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Title

The Mental Health Expert Patient: Findings from a pilot generic Chronic Condition Self-Management program for people with mental illness

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Background

Less than optimal outcomes and escalating costs for chronic conditions including mental illness have prompted calls for innovative approaches to chronic illness management.

Aims

This study aimed to test the feasibility and utility of combining a generic, clinician administered and peer-led self-management group approach for people with serious mental illness.

Method

General practitioners and mental health case managers used a patient-centered care model (the Flinders Model) to assist 38 patients with serious mental illness to identify their self-management needs, and match these with interventions including Stanford peer-led, self-management groups and one-to-one peer support. Self-management and quality of life outcomes were measured and qualitative evaluation elicited feedback from all participants.

Results

Collaborative care planning, combined with a problems and goals focused approach, resulted in improved self-management and mental functioning at 3 to 6 months follow up. The Stanford self-management course was applicable and acceptable to patients with serious mental illnesses. Qualitative feedback was highly supportive of this approach.

Conclusions

Generic, structured assessment and care planning approaches, resulting in self-management education targeted to the individual, improved self-management and

quality of life. Patients and service providers reported considerable gains despite the challenges associated with introducing a generic model within the mental health and general practice sector.

Introduction

Chronic physical and mental health conditions make up the major health burden internationally (Murray and Lopez, 1996; World Health Organisation, 2002) with comorbidity presenting particular challenges and risks (Coughlan *et al.*, 2001). The United Kingdom's Expert Patient Program (EPP), part of primary care reform (Department of Health United Kingdom, 1999), delivers self-management education to patients at the community level via Stanford chronic condition self-management groups (Lorig *et al.*, 2000). The Chronic Care Model (Wagner *et al.*, 2001) which has been used internationally to implement systems of chronic illness care, includes self-management support as one of its key elements. It stresses the interconnection between medical, role and emotional management of the condition and its impact, and a systematic approach to chronic conditions care. However, mental illness has often been excluded from such initiatives except as a co-morbidity, indicating that a range of alternatives are needed. The Flinders Model of care planning is a way of delivering self-management support, linking the patient with general practice and mental health service provision to address both physical health and mental health issues.

Known as the Noarlunga Chronic Disease Self Management (CDSM) project, the current study was one of four South Australian CDSM projects funded by the South Australian Department of Health in late 2001 and managed by the Flinders Human Behaviour & Health Research Unit (FHBHRU). The study utilized two generic approaches to self-management education, the Flinders Model and the Stanford Model.

Since 1999, Battersby and colleagues at FHBHRU have developed a generic consultation liaison model of CCSM for primary care, underpinned by cognitive behavioural therapy (CBT) principles (Bandura, 1977; Battersby *et al.*, 2003). It has been provided to over 1800 clinicians throughout Australia and applied to a wide range of health conditions. It is a clinician-administered, semi-structured assessment of self-management strengths and barriers, and life problem and goal setting, which results in a 12-month care plan with medical and self-management tasks agreed by the clinician and patient. Its strength is its ability to challenge professional assumptions towards a patient's ability to contribute effectively to the management of their condition. .

Self-management training for patients using the Stanford Model has been in use for more than 20 years and works well within the present traditional doctor/patient relationship. It is a 6-week peer-led generic chronic condition group course which aims to teach patients self-management skills. It has been shown to improve health outcomes and reduce service utilization in several randomised controlled trials though it has not previously been trialed with people with chronic mental illnesses (Commonwealth Department of Health and Ageing, 2003; Lorig *et al.*, 1999; Lorig and Holman, 2003; Lorig *et al.*, 1985).

Most interventions to improve chronic illness care are disease specific and do not address the realities of general practice or mental health services where patients have more than one physical or mental illness. The aim of the Noarlunga 12-month pilot study was to test the feasibility and utility of applying generic chronic condition self-management (CCSM) approaches to a 'real world' community sample of patients

with serious mental illness and co-morbid chronic physical illnesses or risk of these. The combined impact of the Flinders Model of individual collaborative care planning, the Stanford Model and one-to-one peer worker support were studied. This included impacts for the patient, the general practitioner, the mental health case manager and peer workers.

Methods

The rationale for the combined individual and group approach used in this study was that the Flinders model provided an alternative for patients who did not want, need or could not tolerate groups. Many patients clearly stated that being in a group would distress them and aggravate their psychiatric symptoms. Developmental work comprised the formation of separate reference groups for GPs, case managers and peer workers and training in the use of both the Flinders and Stanford Model. Ethical approval for this study was given by Noarlunga Hospital and Flinders Medical Centre Clinical Investigations committees.

The Flinders Model creates a partnership between the patient, GP, and mental health case manager in which the patient is the decision maker and the health care provider, a facilitator, coach and advisor. It incorporates tools which assess the person's current capacities pertaining to the six principles for self-management: 1) Have knowledge of their condition, 2) Follow a treatment plan, (care plan) agreed with their health professionals, 3) Actively share in decision making with health professionals, 4) Monitor and manage signs and symptoms of their condition, 5) Manage the impact of the condition on their physical, emotional and social life and 6) Adopt lifestyles that promote health.

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The third tool, the Problems & Goals (P&G) assessment, is conducted by the health professional who asks a number of open-ended questions assessing the patient's self-identified problem(s) from the patient's perspective. This includes the problem, what happens as a result and how it makes the patient feel. Adapted from the therapeutic assessment and intervention used in behavioural psychotherapy (Marks, 1986), by asking, "What would you like to be able to do that the problem stops you from doing?" it enables the patient to set their own goal (rather than the clinician's goal) and provides motivation toward goal attainment (Locke and Latham, 2002). The patient rates the problem on a 0-8 Likert scale with 8 indicating the highest severity. They then rate the goal on a 0-8 Likert scale with 8 indicating no progress towards achieving the goal. Ongoing assessment of problem severity and goal progress strengthens self-efficacy and motivation (Battersby *et al.*, 2001).

Comment [AW1]: Sharon, which Marks 1986 article are you referring to? We have several

Finally the clinician and patient negotiate a care plan including identified issues (including those identified from the C&R interview), management aims, agreed interventions, who is responsible, date to be reviewed with room to record progress. The clinician is encouraged to include as many other supports as necessary (including family, friends, and other carers) to optimize care (Wagner *et al.*, 1996b). When the agreed upon care plan is completed, both the patient and clinician sign the plan and the patient receives a copy to take to others involved in his/her care.

Peer Educators and Peer Support Workers

Lorig *et al* (1999) have established that volunteers with chronic medical conditions who attended a six-week generic self-management education course about chronic illness had significantly better outcomes in randomised controlled trials and that they

produce stronger self-management outcomes when led by at least one peer educator rather than just by health professionals. In this project, each Stanford course was delivered by two trained peer educators and one mental health case manager. Peer educators were also trained to be peer support workers and provided one-to-one education and motivational support to a number of patients undertaking the individual Flinders Model.

Recruitment

All patients had a DSM IV (American Psychiatric Association, 1994) Axis 1 mental illness as diagnosed by their doctor. Current seriousness and problematic management of patients' conditions were evident with patients receiving ongoing case management from mental health services and/or intensive and frequent care from their GP.

Convenience sampling was used to recruit patients by their case manager, based on the expectation that they may benefit from self-management education. Prior to enrolment, all patients' mental state was assessed by their treating doctor to ensure fully informed consent, voluntariness, and safety to others or themselves. Patient on treatment orders were not excluded. Recruitment occurred throughout the project's 12-month period with demographic data collected for each participant. A case note audit was performed at the conclusion of the project to determine hospital admission rates for the 12 months prior to each patient's participation, the 12 months of the project and the 12 months after the project period. The case note audit also helped to confirm other demographic details where these were not clear from patient self-report.

Mental health case managers known to each patient undertook a Flinders Model assessment with them. A further GP appointment for each patient, with their case

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manager, resulted in the completion of an individual care plan. A small number of patients (n=5) did not have a designated GP or refused to link with one; therefore their case manager undertook the care planning process with them.

The care planning process provided appropriate remuneration for GPs using the existing Medicare item numbers for care planning (Australian Government Department of Health and Ageing, 2004). All patients were encouraged to attend the Stanford course as part of the agreed self-management interventions on the care plan. The remainder were offered targeted self-management education from their case manager or GP and support from a peer worker. Review of the care plan and measuring progress towards set goals was built into the care plan. For many patients, this was the first time that they had regular contact with a GP.

Scoring of the PIH at 3-monthly intervals and the P&G at monthly intervals allowed them to also act as measures of change in self-management over time. The Work and Social Adjustment (WSAS) Scale was administered at 3-monthly intervals and the SF-12 was administered at 6-monthly intervals, acting as standardised measures to further test the efficacy of Flinders Model. The WSAS scale is a 5-item self-rated 0-8 Likert scale measuring disability in areas of work, home management, social leisure, private leisure and family relationships. It was originally developed and validated for mental health populations (Marks, 1985; Mundt *et al.*, 2002). The SF-12 is a self-rating of mental and physical health (Gandek *et al.*, 1998).

Qualitative evaluation

Qualitative evaluation comprised a series of process and outcome data collection throughout the project exploring the impact of the approaches used on patients, GPs,

case managers, and peer workers through a series of focus groups during and at the end of the project. Feedback on the Flinders Model involved the following standardised survey and focus group questions, determined by the project steering group and applied across the participant groups:

- Impact of these approaches
- Aspects found to be most and least relevant
- Perceived barriers to applying these approaches
- Recommendations for change

Pre and post Stanford questionnaires were used to elicit feedback from Stanford course participants, peers and case manager group leaders. Peer workers, providing one-on-one support to patients, kept reflective journals of their experiences of providing support.

Results

This paper describes the main quantitative and preliminary qualitative findings of the study. A full description of the qualitative findings will be described elsewhere.

Continuous recruitment of patients over the 12-months of the project, as would naturally occur with a 'real world' clinical setting, resulted in decreasing numbers of participants available for 6-month follow-up and analysis of data. Thirty-eight patients (21 female and 17 male) were recruited. One male participant dropped out soon after commencing due to moving to another location. Thirty-one patients (18 female and 13 male) were followed up for 3 or more months. The remaining 6 participated in the program for less than 3 months and their data was not included. Thirty-five patients received Flinders care planning, 17 of these also attended

Stanford groups, and 3 attended Stanford groups only. Five patients received peer worker support.

The mean age for males (n=17) was 39 and 46 for females (n=21). All participants had serious mental illness that precluded them from employment and for which they relied on government benefits for financial support. Diagnoses ranged from schizophrenia (n=16), schizoaffective disorder (n=4), bipolar affective disorder (n=5), Major depression (n=8), anxiety disorder (n=4), and personality disorder (n=1). More than half of patients had a second axis 1 diagnosis such as depression, anxiety, or post-traumatic-stress-disorder. The level and severity of chronic illness was further evident in that 21 patients had experienced their mental illness for more than 10 years, while 10 reported more than 20 years of mental illness, the range being from 2 up to 50 years. Education level reached was less than Year 10 (average age 15-16 years) for 15 patients. Most patient (n=20) had attained year 10 or 11 education level. Only 3 patients had completed year 12 and none had completed any tertiary study. All except 3 teenage first episode psychosis patients had broad range of physical health conditions, 22 of them had 2 or more conditions. Obesity, asthma and other respiratory conditions, heart disease and diabetes were common. Almost half of patients lived alone in public rental accommodation (n=17). Twenty-nine patients were single, divorced or widowed, with only 9 in either defacto relationships or married. Most patients (n= 33) reported supports were limited to immediate family members; 5 reported no supports other than their mental health service. These details suggest that most patients were largely isolated in their community and relied heavily on informal carers who they variously had good or not so good relationships with.

A case note audit revealed that no patients requiring hospitalisation during the study period, and patients had fewer admissions in the 12 months post participation (n=4) compared to the 12 months prior to participation in the study (n=16). Eighteen patients experienced no change in admission rates across the 3 year audit period. Of these, 13 had never been hospitalised for their mental illness.

Partners in Health (PIH)

Patients' PIH scores showed significant change on all self-management parameters, particularly in terms of knowledge, lifestyle choices, and managing the physical, social and emotional impact of their condition on their lives. At commencement of the study, there was no relationship between scores on the PIH and the SF-12. However at 6 months a significant relationship had developed between the score on the PIH knowledge subscale and the SF-12 measurement of physical functioning ($r(29)=-0.42, p<0.05$).

Problems and Goals

Problems and Goals ratings demonstrated significant improvements from initial to final assessment. Initial problem ratings indicated a moderate level of problem impact ($m=5.19 \pm 2.02$) which was significantly reduced six months later ($m=3.16 \pm 1.97; t(30) = 4.74; p<0.001$). Similarly, initial ratings of progress towards goals were significantly higher ($m=5.35 \pm 2.26$) than final ratings ($m=3.55 \pm 2.43; t(30) = 4.05, p<0.001$). These patients appear to have made considerable progress in achieving their goals. Final Problems and Goals ratings also showed a positive correlation ($r(32)=0.44, p<0.05$).

SF-12 and WSAS

Changes in the mental health scores showed significant improvement over the 6 month period ($p < 0.001$) whilst there was no significant change in the physical health scores. All patients were on some form of government income support, hence the WSAS domain of work was not appropriate for this sample. However, the WSAS results indicate a clear improvement in social leisure activities ($p < 0.05$) and there were trends to improvement in family and relationships as well as private leisure activities.

Qualitative Results

General impacts of these approaches for each group of participants will be reported here. Results are more fully described elsewhere (Urakalo *et al.*, 2004).

Patients reported feelings of increased hopefulness, control, confidence, motivation and wellness as a result of undertaking the Flinders Model process. The process of embedding the Flinders Model into patient/health professional interactions required substantial reorientation for patients, case managers and general practitioners. Despite this, participation in the project was a powerful experience for these patients and clinicians, whose interaction served to challenge entrenched cultural practices, ways of working, and general expectations of mental health service delivery. In this study, respect for the expertise of each member of the partnership, including the patient, was enhanced. Health professionals reported a surprising shift in their view of the competence and capacity of people who were experiencing a chronic mental illness to self-manage. In turn, patients felt more empowered to become an equal partner and

expert in the management of their health. Several patients continued to be more goal focused and to set further health-related goals beyond the project time frame.

(45yo Female patient with paranoid schizophrenia and obesity, diabetes and asthma)

“I always thought the doctor and social worker knew everything and that my opinions weren’t important. After being asked these questions, I feel I can talk better about my illness and more openly now with my key worker. It would have been good to have been asked these questions years ago when I first got unwell.”

(Social worker with 15 years experience reflecting on using the Flinders model with a 45yo patient with paranoid schizophrenia and significant psycho-social problems who had been receiving longstanding support from the mental health services. This patient achieved his goals of reducing his abuse of side effect medication from 30 times the recommended dose to the correct usage and ceasing his amphetamine abuse.)

“Filling in the forms with him, I found that I was surprised by my own assumptions about his mental illness and level of disability. I was in fact holding him back from recovery because I was accepting the ‘dominant’ view of him as beyond it. While filling in the forms, I began to hear him speak in ways that I had not heard or thought him capable of prior to the project in the 7 years that I’d known him. This was a turning point for me, challenging the idea that he would always have drug problems and would continue to be highly dependent on service. After the project ended he couldn’t wait to set another goal, to quit smoking and I have no doubt that he will.”

Clinicians indicated that the Flinders Model provided them with a purposeful, measurable structure to their usual work practices, boosting their overall morale in a

system that they reported as largely disempowering and demoralising for staff as much as patients. They found the process of enhancing patient self-responsibility and structured goal setting particularly powerful. Initially, they found the tools to be time and labour intensive; a particular challenge within a practice environment geared towards responding to crisis situations with high case loads as the norm.

GPs reported increased willingness to work with people with serious mental illness as a consequence of involvement in the project. They particularly gained a greater understanding of the causes of illness relapse and how to work with patients to lessen the impact of co-morbid chronic mental and physical health conditions. They deemed the flinders Model paperwork to be prohibitive, arguing that primary care practice would need to be substantially reoriented to effectively support the holistic needs of patients with serious mental illness. Where the mental health clinician or primary practice nurse undertook this role, GPs indicated that using the model as a mechanism for shared care was viable.

Stanford Course Qualitative Results

All participants identified the value of being able to share experiences and relieve the burdens associated with living with a chronic mental illness, reporting improvements in their relationships, , practical self-management and problem-solving skills, confidence to reconnect with their local communities, and a strong sense of regained dignity and achievement. This was more powerfully evident in the experiences of 2 patients with severe agoraphobia who, by the end of the course, had overcome a profound sense of social isolation. Initially, there was uncertainty about the relevance of the generic content for people with serious mental illness. However, it was

emphatically and unanimously endorsed upon completion of the course. Peer-leaders found the prescriptive and structured program easy to apply and helpful in generating group cohesion and involvement. As with peers providing one-to-one support to patients, peer-leaders reported significant improvements in their personal sense of resilience, self-confidence and overall skills and knowledge in managing mental illness relapse as a result of participation in the project. Supporting people with complex mental health problems prompted them to reflect on the complexity of their own recovery process.

Discussion

Patients reported significant improvements in many aspects of self-management, including improved understanding of their illness, improved symptom monitoring and management, shared decision-making and collaboration with case managers and GPs. Patients were successful at using these approaches to address problems and achieve their goals. Qualitative results support these findings with patients reporting a greater sense of control and a greater willingness to take part in decision-making about their health generally. This had major impacts on the way they interacted with health professionals and the cultural relationship that existed between them.

The data strongly suggests some benefit for reducing hospital admissions. Of the 25 patients who had experienced hospital admissions in the past, 7 experienced a significant reduction in the rate of admissions over the period of the project and the 12 months post involvement, and involvement did not appear to worsen mental health outcomes for those with no change in admission rates. The sample size is too small to

determine if this was directly due to the project interventions, however, results are promising.

Patients, GPs, case managers and peer workers all reported a positive shift in their assumptions about the patient's ability to self-manage as part of the process of implementing the Flinders model. The UK EPP has been specifically criticised because it has no corresponding strategy to challenge professional assumptions towards patients (Wilson, 2001). The Flinders model may provide a structured collaborative clinical process which challenges these assumptions by providing a practical way to incorporate patients' strengths and self-management needs within routine care.

Lack of attendance or inconsistent attendance by patients to a GP for primary health care or care planning is a general concern applicable to many chronically mentally ill patients whose traditional reliance on mental health services at the exclusion of other service providers has been well documented (Australian Health Ministers, 1998; Wagner *et al.*, 1996a). This study articulates an effective structured model for overcoming this problem, with case managers performing a pivotal role as intermediary between patients and GPs.

Of particular note, 5 participants in their early 20s who were diagnosed with first episode psychosis performed well using the Flinders model. This suggests that the model may lend itself to effective use in early intervention and prevention of chronic conditions, though the potential use with mental health populations in this regard would need to be tested with a larger, randomised sample.

This study suggests that Stanford courses are highly appropriate for people with serious mental illness. It further suggests and that individual-based CCSM models such as the Flinders Model can be used effectively to complement group CCSM education models such as the Stanford course and that a flexible clinical environment that offers both options is useful and equitable for people with serious mental illness.

Conclusions

This study represents an important first step in the implementation of the EPP into mental health, demonstrating that generic chronic condition self-management strategies can be effectively used with patients with chronic mental health problems, though more rigorous study is needed. Both the Flinders and Stanford models appear to offer patients and health professionals with tools to promote better self-management and self-management support. The sustainability of such interventions remains a problem for all CCSM approaches, particularly the goal of embedding such models into existing systems and structures that may be resistant to change. Rigid organisational boundaries and cross-discipline professional differences in attitudes towards the patient may vary depending on professional training and underlying philosophies. This is particularly relevant for mental health services, and health services generally, which are grappling with replacing traditional tertiary models of care, with their focus on acute care, with a more primary health care focus on self-management, and health promotion and prevention of further disability (Australian Health Ministers, 2003; Funnell and Anderson, 2003).

The findings of this study suggest that services provided by health professionals can be linked and delivered effectively to complement the Expert Patient Program via specific education programs such as the Flinders Model. Such models not only support collaborative care planning with the patient but may also provide the mechanism through which holistic patient-centred care is realised, risk factors are addressed and complex co-morbid conditions are more effectively managed with input from a range of support providers. For people with mental illness who experience a full range of negative social determinants of health, these physical health/mental health links need to be reinforced and addressed.

Limitations

A convenience sample has significant problems of potential bias and a much more rigorous methodology is required to overcome these difficulties. A randomised controlled trial would determine the relative efficacy of the individual versus group interventions for mental health populations, as well as the significance of peer worker input. For the 20 participants who undertook the Stanford course, it is clearly difficult to disaggregate the effects of the Flinders Model intervention from that of the Stanford course. Rigorously testing the impact and correlation of variables such as the role of family, level of social support, diagnostic differences, years of mental illness, age and gender of patients and other potential influences of patients' progress towards effective self-management is also seen as needed with a larger, random sample. Further study is also needed to test if gains are maintained over longer periods. The impact of involvement by peer workers on their own mental health has not been explored here. Likewise, the role of private allied health professionals with care planning capacity as well as the effectiveness of this model with people living in

community hostels, inpatients and patients not formally linked with public mental health services has also yet to be explored.

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