



REVIEW ARTICLE

Pathways to care in at-risk mental states: A systematic review

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Abstract

Aim: Pathways to care are well studied in the First Episode Psychosis field, but less attention has been given to At-Risk Mental States or prodromal psychosis. This is important because accessing appropriate help at the earliest opportunity is likely to improve outcomes, particularly for those who make transition to psychosis. The present systematic review aimed to synthesize the available literature on pathways to care in ARMS or prodromal psychosis, and investigate the barriers and facilitators to receiving care for ARMS.

Methods: The CINAHL Complete, EMBASE, Medline Complete, PsycINFO and PubMed databases were searched. Studies were included if they were published in English between 1985 and 2019, where reported data came exclusively from an At-Risk Mental State population, and the study described or related to pathways to care.

Results: Ten studies met the inclusion criteria, of which 8 were quantitative. Screening tools and pathways to care instruments varied. Mental health professionals, and general practitioners played a key role in help seeking. Family involvement was also found to be an important factor.

Conclusions: Pathways to care research in At-Risk Mental States are more scarce than in the field of First Episode Psychosis. More research is warranted, especially concerning the role of patient-level characteristics on pathways to care. A validated measure of pathways to care may also be of benefit.

KEYWORDS

at risk mental states, help seeking behaviour, high risk, pathways to care, prodromal psychosis, treatment delays

1 | INTRODUCTION

Psychosis is associated with high levels of disability and suffering (Rössler, Salize, van Os, & Riecher-Rössler, 2005), but outcomes are improved the earlier pharmacological or psychological intervention is initiated (Penttilä, Jääskeläinen, Hirvonen, Isohanni, & Miettunen, 2014). The concept of an At-Risk Mental State (ARMS; also known as clinical high risk and ultra-high risk) for psychosis emerged in the 1990s in response to growing calls that psychotic disorders had a

prodromal period that lay undetected by services (Yung & McGorry, 1996). It was originally posited that positive psychotic symptoms of a lesser severity or duration than in psychosis, together with a drop in social functioning, would be indicative of transition to a first episode of psychosis (FEP; Fusar-Poli et al., 2013), and that intervening at this time would prevent transition.

Since then, whether ARMS is synonymous with prodromal psychosis has been intensely debated (van Os & Guloksuz, 2017). Conservative estimates find only 25% of people with ARMS transition to

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psychosis (Simon et al., 2011), a figure which appears to be reducing over time (Fusar-Poli et al., 2013; Hartmann et al., 2016). One study found only 4% of their sample with FEP came from an ARMS service (Ajnakina et al., 2017). Nevertheless, those who fail to make transition have poor trajectories, with high levels of comorbid conditions and substance use; impairments in quality of life; and poor social functioning in general (Addington et al., 2011; Beck et al., 2019; Brandizzi et al., 2015; Fusar-Poli et al., 2015; Lin et al., 2015; Rietdijk et al., 2013). As a result there is a growing school of thought that ARMS should be viewed through a transdiagnostic lens (Ajnakina, David, & Murray, 2019; McGorry, Hartmann, Spooner, & Nelson, 2018; Perez & Jones, 2019).

Evidence shows that intervening in the ARMS phase appears to be advantageous and cost effective whether or not transition to psychosis is made (Ising et al., 2015; Ising et al., 2017; Van der Gaag, Nieman, & Van den Berg, 2013; Wijnen et al., 2019). In those that transition to psychosis, being treated in an ARMS service has the benefit of already being engaged with services, thus reducing the Duration of Untreated Psychosis (Valmaggia et al., 2015) and improving treatment adherence (Van der Gaag et al., 2013). Intervening in the ARMS stage can also prevent decline in social exclusion (Van der Gaag et al., 2013). Cognitive Behavioural Therapy in ARMS reduces transition rates; lessens severity and distress associated with psychotic symptoms; and improves quality of life (Devoe, Farris, Townes, & Addington, 2019; Hutton & Taylor, 2014; Ising et al., 2015; Van der Gaag et al., 2013; Wilson, Shryane, Yung, & Morrison, 2019).

Given the effectiveness of intervention in the ARMS population, and the poorer outcomes for ARMS patients if left untreated, the question arises whether earlier detection in the ARMS phase is warranted (Dimitrakopoulos, Kollias, Stefanis, & Kontaxakis, 2015). The time between psychotic symptom onset and treatment in ARMS is described variously as the Duration of Untreated Attenuated Psychotic Symptoms (DUAPs), Duration of Untreated Illness (DUI), and Duration of Untreated Prodromal Symptoms (DUPrS). A growing body of research suggests longer DUAPs are predictive of less favourable outcomes, including increased transition rates (Nelson et al., 2016), reduced scores on the Global Assessment of Functioning (Fusar-Poli et al., 2009; Zhang et al., 2019), poorer social functioning (Burton et al., 2019; Carrión et al., 2016), and, in those who transition, increased risk of negative symptoms (Gebhardt et al., 2019).

The 'pathways to care' (PtC) paradigm is used to measure delays in help seeking and treatment, which is important for understanding how people can access services at an earlier stage. 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' (Rogler & Cortes, 1993, p. 555), PtC encompasses help seeking by individuals, carers and organizations, and how agencies respond (Singh & Grange, 2006). PtC generally measures the time between symptom onset, first professional contact and the initiation of appropriate treatment, which gives a proxy timescale of help seeking and treatment delay. This has the potential to identify whether public health or service level intervention would be most of benefit. Given

the growing body of evidence pointing to the importance of intervening early in ARMS, PtC seems a useful paradigm in which to explore this further.

To our knowledge, no systematic review exploring PtC in ARMS alone has been conducted to date. This is surprising given PtC have been given consideration in FEP (Anderson, Fuhrer, & Malla, 2010; Singh & Grange, 2006) and in youth mental health (MacDonald, Fainman-Adelman, Anderson, & Iyer, 2018). Gronholm, Thornicroft, Laurens, and Evans-Lacko (2017a) examined the role of stigma in PtC in FEP and those at risk of psychotic disorders, where nine papers out of 40 were found for the latter. The lack of research may be an indication of the complexities of PtC in an ARMS population. As previously discussed, the ARMS population are a heterogeneous group and those who present in the 'true' prodrome may have different characteristics to those who do not make transition (Cannon et al., 2008; Nelson, Yuen, & Yung, 2011; Yung et al., 2003). In contrast to FEP there is a lack of clarity about when the ARMS period starts, especially given the high levels of psychotic experiences in the general population (Hanssen, Bak, Bijl, Vollebergh, & Van Os, 2005).

The present systematic review is therefore warranted due to the growing evidence base of early intervention in DUAPS, and the implications this may have on whether service or population interventions are required in order to reduce treatment delays. This is important because while service interventions are in place, evidence for population level interventions are lacking in ARMS compared to those for FEP (Ajnakina et al., 2019). The systematic review aimed to examine what care pathways people with ARMS take, and what the barriers and facilitators to receiving care from an ARMS service are.

2 | METHODS

The systematic review protocol was developed according to Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff, & Altman, 2009). It was registered with the International Prospective Register of Systematic Reviews (PROSPERO, <https://www.crd.york.ac.uk/prospero>, registration number CRD42019120243).

2.1 | Search strategy and procedure

The CINAHL Complete, EMBASE, Medline Complete, PsycINFO and PubMed databases were searched, with additional searches carried out on Google Scholar. Search terms were as follows: ('at risk mental state*' or 'at risk' or 'high risk' or 'ultra high risk' or 'clinical high risk' or 'prodrom*' or 'attenuated') and ('pathway*' to care' or 'pathway*' to mental health care' or 'pathway*' to health care' or 'pathway*' to services' or 'pathway*' to mental health services' or 'pathway*' to health services' or 'pathway*' to psychiatric services'). Searches were carried out on 23rd January 2018 for papers published between 1985 and 2018, with an additional search on 26th February 2020 for papers published up to 31st December 2019.

2.2 | Inclusion and exclusion criteria

The following inclusion criteria were adopted: (a) primary papers published in English between 1985 and 2019, (b) sample where available data reported is exclusively from an at risk mental state, at high risk for psychosis, or prodromal psychosis population (c) describes or relates to PtC. Primary papers were defined as research published in an academic journal (ie, not conference proceedings or book chapters) and excluded literature reviews. The choice of 1985 was due to other reviews in the field of PtC adopting this criterion (eg, Anderson et al., 2010).

2.3 | Screening

Abstracts and full texts from the database searches were screened by SA. Twenty percent of full text articles screened for eligibility ($n = 6$) were checked independently by a second reviewer, with one discrepancy resolved following discussions with SO and PB. Double screening was not possible due to this review taking place as part of a doctorate project. A further five full-text articles were discussed in consensus meetings with SO and PB.

2.4 | Quality appraisal

Methodological quality of the studies was measured using the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018). Papers were assessed by SA, with 20 % ($n = 2$) independently checked, with 78.57% agreement (resources did not allow for more than 20% of papers to be checked). Discrepancies were resolved by discussion with SO and PB. The MMAT is a well-established checklist for studies using qualitative, quantitative, mixed or randomized control trial methodologies, and consists of two generic core measures of quality, and a further five questions tailored to the methodology adopted. The scoring system used was that adopted by Gronholm, Thornicroft, Laurens, and Evans-Lacko (2017b), where points were added together to give a total score, which was converted to a percentage (0% no criteria met to 100% all criteria met), with a higher percentage indicating better quality studies.

2.5 | Data extraction and narrative synthesis

Data extracted from studies meeting the inclusion criteria included aims, study design, country, screening tool used, information about the sample (n , genders, ages), and PtC (definition of PtC, instrument, key pathway agents, among others). A narrative synthesis was carried out according to guidelines by Popay et al. (2006). This involved developing a preliminary synthesis based on common patterns across the studies (similar to a thematic analysis type process), exploring relationships between the data and assessing the robustness of the synthesis by going back to the full texts. In accordance

with the guidance, quality appraisal was conducted before the narrative synthesis.

3 | RESULTS

Database searches yielded 4510 papers (3263 without duplicates; see Figure 1). Of these, 26 full texts were screened for eligibility, with 10 meeting the inclusion criteria, with a combined sample size of 720 ARMS individuals (Boydell, Volpe, Gladstone, Stasiulis, & Addington, 2013; Chung et al., 2010; Cocchi et al., 2013; Fridgen et al., 2013; Gronholm et al., 2017b; Platz et al., 2006; Shin et al., 2010; Stowkowy, Colijn, & Addington, 2013; von Reventlow et al., 2014; Wiltink, Velthorst, Nelson, McGorry, & Yung, 2015).

3.1 | Study characteristics

Study characteristics are given in Table 1. All but two studies (Boydell et al., 2013; Gronholm et al., 2017a) were quantitative. Research came from a wide variety of countries, with two each from Canada, South Korea and Switzerland, and one each from Italy, the United Kingdom and Australia. One study (von Reventlow et al., 2014) took place across four European countries. Screening tools varied, but the Comprehensive Assessment of At Risk Mental States (CAARMS; Yung et al., 2005) was the most frequently used ($n = 3$), followed by the Structured Interview for Prodromal Symptoms (SIPS; McGlashan, Miller, Woods, Hoffman, & Davidson, 2001; $n = 2$).

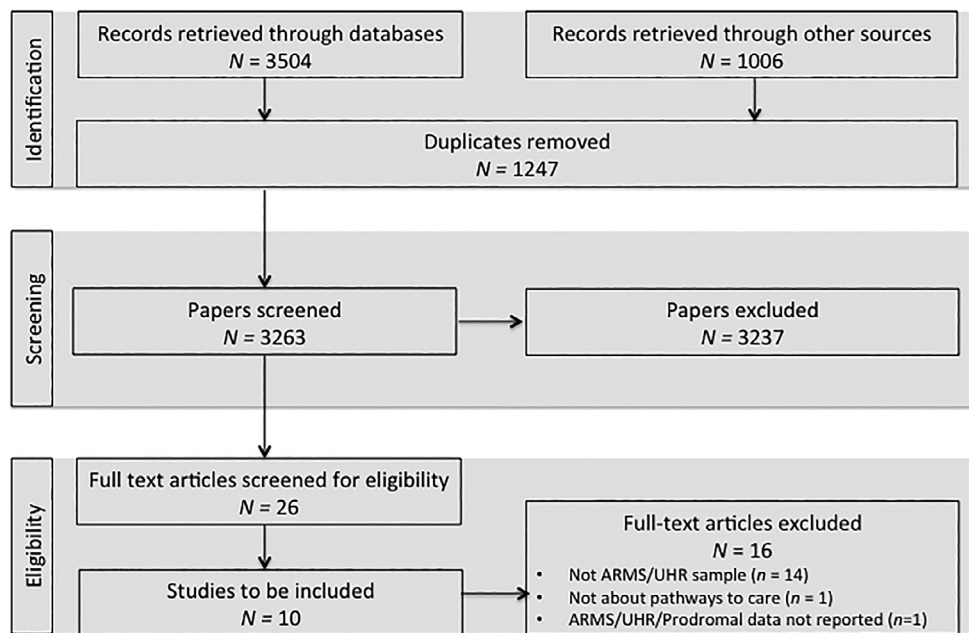
Seven papers consisted of samples from an ARMS population only, with the remaining three (Cocchi et al., 2013; Fridgen et al., 2013; Platz et al., 2006) having samples consisting of ARMS and FEP populations. These three were included in the study because they analysed their ARMS and FEP data separately. Sample sizes for ARMS populations ranged from 10 (Boydell et al., 2013) to 233 (von Reventlow et al., 2014), with a mean of 73. Mean ages of participants were generally in the late teens or early twenties (range = 15.7–26.8 years). Percentages of male participants were a mean of 56.67% (range = 20–81.6%). Ethnicities were reported in 33% of papers ($n = 3$): of those reported, most participants were White or European (Table 1). No studies reported whether their participants lived in urban or rural locations.

3.2 | Pathways to care information

PtC information is given in Table 2.

3.3 | Instruments and data sources

Instruments used to measure PtC varied considerably between studies (Table 2). All but the two qualitative papers (Boydell et al., 2013; Gronholm et al., 2017b) measured PtC quantitatively (the qualitative

**FIGURE 1** PRISMA diagram

studies explored the ways that ARMS individuals access mental health services, and stigma in relations to PtC respectively). Five studies utilized an interview designed for the purposes of the research. Two studies (Stowkowy et al., 2013; von Reventlow et al., 2014) used the Pathways to Care Interview (Perkins, Nieri, Bell, & Lieberman, 1999), although the latter used an adapted version of the instrument. No studies reported information about their measure's psychometric properties, but Fridgen et al.'s (2013) chosen measure, the Basel Interview for Psychosis, has since been shown to have good inter-rater reliability (Riecher-Rossler et al., 2015). All papers collected data using face-to-face interviews, either with the participant alone or with the participant and their significant other(s) (Table 2).

All instruments asked participants to identify the people and or institutions they approached to seek help. Fridgen's Basel Interview for Psychosis specifically asked about the involvement of a number of different social, professional and community contacts, including family, friends, health professionals and religious leaders, rather than relying on the person's recollection alone, which may have provided greater accuracy of reporting. In four papers (Platz et al., 2006; Stowkowy et al., 2013; von Reventlow et al., 2014; Wiltink et al., 2015) information was requested about the type of symptom leading to each contact.

3.4 | Number and duration of pathways to care

All but four studies (Boydell et al., 2013; Chung et al., 2010; Cocchi et al., 2013; Gronholm et al., 2017a) reported the mean number of PtC between initial help seeking and successful referral. Caution should be adopted in pooling the data as a whole, as differences in findings may be reflective of variability in data collection instruments and healthcare contexts. Taken together, the number of PtC ranged between 0 and 9, with a pooled mean of 3.22. Duration of PtC (the time between help seeking is initiated and acceptance to an

appropriate service; reported by five studies) was much more variable, ranging from 1.49 to 30 months (Table 2).

3.5 | The pathway to care and duration of untreated illness

DUI (definitions and mean months) are given in Table 2. DUI or equivalent were reported in five studies (Chung et al., 2010; Cocchi et al., 2013; Fridgen et al., 2013; Shin et al., 2010; von Reventlow et al., 2014). Definitions of DUI varied greatly. Only one of the five papers reporting DUI gave attenuated psychotic symptoms as indicative of illness onset (Chung et al., 2010). The remainder mostly gave less specific indicators of ARMS onset, including 'first self perceived signs or symptoms in a change in wellbeing' (Fridgen et al., 2013), and onset of anxiety, depression or social withdrawal (Cocchi et al., 2013). Taken together, DUI or equivalent ranged between 13.31 and 66.2 months, with a mean of 34.78.

3.6 | Key pathway agents and first help seeking encounter

Table 2 presents the key pathway agents and first help seeking encounter. Key pathway agents (the people or agency involved in help seeking across the whole pathway to care) were most frequently identified as mental health professionals ($n = 6$), followed by family ($n = 4$) and General Practitioners (GPs) or primary care ($n = 3$). School was given as important in the care pathway in two studies. Other key pathway agents identified by one study each include friends, the community, private practice and the emergency/crisis team.

Findings for first help seeking encounters were similar to key pathway agents, with psychiatrists or mental health professionals

TABLE 1 Characteristics of included studies

Study	Study objectives	Country	Population	Setting	Screening tool	N	Mean age (SD)	% male	Ethnicity
Boydell et al. (2013)	Identify ways which UHR youth access mental health services and factors that advance/delay help seeking. Elaborate and refine Revised Network Episode Model	Canada	UHR	Early Intervention Clinic	Criteria of Prodromal Symptoms, Bonn Scale for the Assessment of Basic Symptoms	10	17.0	20.0	60% European 3% Chinese 1% Mixed Race
Chung et al. (2010)	To investigate the help-seeking behaviours, Duration of Untreated Attenuated Psychotic Symptoms, and baseline clinical characteristics in individuals at HR for psychosis.	South Korea	HR	Early Psychosis Centre	Comprehensive Assessment of At Risk Mental States (CAARMS)	38	24.24 (6.43)	81.6	Not reported
Cocchi et al. (2013)	To Investigate patterns of referral in UHR patients	Italy	UHR	Early Detection and Early Intervention team	Early Recognition Inventory Retrospective Assessment of Symptoms Checklist, Brief Psychiatric Rating Scale	9 ^a	22.1 (3.6)	67.0	Not reported
Fridgen et al. (2013)	To investigate duration of untreated illness/psychosis and help-seeking contacts for referrals to specialist clinic	Switzerland	ARMS	Early Detection Clinic	Basel Screen Instrument for Psychosis	61 ^a	26.8 (8.7)	59.0	Not reported
Gronholm et al. (2017b)	To explore stigma and discrimination in relation to initial pathways to care from the perspective of young people putatively in an early stage of increased risk of developing psychotic disorders.	UK	HR ('Putatively at risk of developing psychotic disorders')	Participants from London Child Health and Development Study	Psychotic-like experiences questionnaire, Strengths and Difficulties Questionnaire	29	15.7 (1.6)	34.5	65.5% White 31% Black 3.4% Asian
Platz et al. (2006)	To obtain information on help seeking pathways for patients at putative risk for psychosis, including type of health professionals contacted, number of contacts, symptom, interval between initial contact and referral to specialist service.	Switzerland	ARMS	Prodromal clinic	Schizophrenia Prediction Instrument Adult Version, Scale of Prodromal Symptoms, Positive and Negative Syndrome Scale	50 ^a	21.0	62.0	Not reported
Shin et al. (2010)	To examine help seeking contacts	South Korea	UHR	Early Psychosis Centre	CAARMS	18	16.78 (1.99)	72.2	Not reported
Stowkowy et al. (2013)	To prospectively investigate the pathways to care of those at CHR of developing psychosis	Canada	CHR	Prodromal clinic	Structured Interview for Prodromal Syndromes (SIPS)	35	21.0 (4.2)	71.43	57% White 23% Asian 14% Mixed Race 6% Black
von Reventlow et al. (2014)	To acquire accurate knowledge about pathways to care and delay in obtaining specialized high risk care	Finland Germany Netherlands England	HR	Various, including university based hospital and specialist early intervention in psychosis services	SIPS (version 3.0), Schizophrenia Proneness Instrument Adult Version	233	23.0 (5.3)	54.9	Not reported
Wittink et al. (2015)	To compare changes in referral patterns in an UHR clinic with a previous study, and investigate if this may account for a drop in the rate of transition to psychosis	Australia	HR	ARMS Clinic	CAARMS	150	18.3 (3.2)	44.0	Not reported

Abbreviations: ARMS, at risk mental state; CHR, clinical high risk; HR, high risk; UHR, ultra high risk.

^aStudies contained mixed samples. N reported here refers to participants who met the systematic review inclusion criteria.

TABLE 2 Pathways to care information

Study	PtC definition	PtC Instrument	Mean number PtC (SD), range	Mean months duration PtC (SD)	DUI definition	Mean months DUI (SD)	Key pathway agents	Common first help seeking contacts
Boydell et al. (2013)	The specific path that individuals experiencing psychosis use to access treatment	Interview developed for the study (participant and significant other)	Not reported	Not reported	Not defined	Not reported	Family, community, school	Not reported
Chung et al. (2010)	Not defined	Interview developed for the study (participant and significant other)	Not reported	Not reported	Onset of attenuated psychotic symptoms to first visit to psychiatric services	22.0 (28.59)	Family	Family, psychiatrist
Cocchi et al. (2013)	The range of contacts made by distressed people and their relatives with individuals and organizations to seek help	Interview developed for the study (participant and significant other)	Not reported	Not reported	Onset of anxiety, depression and/or social withdrawal to start of psychotherapy treatment	30.7 (22.3)	Mental health professional, public or private mental health centre, family	Mental health professional, psychiatrist
Fridgen et al. (2013)	Difficulties in finding the right help-seeking contact	Basel Interview for Psychosis	8.57 (8.42)	30	Time between first self-perceived signs or symptoms of a change in well-being and first contact with specialized early detection clinic	66.2 (76.9) ^a	Family, friends	Family, friends, psychiatrist
Gronholm et al. (2017b)	Help seeking and support from informal (eg, family, friends) and formal (eg, primary care, school-based support, specialist services) sources	Not measured	Not reported	Not reported	Not defined	Not reported	Someone with a close relationship to the person (not a specific group)	Not reported
Platz et al. (2006)	Help seeking pathways	Interview developed for the study (participant)	2.38 (1.42) 1–8	28.5 (49.91)	Not defined	Not reported	Psychiatric outpatient services, private psychiatrists/psychologists, GPs	GP
Study	PtC definition	PtC Instrument	Mean number PtC (SD), range	Mean months duration PtC (SD)	DUI definition	Mean months DUI (SD)	Key pathway agents	Common first help seeking contacts
Shin et al. (2010)	The contact process during the period of time from when the illness is suspected until the first psychiatric treatment	Interview developed for the study (participant and significant other)	1.83	Not reported	Not defined (term DUI used)	13.31 (12.57)	Psychiatrists, family, teachers	Family
Stowkowi et al. (2013)	The number of attempts individuals make to obtain help and who is most likely to ensure appropriate treatment is obtained	Pathways to Care Interview	1.7 1–4	Not reported	Not defined	Not reported	GP	GP
von Reventlow et al. (2014)	Number of help-seeking events, initial help-seeking delay (time from onset of at-risk criteria to first help-seeking contact), and treatment delay (time between first help-seeking contact and receiving appropriate treatment)	Adapted version of the Pathways to Care Interview	2.9 (1.4) 1–9	25.29 (36.78)	Duration of unrecognized risk for psychosis: delay between help-seeking and treatment	41.70 (56.28)	Primary care, mental health care centre, private practice	Not reported
Wiltink et al. (2015)	Not defined	Interview designed for research projects in the clinic	1.93 (1.15) 0–6	1.49 (3.08)	Not defined	Not reported	Emergency/crisis response team	Emergency/crisis response team, GP, teacher

Abbreviations: DUI, duration of untreated illness; PtC, pathways to care.

^aReported for FEP and ARMS but difference not statistically significant.

identified by four studies, and family and GPs by three. Friends, emergency/crisis team, and teachers were given as first help seeking encounters in one study each.

3.7 | Factors influencing the pathway to care: barriers and facilitators

Family involvement was identified as important in half of studies meeting the review criteria (Boydell et al., 2013; Chung et al., 2010; Cocchi et al., 2013; Fridgen et al., 2013; Shin et al., 2010). More specifically, family played a key role in facilitating initial help seeking (Chung et al., 2010; Fridgen et al., 2013), and in initiating referrals to the appropriate ARMS service (Cocchi et al., 2013). Studies that identified the importance of family involvement tended to be of higher quality than those who did not (Table 3).

The importance of family involvement was not a universal finding. Wiltink et al. (2015), identified that a greater proportion of first contacts in the care pathway were with emergency or crisis response teams, General Practitioners and school counsellors rather than family. School employees were also found to play a more important role than family by Boydell et al. (2013), who report that young people are more likely to take an active role in the help seeking process. Stowkowy et al. (2013) found only 1% of reported contacts prior to acceptance at the CHR service were by family. The remaining three studies (Gronholm et al., 2017b; Platz et al., 2006; von Reventlow et al., 2014) did not report any influence of family on PtC. The importance of primary care professionals in facilitating referrals to ARMS services, in particular General Practitioners, was identified by three studies (Platz et al., 2006; Stowkowy et al., 2013; von Reventlow et al., 2014), however these were generally lower quality studies (all 42.86%; see Table 3).

Emergency services involvement (including police, ambulance, or attendance at accident and emergency) was reported by four studies (Cocchi et al., 2013; Fridgen et al., 2013; Stowkowy et al., 2013; von Reventlow et al., 2014; Wiltink et al., 2015). Results presented a mixed picture. Wiltink et al. (2015) found the most common source of referral was the emergency or crisis team. von Reventlow et al. (2014) found 6.6% of participants had used emergency hospital but this figure also took into account admissions to general hospital. Cocchi et al. (2013) reported that 2 participants (2% of the sample) used the 'emergency room' during the PtC, but that no police authority, legal authority or ambulance service were involved. One contact (1.6% of contacts) was with 'emergency services' by Stowkowy et al. (2013).

One study reported on compulsory admission on the PtC (Chung et al., 2010), who reported one participant (1% of sample) was detained prior to admission to the service. Compulsory admissions were not reported to occur in the PtC by the remaining studies. No studies commented on the role of ethnicity in the PtC.

Three studies (Platz et al., 2006; Stowkowy et al., 2013; Wiltink et al., 2015) found that patients presenting with positive psychotic symptoms (eg, hallucinations, delusions) were more likely to have a shorter care pathway to the appropriate ARMS service. No other clinical factors or facilitators were identified.

3.8 | Quality appraisal

Methodological quality of studies varied (see Table 3). Percentages calculated using the MMAT ranged between 28.57% and 100%, with a mean of 64.29% (see Supplementary Information for justification of MMAT ratings). Limitations were generally due to a lack of information given in papers, especially sampling strategies and whether the samples were representative of the target population. Some studies lacked clear research aims or objectives.

4 | DISCUSSION

4.1 | Main findings

This systematic review found that PtC in ARMS is a much more neglected area than FEP. Our review found 10 studies meeting the inclusion criteria, whereas a systematic review of PtC in FEP published 9 years ago included 30 papers (Anderson et al., 2010). While the ARMS field is a more recent concept than FEP, it is well out of its infancy, thus the lack of research in this area is concerning. The paucity of research may be in part due to difficulties in defining the onset of illness in ARMS, as evidenced by the varying definitions for illness onset in the papers included in this review.

4.2 | Interpretation of findings

The fact that the papers originate from different countries which have varying healthcare contexts mean taking findings together should be undertaken cautiously.

The review has highlighted that variability in the measurement of PtC continues to be a concern. None of the 10 papers meeting the inclusion criteria used a measure that was validated at the time of the paper's publication, and the majority used a measure designed for the purposes of the study. The need for a validated measure of PtC was recommended in the FEP population over a decade ago (Singh & Grange, 2006), and also, more recently, by MacDonald and colleagues in the field of youth mental health (MacDonald et al., 2018). A psychometrically sound measure of PtC in ARMS appears warranted too. Development of such an instrument is likely to bring its own complexities due to the variation in definitions and terminologies in the field of ARMS, as well as differences in healthcare systems across countries and healthcare systems.

The pooled mean for the numbers of PtC was 3.22 contacts, which was similar to MacDonald's finding of 2.9 across mental health services for young people (2018). DUI ranged between 13.31 and 66.2 months (pooled mean = 34.78 months). This is shorter than an equivalent study of DUI in FEP, where the median was 44.89 months (Anderson, Fuhrer, Schmitz, & Malla, 2013), which is to be expected given people with FEP are likely to present at a later stage.

The fact that family involvement was not a universal finding may perhaps be reflective of the cultural differences in the role of the family, given the variety of countries in which the studies took place, as

TABLE 3 Quality appraisal

Domain	Quality criteria	Quality assessment of included studies									
		Boydell et al. (2013)	Chung et al. (2010)	Cocchi et al. (2013)	Fridgen et al. (2013)	Gronholm et al. (2017b)	Platz et al. (2006)	Shin et al. (2010)	Stowkowy et al. (2013)	von Reventlow et al. (2014)	Wiltink et al. (2015)
Screening questions	Are there clear research questions ^a ?	+	+	+	+	+	+	–	–	–	+
	Do the collected data allow to address the research questions ^a ?	+	+	+	+	+	+	+	+	+	+
Qualitative Studies	Qualitative approach appropriate to answer research question ^a ?	+	n/a	n/a	n/a	+	n/a	n/a	n/a	n/a	n/a
	Qualitative data collection methods adequate to address the research question ^a ?	+	n/a	n/a	n/a	+	n/a	n/a	n/a	n/a	n/a
	Findings adequately derived from the data?	+	n/a	n/a	n/a	+	n/a	n/a	n/a	n/a	n/a
	Interpretation of results sufficiently substantiated by data?	+	n/a	n/a	n/a	+	n/a	n/a	n/a	n/a	n/a
	Coherence between qualitative data sources, collection, analysis and interpretation?	+	n/a	n/a	n/a	+	n/a	n/a	n/a	n/a	n/a
Quantitative Descriptive Studies	Sampling strategy relevant to address the research question ^a ?	n/a	?	+	?	n/a	?	?	?	?	+
	Sample representative of the target population?	n/a	?	+	?	n/a	?	?	?	?	?
	Measurements appropriate?	n/a	+	+	+	n/a	?	?	+	+	+
	Risk of nonresponse bias low?	n/a	+	+	?	n/a	?	?	?	?	–
	Statistical analysis appropriate to answer the research question?	n/a	+	+	+	n/a	+	+	+	+	+
Total percentage		100	71.43	100	57.14	100	42.86	28.57	42.86	42.86	57.14

^aAlso taken to mean research objectives and aims (confirmed by P. Pluye, MIMAT developer, personal communication 16.04.19). +, yes; –, no; ?, can't tell.

well as study quality. Nevertheless, the importance of family echoes the literature in both youth mental health services and FEP (Del Vecchio et al., 2015; MacDonald et al., 2018). It seems that a public health approach to educate parents may be warranted in this area. The important role of family in PtC raises the question of whether treatment delays may occur in people who are socially isolated and those who do not have family to turn to, as is the case in FEP (Anderson et al., 2010).

Emergency services involvement was generally found to be a small percentage of PtC contacts. One paper found that compulsory admissions did not play a significant role in PtC in ARMS, with mental health professionals and GPs more likely to be first help seeking contacts. This is in common with Valmaggia and colleagues' findings (2015) that patients presenting in the prodromal phase who went on to transition to psychosis were less likely to be compulsorily admitted compared to those who did not present prodromally. These findings are somewhat contrary to findings in the FEP literature, where contacts with police, emergency services and compulsory admissions are much more frequent (Anderson et al., 2010). This makes sense given those presenting during the ARMS phase tend by their very nature to have less severe presentations than those with FEP. Interestingly, Anderson et al. (2010) point out that more frequent contacts with emergency services can lead to disengagement with treatment (so-called 'negative' PtC). This reinforces the importance of intervening during the prodromal stage before contact with emergency services occurs, as this may be a more optimal stage to engage patients in treatment.

The impact of ethnicity on PtC was a neglected area in the studies meeting the review's criteria. Only three of the 10 studies reported their participants' ethnicities. No studies reported on the effects of ethnicity on PtC, which is surprising as this is a well researched area in FEP. The literature generally finds those of Black ethnicity are likely to have longer and more negative PtC in psychosis (Anderson, Flora, Archie, Morgan, & McKenzie, 2014), thus this is an area worthy of further consideration. Similarly, no studies in this review compared PtC in rural and urban populations, which warrants further examination considering the evidence that living in a rural community impacts on treatment delays in the field of FEP (Boonstra et al., 2012; Kvig et al., 2017).

Positive symptoms as being indicators of shorter care pathways is understandable given that negative symptoms have higher overlap with other conditions, such as depression, and are associated with social withdrawal. Indeed, in the first episode psychosis samples Anderson et al. (2010) found that people presenting with delusions, hallucinations, depression, suicidal ideation tended to have more successful treatment contacts.

4.3 | Limitations

The findings are limited by the relatively small number of papers meeting the criteria for this review. The fact that they come from countries with different healthcare systems, used various

non-validated screening tools and used different PtC instruments mean results must be interpreted with caution. In addition, having a second rater for all papers rather than 20% would have been preferable if resources allowed for this. The fact that the MMAT does not recommend cut offs for quality rating renders it difficult to objectively judge the quality of the studies.

4.4 | Implications for research and treatment

Mental health professionals, family and primary care were found to be key pathway agents. Family involvement in help seeking was also identified as extremely important for half of studies meeting the inclusion criteria. This points to the importance of developing evidence based interventions to improve early detection of ARMS for both health professionals and the general public. Education of general practitioners in both those at high risk for psychosis and FEP has been shown to be efficacious in improving referral rates and referral quality (Perez et al., 2015), however more research is required in this area. The case for public health interventions is an emerging field in ARMS (Ajnakina et al., 2019; Anderson, 2019); this review appears to support the development of such interventions. For instance in the area of first episode psychosis, the Youthscape campaign in Birmingham, UK included a community psychosis awareness campaign and a youth friendly website, which appeared to reduce DUP in those people coming into Early Intervention in Psychosis services (Connor et al., 2016). Given the findings in this review, similar awareness campaigns may be advantageous, for example advertising in community centres.

The findings in our review also point to the need for a validated measure of PtC. This was recommended in a review published 13 years ago in the area of FEP (Singh & Grange, 2006); to the author's knowledge no such measure has yet been developed. More research is required in the role of ethnicity for PtC in ARMS and the role of emergency services.

4.5 | Recommendations for clinicians

Recommendations must be given with caution given the heterogeneity of the papers, including the countries and different healthcare settings that they originate from. Nevertheless, based on the finding that family play an important role in the PtC, it is important for clinicians (both General Practitioners and specialist mental health services) to actively involve family in the assessment process in order to build an accurate picture of the patient's presentation. Patients with positive psychotic symptoms tended to have shorter PtC compared to those whose symptoms were less specific (eg, decline in social functioning, depression or anxiety). Professionals, in particular general practitioners, should be mindful that those patients presenting with symptoms other than attenuated psychotic symptoms may be in the early stages of ARMS, and to refer to appropriate services as soon as possible.

4.6 | Future directions

More research is required in the area of PtC in ARMS in general. More specifically, the impact of ethnicity and urbanicity is recommended. Studies exploring the role of intervening earlier in ARMS and the impact reducing DUI has on outcomes are also warranted.

5 | CONCLUSION

In summary, this review found evidence is lacking in this area, especially considering the body of PtC research in FEP. The papers meeting the criteria found that family involvement and presentations of attenuated psychotic symptoms were key factors at play. More research into ethnicity and the differences between rural and urban populations may be warranted. Finally, future studies should examine the means of streamlining care pathways in ARMS, with further exploration of whether reducing DUI results in improved outcomes for this population.

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DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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