WHO Regional Office for Europe

Empowerment in Mental Health – Working together towards Leadership

A meeting in partnership with the European Commission

Hosted by EUFAMI

27-28 October 2010, Leuven, Belgium

Self-management of mental health problems

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Summary

This paper sets out our current understanding of self-management among mental health service users and how this relates to empowerment. It provides a brief summary of some of the more recent literature and evidence, cites some examples of existing national policies that have an impact on self-management and identifies potential ways forward.

Background

WHO has defined empowerment as: the level of choice, influence and control that users of mental health services can exercise over events in their lives (WHO & EC, 2010). Self-management is one of the key developments that allow this to happen within the context of the care and treatment that traditionally is entirely controlled by clinicians.

Self-management is about putting patients (service users) in direct control of managing their conditions. There are a number of approaches to self-management but they tend to focus on enabling the patient to cope in one or more of the following areas: problem solving, goal setting, identifying triggers and indicators of deteriorating health and responding to these themselves before relying on clinician-led intervention. The common theme is a structured approach that develops over time through experience so that the patient takes more control over identifying changes and making an initial response to them. Peer support builds on this approach by encouraging group work and mutual support enabling people to draw on each other's experiences.

Self-management has been developed for a range of long-term medical conditions. The Stanford Patient Education Research Centre[1] has developed a wide range of evidence-based interventions for a number of chronic health conditions. Their programmes are aimed at physical rather than mental ill health and their models have been widely adopted, for example, in Spain and the United Kingdom.

This approach has been much less widely used in relation to mental ill health. Psychoeducation for bipolar disorder (formerly manic depression) has been developed by the Bipolar Disorders Programme of the Institut d'Investigacions Biomèdiques August Pi i Sunver (IDIBAPS), Hospital Clinic, Barcelona (Colom & Vieta, 2004) to help people understand and manage their own mental ill heath more effectively. It was designed and is delivered by clinicians. MDF The BiPolar Organization has been running self-management training for people with bipolar disorder since 1998. The MDF course was developed and is delivered by people with a diagnosis of bipolar disorder. The course is well regarded by people who have taken it but it has not been formally evaluated. In Japan, a randomized

[1] Information available at: http://med.stanford.edu/patienteducation/

control trial of a self-management intervention was successful in helping people in the move from institutional care to community care (Naoki, Nobuo & Emi, 2003). There is also evidence on self-management in eating disorders from a European multicentre study using computer-based cognitive behavioural therapy (Carrard, Rouget, Fernandez-Aranda, Volkart, Damoiseau & Lam, 2005). In 2009, the Mental Health Foundation launched a self-management training intervention in Wales. This training, which was developed and is being delivered by people with a range of psychiatric diagnoses (typically schizophrenia, personality disorders, bipolar disorder or severe long-term depression) is more *life skills* than *condition management* orientated. This programme will be subject to long-term evaluation as it proceeds.

Policy implications

Although empowerment is clearly at the heart of developing practice across the WHO European Region, there are other key policy areas in which self-management could contribute significantly.

Deinstitutionalization

Most European countries have policies on developing community-based services and reducing the use of large psychiatric hospitals (WHO, 2008). Reduced reliance on institutional care can only be achieved by replicating it in community settings and reducing access to it at institutional level or by some combination of both. If more evidence emerges that self-management can ease the transition of care from institution to community, it should be included in any related policy (Naoki, Nobuo & Emi, 2003; Stevens & Sin, 2005; Davidson, Chinman, Sells & Rowe, 2006; Hyun, Nawka, Kang, Hu & Bloom, 2008). Countries where the preparation of patients for community life includes patient training should ensure that this training is evaluated in order to increase knowledge in this area.

Social inclusion, recovery and personalization

Social inclusion has become a priority for many European countries (WHO, 2008). Most recognize the disability and disadvantage brought about by mental ill health. Some countries are now talking of a "recovery model" for mental health services. Definitions vary and, in particular, that for "recovery" according to whether it is defined by professionals (clinicians decide when people have recovered), in relation to work/benefit status (here recovery means the possibility of returning to work) or by the individuals themselves (for samples of the

discussion see Jenkins et al, 2007; Pilgrim, 2008; Lal, 2010). Some go further still and talk of personalization in general; direct payments, in particular, are being used where health economies are operating at a micro level (these are relatively rare across the WHO European Region). All these approaches rely on collaboration between statutory agencies and, in many cases, collaboration with, for example, employers or educational establishments.

A number of self-management approaches (for example, the Expert Patient Programme in England and the Mental Health Foundation work in Wales) are centred on goal-setting or problem-solving techniques. Many of the goals and problems identified by participants are not directly related to illness, symptoms or treatments. There is some evidence that these approaches may improve clinical practice and outcomes (Clarke, Crowe, Oades & Deane, 2009). Goal setting may also have a role to play in helping to evaluate the effectiveness of a range of mental health services in meeting the needs of the service users (MacPherson, Jerrom, Lott & Ryce, 1999; Sestini, 2010).

Promotion of mental health, prevention of mental illness and tackling discrimination and stigma

The promotion of mental health and the prevention of mental illness form part of national policy in a significant number of European countries (WHO, 2008). Targeting families and vulnerable groups is an important aspect of this. Peer support has been found to be effective in reducing post-natal depression (Dennis, Hodnett & Reisman, 2009). Self-help and active participation in service user groups have also been shown to have health and mental health benefits (Banres & Shardlow, 1999; Cuijpers, 1997). There are also specific self-management interventions to reduce or prevent recurrence of mental ill health (Stevens & Sin, 2005).

A significant number of countries have national antidiscrimination or antistigma programmes though the majority have not been evaluated (WHO, 2008). Self-management initiatives that put the service user in the role of expert are likely to help challenge existing perceptions and enhance the reputation of people with a psychiatric diagnosis as being capable citizens (Thornicroft, 2006).

Conclusions and recommendations

Self-management is about transferring the focus from treating a condition or illness to enabling people to live with it in the long term. Within the context of mental ill health, the focus does not have to be on a diagnosis or a particular illness; rather it can be on how to respond to the obstacles faced by the individual, whether these are viewed through a neurological, biochemical, psychological, social or spiritual lens.

Self-management is neither pro- nor antipsychiatry, nor is it the preservation of any particular ideology. For many people, the classic narrative following a psychiatric diagnosis is one of hopelessness, lack of self-esteem, loss of life opportunities and loss of control. Dealing with mental ill health and its many consequences is a challenging experience for which there is nothing to prepare people. Historically, clinicians and services have focused on managing symptoms and relieving suffering. Self-management offers the opportunity of enabling people to rebuild their lives within the context of living with mental ill health. It is a structured approach to transferring control back to individuals; it should improve clinical relationships by making partnerships more equal; it should also improve the way in which individuals and their carers work (and live) together by providing a framework for constructive, caring relationships.

Although self-management is a well-established and evidence-based approach to a number of long-term medical conditions, it is still a relatively new one for people with psychiatric diagnoses, particularly those regarded as more severe. Much promising work is in progress and there is a small but growing evidence base, which is certainly enough to recommend expanding the availability of self-management. Much more research is needed, however, particularly into the potential economic benefits of self-management.

References

Banres & Shardlow (1999). From passive recipient to active citizen: participation in mental health user groups. *Journal of Mental Health*, 6(3): 289–300.

Carrard I, Rouget P, Fernandez-Aranda F, Volkart AC, Damoiseau M, Lam T (2005). Evaluation and deployment of evidence based patient self-management support program for bulimia nervosa. *International Journal of Medical Informatics*, 75: 101–109.

Clarke SP, Crowe TP, Oades LG, Deane FP (2009). Do goal-setting interventions improve the quality of goals in mental health services? *Psychiatric Rehabilitation Journal*, 32(4):292–299.

Colom, F., & Vieta, E. (2004). Improving the outcome of bipolar disorder throughnon-pharmacological strategies: the role ofpsychoeducation. *Rev Bras Psiquiatr*, *26* (Supl III), pp. 47–50.

Cuijpers, P. (1997). Bibliotherapy for unipolar depression: a meta analysis. *Journal of Behaviour Therapy and Experimental Psychiatry* (28), 139–147.

Davidson L, Chinman M, Sells D, Rowe M (2006). Peer support among adults with serious mental illness: a report from the field. *Schizophrenia Bulletin*, 32(3):443–50.

Dennis CL, Hodnett E, Reisman HM (2009). Effect of peer support on prevention of postnatal depression among high risk women: multisite RCT. *British Medical Journal.*

Hyun JK, Nawka P, Kang SH, Hu T-W, Bloom J (2008). Recovery- and Community-Based Mental Health Services in the Slovak Republic. *The International Journal of Psychosocial Rehabilitation*, 13(1):67–80.

Jenkins R, Lancashire S, McDaid D, Samyshkin Y, Green S, Watkins J et al (2007). Mental health reform in the Russian Federation: an integrated approach to achieve social inclusion and recovery. *Bulletin Of The World Health Organization*, 85(11):858–866.

Lal S (2010). Prescribing recovery as the new mantra for mental health: does one prescription serve all? *Canadian Journal Of Occupational Therapy*, 77(2):82–89.

MacPherson R, Jerrom B, Lott G, Ryce M (1999). The outcome of clinical goal setting in a mental health rehabilitation service. A model for evaluating clinical effectiveness. *Journal of Mental Health*, 8(1):95–102.

Naoki K, Nobuo A, Emi I (2003). Randomized controlled trial on effectiveness of the community re-entry program to inpatients with schizophrenia spectrum disorder, centering around acquisition of illness self-management knowledge. *Seishin Shinkeigaku Zasshi (Psychiatria Et Neurologia Japonica)*, 105(12):1514–31.

Pilgrim D (2008). 'Recovery' and current mental health policy. *Chronic Illness*, 4(4):309–310.

Sestini P (2010). Epistemology and ethics of evidence-based medicine: putting goal-setting in the right place. *Journal of Evaluation in Clinical Practice*, 16(2):301–305.

Stevens S, & Sin J (2005). Implementing a self-management model of relapse prevention for psychosis into routine clinical practice. *Journal of Psychiatric and Mental Health Nursing, 12* (4), 495–501.

Thornicroft G (2006). *Actions Speak Louder... Tackling Discrimination against people with mental illness.* London, Mental Health Foundation.

World Health Organization (2008). *Policies and practices for mental health in Europe – meeting the challenges.* Copenhagen, WHO Regional Office for Europe.

World Health Organization & European Commission (2010). *User Empowerment in Mental Health: a statement by the WHO Regional Office for Europe* (http://www.euro.who.int/__data/assets/pdf_file/0020/113834/E93430.pdf).

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