would likely be the case if the interviews were conducted by health professionals, a point consistent with the views of Gill, Pratt and Liberera (1998).

However, the involvement of the consumers in these examples has been limited. Essentially, they have been used either as sources of data and data-collectors rather than having active involvement in the conception and design of the evaluation, as well as in the analysis and interpretation of the data. This would suggest there is still some considerable way to go before active consumer involvement in mental health service evaluation is achieved.

A large-scale project was undertaken in New South Wales to develop a framework to facilitate consumer evaluation of mental health services (Viney, Oades, Strang, Eman, Lambert, Malins, Morland, K., & Tooth, 2004). Consumer involvement was fundamental to this project at all stages as stated in the report:

The difference between this project and other projects, and what makes it unique, is that the consumers were not only employed and trained as researchers and collaborators, they actively drove the development of the Evaluation Framework ... Such an approach requires privileging the knowledge that comes from the lived experience of mental illness and hence valuing this 'expert' knowledge in a similar vein to 'expert' professional and academic knowledge (p.3).

The consumers involved in the project were trained as researchers and provided with adequate support to ensure that their potential for involvement could be fully realised.

A subsequent project also conducted in New South Wales known as MHCopes (NSW Department of Health, 2006), developed a four stage framework to facilitate consumer participation in quality improvement within mental health services. The involvement of consumers and carers was central at each stage. The benefits of this approach go beyond the development of the framework. The successful outcomes of the MH-CoPES project, clearly demonstrate the capacity for consumers to have an active role in the evaluation of mental health services.

Promoting recovery

The consumer movement has propagated the notion of recovery as a different way to consider the impact of mental health services to that espoused through the outcome measurement approach (Ralph, 2000). The importance of recovery for people experiencing a mental illness was described by Deegan (1996) as:

... rooted in the simple yet profound realisation that people who have been diagnosed are human beings.

By starting with an appreciation of consumers as human beings, services providers become more likely to appreciate the right and ability of consumers to be active participants in the delivery of mental health services and subsequently in determining whether or not they have been successful in achieving these aims. Many different explanations of the meaning of recovery for consumers have been documented in the literature (Ralph, 2000). Essentially recovery is considered a unique experience for each individual, as expressed in the following quote by Anthony (1993: 13):

... [recovery is] a deeply personal, unique process of changing one's attitudes, values, feelings, and goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness.

Recovery involves the development of new meaning and purpose in the life of the individual diagnosed with a mental illness. Increasingly recovery is considered an important aspect of high quality mental health services (Borg & Kristiansen, 2004; Davidson, O'Connell, Tondora, Styron & Kangas, 2006; Jacobson & Greenley, 2001; Mancini, Hardiman, & Lawson, 2005; Reberio Gruhl, 2005; Resnick, Rosenheck & Lehman, 2004).

Routine outcome measurement – a tool to promote recovery?

There are widespread problems with the rates of completion, i.e., response rates are poor for a number of these measures. Therefore, there would be significant issues associated with the interpretation of analyses performed on the available data, if that were to occur.

Furthermore, the information being gathered routinely is not being used appropriately and/or to its full extent, although it is acknowledged that this varies between States and Territories of Australia. There is a view that simply measuring outcomes, in and of itself, does not assist with the improvement of consumer outcomes (Lakeman, 2004). This view was supported by the results of a randomised controlled trial in the UK (Slade, McCrone, Kuipers, Leese, Cahill, Parabiaghi, Priebe & Thornicroft, 2006). The study found cost savings primarily associated with reduced inpatient admissions for the experimental group, but no difference in outcomes as perceived by the consumers themselves.

If information gathered from ROM is to be useful it needs to be converted into a digestible format (clear, constructive feedback) before it is of any use to services and the consumers who they aim to assist. At present, the time and resources spent on assessing outcomes does not realise any specific benefits to either consumers or clinicians and this will continue unless governments and/or services are actually prepared to facilitate the analysis and interpretation of routine outcome assessment data. While the analysis of data has commenced (Pirkis et al, 2005) as yet there is no clear pathway identified to ensuring this information is received by consumers and clinicians.

However, perhaps of greatest importance, Lakeman (2004) argues that rather than promoting recovery, ROM present a significant impediment to recovery-based nursing care. He describes the time clinicians (largely nurses), take to complete ROM as time that could be better invested in strengthening the consumer-clinician relationship. Enhanced communication is considered an essential element of a recovery-based approach.

Furthermore, Lakeman (2004) criticises ROM as potentially:

... positively damaging if nurses in practice shift their focus from attendance to the person's experience to reducing and measuring it. Little is gained by reducing a person's story to a 12 four item ordinal scales and further reducing these to behaviours, impairment, symptoms and social functioning (p. 213).

It would appear from Lakeman's (2004) work that he does not advocate for the introduction of an alternative or additional outcome measures. Even if such measure(s) were developed as a consequence of rigorous consumer involvement, Lakeman would appear likely still to consider this a largely bureaucratic exercise which detracts from the individual relationship necessary to promote recovery.

This view concurs with the findings of a recent qualitative study exploring consumer perceptions of ROM (Happell et al., 2007). The participants were highly critical of ROM, and expressed a strong preference for service providers to create mechanisms to enable consumers to directly feedback their experiences with services and have these considered and responded to. Such an approach was considered far preferable rather than requiring consumers to complete forms with no apparent changes to services made in response to the data provided.

Conclusions

While policy documents refer to the right and expectation that consumers of mental health services have a significant role in the evaluation of the services they receive, there is a paucity of literature addressing the extent to which this is realised in reality. The literature on this topic suggests that the outcome measures used routinely in Australia do not necessarily measure the aspects of care and treatment considered useful or beneficial by consumers. In particular the ROM currently used were not developed in

collaboration with consumers and subsequently do not reflect the process of recovery valued by service users. It has been argued in this paper that ROM present a barrier to the adoption of consumer-focused, recovery-based care, and that the resources currently invested in ROM could be more appropriately directed towards facilitating genuine consumer participation in the evaluation of mental health services.

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