

# Help-seeking and pathways to care in the early stages of psychosis

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## Abstract

**Purpose** Delay in the treatment of a first psychotic episode can have a negative influence on the future course of the disease. In this context, it is important to examine pathways to care to understand factors contributing to delay in access to adequate care.

**Methods** Using the Basel Interview for Psychosis, we examined the help-seeking behaviour of 61 individuals with an at-risk mental state for psychosis and 37 patients with a first episode of psychosis in a low threshold health care system as part of the Basel early detection of psychosis study.

**Results** The median duration of untreated illness was 3.4 years, of untreated psychosis 12 months. Eighty-six percent of all individuals sought help of some kind before reaching our specialised early detection outpatient clinic, with a mean number of help-seeking contacts of 1.5 prior to referral. The most frequent first help-seeking contacts were family members or relatives  $n = 24$  (26.7 %), close friends  $n = 17$  (17.9 %), psychiatrists in private practice  $n = 13$  (14.4 %) or general practitioners  $n = 11$  (12.2 %). Most patients consulted other health professionals in the early course of the illness before reaching our specialised

service; help-seeking with non-medical institutions was rare. Women had more help-seeking contacts than men before contact with our early detection clinic.

**Conclusions** Family, close friends and medical professionals play an important role in help-seeking leading to specialised psychiatric care. Men seek help less often; specific strategies for encouraging young, at-risk men to seek help should be developed.

**Keywords** Psychosis · Early diagnosis · Pathways to care · Help-seeking · Gender

## Introduction

Schizophrenic psychoses often begin with uncharacteristic symptoms such as impaired functioning, social withdrawal, poor concentration or apathy [1–3]. Several studies show that patients with psychotic disorders experience psychotic symptoms for an average of 1–2 years before appropriate antipsychotic treatment is initiated [2, 4–7]. The duration of untreated psychosis (DUP) has been shown to be associated with more severe symptoms, worse treatment response, increased risk for relapse and poor overall outcome [8–14] in at least some sub-groups of first episode patients [15]. Untreated psychosis has negative effects on the individuals' social networks, vocational and educational achievements [16–18]. It is, therefore, important to recognise and treat psychosis as early as possible.

One factor that may contribute to psychosis not being treated in time is difficulties in finding the right help-seeking contact. Pathways to care are influenced by various factors such as gender, cultural and economic background or the social network of the individual [19–24]. Social withdrawal, lack of social network, belonging to an ethnic

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minority, being unemployed or single or having negative stereotypes about psychiatric diseases hinder help-seeking efforts [20, 21, 23]. Furthermore, pathways to care depend on structure and accessibility of local (mental) health care systems.

The majority of patients with psychotic disorders had been seeking help for other mental disorders in secondary mental health care, most commonly mood and anxiety disorders and substance use disorders, prior to onset of psychosis [25].

In some countries, general practitioners function as gatekeepers to specialised health care [26, 27]. In other countries, where patients have free access to health specialists such as psychiatrists or psychologists, pathways to care are different, but general practitioners probably remain important.

Most people experiencing early psychosis contact a health professional as a first point of contact [21]. Especially in emerging psychosis, general practitioners play a key role in the help-seeking efforts [9, 22, 28–35]. Also, many individuals with an at-risk mental state (ARMS) for psychosis [29, 36] or patients with a first episode of psychosis (FE) consult a psychiatrist or specialised outpatient department as a first help-seeking contact [29, 30, 34, 35].

This study expands on earlier investigations of pathways to care in early psychosis in different ways: In the examined area, an early detection program was newly introduced in 1998. A broad information campaign including scientific symposia, teaching courses for general practitioners, psychiatrists and social service staff, articles in local newspapers and a website [37] was started. It is, therefore, interesting to examine pathways to care after the introduction of this wide information campaign. A wide range of possible pathways to care were explored. Individuals could declare up to 15 different contacts, professional or lay ones. Most other studies only present data about pathways to care via the health care system such as general practitioners or psychiatrists.

We also present data about pathways to care in both ARMS individuals and FE patients. Only few data are available for both groups.

Additionally, only little data are available up to now about gender differences in this group of patients, so we examined differences between men and women in pathways to care in the early stages of psychosis.

## Objectives

The aim of the study was to examine the help-seeking behaviour of ARMS individuals or FE in a low threshold system with easy access to mental health care facilities, in which a specialised early detection clinic was newly established.

Specific aims were to investigate

- the duration of untreated illness (DUI) as well as the duration of untreated psychosis (DUP);
- all first and subsequent help-seeking contacts and the contacts which resulted in the referral to our specialised clinic.

Differences between individuals with an ARMS and FE as well as gender differences were analysed.

## Methods

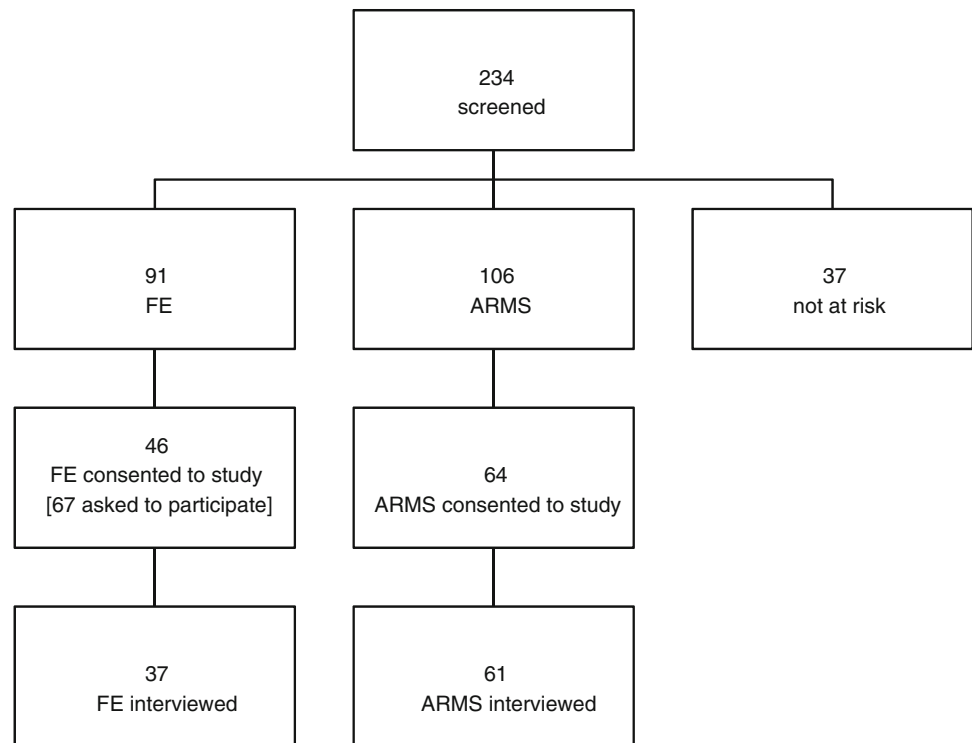
### Setting and recruitment

Access to mental health services in the catchment area is low threshold; medical insurance obligatory for all inhabitants of the country covers the majority of the costs. In the catchment area, there are also psychiatrists in private practice and general practitioners, both with the possibility of referring to the university outpatient clinic. There is also the main university psychiatric hospital providing most of the inpatient psychiatric care, and one private clinic providing mainly inpatient psychiatric care. Before and during our study period, all these facilities were successfully asked to refer all patients with a suspected prodromal or first episode state to our clinic. Cooperation was intense, so that we probably saw most of these patients. According to well-established incidence figures, we would have expected 10 first episode patients per 100.000 inhabitants, which for the 200.000 inhabitants of the canton of Basel would amount to 80 FE Patients over 4 years. In fact we count 91, which confirms that we saw most of these patients.

The study was part of the *FePsy* study (*Früherkennung von Psychosen: Early Detection of Psychosis*). This study has been described in detail elsewhere [37–39]. In short, subjects were recruited into the study via our specialised outpatient clinic at the Psychiatric University Outpatient Department of the Psychiatric University Clinics Basel (see Fig. 1). For screening and assessment of the at-risk mental state, the Basel Screening Instrument for Psychosis (BSIP) was used [40]. Individuals were assessed and classified as ARMS, FE patients or “not at risk for psychosis” (other psychiatric diseases) [37–39]. With the BSIP, a rating of the at-risk mental state as well as the transition criteria can be done, according to Yung et al. [36]. The BSIP was developed based on these criteria around the same time as the Comprehensive Assessment of At-Risk Mental States (CAARMS) [41], using the same criteria, there is one difference in that a low-risk category with unspecific prodromal signs is also included.

Our inclusion and transition criteria are shown in Tables 1 and 2.

**Fig. 1** Overview of the recruitment process of the study sample (ARMS at-risk mental state, FE first episode psychosis)



**Table 1** Inclusion criteria for ARMS individuals

Individuals were classified as ARMS if they met the following inclusion criteria

i. “Attenuated” psychotic symptoms	Psychotic symptoms below the transition cut-off; symptoms at least several times per week; change in mental state persisting for >1 week	BPRS items: hallucinations 2–3, unusual thought content 3–4, or suspiciousness 3–4
ii. Brief limited intermittent psychotic symptoms (BLIPS)	Psychotic symptoms over the transition cut-off; but each symptom lasting <1 week before resolving spontaneously	BPRS items: hallucinations $\geq 4$ , unusual thought content $\geq 5$ , suspiciousness $\geq 5$ , conceptual disorganization $\geq 5$
iii. Genetic risk category	First or second degree relative with a psychotic disorder, and at least two further risk factors according to the screening instrument	
iv. Unspecific risk category	Minimal amount and combination of certain risk factors according to the screening instrument	

Criteria (i), (ii) and (iii) correspond to those of Yung et al. [36]; and *BRPS* Brief Psychiatric Rating Scale (version Lukoff et al. 1986 [57]). Criterion (iv) permits the additional inclusion of individuals at presumably lower risk, i.e. of individuals without pre-psychotic symptoms or genetic risk who only have a combination of certain unspecific risk factors and indicators, such as prodromal symptoms and/or marked social decline

ARMS at-risk mental state

In order to give an impression of the composition of the FE group, we have summarised the clinical ICD-10 diagnoses in Table 3 [42]. Most of these diagnoses were reached in the weeks after the first initial assessment with the BSIP, even if patients at intake often only fulfilled transition criteria for psychosis.

Exclusion criteria were age below 18 years, insufficient knowledge of German, IQ <70, previous episode of schizophrenic psychosis (treated with major tranquilizers for >3 weeks), psychosis clearly due to organic reasons or

substance abuse, or psychotic symptoms within a clearly diagnosed depression or borderline personality disorder [37].

An overview of the recruitment process of the study sample is given in Fig. 1.

Information about the help-seeking behaviour was obtained using a specifically developed interview, the Basel Interview for Psychosis, BIP (Riecher-Rössler et al., in preparation).

The study was approved by the local ethics committee of the University of Basel and written informed consent was obtained from all participants.

**Table 2** Transition and inclusion criteria for FE patients

Criteria according to Yung et al. [36] and BPRS Brief Psychiatric Rating Scale (version Lukoff et al. [57])  
FE first episode psychosis

Patients meeting the following criteria were considered to have made the transition to psychosis and were, therefore, classified as FE patients

- i. At least one of the following symptoms:
- |                            |               |
|----------------------------|---------------|
| Suspiciousness             | BPRS $\geq$ 5 |
| Unusual thought content    | BPRS $\geq$ 5 |
| Hallucinations             | BPRS $\geq$ 4 |
| Conceptual disorganisation | BPRS $\geq$ 5 |
- ii. The symptoms are present at least several times a week  
iii. The change in mental state lasts >1 week

**Table 3** Overview of clinical ICD-10 diagnoses in the FE group ( $N = 37$ )

FE first episode psychosis  
Three cases with no valid information on diagnosis at screening (only transition criteria fulfilled)

ICD-10 code	Diagnoses	Number
F 20.09	Schizophrenia unspecified	8
F 20.0	Paranoid schizophrenia	13
F 20.1	Hebephrenic schizophrenia	1
F 21	Schizotypal disorder	2
F 23.1	Acute polymorph psychotic disorder with symptoms of schizophrenia	5
F 23.2	Acute schizophrenia-like psychotic disorder	2
F 25	Schizoaffective disorder	2
F 22.0	Delusional disorder	1

### Basel Interview for Psychosis (BIP)

After having included subjects based on the screening with the BSIP in a next assessment step an extensive entry examination with a specifically developed extensive interview for the early detection of psychosis, the BIP (Riecher-Rössler et al., in preparation) was done. This interview allows a standardised history taking in patients with (emerging) psychosis. It is partly based on the IRAOS [7] and on different other instruments as well as other indicators and predictors of beginning psychosis as known from the literature (Riecher-Rössler et al., in preparation).

The first section contains questions about the social and physical development of the individual, developmental problems and disorders, school and education, employment situation, partnership, physical diseases, and previous mental disorders and drug use, as well as the psychiatric family history.

A second section of the interview assesses indicators and symptoms for a beginning psychosis. The main reasons for the consultation as well as early signs and the first perceived change in well-being of the individual are asked. Prodromal signs, such as anxiety, difficulties in concentrating, compulsion, social decline, and a range of (pre-) psychotic symptoms and their onset, such as suspiciousness, sub-threshold hallucinations and delusions, are assessed.

The third, relatively short section covers the vulnerability of the individual, which means feeling strain, emotional pressure under certain circumstances such as conflicts, or working in a loud environment or under time pressure.

The fourth section investigates the help-seeking strategies and pathways to care. It covers whether the subject made any help-seeking attempt at all before coming to the early detection clinic, which person was contacted first along the help-seeking pathways and which persons or institutions were contacted subsequently (after the first help-seeking contact). The following help-seeking attempts are specifically asked about: family/relatives, partner, friends, work colleagues, general practitioner, psychiatrist, other physician, pharmacist, psychologist/psychotherapist, school psychologist, priest/clerical counsellor, sect, alternative medicine and others. Previous or on-going medical treatment, especially antipsychotic treatment, earlier psychotherapy or other treatments are also actively inquired about.

### Definition of DUI/DUP

Duration of untreated illness was defined as the time period between first self- perceived signs or symptoms of a change in well-being (even unspecific ones) and first contact with our specialised early detection clinic.

Duration of untreated psychosis was defined as the time period between the appearance of first psychotic symptoms and the first consultation with our early detection service.

### Statistical analyses

SPSS for Windows version 19 was used. Categorical data were analysed using Chi-square tests or Fisher's exact test if expected cell frequencies were low. Because the

**Table 4** Socio-demographic characteristics

	ARMS ( <i>n</i> = 61) <sup>a</sup>	FE ( <i>n</i> = 37) <sup>a</sup>	Significance value
Age	26.8 ± 8.7	31.0 ± 8.5	Mann–Whitney <i>U</i> : 766.0; <i>p</i> = 0.008
Men	36 (59.0)	25 (67.6)	$\chi^2$ : 0.7; <i>df</i> = 1; <i>p</i> = 0.397
Women	25 (41.0)	12 (32.4)	
Educational level			
<9 years	20 (32.8)	16 (43.2)	$\chi^2$ : 1.5; <i>df</i> = 3; <i>p</i> = 0.677
9–11 years	20 (32.8)	10 (27.0)	
12–13 years	14 (23.0)	6 (16.2)	
14–20 years	7 (11.5)	5 (13.5)	
Employment status			
Unemployed	15 (26.8)	16 (50.0)	$\chi^2$ : 4.8; <i>df</i> = 1; <i>p</i> = 0.028
Employed	41 (73.2)	16 (50.0)	
Is the person able to earn his/her living?			
Yes	21 (35.0)	9 (25.0)	$\chi^2$ : 1.0; <i>df</i> = 1; <i>p</i> = 0.306
No	39 (65.0)	27 (77.0)	
Residential status			
Living alone	18 (29.5)	18 (50.0)	$\chi^2$ : 4.1; <i>df</i> = 1; <i>p</i> = 0.044
Not living alone	43 (70.5)	18 (50.0)	

Values are given as mean ± SD or percentage (in brackets)

ARMS at-risk mental state, FE first episode psychosis

<sup>a</sup> Incongruent *N* is due to missing data

continuous variables were not normally distributed, Mann–Whitney *U*-Test was used to compare ARMS individuals and FE patients as well as male and female participants on these variables. Correlational analyses were performed to assess associations between socio-demographic data and help-seeking variables. Due to the level of measurement, Spearman's correlational coefficient was chosen.

## Results

### Sample characteristics

Between 01.03.2000 and 29.02.2004, 234 individuals referred to our specialised clinic with suspected psychosis were screened (see Fig. 1).

There was no significant difference between participants and non-participants regarding age, or gender.

In this paper, we present data of those 98 individuals (61 ARMS, 37 FE) with whom the BIP was conducted and of whom precise information about the help-seeking efforts could be obtained. Three ARMS individuals and nine FE patients could not give reliable information about their help-seeking strategies and where, therefore, excluded from the help-seeking analysis. They did not differ significantly from the examined individuals with regard to gender or other sociodemographic characteristics.

The sociodemographic characteristics of the sample are presented in Table 4. There were no significant differences between FE and ARMS individuals regarding gender; however, ARMS individuals were, as expected, significantly

younger than FE patients. Moreover, FE patients were significantly less likely to be employed and lived alone more often than ARMS individuals.

Men were significantly more often unemployed than women independent of group affiliation. There were no further significant differences.

### Duration of untreated illness (DUI)

The median DUI was 41 months (mean ± SD: 66.2 ± 76.9). DUI did not differ significantly between FE and ARMS (Mann–Whitney *U*: 846.0; *p* = 0.872) nor between men and women (Mann–Whitney *U*: 817.0; *p* = 0.749).

### Duration of untreated psychosis (DUP)

On average, DUP amounted to 46 months with a median of 12 months for the FE patients. This large discrepancy between mean and median DUP was due to a positively skewed distribution, caused by a small number of outliers (four FE patients with DUP over 7 years).

Concerning gender differences, the median value of DUP was 17 months (mean ± SD: 57 ± 91.7) in men and 9 months (mean ± SD: 27.6 ± 52.2) in women.

Due to the considerable range of the DUP, a median split was adopted. The median for our FE group was 12 months and, therefore, a DUP ≤12 months was defined as “short DUP” and a DUP >12 months as “long DUP”. Comparing short versus long DUP, men showed a tendency for longer DUP (Fisher's exact test *p* = 0.064).

## Referrals to our early detection clinic

Most participants were referred to the early detection clinic via the University Psychiatric Outpatient Department of Basel ( $n = 32$ ) or a psychiatrist in private practice ( $n = 22$ ). Referrals also came from other physicians including general practitioners ( $n = 13$ ). Some individuals came on their own ( $n = 9$ ) or on advice of relatives ( $n = 9$ ). Further referrals came from other psychosocial institutions ( $n = 3$ ), a non-medical psychotherapist ( $n = 1$ ) or other psychiatric institutions ( $n = 1$ ). Four persons could not give any information about their referral to the early detection clinic.

## Main reasons for help-seeking

Individuals were asked to give their main reasons leading to the consultation at the time of the interview. Up to three answers were possible. After the interview these answers were coded according to ten predetermined alternatives. Onset or distinct increase of peculiarities in behaviour, appearance or speech were the most frequently mentioned reasons (53.3 % of all cases), followed by 50.0 % of all cases, who sought help because of self-perceived changes in well-being. Further reasons for consultations were attempted suicide, self-harming, or recent changes or a crisis in the family/household of the patient. A detailed description of the main reasons comparing ARMS individuals and FE patients is shown in Table 5.

## Help-seeking pathways

### *Help-seeking attempts prior to referral to our early detection clinic*

94.1 % of the FE patients and 81.4 % of the ARMS individuals stated having at least one help-seeking effort before coming to the early detection clinic.

The number of help-seeking contacts prior to that with our early detection clinic ranged between zero and six. Contact with the Psychiatric University Outpatient Department of the Psychiatric University Clinics Basel subsequently followed by the referral within the same institution to the early detection clinic was defined as “one help-seeking effort”.

Mean number of prior contacts for both, the FE patients and the ARMS individuals was 1.5 (median: 1). Most individuals had requested help once or twice (together 44.7 %) before contacting our specialised service. There were no significant between-group differences. Table 6 shows a detailed description of the number of help-seeking contacts for the different subgroups.

Gender comparison resulted in a significant difference in the number of help-seeking attempts between men and women (Mann–Whitney  $U$ : 609.0;  $p \leq 0.001$ ), showing that women had requested help more often (on average 2.1 times) than men (1.2 times).

### *Time between first help-seeking effort and consultation with the early detection clinic*

On average, the first help-seeking contact was 38 months (median 9 months) before consulting our specialised early detection clinic.

FE patients had requested help for the first time on average 52 months (median 7 months), ARMS individuals 30 months (median 11 months) beforehand. This delay was positively skewed (Kolmogorov–Smirnov-test:  $p < 0.001$ ): 61 % of the study population reached our specialised early detection clinic in less than 1 year, but about 20 % needed over 4 years.

For women, the first help-seeking attempt was 46 months before the first contact with our early detection clinic (median 11 months), for men 33 months (median 8 months).

There were neither significant differences between FE patients and ARMS ( $p = 0.856$ ), nor between men and women ( $p = 0.574$ ).

**Table 5** Main reasons for consulting the psychiatric outpatient clinic

	ARMS $n = 56$ (% of all cases)	FE $n = 36$ (% of all cases)	$P$ value
Onset/increase of “peculiarity”	32 (57.1)	17 (47.2)	0.352
Self-recognised changes in behaviour	29 (51.8)	17 (47.2)	0.669
Other reasons	9 (16.1)	8 (22.2)	0.458
Attempted suicide	3 (5.4)	0	0.278 <sup>†</sup>
Self-endangering behaviour	3 (5.4)	2 (5.6)	1 <sup>†</sup>
No current reason	2 (3.6)	0	0.518 <sup>†</sup>
Change/crisis in family/household of the patient	2 (3.6)	0	0.518 <sup>†</sup>
Signs/symptoms of physical disease	0	1 (2.8)	0.391 <sup>†</sup>

ARMS at-risk mental state, FE first episode psychosis  
Percentages add up to more than 100 %, because up to three reasons could be declared

<sup>†</sup> Fisher exact test

**Table 6** Number of help-seeking contacts for the different subgroups

	Total <sup>a</sup> <i>n</i> = 94	ARMS <i>n</i> = 60	FE <i>n</i> = 34	Significance value	Female <i>n</i> = 35	Male <i>n</i> = 59	Significance value
Zero	13	11	2	Mann–Whitney <i>U</i> : 695.5; <i>p</i> = 0.650	2	11	Mann–Whitney <i>U</i> : 609.0; <i>p</i> < 0.001
One	42	24	18		11	31	
Two	21	13	8		10	11	
Three	13	8	5		8	5	
Four	4	3	1		3	1	
Six <sup>b</sup>	1	1	0		1	0	

ARMS at-risk mental state, FE first episode psychosis

<sup>a</sup> Some individuals could not provide this information

<sup>b</sup> No individual made five help-seeking contacts

### Type of help-seeking contacts

**First help-seeking contacts overall** Tables 7 and 8 show the distribution of all first help-seeking contacts for the different subgroups. The most frequent first contacts were with family members or relatives, close friends, general practitioners or psychiatrists.

Altogether 45.6 % sought help first from family members or close friends. This is nearly twice as much as first help-seeking attempts to professionals such as psychiatrists in private practice or general practitioners.

FE patients sought first help significantly more often within the family than ARMS individuals ( $\chi^2 = 5.88$ ; *df* = 1; *p* = 0.015).

The individuals who requested help first from a family member needed on average 42 months (median 12 months), those who first contacted close friends needed on average 12 months (median 6 months) before the first contact with our early detection clinic. For those seen first by a general practitioner, the duration was on average 29 months (median 12 months). Those who had first

contacted a psychiatrist in private practice needed on average 50 months (median 6 months) before referral to our early detection clinic. Further persons the individuals sought help from were partners, work colleagues, other physicians, psychologists/psychotherapists, school psychologists or priests/clerical counsellors.

### Subsequent help-seeking pathways

Overall, the most frequent subsequent help-seeking contacts were with a psychiatrist in private practice (*n* = 15; 38.5 % of those with more than one help-seeking contact). Frequently, subsequent contact was also with a general practitioner (*n* = 9; 23.1 %), friends (*n* = 8; 20.5 %) or family members (*n* = 7; 17.9 %). There were no significant differences, neither between the two study groups nor between men and women regarding subsequent help-seeking contacts.

The most common contacts that finally resulted in referral to our specialised early detection clinic were psychiatrists (23.1 %), also family members (14.3 %), friends

**Table 7** Comparison of first help-seeking contacts between ARMS and FE

	ARMS <i>n</i> = 56 (%)	FE <i>n</i> = 34 (%)	<i>P</i> value
Family/relatives	10 (17.9)	14 (41.2)	0.015
Friends	10 (17.9)	7 (20.6)	0.748
Psychiatrist	9 (16.1)	4 (11.8)	0.759 <sup>†</sup>
General practitioner	7 (12.5)	4 (11.8)	1 <sup>†</sup>
Colleagues from work	1 (1.8)	0	1 <sup>†</sup>
Partner	2 (3.6)	2 (5.9)	0.631 <sup>†</sup>
Other physician	3 (5.4)	0	0.287 <sup>†</sup>
Psychologist/psychotherapist	2 (3.6)	0	0.525 <sup>†</sup>
School psychologist	0	1 (2.9)	0.378 <sup>†</sup>
Priest	1 (1.8)	0	1 <sup>†</sup>
Alternative medicine	0	0	1 <sup>†</sup>
No help-seeking contact	11 (19.6)	2 (5.9)	0.12 <sup>†</sup>

ARMS at-risk mental state, FE first episode psychosis

<sup>†</sup> Fisher exact test

**Table 8** Comparison of first help-seeking contacts between women and men

	Women <i>n</i> = 34 (%)	Men <i>n</i> = 56 (%)	<i>P</i> value
Family/relatives	9 (26.5)	15 (26.8)	0.974
Friends	7 (20.6)	10 (17.9)	0.748
Psychiatrist	7 (20.6)	6 (10.7)	0.226 <sup>†</sup>
General practitioner	3 (8.8)	8 (14.3)	0.524 <sup>†</sup>
Colleagues from work	0	1 (1.8)	1 <sup>†</sup>
Partner	3 (8.8)	1 (1.8)	0.149 <sup>†</sup>
Other physician	2 (5.9)	1 (1.8)	0.554 <sup>†</sup>
Psychologist/psychotherapist	1 (2.9)	1 (1.8)	1 <sup>†</sup>
School psychologist	0	1 (1.8)	1 <sup>†</sup>
Priest	0	1 (1.8)	1 <sup>†</sup>
Alternative medicine	0	0	1 <sup>†</sup>
No help-seeking contact	2 (5.9)	11 (19.6)	0.12 <sup>†</sup>

<sup>†</sup> Fisher exact test

(12.1 %) or general practitioners (11.0 %). Overall, help-seeking contacts to non-medical institutions such as those of alternative medicine were rare.

## Discussion

We investigated in detail the pathways to care in individuals with emerging psychosis in an area with a well-developed, low threshold mental health care system, in which an early detection clinic was established accompanied by widespread information campaigns at the beginning of the study. The results showed the important role on the help-seeking pathway of family and friends as well as psychiatrists in private practice in the investigated area. Almost half of all individuals requested help first from a family member or from close friends followed by psychiatrists in private practice. Moreover, FE patients were more likely to seek help within the family than ARMS.

Comparing men and women, we found a significant difference concerning help-seeking patterns: women had more help-seeking contacts than men before they presented to our early detection clinic.

Concerning the duration of untreated illness and psychosis (DUI, DUP), our results are in line with those of other studies. The median DUI was 41 months (SD ± 77) for the whole study population with a wide range which is similar to results described earlier [2, 43]. The median DUP of 12 months is similar to results of other studies [32, 44].

Also, our findings regarding referrals and main reasons for consultation are similar to results reported by others [9, 33, 34]. Most individuals were referred to our early detection clinic via the University Psychiatric Outpatient Department, where they sought help because of self-perceived signs or symptoms. Some individuals came on their own initiative directly to the early detection clinic or after

advice from relatives. The most frequently mentioned reasons for the consultation are similar to findings in previous studies [9, 29, 33, 35].

Less than half of our patients needed more than one other help-seeking contact to finally reach our early detection clinic. This may be due to our intensive cooperation with general practitioners, psychiatrists in private practice and other institutions [37]. The amount of help-seeking contacts before we saw patients in our specialised clinic ranged between zero and six, which is similar to most other studies [29, 33, 35], but some authors describe up to over 40 help-seeking attempts [31, 45]. Within the subsample of FE patients, only 6 % had not sought any help prior to referral to the early detection clinic. These are less than described in other studies where up to a third had not sought any other help previously [9, 29, 44]. This could be due to the fact that we also asked for contacts with non-professionals, but also due to the low threshold mental health care system in Switzerland, where every inhabitant has an obligatory health care insurance and access to outpatient care facilities. The threshold to access to medical care is lower [46] than in other countries with more restrictive, canalised structures within the health care system, for example in Great Britain, USA or Australia.

The longest time to reach specialised care, in this report meaning our outpatient department, was for those who first saw a psychiatrist. It is to be expected that psychiatrists in private practice treat these patients themselves first and refer them later.

We found that women initialised more help-seeking contacts than men. Women seem more likely to seek help from mental health professionals than men, maybe due to a more positive attitude towards health professionals and their being more open to psychology [47–49]. Probably due to this they had a tendency for a shorter DUP. Despite this, earlier studies with large and representative samples have not found any sex differences in the DUP or DUI



between men and women [50–55]. One explanation might be that our information campaigns were more effective in women.

It may be useful to plan information campaigns to raise the knowledge about the necessity of help-seeking and establish early detection strategies which specifically target young men.

Concerning the first help-seeking effort, we found that it was mainly directed at a family member or significant other. Two other studies provide data about non-medical first help-seeking contacts [33, 45]. Whereas in our investigation, almost half of the individuals declared a family member, partner or friend as a first help-seeking contact, the amount of such non-medical contacts was comparatively small in the studies of Lincoln and Addington. The proportion of consulted general practitioners or psychiatric professionals was higher than in our investigation. This may possibly be due to different methods of questioning and mapping the pathways to care.

The fact that general practitioners were contacted less often in our study than the ones mentioned above may be attributed to the gate-keeper role of general practitioners in Canada [33] and Australia [45], as described by Malla [8] earlier. In a Canadian sample of 35 clinical high risk individuals, it was found that the majority of contacts were made to general practitioners [56].

Considering only medical professionals as first help-seeking contact, many studies consistently report the important role of general practitioners, because they are most likely to be the first help-seeking contact [9, 22, 29, 35]. Fuchs and Steinert [30] and Köhn [34] report different results from Germany. Both showed a higher frequency in consulting a psychiatrist in private practice first with 39.4 % [30] and 23.8 % [34]. Analysing only medical professionals as first help-seeking contact, we also found that a psychiatrist in private practice was most often consulted first, followed by a general practitioner. In the subsample of the FE patients, the first help-seeking contacts were equally distributed between psychiatrists in private practice (12 %) and general practitioners (12 %).

A tendency of more general help-seeking contacts in the beginning towards help-seeking from more specialised services later on, as described by other authors [29, 35, 45] can be confirmed by our results.

## Limitations

Finally, the limitations of this study should be mentioned. The data in this kind of study can only be collected retrospectively and, therefore, rely largely on recall precision. These findings on pathways to care and duration of untreated psychosis are predominantly based on patients'

self-report. Apart from recall errors, also selective reporting can be a problem.

Another weakness is the modest sample size, which leads to limited statistical power

Pathways to care were studied in those patients who were referred to our specialised early detection clinic. Due to the large number of psychiatrists in private practice in the area, we cannot exclude that there were some prepsychotic patients who were treated by private psychiatrists and were not referred to our early detection service. As regards FE patients, obviously most were referred at some stage.

Finally, structure and accessibility of the mental health care system varies across countries. Thus, not all our findings can be directly compared with results from other studies.

## Conclusions

Our study confirms the importance of a specialised early detection service for psychosis. It is necessary to continue early detection programs and information campaigns to increase the knowledge about schizophrenic psychoses and the necessity of adequate treatment. Investigating gender differences in help-seeking could help to understand obstacles in getting help.

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