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Measuring Pathways to Care in First-episode Psychosis: A Systematic Review

Background: Adequately measuring pathways to care is a prerequisite for early detection and effective treatment of first-episode psychosis.

Method: We conducted a systematic review of studies on pathways to care in first-episode psychosis to establish what measures currently exist to assess pathways in first-episode psychosis and to compare these measures.

Results: We identified 15 studies which had used six different measures of pathways to care. Differences in aims, methodology and lack of psychometric data did not allow a direct comparison of pathways measures but certain common themes emerged.

Discussion: Pathways to care in first-episode psychosis are diverse and varied. There is no measure with established psychometric properties that has been devised on a well-developed theoretical or conceptual framework and had its psychometric properties established. The conflict between exploring the patient's narrative and journey through the healthcare system and developing an empirical measure of pathways with optimal outcomes has hindered the development of such a measure.

Introduction

In non-psychiatric specialities, there is a well-developed concept of 'integrated care pathways' (ICP) which is a multidisciplinary outline of anticipated care, placed in an appropriate timeframe, to help a patient with a specific condition or set of symptoms move progressively through a clinical experience to positive outcomes (Middleton and Roberts, 2000). ICPs help to reduce unnecessary variations in patient care and outcomes, support the development of care partnerships, facilitate the incorporation of local and national guidelines and meet the requirements of clinical governance. ICPs were initially developed for surgical procedures with 'predictable' outcomes, although attention has since shifted to complex medical conditions treated in the community.

In mental health in general, and in psychosis in particular, routes of access to help are diverse and varied, and may involve non-healthcare agencies such as social services and the criminal justice system. There is often disagreement between professionals and patients, and even among professionals from different disciplines on what constitutes best treatment and optimal outcomes. It is not surprising therefore that there are few ICPs for psychiatric disorders. Research has instead focussed on pathways to mental health care. Pathways to care are defined as "the sequence of contacts with individuals and organisations prompted by the distressed person's efforts, and those of his or her significant others, to seek help as well as the help that is supplied in response of these efforts"(Rogler and Cortes, 1993). In this definition, a pathway has direction and structure, in as much as help-seeking efforts are not random and can be meaningfully understood within the larger socio-cultural milieu of the patients and

their families. Pathways to care is a much broader concept than simply help-seeking, since it encompasses service structures and 'non-sought' routes to care, as well as help-seeking by individuals or people close to them.

Two recent strands of evidence have concentrated attention on pathways to care in psychosis: one that certain ethnic groups experience adverse pathways into care (Bhui et al., 2003), (Morgan et al., 2005, Morgan et al., 2005b) and second, that reducing treatment delays may improve outcomes in early psychosis (Norman and Malla, 2001). Early intervention strategy is based upon the presupposition that at least some reasons for treatment delay are malleable and could be targeted for intervention. The two key aims of early intervention, reducing duration of untreated psychosis and providing evidence based care during the early 'critical period' (Birchwood et al., 1998), both require early detection of psychosis in the community and understanding factors associated with, and contributing to, delay in help seeking. Understanding pathways to care therefore underpins early intervention policy and practice. Yet there have been few attempts to develop and validate a structured measure of pathways to care in first-episode psychosis.

We conducted a systematic review of studies on pathways to care in first-episode psychosis. We aimed to

1)   establish what measures currently exist to assess pathways to care in first-episode psychosis;

2)   explore similarities, differences, strengths and limitations of these measures; and

3)   summarise factors associated with adverse or protracted pathways to care.

Method

A systematic review of measures used to assess pathways to care in individuals with a first-episode of psychosis was undertaken using methodology detailed in the NHS centre for reviews and dissemination (Dissemination, 2001). The following databases were used; Psychinfo (1872 – 01/06/05), Embase (1980 – 01/06/05), AMED (Allied and Complementary Medicine) (1985 – 01/06/05) CINAHL (Cumulative Index to Nursing & Allied Health Literature) (1982 – 01/06/05) and Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) (1966 – 01/06/05).

Search strategy

A textword search strategy was used for two searches, search one using 'pathways to care', 'pathways to psychiatric care' 'pathways to mental health care' and search two, 'first-episode of schizophrenia', 'emerg$ schizophrenia', 'early onset schizophrenia', first onset schizophrenia', 'first onset psychosis', 'early onset psych$', 'emerg$ psycho$', 'first-episode psycho$', 'first psycho$ episode', 'first hospitalization'. A search was conducted to identify papers combining the two searches, i.e. papers that contained terms from both the pathways to care category and the first-episode psychosis category.

Inclusion criteria were:

-      The study must be data-based and have used a specific measure of pathways to care for individuals experiencing a first-episode of psychosis

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(schizophrenia spectrum disorders). The reason for measuring pathways to care will not influence an articles inclusion/exclusion.

- The paper must be in English.

Exclusion criteria were:

1) Studies measuring pathways-to-care for all physical and non-psychotic mental health problems and/or where psychosis has an organic cause (e.g. dementia/brain injury).

2) Studies that examine pathways to care where the sample includes individuals with non-psychotic mental health problems or those with non-schizophrenia spectrum disorders such as bipolar disorders.

3) Measures of pathways to care exclusively studying non-statutory services such faith healers, private psychotherapy services, social care etc.

4) Case reports, letters or non-data based papers.

Selection of relevant studies:

The titles and abstracts of all studies generated above were examined on the inclusion and exclusion criteria. If the reviewer was uncertain as to whether an article fulfilled the criteria, the full paper was requested. Reference lists of all included articles were searched manually for additional studies meeting the inclusion criteria. Once the measurement tool had been identified, we attempted to obtain copies of these measures and any literature attesting to the reliability/validity and strengths/limitations of these measures.

Data extraction and synthesis:

SS and TG separately extracted data from all full length articles using pre-designed tables corresponding to the three aims, ensuring that data extraction was standardised. Findings were compared on each paper to ensure reliable extraction of data. We extracted all results pertaining to a) measures of pathways to care including their content and psychometric properties and, b) 'key findings' which were defined as social and clinical associations of adverse or protracted pathways to care. We did not include length of DUP or any other results not directly related to pathways to care in the key findings. As the papers were heterogeneous, a formal meta-analysis was not attempted. A narrative summary has therefore been used to present the findings.

Results

In total 19 studies were identified from the database search. Ovid Medline identified 10, Embase identified 3, PsycINFO identified 3 and a further 3 were identified from manual search of reference section of other identified articles. Four articles initially identified were later excluded as 2 were not in English and 2 were not considered relevant after further perusal. Fifteen studies therefore met the inclusion criteria, all of which we were able to locate. The findings from these papers are summarised in Table 1.

Insert Table 1 here

Study aims

Studies varied greatly in their aims, some of which were not directly relevant to pathways to care. Some papers sought to answer more than one question. Six studies explored reasons for treatment delays and barriers in pathways to care

in first-episode psychosis (Larsen et al., 1998, Lincoln et al., 1998, Addington et al., 2002, Etheridge et al., 2004, Fuchs and Steinert, 2004, Norman et al., 2004), five explored the influence of ethnicity on pathways (Cole et al., 1995, Burnett et al., 1999, Morgan et al., 2005b, Morgan et al., 2005, Bhugra et al., 2000) Two studies explored social determinants of pathways (Bhugra et al., 2000, Cougnard et al., 2004), one investigated clinical influences on pathways (Cougnard et al., 2004) and two articles examined the relationship between DUP and pathways to care (Larsen et al., 1998, Chong et al., 2005). One paper looked at the usefulness of a pathway to care model and tool (Perkins et al., 1999), one sought to understand help-seeking contacts (Fuchs and Steinert, 2004), one investigated the time point in early psychosis when antipsychotics were initiated (Cougnard et al., 2004) and one paper made cross-national comparison on the epidemiology and presentation of first-episode psychosis (Sartorious et al., 1986)].

Study settings and populations

Most studies came from the UK (Cole et al., 1995, Burnett et al., 1999, Morgan et al., 2005b, Morgan et al., 2005, Bhugra et al., 2000, Etheridge et al., 2004), three were from other European countries(Larsen et al., 1998, Cougnard et al., 2004, Fuchs and Steinert, 2004), three were from North America/Canada (Perkins et al., 1999, Addington et al., 2002, Norman et al., 2004) and one each from Australia (Lincoln et al., 1998) and Singapore (Chong et al., 2005) and one study was multinational (Sartorious et al., 1986). The smallest study had 9 subjects (Perkins et al., 1999) while the largest had 1379 subjects (Sartorious et al., 1986) the mean number of subjects being 210 (SD= 352; mode 86).

Pathways measure used.

We obtained copies of measures used in eleven studies (Sartorious et al., 1986, Perkins et al., 1999, Lincoln et al., 1998, Bhugra et al., 2000, Addington et al., 2002, Cougnard et al., 2004, Etheridge et al., 2004, Norman et al., 2004, Morgan et al., 2005b, Morgan et al., 2005, Burnett et al., 1999). In one study, the pathways measure was available in French with no English translation (Cougnard et al., 2004). Five studies had developed their own measures of pathways for the specific purposes of that study (Sartorious et al., 1986, Cole et al., 1995, Perkins et al., 1999, Cougnard et al., 2004, Fuchs and Steinert, 2004). The Pathways to Care section of the Psychiatric and Personal History Schedule (PPHS) was used in five studies (Sartorious et al., 1986, Burnett et al., 1999, Bhugra et al., 2000, Morgan et al., 2005b, Morgan et al., 2005), two had modified the PPHS (Morgan et al., 2005b, Morgan et al., 2005) by including a written narrative of pathways to care. One study developed a 'Pathways to care tool' (Perkins et al., 1999) based on a theoretical construct of pathways determining number of help-seeking attempts before appropriate treatment was received, subsequent compliance, who first noticed the symptoms and where help was sought. This tool was also used by one other study (Addington et al., 2002). Two studies reported using semi-structured questionnaires (Cole et al., 1995, Cougnard et al., 2004) and one reported simply asking patients for information on their contacts with professionals before admission and their pathways to care (Fuchs and Steinert, 2004). One study used the Encounter Form (Gater et al., 1991) and two others based their measures on other assessment tools (Etheridge et al., 2004, Norman et al., 2004); one on the IRIS audit tool kit (Partnerships, 2001) and the other, the Circumstances of Onset and

Relapse Schedule (CORS) which is based on the Interview for the Retrospective Assessment of Schizophrenia (IRAOS) (Hafner et al., 1992). One study gathered data on pathways to care using qualitative techniques i.e. case studies. (Larsen et al., 1998). One paper defined first help-seeking contact but used no structured assessment of pathways (Chong et al., 2005).

Psychometric Properties of Pathways to Care measures

None of the studies provided any details on the psychometric properties of their pathways to care measures. One paper stated that the Encounter Form (Lincoln et al., 1998) was 'unsuitable to adequately record multi-layered and complex helping strategies or accommodate multiple contacts with a service provider over a period of time'. Cross-referencing of data sources was used by one study (Norman et al., 2004). In the absence of any psychometric data, a direct comparison of the different measures was not possible.

Key findings related to pathways to care (see table 1)

Despite the widely differing aims and measures used in the studies, certain common themes regarding pathways emerged. Pathways to care in first-episode psychosis are highly varied and diverse. Health professionals are the first point of contact for most people experiencing early psychosis (Sartorious et al., 1986, Bhugra et al., 1999, Addington et al., 2002, Cougnard et al., 2004, Etheridge et al., 2004, Fuchs and Steinert, 2004, Norman et al., 2004, Chong et al., 2005, Burnett et al., 1999). Contact with non-statutory agencies such as religious agencies or faith-healers is not common (Sartorious et al., 1986, Chong et al., 2005). Irrespective of the setting, there is a considerable delay in

adequate treatment of first-episode psychosis. While some delays occur because of failure of carers and primary care services in recognising incipient psychosis (Perkins et al., 1999, Etheridge et al., 2004), one study interestingly found that there is also a delay in initiating treatment for psychosis in those patients who are already engaged within mental health services when they develop psychotic symptoms (Norman et al., 2004). Withdrawal and lack of a social network are important obstacles to help seeking (Larsen et al., 1998) and where individuals do not make help-seeking efforts or such efforts fail, the role of relatives and carers is vital (Lincoln et al., 1998). In the absence of help seeking by a friend or carer and GP involvement, detention is also more likely (Cole et al., 1995). A marked change in pre-morbid functioning (Larsen et al., 1998, Addington et al., 2002), presence of positive psychotic symptoms such as delusional thinking (Addington et al., 2002, Norman et al., 2004), incomprehensible speech (Sartorious et al., 1986) exacerbation of symptoms (Sartorious et al., 1986, Bhugra et al., 2000), mood symptoms with overt depression, suicidal ideation (Addington et al., 2002) risk of self-harm or harm to others (Bhugra et al., 2000) and occupational deterioration (Sartorious et al., 1986) facilitate help-seeking. Demographic factors adversely influencing pathways include being single (Cole et al., 1995), being unemployed (Morgan et al., 2005, Burnett et al., 1999), living alone, living in public housing (Burnett et al., 1999) and ethnic minority status (Morgan et al., 2005).

Discussion

To the best of our knowledge, this is the first systematic review of pathways to care in first-episode psychosis. The findings suggest that while several

pathways to care measures have been used in first-episode psychosis population, there is no measure with established psychometric properties that has been devised on a well-developed theoretical or conceptual framework and had its psychometric properties established. Methodological variations between studies do not allow either a meta-analysis of pooled data or a direct comparison between studies. Without a meta-analysis, we also could not weight the studies according to sample size, which varied considerably, or methodological quality. The lack of psychometric data also meant that we could not attempt a direct comparison of the various pathway measures. Well-known problems of recall bias, selective reporting, differences in samples chosen, variations in sources of information and relating pathways to the clinical picture therefore remain unaddressed. All we can say with some certainty is that pathways to care in first-episode psychosis are highly varied, with certain ethnic groups in the UK experiencing more adverse pathways to care; delayed help-seeking is associated with under-recognition of prodromal and early psychotic symptoms; and families/carers play a crucial role in accessing help for patients. There is inadequate evidence to confirm that patients with first-episode psychosis seek help from alternative helping agencies such as faith-healers or that delay in help-seeking can be explained by cultural differences such as attribution style or explanatory models of mental illness, although these possibilities have not been adequately explored. We excluded studies which were primarily about non-statutory organisations so contact with such agencies would be under-represented in this review. Our findings confirm the conclusions of Lincoln and McGorry (Lincoln and McGorry, 1995) that there is insufficient empirical information to guide secondary

prevention strategies in early psychosis. The predominantly European origin of the studies means that our findings are more applicable to countries with nationalised healthcare systems and we know even less about pathways to care in areas with significant input of the private sector into mental health care.

There are three possible reasons for delay in treating first-episode psychosis: sufferers do not want treatment, are not offered treatment or are deemed not to need treatment. The first reason, suffers do not want treatment, is often a critical issue in managing early psychosis. Many individuals experiencing early psychosis neither seek help nor view mental health services as helpful. The well-known 'levels and filters' model of pathways to care described by Goldberg and Huxley (Goldberg, 1992) has therefore only a limited application in early psychosis, since the model presupposes that patients initiate help seeking within primary care. The related and crucial question: what prevents families from seeking help when problems become apparent also remains relatively unexplored and may be associated with other variables such as explanatory models of illness, stigma and socio-economic or educational background. Some studies have assessed the influence of presenting symptoms, coping styles, health locus of control and help-seeking behaviour on DUP but not used measures of pathways into care and were therefore not included in this review (Skeate et al., 2002, Drake et al., 2000). The very interesting finding that individuals who develop psychosis while under the care of mental health teams have a long delay before treatment is initiated ((Norman et al., 2004) suggests that even mental health services might contribute to the other two reasons for delayed intervention: sufferer are not

offered treatment or are deemed not to need it. Perhaps educating mental health professionals about the need for early treatment is as important as public education campaigns.

There are two ways to study pathways to care: one way is to explore the empirical relationship between service utilisation and factors affecting such utilisation; and the other is to study the dynamic social and interpersonal processes that affect help-seeking in the community at large, not simply within psychiatric clinics. The first requires determining pathways and then understanding what facilitates or impedes access to care. The second approach is based upon a topographical view of pathways that requires understanding the personal narratives and journeys of individuals experiencing symptoms. Morgan et al (Morgan et al., 2004) consider this dichotomy as one between the medical and the social sciences approach, considering the medical approach as a static, one dimensional model where selected fixed variables are tested for associations with fixed outcomes, while the social sciences approach considers help-seeking to be a dynamic and socio-culturally determined process. This however begs the question: should pathways be defined before these are researched or should a narrative of help-seeking be established before pathways are determined in a post hoc manner?

A generic formulation of pathways which considers all help-seeking efforts from all help-giving institutional and informal structures within a culturally plural society requires socio-anthropological studies based upon community-based rather than clinical samples. This would take into account culturally-determined

explanatory models of illness, social networks and the range of services available. However the teleological precondition imposed upon early intervention services by the need to reduce DUP necessitates the development of an easy-to-use, clinically relevant, user–friendly, valid and reliable instrument to study pathways in early psychosis.

We suggest that both approaches to studying pathways are valid and necessary. Perhaps the potential conflict between respecting cultural beliefs/explanatory models and the imperative of providing adequate and appropriate treatment for a serious mental disorder is more 'apparent' than real. The widely held assertion that differences in pathways are culturally determined has not been substantiated with robust evidence. It remains a possibility, and a fruitful area for future research (Bhui and Bhugra, 2002) since any systematic differences between ethnic groups will help develop culturally appropriate strategies to assist illness-recognition, facilitate engagement and deliver optimal interventions. Meanwhile early interventions services still need a simple, easy to use, user-friendly, reliable and valid measure of pathways to care in early psychosis.

In the era of clinical governance and quality assurance, understanding pathways to care is a crucial first step in ensuring improved clinical decision-making and effective service delivery. We are piloting a pathways to care measure that combines clinical presentation of unfolding psychosis from an onset scale: the Nottingham Onset Scale (Singh et al., 2005) with help-seeking efforts of patients and their carers and reasons for seeking or not seeking help

at each stage. We hope that the pilot will help us develop a valid and reliable measure of pathways to care for both clinical and research use. Meanwhile we recommend that studies on pathways to care explicitly define pathways, explain the theoretical or conceptual underpinnings of the definition used, describe how pathways will be assessed and justify why that particular method of assessment is suited for the study hypothesis. Having a well-defined, hypothesis-driven and reliable way of assessing pathways to care will be a significant advance from the current dearth of knowledge in this important area.

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Table 1: Summary of Studies of Pathways to Care in First-episode psychosis

Authors, site	Study aims, setting, sample size	Pathways measure used	Psychometric properties of PTC measure	Key findings related to pathways
(Sartorious et al., 1986), multinational	WHO 10-country study of first-ever contact with any 'helping agency' n =1379	Pathways to care section of Psychiatric and Personal History Scale (PPHS)	No details provided.	Main first contact a medical professional; non-statutory bodies (e.g. religious officials) involved significantly in only 3 centres in the developing world. Main reasons for seeking help were bizarre, behaviour, thought disorder or occupational deterioration.
(Cole et al., 1995), UK	Association between ethnicity and pathways n = 93	Semi-structured questionnaire	No details provided.	Being single predicted late presentation. Detention associated with lack of help-seeker and GP, not detention
(Larsen et al., 1998), Norway	Relationship of DUP to pathways. n= 34	Described as qualitative case studies.	No details provided.	Pre-morbid deterioration functioning associated with early detection, withdrawal and lack of social network with delayed treatment
(Lincoln et al., 1998), Australia	Treatment delays in first-episodes of psychosis. n= 62	Encounter form (Gater et al, 1991).	No details provided.	Main delays between onset and initial contact with services, and between reaching services and commencing treatment. Role of relatives vital in help-seeking
(Burnett et al., 1999), UK	Ethnic differences in admission rates n= 100	Pathways to care section of the PPHS	Sartorious et al, 1986	GP referral associated with lower detention rates No ethnic difference in compulsory first admission, for readmissions, African-Caribbeans more likely to be detained. Unemployment and living alone associated with compulsory admission.
(Perkins et al., 1999), USA	Develop a pathways to care instrument , n= 9	'Pathways to care' interview.	No details provided.	Early changes not recognised as part of an illness
(Bhugra et al., 2000), UK	Comparing pathways between Trinidad and London, n= 46	Pathways to care section of the PPHS	Sartorious et al, 1986	Risk factors common reasons for presentation. More cases in London received initial help through primary care or psychiatrists.
(Addington et al., 2002), Canada	Understand treatment delays n= 86	'Pathways to care' interview (Perkins et al 1999).	Inter-rater reliability conducted, no data provided.	Concerns evident in prodrome, but help not sought till onset of psychosis. Help seeking contacts are more successful in the presence of psychotic symptoms, depression and suicidal ideation.
(Cougnard et al., 2004), France	Factors influencing access to treatment, n=86	Semi-structured questionnaire (French, no English translation	No details given.	Type of first contact not predicted by demographic or clinical characteristics, Poor pre-morbid functioning or at-risk behaviour associated with delayed access to care.

(Etheridge et al., 2004), UK	0bstacles to early treatment, n= 18	Questionnaire based upon IRIS audit tool kit (2001)	No details provided	Delays due to lack of awareness of who to approach, poor recognition and lack of appropriate treatment in primary care and delay in treatment because of substance abuse.
(Fuchs and Steinert, 2004), Germany	Understand delays in Germany n=66	Semi-structured interview	No scale used	Duration between first symptom and first help seeking contact about 1.5 years
(Norman et al., 2004), Canada	Reasons for treatment delay. n= 110	Circumstances of Onset and Relapse Schedule (CORS), and IRAOS (Hafner *et al* 1992).	Data cross-referenced between at least two sources	Individuals with a younger age of onset, or who were under psychiatric care when psychosis emerged had longer delays to initiation of treatment.
(Chong et al., 2005), Singapore.	Determinants of DUP and pathways in Singapore, n= 112.	First help-seeking contact defined and reasons for help-seeking explored.	No details provided.	A quarter sought help from a traditional healer prior to consulting a psychiatrist but DUP in this group was not significantly different to those who sought help elsewhere.
(Morgan et al., 2005),UK.	Association between detention and ethnicity, n= 462	Modified version of PPHS with detailed narrative of pathways.	Sartorious *et al*, 1986	Being Afro-Caribbean, unemployed, criminal justice referral, perceived risk to others, help-seeking not initiated by self were independently associated with a risk of compulsory admission
(Morgan et al., 2005b),UK	Association between detention and ethnicity n= 462	See above	See above	Compared with White British patients, GP referral was less frequent for both African-Caribbean and Black African patients and referral by a criminal justice agency was more common.