

## REVIEW

# Recovery, self management and the expert patient – Changing the culture of mental health from a UK perspective

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### Abstract

*Background:* Self management approaches with mental health problems have been developing recently through *condition-specific* courses, e.g., the Manic Depression Fellowship Course, Rethink Self Management Course and *generic* courses, e.g., the Wellness Recovery Action Plan (WRAP) and the Expert Patient Programme. These approaches have been service user led and developed and are now beginning to be taken seriously by mental health professionals.

*Aims:* To trace the development of recovery and self management approaches in the UK and abroad and to explore whether self management models transferred from physical health are helpful for mental health.

*Results:* Programmes for recovery derived from physical illnesses cannot be implemented in mental health without some changes and disorder specific self management programmes are complementary rather than alternatives. Both have their advantages and disadvantages. In particular, models which are professionally led are not only less attractive to service users but also seem to “lend responsibility” rather than sharing it.

*Conclusion:* Self management models derived from a recovery model and service users’ experiences may have more value than models derived from physical health.

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Many of the skills required to manage their lives and their emotional distress can be acquired once people begin to believe in their own capacity to recover, to develop self belief. Self managed care may include a range of strategies; including holistic remedies, spirituality, physical exercise, creativity and medication. . . . We could see how to protect ourselves better and begin a kind of practice of natural protection. I am talking about the ordinary things people tend to do when they have a good life. I mean some of the things you may take for granted – like being kind to yourself, getting enough rest, some exercise, eating nutritious food, having little treats, having fun. What is extraordinary is that for many of us with a mental illness, seeing the importance of these things is a kind of

revelation. They are something we have to learn how to do, and then do almost self consciously, until they become second nature. (Leibrich, 1999: “A Gift of Stories”)

### **Recovery and self management**

In April 2002, in “Discovering Hope for Recovery from a British Perspective” (Allott & Loganathan, 2002), the concept of recovery was described as “only just beginning” to be recognized. Since then, recovery ideas and concepts have been advancing rapidly throughout the mental health community and these ideas have now achieved enough critical mass to significantly change the culture and emphasis of mental health services in a similar way to the ideas of normalization and social role valorization (Wolfensberger, 1983), which accompanied deinstitutionalization. Recovery ideas have their roots in apparently diverse threads of mental health development: person-centred planning approaches, service user and carer involvement, social role valorization, social inclusion, narrative research, radical political pressure groups and self management approaches.

Recovery ideas are not easy. The word itself causes confusion because of its link to “cure”. The diverse ways the concept has been used has not helped, being explained as: “an approach, model, philosophy, paradigm, movement, vision and illusion” (Roberts & Wolfson, 2004). Perhaps the most useful differentiation between cure and recovery is between the ideas of “recovery of *the disorder in the person* and the recovery of *the person* with or without the disorder.” “The role of recovery is not to become normal. The goal is to embrace the human vocation of becoming more deeply, more fully human.” (Deegan, 1988).

Recovery has become a focal point that pulls together at least five strands of current ideas in mental health:

- *Social inclusion* – removing barriers to recovery linked to social deprivation and disadvantage. The Social Inclusion Unit Report (June 2004) is the main vehicle for change in this arena.
- *Service redesign* – developing more responsive services matched to the real needs of people, for instance in the UK through the National Service Framework (NSF) for Mental Health (Department of Health, 1999). The development of crisis resolution, assertive outreach, early intervention teams and the Support, Time and Recovery Workers are examples of a more person centred/recovery approach.
- *Conceptual changes about the nature of mental health problems* – the Hearing Voices Network has challenged the way extraordinary experiences have been perceived. There has been a renewed emphasis on strengths, wellness and the commonality of experiencing mental health problems as a shared human process, rather than an illness.
- *An emphasis on individual, rather than collective solutions* – there has been a renewed interest in spirituality, creativity and unique coping strategies. Though apparently only a subtle change of emphasis, there is potential for a meaningful change in the balance of power between being a “recipient patient” who fits into a “menu” of options on offer, towards becoming the “architect of one’s own recovery”.

#### *Self management*

Self management is one aspect of recovery which begins to translate the heady ideas of recovery and turn them into practical tools of everyday living. Although self management sounds suspiciously mechanistic to many, it does provide a term that most people can

understand and work with across a range of positions within the mental health community. Other terms such as “wellness recovery”, “seeking after wellness”, “personal wellness tools” or “wellness toolbox” are waiting in the wings, but they come from the US and New Zealand and do not yet fit comfortably into every day speak in the UK.

The essence of self management is having what New Zealand researchers into recovery called, “agency”.

Having agency means believing that one can control, or at least influence, the circumstances of one’s life. Even though our lives are affected by external circumstances, believing one does have some control is important to mental health. Alternatively, feeling helpless is inimical to mental health. Agency is a key element in narratives of illness in recovery, because it is integral to the most dramatic moment of narratives, the turning point – when participants truly become the heroes of their own lives and cease to be victims of circumstance or controlled by others, including health professionals. Although support and intervention from others was crucial too, it was important that support stimulated personal initiative, rather than creating dependency. (Lapsley, Nikora & Black, 2002)

Rethink, a UK mental health charity, devised a working definition of self management which reads,

Self-management is something we all do. It is whatever we do to make the most of our lives by coping with our difficulties and making the most of what we have. Applied specifically to people with a schizophrenia diagnosis, it includes the ways we cope with, or manage, or minimise, the ways the condition limits our lives, as well as what we do to thrive, to feel happy and fulfilled, to make the most of our lives despite the condition. (Martyn, 2002)

Given that we have many of the right conditions for a radical shift in control from professionals to individuals, the UK primary care “Expert Patient Programme” would seem to be a timely development to provide a structure for developing self management programmes.

### **The Expert Patient Programme: The UK perspective**

The concept of the “Expert Patient” (EPP) started in the 1970s with Kate Lorig’s patient education programme for arthritis patients in California (Lorig, Mazonson & Holman, 1993). The programme was imported to the UK in 1994 and the Long Term Medical Conditions Alliance funded the setting up of lay-led self management programmes for long-term conditions such as diabetes, heart disease, asthma, arthritis, multiple sclerosis, endometriosis, irritable bowel syndrome, colitis and HIV/AIDS.

In 1999, the Expert Patients Task Force was set up under the Chief Medical Officer, Liam Donaldson. “The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century” (Department of Health, 2001) was published and the Expert Patient project was launched.

Training is offered to lay people with experience of managing their own conditions for 2½ hours per week for six or seven weeks. They are then obliged to deliver at least two courses a year. The model was initially prescriptive and firmly structured.

Mental health featured in the early documentation, specifically citing the work of the Manic Depression Fellowship Self management Programme, which began in 1998. There

were two members of the Fellowship on the Task Force and this may account for its early prominence and some support was given by Primary Care Trusts to the MDF programme.

Since that time, mental health appeared to have fallen behind in the Expert Patient agenda. More recently, the Chronic Disease Management Programme has taken the experience of the EPP and developed a variety of self management options within primary care, including anxiety and depression and, more recently, schizophrenia.

### **Parallel developments in mental health**

While the Expert Patient Programme has been rolled out within the UK health services, a number of significant self management developments have taken place in the mental health field here and abroad.

The “Strategies for Living Project”, run by the Mental Health Foundation, reported in 2000 that: “This report poses a real challenge to the assumptions made every day by medical professionals. We need to start listening to people about what works for them, just as we would if they had diabetes and were managing their own condition”. It recommended that: “mental health organisations disseminate information about the range of strategies that people find helpful, in order to assist people find and develop their own strategies and to locate alternative sources of help” (Faulkner & Wallcraft, 1999).

A series of workbooks published from 2000 under the “Victim to Victor” series (Coleman, 1999, 2003; Coleman, Baker & Taylor, 2000; Coleman & Smith, 2000; Smith, 2003) gave a tool for people to explore and develop their own strategies for recovery. The work of the Hearing Voices Network (Downes, 2001) has had success in overturning prejudice and pessimism and looking at how symptoms can be managed rather than suppressed. Other, more autobiographical books, e.g., on the experience of manic depression (Jamison, 1995) and depression (Lewis, 2002) have added to self management insights.

Other self management tools have been developed under the person-centred planning umbrella: Essential Lifestyle Planning (ELP) (Smull & Burke-Harrison 1996), Personal Futures Planning (PFP), Planning Alternative Tomorrows with Hope (PATH), MAPS, (Pearpoint, O’Brien & Forest, 1993), Safe, Holistic, Integrated Recovery Environment (SHIRE) (Coleman, 2003) and the TIDAL Model (Barker, 2001). Each has something to contribute to self directed recovery.

In New Zealand, the publication of “A Gift of Stories” started a renewal of interest in the stories of people who had experienced severe mental health problems and had discovered their own individual strategies for maintaining wellness. The research project, “Kia Mauri Tau, Narratives of Recovery from Disabling Mental Health Problems” (Lapsley et al., 2002) heard the stories of 40 people and found many common elements of recovery and self management across diagnosis and cultures.

In the UK, Rethink (Martyn, 2002) conducted a similar research project with 48 people with a schizophrenic diagnosis. The “top ten” themes identified in that research in relation to self management were:

- (1) Occupation, including education, voluntary work, work with the user movement, art and creative occupations, and paid employment.
- (2) Relationships with other people, including family and friends and other ‘users’.
- (3) Personal qualities involved in maintaining morale.
- (4) Coping strategies for the experiences of schizophrenia.
- (5) Managing medication, including managing relationships with prescribers.

- (6) Exploring and understanding the experience labelled schizophrenia, including getting information.
- (7) Religion.
- (8) Counselling and psychotherapy.
- (9) Complementary therapies.
- (10) Healthy living, such as diet and exercise.

In Vermont, US, Mary Ellen Copeland came at self management from a different perspective than the research base described above. Basing her work on the recovery principles of hope, personal responsibility, self-advocacy, education and support, she developed a practical way of turning those principles into a self management approach. Having been diagnosed with manic depression, major depression, fibromyalgia and chronic myofascial pain syndrome, she developed an approach which firstly worked for her and then became an approach which “can easily be adapted for use with virtually any chronic mental and physical illness” (Copeland, 1999).

The WRAP (Wellness Recovery Action Plan) (Copeland, 1992, 1997, 1998, 1999, 2002) is a structured approach to self management working in groups with each stage of self management from recognizing what wellness looks like, through identifying early warning signs and triggers to developing a crisis and post crisis plan.

The levels of self management within WRAP range through:

- Increasing awareness at the day to day level of what triggers off small changes that can upset our equilibrium.
- More general ways of ensuring our good health through our lifestyle.
- Signs that things are deteriorating.
- Letting others know what we want to happen and who we want involved if we are in crisis
- Being quite specific about interventions and treatment.
- Semi-legal written advanced directives.

Bringing the discussion back to the UK, there are three main questions that should be addressed as we develop national models for self management in mental health. Firstly, does the EPP model which has derived from self management of physical conditions suit the mental health context? Secondly, do self management approaches designed for primary care fit as well into secondary mental health services? Thirdly, do condition-specific or generic self management approaches best fit the mental health context? Fourthly, are professionally designed or service user designed self management courses more acceptable to service users?

#### *Physical health derived models and mental health specific models*

Whilst the more formal EPP approach may suit specific physical illnesses with fairly well defined parameters, the prescriptive style may not be as well suited to mental health. The content may well cover similar areas as EPP, which are given as:

- Recognising and acting on symptoms.
- Learning techniques that can reduce stress.
- Using medication correctly.
- Getting the most out of health services, by using them as effectively as possible.
- Managing the distress and depression that can come with a chronic illness.

- Taking adequate physical exercise, managing relationships with professionals and family
- maintaining a healthy diet.
- Using community resources. (Department of Health, 2001)

The content may be similar, but the style of learning seems to be different. WRAP style approaches start from the premise that we are all very different and that each self management strategy is valid to the person for whom it works.

The language used in EPP is geared up to physical health problems and does not seem to fit with current mental health language in the UK. An example is from a presentation by Sobel, Director of Kaiser Permanente, California.

Though some of the points made are laudable, the language of disease is still present. Even the improved focus still feels paternalistic.

**Self management approaches applied to secondary care mental health services**

The essence of self management is about retaining control, even in situations where control is most likely to be taken away. There are times when even the best made plan will fall apart or never be used. The Care Programme Approach (CPA) is the method of planning and communicating care plans to ensure continuity of care. In reality, very few plans are sufficiently sophisticated or have enough authority to influence the actions taken in a crisis. Very strong contingency plans/relapse signatures are needed to record the wishes of those involved, which may include the family and other significant people as well as the service user. Henderson, Flood, Leese, Thornicroft and Sutherby (2004) showed that the use of the Mental Health Act was significantly reduced with the use of joint crisis plans, length of admission and number of admissions were also reduced.

Self management approaches offer a process for developing robust crisis plans which can be developed with professionals or others to spell out very clearly what should happen and what should not happen. Approaches which work to a formula such as WRAP, record in the person’s own language a description of what goes right, what can go wrong and what might be helpful responses to both eventualities. This could be applied in key areas of the National Service Framework for Mental Health; in particular, crisis resolution, assertive outreach, early intervention, primary care and admission and discharge from hospital. The new Support Time and Recovery (STR) Workers are required to complete a nationally prescribed induction programme which is based on recovery and self management approaches (Allott, 2004).

Table I. Comparison between traditional care and collaborative care.

Issue	Traditional care/Patient education	Collaborative care/Self- management education
Relationships	Professionals are expert. Patients are passive	Shared expertise with active patients. Patient expert in their experience of disease
Needs assessment	Provider defines what patients need to know	Patient defined problem
Content	Disease management	Disease, role and emotional management
Process	Prescribed behaviour change. Provider solves problems. External motivation. Didactic presentations	Self-defined goals. Patient learns problem-solving skills. Focus on internal motivation and self-efficacy. Interactive
Outcomes	Knowledge and behaviour	Health status and appropriate utilization

Knowing themselves and their limitations well, people were able to enact strategies to keep themselves safe when confronted with stressors or situations of special risk. Most people seemed to feel that they would never return again to the very worst state they had been in, even if subjected to the same stresses. (Lapsey et al., 2002)

### **Condition specific versus generic approaches to self management in mental health**

UK mental health charities such as the Manic Depression Fellowship, Rethink, Depression Alliance, and No Panic have self management programmes currently running or in development. The approach taken by these and other condition specific groups in the UK has been to devise a self management course which suits the particular needs of a group of people who share a similar experience.

The advantages of a condition specific self management course are:

- Evidence-based approaches can be developed and more closely evaluated.
- People with a similar condition can share their self management strategies and provide mutual support in implementing them.
- The process itself creates a self help network for people facing similar pressures .
- There may be greater appreciation within the group of the obstacles to recovery.
- Self management courses for different conditions may require differing levels of safety and pace which can best be achieved in a specific group.

A possible disadvantage of the condition specific group could be segregation from others whose condition may be different but for whom the process of self management may be similar.

The advantages of the generic approach may be:

- People with a variety of helpful or unhelpful labels/diagnoses or no labels at all, can train together, which helps reduce stigma and creates a helpful culture of commonality. Mixed training groups of service users, carers, statutory and voluntary staff have the potential to break down traditional views about the nature and prevalence of mental health problems. They tend to encourage participation and shared learning. This process of joint training reflects the NSF Standard 1 aspiration of reducing stigma and prejudice.
- Generic self management can be used as a foundation approach for mental health teams and services as is happening currently with the STR workers. It could also inform the evolution of the Care Programme Approach and services such as crisis resolution, assertive outreach and early intervention.

Possible disadvantages of a generic approach are:

- Not reaching a sufficiently meaningful level for people with more serious or enduring mental health problems.
- Not achieving the levels of safety and support of sharing with others with whom one may have more in common.

It is clear that both approaches should be encouraged as complementary rather than as alternatives. Both approaches have merit and should have a place in the development of primary and secondary self management strategies. The Expert Patient Programme should

take into account the more flexible approaches needed to fit with the current mental health self management culture.

### **Professionally led or service user-led course design**

Are the aims of self management programmes shared by professionals and service users? Some leaders are both professionals and service users so their credibility is not doubted. The Expert Patient Programme was designed by Kate Lorig, Professor of Medicine and Director of the Patient Education Research Center at Stanford University in California. She has also suffered from Gaucher's Disease from the age of nine. Mary Ellen Copeland had several admissions to psychiatric wards and is also a successful author and teacher. Both have exceptional credibility and have roles as both patient and expert.

People with experience of using mental health services have often been the most effective catalysts for change. Pat Deegan, Judi Chamberlin and Mary Ellen Copeland in the US, Mary O'Hagan in New Zealand, Ron Coleman and Peter Campbell in the UK are just a few of the ex or current service users who have been influential in changing the way wellness, mental health and mental illness are perceived

The role of professionals is seen in recovery literature as that of a companion or fellow traveller rather than as expert. Mental health professionals may see recovery and self management as having been an integral part of their work for many years. Although this is certainly true of many professionals, the change from "caring for" or "case working" to encouraging self management is subtle but significant. Handing back control is not an easy step for all professionals to take, particularly within a risk culture. It is not about abdicating responsibility or abandoning people, but about finding a way of working that fully respects and builds on individual perspectives on wellness and self management. For some, this is an easy transition or no transition at all. For others, it threatens their self perception as experts. An example would be the traditional "case study" approach which has been employed in mental health services highlights the mental health professional who is:

The hero of case studies . . . . who guides the patient towards recovery by providing therapeutic interventions, whether medical or psychotherapeutic. (Lapsley et al., 2002)

Mary Ellen Copeland describes the shift in power differentials.

Mental health workers have to dare to be human and relate in normal ways. Recovery orientated relationships are real and authentic even when different roles need to be played. When mental health workers take power, they take it away from the other person. There are practices, procedures, therapies and physical environments which take away power. The measure of recovery orientated practices would be in the amount of power and control they give or take away. (Copeland & Mead, 2000)

It is very important to recognize the huge value of the treasury of accumulated knowledge from decades of psychotherapeutic, biological and social care work by mental health professionals. Where this becomes useful in self management is when professionals have taken the trouble to translate the key messages from the literature and turn it from "kept knowledge" into "shared knowledge". Through popular self help books and an educational style of therapeutic intervention, professionals and service users over the years have translated complicated theory into digestible wellness tools. Many of the self management

tools have come from this source, e.g., assertiveness, relaxation, cognitive, problem solving, organizational and communication skills. Others have come from spiritual sources, eastern techniques, medicine, dietary information, work and leisure options, philosophy and plain common sense.

Results from the narrative studies show that strategies that work with people with a manic depressive or schizophrenia diagnosis are the same or similar to those that work with the rest of the population. It may be that self management strategies need to be more formal and robust where the consequences of not implementing those strategies are more serious. What is certain is that we need to be listening to those who have experienced serious mental health problems but have managed to live full and satisfying lives despite symptoms that may endure. In the past, professionals have often focused on failure or problems rather than successes.

It is the “Experts by Experience” who may be best placed to help others to keep well because they often have a deeper level of understanding about the nature of mental health distress. Working with the fruits of that experience is what self management is all about. Service user led self management programmes, particularly using WRAP, self management groups run entirely by service users and service user led crisis houses are already a reality and are often seen by service users as more appropriate to their needs. Professional help, treatment or medication may be aspects of a recovery plan, but are only equals among many other ways of maintaining wellness and recovering. A person’s self management is not owned by professionals, but is owned by the individual.

“Leasing” power to service users as “expert patients” is one thing. Handing back power to service users in a real and meaningful way is something else. Is the Expert Patient Programme at a stage of its evolution where it can hand over more power to the expert patient? That could include commissioning service users to design and run their own expert patient courses.

### **An Expert Patient Programme for mental health**

The current Expert Patient Programme may be limited in its applicability to mental health by its style of delivery, restrictions imposed centrally on copyright and the way the course is delivered. There may be more value in self management approaches arising from a recovery philosophy and the experience of service users rather than an adapted physical health model. Similarly, approaches which focus on individual perspectives and solutions may have more value than a prescribed, professionally focussed approach. They may be less predictable and may not fit into the time allocation of the present scheme, but they may have more meaning.

The EPP has developed over time to become more flexible and has run with mixed condition groups. The question is whether it can successfully adapt the current model to the mental health context, or whether a new model, or a choice of models, need to be developed which more faithfully reflect the experience of self managing mental health distress.

### **There’s a Hole in My Sidewalk – Portia Nelson**

1. I walk down the street  
    There is a deep hole in the sidewalk  
    I am lost . . . I am hopeless  
    It takes forever to find a way out
  
2. I walk down the same street  
    There is a deep hole in the sidewalk

I pretend I don't see it  
 I fall in again  
 I can't believe I'm in the same place  
 But it isn't my fault  
 It still takes a long while to get out

3. I walk down the same street  
 There is a deep hole in the sidewalk  
 I see it is there  
 I still fall in . . . its a habit  
 My eyes are open  
 I know where I am  
 It is my fault  
 I get out immediately

4. I walk down the same street  
 There is a deep hole in the sidewalk  
 I walk around it

5. I walk down another street

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