

The pathways to mental health care of first-episode psychosis patients: a systematic review

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Background. Although there is agreement on the association between delay in treatment of psychosis and outcome, less is known regarding the pathways to care of patients suffering from a first psychotic episode. Pathways are complex, involve a diverse range of contacts, and are likely to influence delay in treatment. We conducted a systematic review on the nature and determinants of the pathway to care of patients experiencing a first psychotic episode.

Method. We searched four databases (Medline, HealthStar, EMBASE, PsycINFO) to identify articles published between 1985 and 2009. We manually searched reference lists and relevant journals and used forward citation searching to identify additional articles. Studies were included if they used an observational design to assess the pathways to care of patients with first-episode psychosis (FEP).

Results. Included studies ($n=30$) explored the first contact in the pathway and/or the referral source that led to treatment. In 13 of 21 studies, the first contact for the largest proportion of patients was a physician. However, in nine of 22 studies, the referral source for the greatest proportion of patients was emergency services. We did not find consistent results across the studies that explored the sex, socio-economic, and/or ethnic determinants of the pathway, or the impact of the pathway to care on treatment delay.

Conclusions. Additional research is needed to understand the help-seeking behavior of patients experiencing a first-episode of psychosis, service response to such contacts, and the determinants of the pathways to mental health care, to inform the provision of mental health services.

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Introduction

Recent efforts in psychosis research have focused on the period from the onset of psychotic symptoms to appropriate psychiatric intervention, known as the duration of untreated psychosis (DUP). Findings from literature reviews suggest that delays in the treatment of the first episode are associated with poor clinical and functional outcome, and that it may be possible to reduce the duration of this delay (Norman & Malla, 2001; Melle *et al.* 2004; Marshall *et al.* 2005; Perkins *et al.* 2005). Although there is little consensus as to what constitutes a long DUP, it is consistently associated with lower overall functioning, more severe positive and negative symptoms, lower quality of life, and a reduced likelihood of achieving remission (Marshall *et al.* 2005), in addition to poor response to

psychiatric treatment (Perkins *et al.* 2005). This evidence has sparked substantial efforts in secondary prevention and early intervention for psychosis (McGorry *et al.* 2007).

The emphasis on early detection and reduction of treatment delay in first-episode psychosis (FEP) has led to an interest in the modes and routes by which patients experiencing psychotic symptoms access help. These pathways to care are defined as 'the sequence of contacts with individuals and organizations prompted by the distressed person's efforts, and those of his or her significant others, to seek help' (Rogler & Cortes, 1993). Care pathways are not random, and are influenced by social, cultural, and health service factors. The pathways to care encompass not only the help-seeking behavior of the patient and family members, but also the accessibility of health services and the identification of, and response to, the symptoms of early psychosis by each contact on the pathway (Singh & Grange, 2006). This concept is of particular importance in FEP, given the poor functional and clinical outcomes associated with a long

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DUP (Norman & Malla, 2001; Marshall *et al.* 2005; Perkins *et al.* 2005), and the suffering endured by patients and their families. Both help-seeking and referral delays impact the length of time that psychotic symptoms go untreated, and there is evidence that referral delays may be responsible for a substantial proportion of the DUP (Norman *et al.* 2004; Bechard-Evans *et al.* 2007).

Prior research on the pathways to care of patients with FEP presents a complex picture. In addition to general practitioners and psychiatrists, the pathways may involve such diverse contacts as emergency services, social services, police, school counselors, and religious agencies. Involuntary and negative contacts are frequent (Garety & Rigg, 2001), such as with police or emergency services, and may be subsequently associated with poor engagement in treatment (Compton, 2005) and dissatisfaction with services (Bhugra *et al.* 2004). Thus, gaining an understanding of the factors that influence the pathways to care of patients with FEP is crucial to achieving the objectives of improving access to treatment through early symptom detection and reductions in treatment delay.

The objective of this systematic review was to summarize the literature on the pathways to care of patients with FEP, and to describe the sex, socioeconomic, and ethnic determinants of these pathways, to the extent that they are known in the nascent research literature. Additionally, we sought to examine the evidence on the association between the pathway to care and the DUP.

Method

Definition of terms

The term *Care Pathway Contact* refers to the individual, agency, or service provider with whom the patient came into contact on the pathway to mental health care. The *First Contact* refers to the care pathway contact from whom help was first sought after the onset of psychotic symptoms. This is of interest because it gives an indication of how patients and family members initiate help-seeking and highlights the care pathway contacts who could be targeted for early intervention. The *Referral Source* denotes the care pathway contact who suggested or arranged for contact with mental health services or a specialized treatment program. This care pathway contact highlights the service providers who are most involved in facilitating connections with mental health services and is of interest for informing policies on access to specialized services, whether through an open referral system or a gatekeeper mechanism.

Search strategy

We conducted an electronic search using the Medline (1950–2009), HealthStar (1966–2009), EMBASE (1980–2009) and PsycINFO (1985–2009) databases. The Medline search terms are presented in Appendix 1. This search strategy was developed in consultation with a professional librarian, and was adapted for EMBASE, PsycINFO and HealthStar using analogous terms.

We obtained further studies by a manual search of 15 relevant journals (Appendix 2). We also manually searched personal files and the bibliographies of all relevant studies and review articles, and conducted forward citation searching using the ISI Web of Knowledge to locate all articles that had cited the included studies. Finally, we located a systematic review that focused on the psychometric properties of pathways to care instruments for patients with FEP (Singh & Grange, 2006), and used it to corroborate the findings from our search strategy. We regularly updated all segments of the literature search, with the final update in December 2009.

Selection of relevant studies

We screened the titles and abstracts of all citations and obtained the full-text version of relevant studies to review for inclusion eligibility. The studies were included if they had used an observational design and presented quantitative data on the pathways to care of patients with FEP. We did not impose any language restrictions in our search strategy.

We used a cut-off publication year of 1985, given that the concept of pathways to psychiatric care was first introduced in 1980 (Goldberg & Huxley, 1980) and the earliest article identified by the systematic review of Singh & Grange (2006) was published in 1989.

Data extraction and synthesis

For all studies that met the inclusion criteria, two independent reviewers extracted data on the proportion of patients seeking help from each type of care pathway contact. We extracted the data using pilot tested forms, and we resolved discrepancies by consensus. Authors were contacted for further information or clarification when the data were aggregated or unclear.

Studies were subdivided based on whether they examined the first contact on the pathway to care or the referral source. Contacts were categorized as follows: (a) Physician: includes general practitioners, psychiatrists, or out-patient mental health services; (b) Non-Physician: includes private psychologists,

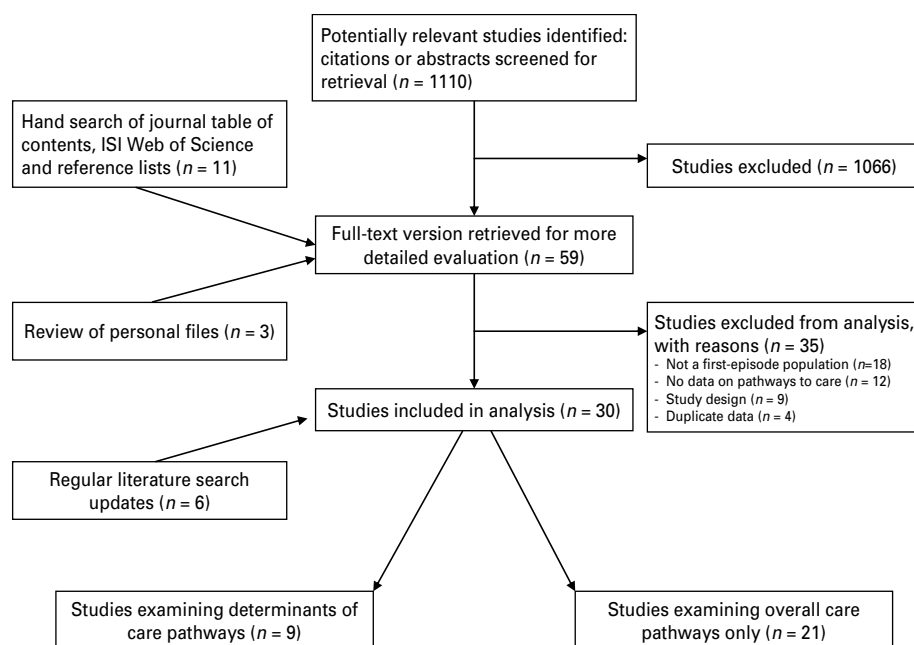


Fig. 1. Flow chart of systematic review search strategy and study inclusion.

counsellors, social workers, religious agencies, or self-referral (referral source only); (c) Emergency: refers to emergency departments, crisis teams, or in-patient units. The care pathway contacts were grouped as 'Emergency Services', given that involuntary and negative pathways to care are associated with poor engagement with services (Compton, 2005). Additionally, we aggregated contacts with 'Physician Services' because many health-care systems require a physician referral to access specialized mental health services. Studies differed on whether they included family and/or police as care pathway contacts. When they were included, we grouped these data in the non-physician and emergency categories respectively.

Substantial clinical, statistical, and contextual heterogeneity precluded a meta-analysis, therefore we synthesized the data descriptively. This heterogeneity probably resulted from the variation in study settings, as studies were conducted across several countries and health-care systems. The lack of a validated tool with established psychometric properties for measuring pathways to care also prevented a meta-analysis (Singh & Grange, 2006), as the included studies used a variety of different definitions of pathways to care and methods for assessment.

Results

The electronic database search retrieved 1110 studies, of which 45 were deemed relevant for this review.

The manual search additionally retrieved 14 studies that were missed in the electronic search, likely due to the lack of a standardized search term for pathways to care (Appendix 1). In total, 59 full-text articles were identified, and we excluded 35 of these studies because they did not use an FEP population ($n=18$), provide quantitative data on pathways to care ($n=12$), and/or use an observational design ($n=9$), or because they presented duplicate data that were available in another article ($n=4$) (Bhugra *et al.* 1999; Fuchs & Steinert, 2002; Cougnard *et al.* 2004a; Morgan *et al.* 2005a). An additional six studies were located through regular updates of the literature search.

Thirty studies met the inclusion criteria for our review (Appendix 3). Specifically, 21 studies examined pathways to care generally, and nine explored the sex, socio-economic, and/or ethnic determinants of the pathways (Fig. 1). Additionally, 15 studies examined the impact of the pathway to care on the DUP.

Study characteristics

The characteristics of the included studies are summarized in Table 1. Studies were conducted in a variety of countries ($n=16$), and one was published in a language other than English (Kohn *et al.* 2004). The sample sizes varied substantially, ranging from 21 to 462 participants (median across studies = 86). The studies generally used a descriptive and cross-sectional design. Given that there is no validated instrument for measuring pathways to care

Table 1. Characteristics of studies included in the review (n = 30)

Study	n	Country	Pathways data source	Sample source	% Male	% Schizophrenia spectrum	Care pathway contact	No. contacts, median (range)	Covariates of interest
Lincoln <i>et al.</i> 1998 ^c	62	Australia	PI	SP	65	52	First contact	4.5 (1–17)	–
Addington <i>et al.</i> 2002	86	Canada	PI, FI	SP	66	100	Referral source	2 (1–6) ^e	–
Scholten <i>et al.</i> 2003	134	Canada	PI, FI, MR	SP	74	84	Referral source	–	DUP
Norman <i>et al.</i> 2004	110	Canada	PI, FI, CI, MR	SP	80	76	Both	–	–
Addington & Addington, 2006	373	Canada	N.A.	SP	N.A.	75	Referral source	–	DUP
Bechard-Evans <i>et al.</i> 2007	98	Canada	PI, FI, CI, MR	SP	69	81	First contact	–	DUP
Archie <i>et al.</i> 2009	200	Canada	PI, FI, CI, MR	SP	78	100	Both	3 (N.A.)	Sex, SES, ethnicity
Chiang <i>et al.</i> 2005	35	China	PI, FI	SP	40	N.A.	Both	1 (0–3)	DUP
Cougnard <i>et al.</i> 2004	86	France	PI, FI	IP	64	62	First contact	2 (1–7)	DUP, sex, SES
Fuchs & Steinert, 2004 ^f	66	Germany	PI	IP	59	100	Both	–	DUP
Kohn <i>et al.</i> 2004 ^c	80	Germany	PI	IP	73	100	Both	3 (N.A.)	DUP, sex, SES
Sharifi <i>et al.</i> 2009	91	Iran	PI, FI, MR	IP	58	47	Both	–	DUP
O'Callaghan <i>et al.</i> 2009	142	Ireland	PI, FI	SP	62	74	Both	2 (0–8)	DUP
Yamazawa <i>et al.</i> 2004	83	Japan	MR	OP	42	100	Referral source	–	–
Gill <i>et al.</i> 2005	38	Malaysia	PI	IP	58	76	First contact	–	–
Razali & Mohd Yasin, 2008	60	Malaysia	PI, FI	OP	80	100	First contact	–	–
Turner <i>et al.</i> 2006	184	New Zealand	PI, CI	SP	72	55	Referral source	4 (0–42) ^e	Ethnicity
Chong <i>et al.</i> 2005 (i)	112	Singapore	PI, FI, MR	PS	57	100	Both	–	DUP
Chong <i>et al.</i> 2005 (ii)	287	Singapore	PI, FI	SP	55	33	Referral source	–	–
Temmingh & Oosthuizen, 2008	21	South Africa	PI, FI, MR	IP	52	95	Both	3 (1–6)	DUP, sex, ethnicity
Platz <i>et al.</i> 2006 ^c	104	Switzerland	PI, FI	SP	75	N.A.	Both	3 (1–8)	DUP
Bhugra <i>et al.</i> 2000 ^{a,d(i)}	46	Trinidad	PI, FI, MR	PS, CS, CJ	57	100	First contact	–	–
Bhugra <i>et al.</i> 2000 ^{a,d(ii)}	38	UK	PI, FI, MR	PS, CS, CJ	74	100	First contact	–	–
Harrison <i>et al.</i> 1989 ^a	131	UK	PI, FI, MR	CA	65	68	First contact	–	Sex, ethnicity
Cole <i>et al.</i> 1995	93	UK	PI, FI, MR, Q	CA	54	62	First contact	–	Sex, SES, ethnicity
Burnett <i>et al.</i> 1999	100	UK	PI, FI, MR	CA	65	100	Referral source	–	SES, ethnicity
Garety & Rigg, 2001	21	UK	CI, MR	PS, CA	76	100	Referral source	–	–
Morgan <i>et al.</i> 2005	462	UK	PI, FI, MR	CA	58	74	Referral source	–	DUP, sex, SES, ethnicity
Cratsley <i>et al.</i> 2008	59	UK	MR	SP	68	81	Referral source	–	DUP
Compton <i>et al.</i> 2006 ^{b,c}	25	USA	PI, FI, CI, MR	IP	76	100	Both	3 (1–7) ^e	DUP
Chien & Compton, 2008	76	USA	PI, FI, CI, MR	IP	78	100	Both	2 (1–8) ^e	–

Data source: PI, patient interview; FI, family/friend interview; CI, clinician/caseworker interview; MR, medical records; Q, questionnaire.

Sample source: SP, specialized treatment program; PS, psychiatric services; CS, community services; IP, in-patient; OP, out-patient; CA, catchment area; CJ, criminal justice.

Covariates examined: DUP, duration of untreated psychosis; SES, socio-economic status.

^a All patients in the sample were African Caribbean.

^b All patients in the sample were African American.

^c Contacts included prodromal period.

^d Samples from two different countries within the same study.

^e Range presented, median estimated from mean value. N.A., not available.

Table 2. Summary of findings from studies examining the first contact on the pathway to care ($n=21$). Data represent the percentage of patients making contact with a physician, non-physician or emergency services. Shaded cells indicate the type of contact that the largest proportion of patients used in each study, and bolded figures indicate that similar percentages of patients made contact with two of the care pathway contacts

Study	<i>n</i>	Country	Physician contact (%)	Non-physician contact (%)	Emergency contact (%)	DUP (weeks), median (range)
Lincoln <i>et al.</i> 1998 ^b	62	Australia	52	26 ^c	23 ^d	23.9 (N.A.)
Norman <i>et al.</i> 2004	70 ^a	Canada	44	13	43	21.1 (N.A.)
Bechard-Evans <i>et al.</i> 2007	98	Canada	27	20	53	13.1 (0.1–293.7)
Archie <i>et al.</i> 2009	200	Canada	36	25	34	22.1 (N.A.)
Chiang <i>et al.</i> 2005	35	China	23	63	14	17.4 (0–500.6)
Cougnard <i>et al.</i> 2004	86	France	63	22 ^c	15 ^d	28 (IQR 4–104)
Fuchs & Steinert, 2004 ^b	66	Germany	58	8	35	68 (N.A.)
Kohn <i>et al.</i> 2004 ^b	80	Germany	50	26	24 ^d	Overall DUP N.A.
Sharifi <i>et al.</i> 2009	91	Iran	57	23 ^c	14 ^d	11 (0.1–888)
O'Callaghan <i>et al.</i> 2009	142	Ireland	60	22	8 ^d	Mean = 82 (s.d. = 152)
Gill <i>et al.</i> 2005	38	Malaysia	16	18	66	12 (1–260)
Razali & Mohd Yasin, 2008	60	Malaysia	38	62	0	–
Bhugra <i>et al.</i> 2000 (i)	46	Trinidad	98	2	0 ^d	–
Chong <i>et al.</i> 2005 (i)	112	Singapore	45	29	26 ^d	48 (0.4–1344)
Temmingh & Oosthuizen, 2008	21	South Africa	57	19	24 ^d	18.1 (IQR 0–36.8)
Platz <i>et al.</i> 2006 ^b	104	Switzerland	78	15	7	Overall DUP N.A.
Harrison <i>et al.</i> 1989	131	UK	76	10	11 ^d	–
Cole <i>et al.</i> 1995	93	UK	43	35	22 ^d	–
Bhugra <i>et al.</i> 2000 (ii)	38	UK	50	26	24 ^d	–
Compton <i>et al.</i> 2006 ^b	25	USA	48	0	52 ^d	32.9 (0.4–337.7)
Chien & Compton, 2008	76	USA	33	0	64 ^d	27.7 (0.4–590.3)

DUP, Duration of untreated psychosis; N.A., not available; s.d., standard deviation; IQR, interquartile range.

^a Prodromal patients removed from sample.

^b Contacts included prodromal period.

^c Family members included as potential care pathway contacts.

^d Police included as potential care pathway contacts.

(Singh & Grange, 2006), the data collection methods varied across the studies, which used some combination of patient, family, or clinician interviews and/or medical records (Table 1).

The studies used different indices of the pathway to care, with eight examining the first contact, 10 examining the referral source, and 12 presenting data on both (Table 1). Additionally, 12 studies assessed the total number of care pathway contacts (Table 1), with the median number of contacts ranging from 1 to 4.5 (median across studies = 3). In some circumstances, the first contact on the pathway to care was also the referral source into treatment, but only five studies provided the data in sufficient detail to allow the impact of this to be assessed (Fuchs & Steinert, 2004; Kohn *et al.* 2004; Chiang *et al.* 2005; Chong *et al.* 2005; Sharifi *et al.* 2009). Finally, six studies included family members and 19 included police as potential care pathway contacts (Tables 2 and 3), highlighting differences across studies in the definition of the pathway to care.

First contact on the pathway to care

Twenty studies examined the first contact on the pathway to care, with one study presenting data from two different countries (Bhugra *et al.* 2000), for a total of 21 datasets (Table 2). The first contact for the largest proportion of patients was a physician in 13 of 21 studies. Three additional studies found a similar proportion of patients used a physician or emergency services as the first contact, three studies found that the majority (52–66%) used emergency services, and two found that the majority (62–63%) of patients made first contact with a non-physician.

When we examined the findings by region, all of the eight European studies found that a physician was the first contact for the largest proportion of patients. By contrast, none of the five North American studies found that a physician was the first contact for the largest proportion of patients, with two studies finding that the largest proportion of patients used emergency services, and three finding that

Table 3. Summary of findings from studies examining the source of referral on the pathway to care ($n=21$). Data represent the percentage of patients making contact with a physician, non-physician or emergency services. Shaded cells indicate the type of contact that the largest proportion of patients used in each study, and bolded figures indicate that similar percentages of patients made contact with two of the care pathway contacts

Study	<i>n</i>	Country	Physician contact (%)	Non-physician contact (%)	Emergency contact (%)	DUP (weeks), median (range)
Addington et al. 2002	86	Canada	36	12 ^a	52	27 (0–780)
Scholten et al. 2003	134	Canada	39	16	46	19.4 (IQR 7.3–44.8)
Norman et al. 2004	110	Canada	41	10	49	21.1 (N.A.)
Addington & Addington, 2006	373	Canada	46	7	47	Overall DUP N.A.
Archie et al. 2009	200	Canada	31	5	51	22.1 (N.A.)
Chiang et al. 2005	35	China	23	48	29	17.4 (0–500.6)
Fuchs & Steinert, 2004	66	Germany	50	38	12	68 (N.A.)
Kohn et al. 2004	80	Germany	46	23	29^b	Overall DUP N.A.
Sharifi et al. 2009	91	Iran	42	36 ^a	16^b	11 (0.1–888)
O’Callaghan et al. 2009	142	Ireland	73	0	27^b	Mean = 82 (s.d. = 152)
Yamazawa et al. 2004	83	Japan	19	63	14^b	20 (N.A.)
Turner et al. 2006	184	New Zealand	13	7 ^a	80^b	4.3 (N.A.)
Chong et al. 2005 (i)	112	Singapore	21	44	35^b	48 (0.4–1344)
Chong et al. 2005 (ii)	287	Singapore	24	41^a	14^b	Mean = 13.3 (s.d. = 26.0)
Temmingh & Oosthuizen, 2008	21	South Africa	76	19	5^b	18.1 (IQR 0–36.8)
Platz et al. 2006	104	Switzerland	80	10	11	Overall DUP N.A.
Burnett et al. 1999	100	UK	57	5	36^b	–
Garety & Rigg, 2001	21	UK	N.A.	N.A.	62^b	–
Morgan et al. 2005	462	UK	40	8	52^b	9.4 (N.A.)
Cratsley et al. 2008	59	UK	47	3	37^b	13 (0–182)
Compton et al. 2006	25	USA	20	4	76^b	32.9 (0.4–337.7)
Chien & Compton, 2008	76	USA	12	0	78^b	27.7 (0.4–590.3)

DUP, Duration of untreated psychosis; N.A., not available; s.d., standard deviation; IQR, interquartile range.

^a Family members included as potential care pathway contacts.

^b Police included as potential care pathway contacts.

approximately equal proportions used a physician or emergency services (Table 2). We also examined the findings by availability of universal health insurance and by whether the country uses a gatekeeper system for access to specialist services, but did not observe notable trends for either of these factors.

Referral source on the pathway to care

Twenty-two studies examined the referral source on the pathway to care (Table 3). In contrast to the first contact, the referral source for the largest proportion of patients was emergency services in nine of 22 studies. One additional study found that an approximately equal proportion of patients were referred by emergency services and a physician. A physician was the referral source for the largest proportion of patients in eight studies, and a non-physician in four studies.

When we examined the findings by region, six of the eight European studies found that the physician was the source of referral for the largest proportion of patients. By contrast, six of seven North American

studies found that emergency services were the referral source for the largest proportion of patients, with the seventh study finding an equal proportion referred by emergency services and a physician. Four of five Asian studies found that the largest proportion of patients used a non-physician as the referral source (Table 3). We again examined the findings by both the availability of universal health insurance and the use of a gatekeeper system in the jurisdiction of interest, but did not observe any notable trends.

Determinants of the pathway to care

Of the 30 included studies, only nine examined the sex, socio-economic, and/or ethnic determinants of the pathways to care of patients with FEP (Table 1). Some studies also explored other determinants of the pathway to care. However, these are beyond the scope of this review given our stated objective and the limited number of studies available.

Seven studies explored sex as a determinant of the care pathway (Table 1), and three found no association

(Cole *et al.* 1995; Cougnard *et al.* 2004*b*; Kohn *et al.* 2004). A Canadian study found that males were nearly five times more likely to make first contact with the emergency department (Archie *et al.* 2009), and a British study found that males were less likely to be admitted by a general practitioner (Morgan *et al.* 2005*b*). A study from South Africa found that males were more likely to be admitted involuntarily (Temmingh & Oosthuizen, 2008). Two British studies found evidence that sex may act as an effect modifier in the relationship between ethnicity and compulsory admission; however, the findings were conflicting, with one finding ethnic differences for males only (Morgan *et al.* 2005*b*) and the other finding ethnic differences only for females (Harrison *et al.* 1989).

Several socio-economic indicators were examined as determinants of the pathway to care in six studies (Table 1). Five studies found no evidence that socio-economic factors are predictive of the care pathway (Cole *et al.* 1995; Burnett *et al.* 1999; Cougnard *et al.* 2004*b*; Morgan *et al.* 2005*b*; Archie *et al.* 2009). Findings from a German study suggest that patients with semi-skilled or no vocational training were more likely to make first contact with police (Kohn *et al.* 2004).

Ethnicity as a determinant of the pathway to care was examined in seven studies (Table 1), of which three found no evidence of ethnic differences (Cole *et al.* 1995; Turner *et al.* 2006; Temmingh & Oosthuizen, 2008). Two British studies found that Afro-Caribbean patients were less likely to be referred by a general practitioner and more likely to have police involvement on their pathway to care (Burnett *et al.* 1999; Morgan *et al.* 2005*b*), and a third found longer treatment-delays for Afro-Caribbean patients (Harrison *et al.* 1989). A study from Canada found that Asian and patients of other ethnic backgrounds (not including Afro-Canadian) were three to four times more likely to make first contact with emergency services than white patients (Archie *et al.* 2009). Lastly, three of the four studies reporting ethnic differences in the pathway to care also found evidence of differences in compulsory admissions for ethno-racial minority patients (Harrison *et al.* 1989; Morgan *et al.* 2005*b*; Archie *et al.* 2009).

The pathway to care and DUP

Twenty-four studies provided data on the DUP of participants, which varied substantially across studies (Tables 2 and 3), probably due in part to differences in definition and measurement (Compton *et al.* 2007). The median DUP ranged from 4 weeks for a study from New Zealand (Turner *et al.* 2006) to 68 weeks for

a study from Germany (Fuchs & Steinert, 2004) (median across studies = 21.6 weeks).

Of the 23 studies that measured DUP, 15 examined a putative association between the pathway to care and DUP (Table 1). Ten studies assessed the impact of the first contact, with two finding no significant association (O'Callaghan *et al.* 2009; Sharifi *et al.* 2009) and a third having an insufficient sample to allow conclusions to be drawn (Temmingh & Oosthuizen, 2008). A Canadian study found evidence that patients whose first contact was with a non-physician had a significantly longer DUP (Bechard-Evans *et al.* 2007). Descriptive data from German studies also indicated a longer DUP for patients who made first contact with a non-physician or at a hospital for another complaint (Fuchs & Steinert, 2004), and a shorter DUP for patients who made first contact with emergency services (Kohn *et al.* 2004). By contrast, a U.S. study found longer treatment delays when first contact was with a general practitioner (Compton *et al.* 2006). Data from France suggest longer delays when first contact is with a private psychiatrist, as compared with a general practitioner or public psychiatrist (Cougnard *et al.* 2004*b*). Similarly, a study from China also suggests that DUP is longest when the first care pathway contact is a psychiatrist or psychologist (Chiang *et al.* 2005). Finally, a study from Singapore found no difference between making first contact with a traditional or religious healer as compared with those who sought help from another type of care pathway contact (Chong *et al.* 2005).

Five studies assessed the impact of the referral source on the DUP, with two finding no significant association (Scholten *et al.* 2003; O'Callaghan *et al.* 2009). A study from Canada found that patients referred from in-patient units to early intervention services had a significantly shorter DUP, whereas patients referred by community agencies, psychologists, or psychiatrists had a significantly longer DUP (Addington & Addington, 2006). Similarly, a study from Switzerland found delays in time to referral when the referral source was a psychiatrist, psychologist, or non-physician service, as compared with referral by a general practitioner or psychiatric services (Platz *et al.* 2006). Data from the UK suggest that individuals referred by a home treatment team or the emergency department had the lowest DUP (Cratsley *et al.* 2008).

Lastly, a study from the UK reversed the direction of the association and looked at the impact of DUP in predicting the type of care pathway contact. This study found that having a long DUP (>66 days) was not predictive of having a general practitioner or criminal justice source of referral (Morgan *et al.* 2005*b*).

Discussion

The findings from our systematic review on the pathways to care of patients with FEP suggest that the type of contact differs depending on whether the first contact or the referral source is considered. These contact points represent different time-periods in the course of illness, and may suggest a failure to identify previously untreated patients with psychotic symptoms presenting to a general practitioner. This could be because the symptoms are subtle, the assessment contact is too brief, or the presentation of a psychotic disorder is an infrequent event in a general practice. The care pathways also differed by geographical region, probably because of differences in social, cultural, and health service contexts. These regional trends highlight the need for research that is specific to the jurisdiction of interest.

Our findings support prior claims that involuntary and negative pathways to care, such as with police or emergency services, are frequent for patients with FEP (Garety & Rigg, 2001). This is of particular concern given that negative pathways to care may be associated with poor engagement in treatment (Compton, 2005) and greater dissatisfaction with services (Bhugra *et al.* 2004). Qualitative research on help-seeking in FEP also indicates that negative experiences with psychiatric services may have an impact on future delays in help-seeking (Monteiro *et al.* 2006). Taken together, these findings suggest that we need to pay greater attention to the potentially deleterious impact of the involvement of police, ambulance, and emergency services on the pathway to care.

Contacts with non-physicians tended to be infrequent relative to contacts with physicians and emergency services, except in some specific Asian jurisdictions. Lincoln *et al.* (1998) suggest that non-physician contacts may be involved as part of a 'parallel help-seeking strategy', which would not be captured by the indices used by the included studies. Qualitative research on help-seeking in early psychosis indicates that non-physician contacts play an important role in linking the families of patients with psychiatric services (Wong, 2007*a, b*) and families may use personal contacts as resources to expedite the help-seeking process (Bergner *et al.* 2008). There is also evidence that patients tend to under-report contact with non-physician services, possibly because of the perception that informal contacts do not warrant equal status on the help-seeking pathway (Lincoln & McGorry, 1995).

The studies that explored the sex, socio-economic, or ethnic determinants of the pathways to care had conflicting findings, probably reflective of contextual differences across studies. In addition, the objective of

the included studies was generally not to explore the sociodemographic determinants of the pathway to care, but rather to use these variables as covariates for other analyses. Of exception, several studies did focus on ethnic differences as the primary objective. The included studies were also limited in their power to explore these determinants, and future research may obtain a better understanding from studies that are designed and powered to examine the socio-demographic determinants of the pathway to care.

There is some evidence to suggest that the pathway to care has an impact on the DUP; however, the results were inconsistent across studies, so it is difficult to draw conclusions. It is probable that the type of care pathway contact varies the length of time between contact and referral into an appropriate treatment program. Indeed, data from Canada suggest that referral delay between the first contact and the initiation of adequate treatment accounts for a substantial proportion of the total DUP (Bechard-Evans *et al.* 2007). There is also evidence that patients who are already receiving mental health care at the time of onset of psychosis have a referral delay that is almost four times that of those who seek care after onset (Norman *et al.* 2004), which is consistent with several of the included studies that found a longer DUP was associated with contact with a psychiatrist and/or psychologist (Cougnerd *et al.* 2004*b*; Chiang *et al.* 2005; Addington & Addington, 2006; Platz *et al.* 2006). This may be due to the difficulties that service providers face in recognizing and responding to the changes in symptoms that occur at the onset of psychosis if patients are in treatment for other psychiatric conditions. It is also possible that clinicians have difficulties persuading patients to accept treatment for a different condition.

It is noteworthy that several additional factors have been found to impact the pathway to care in FEP. However, a comprehensive summary of these factors is beyond the scope of this review, and the small number of studies examining such determinants limits drawing any conclusions. In brief, living alone at the time of onset (Cole *et al.* 1995; Burnett *et al.* 1999) and a lack of family involvement on the pathway to care (Cole *et al.* 1995; Morgan *et al.* 2005*b*) increased the likelihood of a negative care pathway. Additionally, the presence of definitive psychotic symptoms, as compared with insidious symptoms, impacts the type of care pathway contacts used (Platz *et al.* 2006), and patients presenting with delusions, hallucinations, depression, or suicidal ideation tend to be more likely to have successful treatment contacts (Addington *et al.* 2002). However, the mode of onset of psychosis was not found to impact various indices of the pathway to care (Chien & Compton, 2008). There is also some

evidence to suggest that specific diagnostic groups may have a different likelihood of a negative pathway to care (Cougnard *et al.* 2004a; Morgan *et al.* 2005a).

Although we have presented the findings on the determinants of the pathway to care independently, it is probable that there is substantial interaction between various factors. Some investigators have acknowledged this by including interaction terms in their multivariate models, and have found some evidence of an interaction between socio-economic status (SES) and ethnicity (Burnett *et al.* 1999) and for both sex and age with ethnicity (Morgan *et al.* 2005b). It is also possible that patients entering the treatment system through emergency services may have shorter delays but may be more likely to be admitted involuntarily. Similarly, there may be some overlap between an insidious mode of onset of psychosis and long prodromal period, as the transition from prodromal phase to psychotic phase is usually less dramatic. In general, the limited evidence on such interactions prevents us from speculating on the exact nature of the complex interplay between the various factors. Future studies will need to employ more comprehensive approaches using alternative methodologies to gain further insight into the mode of action of such interactions.

Finally, it is also important to consider the nature of the pathway to care during the prodromal phase of FEP, when the symptoms are first beginning to emerge. Despite this, few studies included in our review examined prodromal contacts. Findings from these studies suggest that individuals are more likely to make contact with physician and non-physician services during the prodrome, and with emergency services after the onset of psychotic symptoms (Norman *et al.* 2004; Addington & Addington, 2006; Platz *et al.* 2006). A more complete understanding of the help-seeking attempts made during the prodromal phase of illness is crucial for secondary prevention and early intervention efforts.

Our findings are limited by the lack of a standard and validated measure of pathways to care (Singh & Grange, 2006), which restricts the comparability of the outcome data across studies. Furthermore, the included studies differed with respect to the definition of the pathway to care, and the inclusion or exclusion of different types of contacts can have an impact on the observed indices of the pathway to care. The trends and conclusions drawn from these data should be interpreted with caution given this heterogeneity in the outcome measure.

Despite these limitations, we are able to conclude that prior research on the pathways to care of patients with FEP has not sufficiently explored whether sex, SES, or ethnicity are determinants of the care

pathways, or the impact of the pathway to care on DUP. Additional determinants warrant further investigation; greater understanding of the complex interactions between individual determinants and of the nature of the pathway to care during the prodrome is needed. Future studies should be designed and powered to examine these determinants of the pathways to care, and investigators should make explicit the definitions of pathways to care used. Finally, studies that aim to understand the potential impact of negative pathways to care on subsequent engagement and satisfaction with services are needed, and research specific to the jurisdiction of interest is warranted.

Understanding the determinants of the pathways to mental health care and the impact on DUP is crucial for informing the provision of mental health services. Such research is needed to identify disparities in the delivery and uptake of health and social services, the barriers that patients face when seeking help for psychotic symptoms, and inconsistencies in the response of service providers to help-seeking contacts. By increasing access for patients experiencing a first episode of psychosis, we can potentially improve the outcomes of the disorder, prevent significant disability and delay in achieving social, educational and career milestones, and help to ease the psychological distress experienced by patients and their family members.

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Declaration of Interest

None.

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Appendix 1. Terms used for Medline search strategy

[exp. Schizophrenia and Disorders with Psychotic Features/ OR
exp. Affective Disorders, Psychotic/ OR
psychosis.mp OR
psychotic disorder\$.mp OR
severe mental illness\$.mp]

AND

[exp. Health Services Accessibility/ OR
pathways to care.mp OR
pathways to mental health care.mp OR
pathways to health care.mp OR
pathways to psychiatric care.mp OR
pathways to services.mp OR
pathways to mental health services.mp OR
pathways to health services.mp OR
pathways to psychiatric services.mp]

Appendix 2. Journals included in the manual search strategy

Acta Psychiatrica Scandinavica
*Administration and Policy in Mental Health and
Mental Health Services Research*
American Journal of Psychiatry
Archives of General Psychiatry
British Journal of Psychiatry
Canadian Journal of Psychiatry
Community Mental Health Journal
Early Intervention in Psychiatry
Psychiatric Bulletin
Psychiatric Services
Psychological Medicine
Schizophrenia Bulletin
Schizophrenia Research
Transcultural Psychiatry
Social Psychiatry and Psychiatric Epidemiology

Appendix 3. Complete list of citations for studies included in the systematic review ($n = 30$)

- Addington J, Addington D** (2006). Early intervention for psychosis: who refers? *Schizophrenia Research* **84**, 176–177.
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