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Title: Factors associated with good self-management in older adults with a schizophrenic disorder compared to older adults with physical illnesses.

Short title: Older adults' self-management of schizophrenia

Authors

***Jane Stein-Parbury RN BSN MEd PhD**

Professor of Mental Health Nursing

Faculty of Nursing, Midwifery & Health

University of Technology Sydney, Lindfield, NSW, Australia

Director, Mental Health Nursing Professorial Unit

South Eastern Sydney and Illawarra Area Health Service, NSW, Australia

Robyn Gallagher RN CT Cert BA (Psych) MN PhD

Associate Professor of Chronic and Complex Care

Faculty of Nursing, Midwifery & Health

University of Technology, Sydney, Lindfield, NSW, Australia

Lynn Chenoweth DRec BA MA Grad Cert Tch/Lrn MAdEd RN PhD

Professor of Aged and Extended Care Nursing

Faculty of Nursing, Midwifery & Health

University of Technology Sydney, Lindfield, NSW, Australia

Director, Health and Ageing Research Unit

South Eastern Sydney and Illawarra Area Health Service, NSW, Australia

Georgina M Luscombe, BSc (Hons) PhD

Adjunct Lecturer

Obstetrics and Gynaecology, Faculty of Medicine

University of Sydney, NSW, Australia

***Corresponding author: Jane Stein-Parbury: jane.stein-parbury@uts.edu.au**

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Abstract

The number of older people living with a schizophrenic disorder (SD) is increasing yet little attention paid has been paid to the needs of this population relative to people with other chronic illnesses. In order to achieve optimal functioning people with a SD need to manage their illness and its impact, therefore this study set out to determine the factors associated with self-management in this population. The illness management of people over 50 years of age and living with schizophrenia (n = 84) was compared to their peers who were diagnosed with a chronic physical illness (n = 216). Participants completed a survey which included an illness management inventory, self-rated health and sense of coherence. The results demonstrated that participants with a SD had lower illness management levels, particularly for understanding their symptoms and taking appropriate actions in relation to health care. Poor self-rated health and the presence of comorbid conditions had a pervasive negative effect on self-management factors in the SD group, whereas being married, having a greater sense of coherence and being voluntary to treatment had a positive effect. Nurses need to develop strategies to address general health and self management in older adults living with a SD.

Accessible summary

- There are an increasing number of older people living with a schizophrenic illness and the specific needs of this population have received scant attention especially in relation to their illness self-management.
- This study demonstrated that the illness self-management of a group of older adults diagnosed with a schizophrenic illness was worse in comparison to their peers with a diagnosed chronic physical illness.
- In people with a schizophrenic disorder poor self-rated health and the presence of comorbid conditions negatively affect self-management factors, whereas being married, voluntarily treated and a greater sense of coherence have a positive effect.
- Nurse can assist older people with a schizophrenic disorder to improve their illness self-management by working collaboratively with them and enabling them to gain a better understanding of their illness, monitor their symptoms, attend to their general health and respond appropriately to symptoms of ill health.

Introduction

The number of older adults living with a serious mental illness is likely to increase with an ageing population and a rise in mental health problems worldwide (Cohen *et al.* 2000). Serious mental illness, a diagnosis of a schizophrenic, schizoaffective, bipolar or psychotic disorder, is “accompanied by persistent impaired functioning that requires ongoing supportive services” (Pratt *et al.* 2008a, p 42). Scant attention has been paid to the health care needs that are specific to older persons living with serious mental illness (Bartels & Mueser 2008, Pratt *et al.* 2008a, Berry & Barrowclough 2009). It is imperative to address their needs, given the increasing burden of disease and health care costs associated with serious mental illness (Bartels *et al.* 2003).

This paper reports the results of a secondary analysis of data from an investigation of the factors supporting self-management of older adults living with four different types of chronic illnesses. This study (Gallagher *et al.* 2008) revealed that diagnostic category was the strongest predictor of illness self-management. The study participants who were diagnosed with a schizophrenic disorder (SD) were less able to manage their illness than people with chronic physical illness; therefore, secondary analyses, presented in the current manuscript, were conducted in order to determine the factors that accounted for the differences.

Ageing and schizophrenia

Although schizophrenic illnesses are marked by exacerbations and remissions of symptoms, there is a tendency for the illness to stabilise as people age (Harrison *et al.* 2001, Jeste *et al.*

2003). With age there is improvement in positive symptoms such as hallucinations and frank thought disorder, yet negative symptoms such as apathy and blunted affect tend to persist (Cohen *et al.* 2008). As they age people with schizophrenia adapt to their illness and feel less controlled by it (Solano & Whitbourne 2001): nevertheless, a large majority of older people with schizophrenia do remain symptomatic and impaired (Jeste *et al.* 2003). Of all the serious mental illnesses, schizophrenia is associated with the poorest outcomes (Silverstein & Bellack 2008).

Traditionally, the treatment focus for SDs has been prevention of relapse and short term improvement, with less focus on longer term management (Andreasen *et al.* 2005). A tendency among health care providers to view schizophrenia as unremitting has resulted in pessimism about the likelihood of recovery (Harrison *et al.* 2001, Ridgeway 2001, Liberman *et al.* 2002, Lawn *et al.* 2007). However, there is reason to challenge this belief as current research supports the case for maintaining therapeutic optimism (Harrison *et al.* 2001, Lawn *et al.* 2007), especially as there is evidence that older adults can achieve remission (Bankole *et al.* 2008) and people with schizophrenia can experience periods of recovery (Bonney & Gamble 2005, Harrow *et al.* 2005). In the case of a serious mental illness such as schizophrenia, recovery includes a process of 'gaining mastery over the illness' (Onken *et al.* 2007, p10); including an ability to self-manage the illness and its impact (Bonney & Stickley 2008).

Illness management and schizophrenia

In order for people to successfully manage any illness, they need to understand the nature of the illness and manage its impact on their lives, to handle the associated treatment, and to work in partnership with health care providers in decision making (Lorig & Holman 2003). That is, they

must be active agents in their own health care. However, older adults living with schizophrenia are impaired in their ability to manage their general health and access appropriate health care (Pratt *et al.* 2008b).

Most of the investigations into self-management of a chronic illness have excluded people with a serious mental illness: one exception is a study by Lawn and colleagues (2007). They demonstrated that illness self-management that has been investigated with physical illnesses is relevant to serious mental illness. More importantly, the study demonstrated that self-management of mental illness can be improved with interventions that enable active participation in one's own care (Lawn *et al.* 2007).

People with a SD often lack the insight that is necessary to self-manage their illness. In SD insight includes: awareness of the illness and its social consequences, perception of the need for and cooperation with treatment, and an awareness of symptoms that are attributable to the illness (Mintz *et al.* 2003, Osatuke *et al.* 2008). Each of these aspects of insight is directly related to illness self-management. Understanding factors that result in good self-management of a serious mental illness such as SD is vital to the development of interventions that promote the possibility of recovery.

Method

Four groups of people with a chronic illness (n=300) were surveyed to assess how they managed their illness in relation to their sense of coherence and self-assessed health. The four diagnostic

groups were: chronic respiratory disease, chronic heart failure, Parkinson's disease, and chronic schizophrenic disorders.

The study was a prospective, descriptive design with data collected at two time periods: within a week of a clinic visit or home visit by a case manager, and one month later. A convenience sample was used with patients recruited from those being treated in South Eastern Sydney Area Health Service in Australia. Human research ethics committees of the area health service and the associated university approved the study.

Participants

The selection criteria for the parent study were a diagnosis of chronic heart failure, chronic respiratory disease, Parkinson's disease, or a chronic schizophrenic disorder (schizophrenia and schizoaffective), over 50 years old, living at home, able to understand and read English, and with moderate levels of disease. For participants with a SD (n=84) moderate level was assumed at a Global Assessment of Functioning (American Psychiatric Association, 2000) score >50.

Exclusion criteria included having no fixed address and more than one hospitalisation in the three months prior to recruitment.

Measures

Self-management was assessed with a general measure, the Partners in Health Scale (Battersby *et al.* 2003), an 11-item Likert scale with eight possible responses (0 = very good and 8 = poor).

This scale measures knowledge of the diagnosed illness, level of collaboration with health care providers, medication adherence, symptom monitoring and maintaining appointments with health care providers. Although chronic illnesses vary in their presentation and course, people coping with different illnesses have similar self-management tasks (Lorig & Holman 2003). The scale has been used in several illness populations (Battersby *et al.* 2003) including mental illness (Lawn *et al.* 2007). It had high internal consistency in the study, as demonstrated by a Cronbach's Alpha coefficient of 0.92 at time one.

Sense of coherence was measured using the Orientation to Life Questionnaire (Antonovsky 1993) which has been used internationally in both healthy and ill populations (Souminen *et al.* 2001, Veenstra *et al.* 2005, Eriksson, & Lindström 2006), including people with schizophrenia (Bengtsson-Tops & Hansson 2001, Bengtsson-Tops *et al.* 2005, Langeland *et al.* 2006). This scale consists of 29 items addressing three core components of comprehensibility, manageability and meaningfulness. Each item is scored from 1 (low) to 7 (high) using a semantic differential scale and total scores range from 29 to 203, with higher scores representing a stronger sense of coherence. The scale has been reported to have high internal consistency with Cronbach's Alpha coefficients of 0.86 to 0.95 and demonstrated construct validity in different populations (Antonovsky 1993). The questionnaire proved reliable in the current study with a Cronbach's Alpha coefficient of 0.92 at time one (baseline).

Participants self-rated their overall health using the Self-Rated Health Scale, a single item scale in which participants rate their health using a semantic differential from 1 (excellent) to 5 (poor) in response to the question 'In general, how would say your health is?'. This scale has been used

in chronic illness populations (Lorig *et al.* 1999, Lorig *et al.* 2001) and has shown to have good predictive value for mortality in a systematic review of 22 cohort studies, with patients reporting ‘poor’ self-rated health having double the mortality of patients reporting ‘excellent’ self-rated health (DeSalvo *et al.* 2005).

Procedure

Participants were recruited through their community case managers or during attendance at a medication clinic. Home interviews with the SD group were conducted by an experienced mental health nurse and included the participant’s case manager (where relevant).

Analyses

All statistical analyses utilised SPSS version 14 (SPSS Inc., Chicago, USA). Comparisons between the SD group and the combined physical illness groups were made using independent samples t-tests where the demographic data were normally distributed (e.g. age) and the non-parametric equivalent Mann-Whiney U test where data were significantly skewed (e.g. years of education). Group comparisons on categorical data (e.g. gender) were made using chi-square analyses. Where cell sizes were too small, Fisher’s Exact Test p values are reported (e.g. employment). Differences between the groups on self-rated health status were examined using a linear-by-linear association chi-square test. Alpha was set at 0.02 to account for multiple testing and, where appropriate, analyses were two-tailed.

In order to understand the differences in the self-management of people with a SD, an exploratory factor analysis with principal axis factoring and oblique rotation was performed including all 11 items of the Partners in Health Scale (Battersby et al., 2003). The Kaiser-Meyer-Olkin (KMO) measure verified the sampling adequacy for the analysis, $KMO = 0.87$ (which is 'very good' close to 'excellent' according to Field, 2009) and all KMO values for individual items ranged between 0.70 and 0.82, which is above the acceptable limit of ≥ 0.45 . An initial analysis was run to obtain eigenvalues for each factor in the data. Three factors had eigenvalues over Kaiser's criterion of 1 and in combination explained 75% of the variance and the outcomes have been reported in the results section. Mean factor scores were compared between the SD and the combined physical illness groups using independent samples t-tests.

The independent factors associated with self-management in people with SD were then determined by multiple regression analysis using the variables age, gender, education, marital status, self-rated health, legal status, poor treatment adherence, a hospital admission in the last year, number of comorbidities and sense of coherence. Backwards methods were used to create the most parsimonious model as this method is recommended when there is the potential for relationships between the variables (Katz 2008). Predictors were considered significant at $p < 0.05$ and variance inflation factors used to determine if collinearity was present. All assumptions for regression analysis including collinearity, homoscedasticity and independent errors were assessed and none were found to be violated (Field 2009)

Results

A total of 84 participants with a long-standing SD completed the study. Their mean age was 60.3 years old (range 50-86). Sixty-seven percent were female, 18% were married, and the majority (55%) lived alone and were on a disability pension (65%). Half were being case managed because of an involuntary community treatment order and 29% were prescribed a depot form of antipsychotic due to adherence problems.

The participants with SD demonstrated statistically significant differences in demographic profile, self-rated health and sense of coherence (Table 1). This cohort: were younger; reported less concurrent illnesses; were less likely to be married; were more likely to be living alone, had fewer social contacts; were more likely to be classified as disabled; and had been diagnosed with their illness for a longer period of time. Although they rated their overall health as better than other groups, their sense of coherence was lower.

Insert Table 1

Table 2 shows the outcomes of the exploratory factor analysis. The items clustering on the same factors suggest that factor one represents understanding of symptoms, factor 2 knowledge of illness and factor 3 appropriate actions. ‘Understanding symptoms’ comprised an ability and an appreciation of the importance of observing and monitoring symptoms and knowing what to do if they worsened. The factor labelled ‘knowledge of illness’ included comprehension of the condition and its treatment and management. ‘Taking appropriate action’ related to keeping medical appointments and taking medications as prescribed. A comparison of means for each factor revealed that patients with SD had significantly different scores than the other groups on

two of the three factors ($p < 0.001$) (Table 3). Despite having similar knowledge of their illness, they were much less likely to monitor their symptoms or to take action in relation to their health.

Insert Tables 2 and 3

The independent predictors of the three self-management factors in people with SD were determined using multiple regression analyses and the resulting model statistics and independent predictors are detailed in Table 4. People with SD had better *understanding of symptoms* if they had a stronger sense of coherence ($\beta = -.14$), were not case managed, ($\beta = 2.86$) and had better self-rated health ($\beta = 2.24$), which together explained 45% of the variance in understanding symptoms. People with SD had better *knowledge of their illness* if they were married ($\beta = -2.03$), had fewer comorbidities ($\beta = .82$) and better self-rated health ($\beta = 2.49$), with these three variables explaining 46% of the variation. Finally, people with SD were more likely to *take appropriate actions* if they had better self-rated health ($\beta = 2.61$), although they tended also to do so if less educated ($\beta = .29$) and had fewer comorbidities ($\beta = .73$). This model explained 46% of the variation in taking appropriate action.

Insert Table 4

Discussion

The results of this study support other findings that older people who are diagnosed with SD are socially isolated (Berry *et al.* 2006) and often lonely (Beebe 2010). Those who were married had better illness management. Poor social functioning impairs a person's ability to engage with

health care providers (Pratt *et al.* 2008b), thus reducing the likelihood of collaboration that is needed for illness management.

The sense of coherence in the participants with SD was lower than has been reported in people with schizophrenia (Bengtsson-Tops *et al.* 2005). Importantly, those participants with a higher sense of coherence were better at illness self-management. Recovery in mental illness is associated with an increase in sense of coherence (Griffiths 2009, Skärsäter *et al.* 2005), and psychotherapy focused on increasing a sense of coherence has been shown to improve coping with mental illness (Langeland *et al.* 2006).

The difference observed in the current study between those with SD and other chronic illness in specific aspects of self management is useful. For instance, people with SD were less likely to understand symptoms including monitoring and knowing what to do if symptoms become worse. These results may reflect a tendency to direct attention away from symptoms as people with a SD grew older (Solano & Whitbourne, 2001). They could also reflect a lack of insight (Mintz *et al.* 2003, Osatuke *et al.* 2008). Importantly, when compared to the other three groups, people with a SD were lacking in ability to take appropriate actions in relation to their illness.

In addition, the findings also identified a connection between illness management and involuntary treatment orders, although no direction can be implied because it is a cross-sectional study. It may be that having involuntary treatment results in poorer understanding of symptoms or that people who do not have insight into their symptoms require involuntary treatment orders.

These involuntary orders were not temporary, being either 6 or 12 month duration. Voluntarily consenting to treatment would indicate that the person with a SD would be more likely to engage in illness management behaviours.

The finding that the participants with a SD rated their overall health as better than the other three groups may reflect the course of the disorder, in that the positive symptoms stabilise with age, unlike physical illnesses such as heart failure, which are progressive in nature. Nonetheless, it is clear that there was a strong connection between the SD participants' perception of their overall health and the presence of comorbid conditions and their illness management. A higher rating of overall health and reporting of fewer comorbid conditions could be an indication that they were managing their illness with better understanding and knowledge. This is reinforced by the finding that within the group with a SD worse self-rated health predicted poor illness management.

It was interesting to note that participants with a SD reported fewer concurrent illnesses than the participants with other illnesses, and is inconsistent with reports of a high rate of medical comorbidities that are associated with poor health care behaviours in this population (Bartels 2004). This finding may indicate that they were not seeking help for illnesses, which then go undetected and untreated. An inability to take action in relation to their general health has been highlighted as a clinical concern for people with mental illnesses and now given the connection with poor self-management, the importance of general health care becomes clearer (Cohen *et al.* 2000, Lawn *et al.* 2007, Pratt *et al.* 2008b).

The limitations of this study are that recruitment was through case managers and medication clinics and therefore not representative of older people with a SD. In addition, the differences between the SD group and other three chronic illness groups could be indicative of managing an illness that has stabilised, rather than one that is progressive. Furthermore, it is possible that external variables that were not measured in this study may also influence the components of self-management.

Implications for mental health nurses

Two of the factors associated with poor self-management, poor sense of coherence and being treated involuntarily, are amenable to intervention. The development of nursing interventions specifically aimed at these factors may assist people with SD to better manage their illness. In particular, increasing understanding of the nature of a SD, symptom monitoring and management are all strategies that have been shown to be successful in improving illness management (Lawn *et al* 2007). Nurses can also assist in the development of action plans should symptoms become worse. These strategies may help improve sense of coherence by increasing two of its core components, comprehensibility and manageability.

Keeping appointments for health care is an area that needs attention and could be addressed with regular reminders (Beebe 2010) and assistance in transport. Decisions to continue involuntary treatment should include an ongoing assessment of capacity to collaborate in care planning, as partnerships with consumers are central to chronic illness management. In addition, the development of general self-care would also address the high rate of comorbid illnesses that is associated with poor health care behaviours in this population.

Conclusion

This study has shown that the ability of people with SD to self-manage their illness is poor in relation to their peers with diagnosed physical illnesses. Recovery for people with a SD can be fostered by a focus on enabling self illness management; this could be addressed by interventions that focus on factors associated with poor self management. Mental health nurses are well-placed to promote these strategies as collaborative relationships with consumers lies at the heart of practice.

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Table 1: Comparison of demographic profile between participants with schizophrenia and other chronic illnesses (n=300)

Characteristic	Schizophrenia (n = 84)	Other Illnesses (n = 216)	P value *
Age, years, mean (SD)	60.3 (8.3)	74.2 (8.1)	< .001
Education, years			
median (IQR)	10.0 (3)	10.0 (3)	0.20
range	6 - 16	0 - 26	
Concurrent illnesses,			
median (IQR)	0.0 (1)	2.0 (2)	< .001
range	0 - 4	0 - 7	
Male	n (%) 28 (33.3)	n (%) 120 (55.6)	<.001
Married	15 (17.9)	138 (63.9)	< .001
Live alone	46 (54.8)	56 (25.9)	< .001
Someone to talk to	49 (59.8)	196 (90.7)	< .001
Employed full or part-time	3 (3.6)	10 (4.6)	1.00
Disability	54 (65.1)	8 (3.7)	< .001
English primary language	61 (72.6)	187 (87.0)	.005
Length of time diagnosed			
<1 year	0 (0.0)	34 (16.2)	
2–4 years	2 (2.4)	52 (24.8)	
5–10 years	4 (4.8)	60 (28.6)	
11–20 years	10 (12.0)	35 (16.7)	
>20 years	67 (80.7)	29 (13.8)	< .001
≥ One hospital admission this year for primary diagnosis	30 (36.6)	95 (44.4)	0.28
If admitted, number of hospitalisations median (IQR)	1.0 (1) 1 - 3	1.0 (1) 1 - 8	0.35
Good or better self-rated health	76 (89.4%)	99 (45.8%)	<.001
Sense of Coherence (range 29- low, to 203- high)	115.62 (12.80)	139.11(25.11)	<.001

* t-test, χ^2 or Mann-Whitney tests used as appropriate

Table 2: Three-factor solution for Partners in Health Scale, after oblique rotation (n=300).

	Understanding symptoms	Knowledge of illness	Appropriate actions
1. Knowledge of my condition	0.09	0.93	0.04
2. Knowledge of the treatment of my condition	0.03	0.86	0.04
3. Ability to share in decisions made about the management of my condition	0.26	0.55	0.06
4. Ability to arrange appointments as recommended by my doctor or health service provider	0.16	0.26	0.45
5. Attendance at appointments	0.10	0.04	0.95
6. Ability to take my medication as directed by my doctor	0.16	0.10	0.69
7. Understanding of why I need to observe, measure and record symptoms	0.79	0.04	0.08
8. Ability to observe, measure and record my symptoms	0.87	0.03	0.04
9. Understanding of what to do when my symptoms get worse	0.80	0.03	0.02
10. Ability to take the right action when my symptoms get worse	0.88	0.04	0.01
11. Progress towards adopting habits that improve my health	0.63	0.03	0.11
Eigenvalues	5.89	1.32	1.04
% of variance	53.59	11.97	9.41

Note: $R^2=75\%$. Bold numbers indicate the factor to which each item was assigned; factor loadings ≥ 0.45 .

Table 3. Comparison of means on Partners in Health Scale components (n=300).

Partners in Health components (Higher scores worse)	Schizophrenia (n = 84) Mean (SD)	Other illnesses (n = 216) Mean (SD)	P value *
Understanding symptoms (sum) (range 0-32)	15.86 (6.0)	9.8 (9.57)	<.001
Knowledge of illness (Sum) (range 0-24)	8.76 (3.59)	7.73 (5.73)	.06
Appropriate actions (sum) (range 0-24)	8.74 (3.60)	2.68 (3.76)	<.001

*independent samples t-test

