



Coping strategies in carers of young people with a first episode of psychosis

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ABSTRACT

Background: Carers of young people with first episode psychosis (FEP) often face burden. Understanding ways in which carers cope is not only important for providing support to them but might maximise patient outcomes. The aim of this study was to examine strategies carers use to cope with the burden of caring for a young person with FEP.

Methods: The study was part of a randomized controlled trial focusing on the effectiveness of a problem-solving bibliotherapy intervention for carers of FEP patients, in terms of promoting coping and reducing psychological distress. Baseline data on the Ways of Coping (WOC) scale was available for 124 carers aged between 18 and 66 years. Principal component analysis with PROMAX rotation was used to determine the number of factors that could be used to characterise coping behaviour. Regression analyses were used to determine how the factors were related to carers' demographics, burden, psychological well-being and expressed emotion.

Results: Approximately half of the carers reported that they frequently use positive coping techniques such as self-talk, active problem solving, and positive reframing.

The factor analysis yielded five factors: (i) cognitive-escape coping; (ii) optimistic coping; (iii) seeking connections; (iv) tension reduction; and (v) distancing. The relationships between these factors and demographic characteristics, carers' perception of burden, expressed emotion, and psychological distress are reported.

Conclusions: Avoidance coping strategies are related to psychological distress, emotional over-involvement, and increased carer burden. Interventions facilitating the use of adaptive problem solving and positive re-appraisal will promote carer coping and reduce psychological distress.

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1. Introduction

Coping has been conceptualised as changing one's cognitions and behaviour in order to address stressful situations (Folkman and Lazarus, 1985). A range of coping strategies are available including avoidance, regulating emotional responses, or actively addressing the cause of the problem. The stress-coping model proposes that appraisal of problems influences coping strategies employed and the subsequent distress experienced (Folkman and Lazarus, 1985). This classic model has been influential in psychology for several decades.

Carers of people with psychosis face significant emotional, psychological, and economic burden (Kuipers et al., 2010; McCann et al., 2011a, 2011b). Understanding ways in which carers cope with this burden is

not only important for providing them with support, but may improve patient outcomes (O'Brien et al., 2009).

An array of studies has investigated coping in carers of patients with either severe mental illness or chronic schizophrenia; several key findings have been noted. First, carers use a range of strategies to deal with behavioural change associated with mental illness (Birchwood and Cochrane, 1990). Coping strategies may be either problem-focused (e.g., problem-solving) or emotion-focused (e.g., avoidance; Folkman and Lazarus, 1985). Second, coping may differ according to the stage of illness. Avoidance is more likely to be used by carers of chronic patients compared to those caring for patients early in illness course (Gerson et al., 2011). Third, poor coping in carers of patients with chronic illness has been associated with carer distress, depression and anxiety (Sczufca and Kuipers, 1999), negative appraisal of the care-giving experience (Sczufca and Kuipers, 1999; Onwumere et al., 2011b) and high expressed emotion (EE, Birchwood and Cochrane, 1990; Sczufca and Kuipers, 1999).

Understanding carers' coping when a young person first presents with psychosis has received scant attention; only a few studies have

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been noted (e.g., Tennakoon et al., 2000; Gerson et al., 2011; Onwumere et al., 2011b). Most patients with FEP reside with, and are dependent upon, their families. Given the majority of first develop psychosis in late adolescence/early adulthood, many carers face problems that are at odds with the expected developmental trajectory of growing independence in their child. Carer distress is prominent (Onwumere et al., 2011b), including symptoms resembling post-traumatic stress disorder (Onwumere et al., 2011a). The carer also has to confront issues of stigma and guilt (McCann et al., 2011a, 2011b). Care-giving is burdensome, demanding and unpredictable (McCann et al., 2011a, 2011b). Interventions are required before use of poor coping strategies becomes entrenched and poor clinical outcomes for the carer and the patient ensue (Scazufca and Kuipers, 1999).

Gerson et al. (2011) conducted a small study of family members of 11 ultra high risk and 12 recent onset psychosis patients. Coping was assessed using a modified version of the Carver's Coping Orientations to Problems Experienced questionnaire (COPE, Carver et al., 1989). This questionnaire assesses 14 coping dimensions. Both groups of carers were more likely to use approach coping strategies such as seeking support and expressing emotions. There was less reliance on avoidant coping strategies such as denial and disengagement.

Onwumere et al. (2011b) examined avoidant coping in two different groups of carers; carers of patients with recent ($n = 60$) and long-term ($n = 81$) non-affective psychosis. The COPE inventory was used to assess coping. No associations were found between avoidance coping and a range of variables including carer demographic variables (sex, age, or living with the patient) and patient characteristics (sex, age, length of illness). Avoidance coping, however, was associated with greater levels of carer distress, even after controlling for length of illness. However, neither Gerson et al. (2011) nor Onwumere et al. (2011b) considered the full range of coping strategies and their relationship with carer burden, distress and EE.

Most studies conducted to date, have used small and unrepresentative samples of carers of chronic patients with schizophrenia. The age of the patient and duration of illness are other potential confounds; the dynamics of the patient–carer relationship is different when the patient is young and early in illness course compared to an older patient with unremitting illness (Gerson et al., 2011). Most FEP studies have included patients of a wide age range (e.g., 18–65 years). The impact of developmental changes on the patient–carer relationship needs to be considered.

The aim of the study was threefold. First, to characterise coping strategies carers use when caring for a young person during the first year after commencement of treatment for a FEP; second, to examine how coping strategies relate to the demographic characteristics of the carer and patients' illness characteristics; and third, to examine how coping relates to carer burden, psychological distress and EE. It was hypothesized that carers would use both positive and negative coping strategies. Use of positive coping strategies would be associated with lower levels of carer burden, psychological distress, and EE. Conversely, use of avoidance coping strategies would be associated with higher levels of burden, psychological distress, and EE.

2. Methods

2.1. Design

The study was part of a clinical trial focusing on the effectiveness of a problem-solving bibliotherapy intervention (PSBI) for 124 carers of FEP patients (McCann et al., in press). Baseline data was the focus of this paper (Table 1).

2.2. Participants and setting

First-time carers were recruited through two specialist early intervention (SEI) services in Melbourne, Australia: Orygen Youth Health (OYH) and the Recovery and Prevention of Psychosis Service (RAPPS).

Table 1
Characteristics of 124 carers of clients with FEP.

		Total ($n = 124$)
Gender % female	% (n)	82.3 (102)
Age	M (SD)	47.2 (8.3)
Relationship with FEP patient % parent	% (n)	91.1 (113)
Living with client % yes	% (n)	82.3 (102)
Country of birth % other than Australia	% (n)	34.7 (43)
Length of time in Australia if born in other country (in months)	% (n)	345.0 (187.5)
Language spoken at home % English	% (n)	91.9 (113)
Work status		
Professional/management/business	% (n)	35.5 (44)
Clerical/trade/retail/hospitality	% (n)	25.0 (31)
Other	% (n)	39.5 (49)
Still working in occupation % yes	% (n)	79.2 (95)
Highest level of education		
Primary school	% (n)	4.8 (6)
High school	% (n)	35.5 (44)
TAFE	% (n)	21.8 (27)
Tertiary education	% (n)	37.9 (47)
Yearly household income		
Below \$AUD 20,000	% (n)	15.0 (18)
Between \$AUD 20,000–\$AUD 50,000	% (n)	38.3 (46)
Between \$AUD 51,000–\$AUD 100,000	% (n)	32.5 (39)
Above \$AUD 100,000	% (n)	14.2 (17)
Characteristics of FEP patient		
Time since diagnosis of psychosis (in months)	M (SD)	10.7 (8.8)
Duration of support from early intervention service (in months)	M (SD)	8.3 (6.5)
Number of contacts with early intervention service	M (SD)	2.6 (2.5)
Phase of recovery		
Acute	% (n)	14.7 (17)
Recovery	% (n)	85.3 (99)

Young people had a first episode of a DSM-IV psychotic disorder and were aged between 15 and 25 years.

Inclusion criteria included: (i) first-time carer (no previous caregiving role with any other individual); (ii) in carer role for less than 3-years; and (iii) ability to communicate and understand English. Exclusion criteria were: (i) had been in receipt of family therapy; and (ii) self-reported recent personal history of serious and enduring mental illness.

2.3. Measures

2.3.1. Demographic data

A range of carer demographics were collected, such as age, gender, relationship status with patient, and country of birth.

2.3.2. Patient illness characteristics

Details on length of time since diagnosis, duration of SEI support, number of contacts with the SEI service, and stage of illness were documented.

2.3.3. Coping

Coping style was assessed using the 28-item version (MacCarthy and Brown, 1989) of Folkman and Lazarus' (1985) Ways of Coping Checklist (WOC). Each item was rated on a five-point scale with scores ranging between 0 (*never*) and 4 (*all of the time*). Carers are asked how often they have chosen to cope in particular way in the last 3 months. Examples include "tried to take my mind off things by smoking, drinking or taking pills to relax" or "prepared for the worst". The WOC has been used in some studies of carers with chronic schizophrenia (MacCarthy et al., 1989; Scazufca and Kuipers, 1999; Chadda et al., 2007) and has only been used in one study of carers of patients with FEP (Tennakoon et al., 2000). Most of the studies have used MacCarthy and Brown's (1989) version of the WOC, which was adapted

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