

## SPECIAL SECTION: CULTURAL ISSUES IN MENTAL HEALTH SERVICES AND TREATMENT

# Assessing the stability of schizophrenia patients' explanatory models of illness over time

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### Abstract

*Background:* There is increasing interest in explanatory models of illness in mental health care and the possibility that they vary according to cultural background. However, little is known about their stability over time as a factor influencing long-term outcome.

*Aims:* To assess the stability over time of explanatory models of illness among people with schizophrenia.

*Methods:* A modified version of the Short Explanatory Model Interview was used to elicit explanatory models with 8 participants from four ethnic groups on two occasions. The interviews took place approximately 1 year apart.

*Results:* The concept and cause of illness along with treatment preferences tended to be inconsistent in all patients between the baseline and follow-up interview. On the other hand, perceived severity of illness and prognosis were more inclined to be consistent over time. The consistency in responses was partly a function of the question type. Open-ended questions were more likely to elicit less consistent responses than questions with implied choice responses.

*Conclusions:* The lack of stability of explanatory models may be a feature of explanatory models or it may be a weakness of the method used. This instability may limit their usefulness in predicting long-term outcome. Future research is warranted to investigate whether a more valid method could identify a stable component of explanatory models over time, whether this is then related to outcome and, if so, in what ways.

*Declaration of interest:* None

**Keywords:** *Explanatory model, schizophrenia, stability, test–retest reliability.*

### Introduction

The shift in medicine towards more patient-centred care has fundamentally recast the patient from a passive recipient to an active partner in the treatment process. A central element of partnership models of care involves engaging with the patient's subjective perspective on what is wrong and what they think of the treatment they receive. This, in turn, involves eliciting the patient's account of their illness (e.g., Barker, Lavender, & Morant, 2001) and working with this account to optimize the therapeutic relationship and

treatment efficacy. In mental health care, there is increasing interest in how peoples' accounts of illness vary according to cultural background and in the possibility that this may explain the different rates of service use and satisfaction between minority ethnic groups in the UK. In this context of inequalities in health care between different ethnic groups, Bhui and Bhugra (2002) recently revisited Kleinman's thesis that exploring patients' explanatory models of their illness may lead to more culturally sensitive practice and by implication fewer inequalities in care.

Explanatory models of illness encompass a person's ideas about the nature of their problem, its cause, severity, prognosis and preferences for treatment (Kleinman, 1980). Depending on the perspective, a person's own ideas about their illness are considered important for a variety of reasons. How a person constructs meaning from their experience of illness, particularly if it is life threatening or chronic, has consequences for their self identity and self-esteem (e.g., Charmaz, 1987). From this perspective, how a person integrates and accommodates the illness psychologically and, as a result, in the realisation of their social role and activities, can be adaptive or maladaptive. From a more pragmatic perspective, in the context of healthcare provision, agreement between the patient and professional about the nature of the problem may be prior to successful intervention. In chronic illness, ongoing collaboration between the patient and professional about the best way to view and treat the illness is crucial over a long period of time. There is some evidence that patients are more satisfied (Callan & Littlewood, 1998) and have better therapeutic relationships with their treating practitioner (McCabe & Priebe, in press) when there is a shared model of understanding.

The underlying rationale is that explicitly asking about the patient's subjective experience of their illness and giving them the opportunity to share this information with the clinician reduces distance (doing this explicitly may be more important when the distance, e.g., cultural, is great) between patient and clinician, thus promoting greater collaboration and meaningful communication between them. The patient may feel that the clinician is taking them seriously, leading to greater patient satisfaction and treatment outcomes. There is evidence that patient-centred communication and a more partnership model of care is associated with better patient satisfaction, less symptom burden and lower rates of referral to other services (Little *et al.*, 2001). However, if clinicians are to take the time to routinely assess patients' explanatory models with the expectation that this will positively affect treatment outcome, they will be interested in how stable they are over time.

A single study to date by Williams and Healy (2001) has investigated this issue among a group of new referrals to a community mental health team, who were interviewed prior to a first appointment and again two weeks following the appointment. No specific schedule was used to elicit explanatory models. In-depth interviews were used in which participants were asked to explain how they had arrived at their current situation. This approach elicited the person's narrative about why they were referred to a mental health service. The participants cited a variety of causes throughout a single interview, their beliefs being changeable rather than fixed. As a result, the authors suggested that "explanatory map" rather than "explanatory model" might more aptly convey the fluidity of peoples' beliefs. The fluid character of these peoples' beliefs might have been attributable to their status as new referrals, who were in the process of receiving a diagnosis. Their ideas about what was wrong may have altered after their first consultation with a specialist mental health professional. No research to date has addressed the stability of explanatory models over time in a long-term group of patients, whose beliefs may be less changeable because they have been receiving services for a number of years and so are less likely to be receiving new information that might substantively alter their beliefs.

## Method

### *Participants*

Participants were recruited from secondary mental health services, specifically from four community mental health teams, a day hospital and a psychology service. Inclusion criteria were: a clinical diagnosis of schizophrenia according to DSM-IV; being in the care of a community mental health team; no known organic impairment; and no significant formal thought disorder as assessed on the Brief Psychiatric Rating Scale (Overall & Gorham, 1962). Service managers, psychiatrists and support workers were consulted in order to identify clients meeting the inclusion criteria. On clinicians' recommendations, patients were contacted either by letter or by telephone. All participants provided written informed consent to take part in the study.

Eight participants were recruited in East London as part of a more extensive cross-cultural comparison study investigating explanatory models in relation to psychological and treatment variables (McCabe & Priebe, in press). One of the participants was UK White, 3 were African-Caribbean, 3 were West African and one was Bangladeshi.

### *Measures*

A modified version of the Short Explanatory Model Interview (SEMI: Lloyd *et al.*, 1998) was used to elicit explanatory models. Employing the SEMI enabled a qualitative assessment of patients' conceptualizations of their illness, within a structured framework, that allowed for eventual quantification of data. Questions originally developed for primary care, that were not entirely relevant for people with chronic illness, were disregarded. The modified version was divided into three main sections on the nature of the problem and its consequences, etiology and treatment.

### *Procedure and analysis*

Each participant was interviewed with the SEMI and the interview was audiotaped. The participants were re-interviewed approximately one year later with the same instrument. The verbatim data collected using the SEMI from the first interview were analysed for content. The verbatim data from the second SEMI interview were then compared with the first set of responses and coded as to whether they were identical, similar or different. Responses were coded as identical if they used almost the same words as in the first interview, as similar if they reported a similar response (e.g., with more or less detail), or as different if they were clearly conveying different information. For example, in response to the question "What does your illness do to you?", a first response was "Makes me feel ill, I don't feel right when I hear the voices" and a second was "makes me feel bad". These were coded as similar because they both referred to an affective consequence, feeling ill or bad, although they did not use identical words. In response to "What do you call your problem?", a first response "schizophrenia" and a second "paranoid schizophrenia" were coded as identical. In response to "What are the symptoms that distress you the most?", the first response "Voices make me paranoid" and the second "Thought somebody was out to kill me" were coded as similar. Another first response to the same question "Unexplained voices that occur sometimes" and the second "Initially it was a fear that something would happen to my family through the trouble I was having at work, the kind of things they were doing which made me think how far they would go. Now I just see it as them playing with the mind. If they can produce a mind effect and make me think something, they'd rather do that than

commit a crime. To me, it's about society, it's mostly about mind control" were coded as different.

Where questions provided multiple, not mutually exclusive, response categories (i.e., "Does your illness mainly affect your mind/body/relations with others?" and "Would you say the cause of your illness is in your mind/body/relations with others?"), responses were coded as similar if either response contained the same category, even if an additional category was added to one of the responses. For example, if a person said "mind" and then "mind and relations with others", they were coded as similar.

Inter-rater agreement in classifying the second set of responses as identical, similar or different was calculated using the kappa statistic.

## Results

The frequencies for each question of identical, similar or different responses are presented in Table I. The chance corrected proportional inter-rater agreement between four independent raters,  $\kappa = 0.88$  ( $p < 0.000$ ), was very good (Altman, 1991).

Table I. Frequencies of identical, similar and different responses to SEMI questions.

SEMI	Question	Identical	Similar	Different	Missing*
Concept	1. What do you call your problem	2	0	6	–
	2a. What does your illness do to you	0	2	5	1
	2b. Does it mainly affect your mind/body/relations with others	2	3	2	1
	4. What symptoms distress you the most	1	2	5	–
	5. What do you fear most about your illness	0	2	4	2
	6. What are the chief problems your illness has caused	1	3	4	–
Severity	3a. How severe is your problem	1	4	3	–
Prognosis	3b. Does your illness have a long/short course	4	1	3	–
Cause	7a. What do you think caused your problems	0	1	7	–
	7b. Is there anything you have/have not done to cause your illness	6	0	1	1
	7c. Is there anything someone else has/has not done to cause your illness	3	1	4	–
	7d. Who or what is the cause of your illness	3	1	3	1
	7e. Would you say the cause of your illness is in your mind/body/relations with others	1	4	3	–
	7f. Since your problems started, have you changed your mind about what caused them	3	1	3	1
	8. Why do you think your problems started when they did	1	3	4	–
	Treatment	10a. What kind of treatment do you think you should receive	1	0	7
	10b. What are the most important results you hope to gain from treatment	0	2	6	–
	11. Have you asked for advice from anyone about your problems	0	0	7	1
	12a. Do you treat yourself for your illness	3	0	4	1
	12b. Are you taking any other cures/remedies other than your medication	5	0	1	2

\*If one of the two responses were missing, this made a comparison impossible.

The number of times each question had an identical or similar response across the two interviews gives an index of how consistent the responses to these questions were over time. Questions which had 0–2 identical/similar responses (out of a possible total of 8) were the least stable, those with 3–4 identical/similar responses were moderately stable and those with 5–6 identical/similar responses were the most stable. Only one question had 6 identical/similar responses (Is there anything you have or have not done to cause your illness?) and no question had a higher number of identical/similar responses. The questions about concept of illness (in particular, the questions “What do you call your problem?” and “What does your illness do to you?”), cause of illness (in particular, “What do you think caused your problem?”) and ideas about treatment (in particular, “What kind of treatment do you think you should receive?” and “What are the most important results you hope to gain from treatment?”) were unstable over time, whereas perceived severity of illness and prognosis were more stable over time. As not all questions pertaining to concept, cause and treatment were inconsistent, this conclusion is based on the main questions in these 3 categories, provided in brackets above.

In order to explore whether some participants were more likely to be inconsistent over time than others, the frequency of different responses was examined for each participant. They did not differ substantially from each other on this count with the exception of one participant who responded identically or similarly to only 1 out of 12 responses. In the first interview, he described his problem as being mad and in the second as having asthma. Hence, his explanatory models were relating to two different problems, one physical and one psychological.

## Discussion

It is clear that the administration of the SEMI at two time-points, approximately one year apart, did not elicit identical (or for the most part even similar) explanatory models from the same individuals. The inter-rater reliability in coding individuals’ responses as identical, similar or different was very good. There was some difference in the consistency of responses depending on the type of question. Not surprisingly, responses to open-ended questions were less consistent than responses to questions with implied choice response categories (e.g., “Does your illness mainly affect your mind/body/relations with others?”, “Is there anything you have or have not done to cause your illness?”). It may be that the interval for assessing stability was too long. One year is much longer than typical intervals in conventional studies of test–retest reliability. Nevertheless, the main questions on concept, cause and treatment did not elicit consistent responses and there were no marked differences between the participants in the consistency of their explanatory models.

In considering the stability of explanatory models over time, some epistemological and associated methodological issues must be taken into account. Epistemologically, the very idea of measuring explanatory models so that they can be quantified and integrated into survey research (e.g. to investigate their stability over time or their relationship to service use) is problematic (McCabe & Priebe, in press). It necessarily involves reducing complex narratives to discrete variables. This is not entirely compatible with the anthropological framework within which the concept of explanatory model of illness was originally developed. This involved developing an understanding of the person’s experience of illness in the wider context of their lives and how they make sense of it. Within this framework, a person draws on social and cultural resources in actively making sense of their experiences, resulting in a complex story, not easily broken down into simple and discrete units.

Explanatory models are complex “constituted wholes” (cf. Fenton & Charsley, 2000), and it may be problematic to consider that such a whole can be elicited with a semi-structured interview, which necessarily breaks down the narrative into its component parts. An additional, and possibly related, problem is that the results of interviews are more realistically understood as products of the contingencies of the interview situation, and not, as is more often assumed, unmediated expressions of respondents’ real opinions (Houtkoop-Steenstra, 2000). This is illustrated by the common problem of how to generate codable answers to pre-coded questions when the respondent’s answer does not quite fit into the possible categories.

As Fenton and Charsley (2000) point out, both the anthropological and the epidemiological models are vulnerable to critiques. On the one hand, the anthropological model considers observability and measurement extremely problematic because the social world is a “constituted whole” which cannot be deconstituted in any meaningful way. Hence, the problem of identifying discrete variables renders epidemiological investigation invalid. On the other hand, the epidemiological model can be criticised for an overly simplistic approach in abstracting variables from the context in which they occur. This fundamental problem continues to be relevant in research integrating qualitative and quantitative methods in statistical analyses. In the present study, this trade-off would appear to have contributed to the instability over time of explanatory models.

In addition to the methodological issue of how explanatory models can be accessed and assessed, there is the issue of how stable explanatory models could be expected to be over time. Going back to their origin, explanatory models were not viewed as static mental templates that would remain constant and unchanging. Rather, they were deemed to be dynamic and subject to ongoing revision given that they drew on the person’s “life” and social world, which is constantly changing (Kleinman, 1988). This is supported by the present findings, which suggest that accounts of illness, in particular the concept, cause and preferences for treatment, vary over time.

Notwithstanding the methodological limitations outlined above, what are the implications of this finding? If explanatory models are unstable, and patients’ reports about basic aspects of their illness change over time, what is the point in assessing them in clinical practice or research? It appears that when the patient and clinician share the explanatory model of illness, patients are more satisfied with treatment and have better therapeutic relationships (Callan & Littlewood, 1998; McCabe & Priebe, *in press*). If this finding, that explanatory models mediate patient satisfaction and the quality of the therapeutic relationship between patient and clinician (assessed concurrently) is further replicated, it would suggest the importance of eliciting explanatory models regularly in clinical practice. The finding that peoples’ preferences for the kinds of treatment they would like to receive and the benefits they hoped to gain from it varied in the space of one year may be particularly important. Having the patient on board as far as treatment is concerned is one of the key concerns of clinicians. If the patient does not believe that the treatment is beneficial or cannot be convinced of this, the success of treatment is substantially diminished.

However, if explanatory models are not stable over time, they cannot predict long-term outcome. It may be that there is a stable component of explanatory models that is important and predictive of outcome, which has not been identified by this non-specific method. It is even possible that such a component might be different in different people, highlighting the tension between ideographic and nomothetic methods in this field. By investigating larger samples dynamically over time, it might be possible to identify key components at various stages of illness. If explanatory models change over time, they could be dependent on emotional and situational factors. Indeed, it may be only explanatory models in certain

situations and emotional conditions that are really relevant, e.g., when people first come into contact with services they may be more “make or break” than for people who have been in contact with services for some time when a certain equilibrium has been established. Information elicited in a research context may also be quite different to that elicited in the actual clinical situation as it is independent from the treatment process. It is conceivable that different elements of complex, multifaceted explanatory models may be elicited in the consulting room by the treating clinician in a specific treatment situation. Finally, the current findings cast doubt on whether short standardized interviews are really helpful in research and warrants further investigation.

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