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Complete List of Authors:	van Beek, Atousa; University of Groningen Faculty of Medical Sciences; University Medical Centre Groningen de Zeeuw, Janine; University of Groningen, Department of Health Sciences; University Medical Centre Groningen de Leeuw, Menno; University of Groningen Faculty of Medical Sciences; University of Groningen Faculty of Medical Sciences Poplawska, Mia; University of Groningen Faculty of Medical Sciences; University Medical Centre Groningen Kerkvliet, Lise; University of Groningen Faculty of Medical Sciences; University Medical Centre Groningen Dwarkasing, Rudi; Psychiatric Centre Suriname Nanda, Randhir; Psychiatric Centre Suriname Veling, Wim; Academic Medical Centre Groningen University Center of Psychiatry
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Duration of untreated psychosis and pathways to care in Suriname: a qualitative study among patients, relatives and general practitioners.

Atousa van Beek[1], Janine de Zeeuw[1,2], Menno de Leeuw[1], Mia Poplawska[1], Lise Kerkvliet[1], Rudi Dwarkasing[3], Randhir Nanda[3], Wim Veling[4]

Affiliations:

1. University of Groningen, University Medical Center Groningen, Department of Medical Sciences, Groningen, The Netherlands

2. University of Groningen, University Medical Center Groningen, Department of Health Sciences, Groningen, The Netherlands; j.de.zeeuw@umcg.nl

3. Psychiatric Centre Suriname, Paramaribo, Suriname

4. University of Groningen, University Medical Center Groningen, Department of Psychiatry, Groningen, The Netherlands

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ABSTRACT

Purpose Psychosis is a severe mental health problem and is responsible for poor health outcomes, premature mortality and morbidity, especially in low- and middle-income countries. The duration of untreated psychosis is one of the main determinants for successful treatment in western settings. This study aims to qualitatively explore the duration of untreated psychosis amongst Surinamese patients using the perspectives from patients, their families and first-line healthcare professionals in Suriname.

Methods Semi-structured interviews were conducted with patients having a history of psychosis, family members and general practitioners between February 2019 and April 2019 in Suriname. Interviews were tape-recorded and transcribed verbatim. Data was analysed using a thematic analysis for which an inductive and deductive approach was applied.

Results Five patients were excluded from the study. In total, 28 patients, 13 family members and 8 general practitioners were interviewed. A median DUP of 4 months was found (IQR 1–36). Identified themes included presentation of symptoms and illness awareness, help seeking behaviour and alternative medicine, social support and stigma, financial and practical factors.

Conclusion Multiple factors were found to be related to DUP, of which poor illness awareness, traditional medicine, stigma and social support were predominant. Poor illness awareness and use of alternative medicine were related to a longer duration of untreated psychosis. Stigma was often an obstacle for patients and their families. Social and family support was important in helping patients to get medical help sooner. Other explored factors including financial and practical factors were not significant in relation to DUP.

Strengths and limitations of this study

- This study included participants from a broad geographical spread within Suriname.
- Assistance of local nurses during interviews ensured mutual understanding between interviewer and interviewee securing reliable data.
- This study collected data from patients, families and general practitioners to combine multiple perspectives on psychosis in Suriname.
- Due to its' retrospective design, this study is restricted by recall bias.

INTRODUCTION

Globally, mental and addiction disorders caused 7% of all burden of disease measured in DALY's and 19% of all years lived with disability in 2016,[1], along with a percentage of 16% of the world population being affected by mental disorders,[1]. People with mental health disorders are at high risk for disabilities and mortality,[2], stigma and discrimination,[3]. In most countries, especially low- and middle-income countries, health systems are inadequately designed to manage mental health problems,[2,4]. An alarming 76-85% of people with severe mental disorders in low- and middle-income countries do not have access to proper mental healthcare,[2].

One such severe mental disorder, schizophrenia, affects over 21 million people worldwide. The global incidence of schizophrenia is 1.5 per 10.000,[5],and the global burden of schizophrenia alone accounts for 1.7% of YLD's,[4]. Psychotic symptoms are a core feature of schizophrenia, which is characterised by sensory and/or cognitive disturbances. It has a broad clinical presentation with most prominently symptoms such as hallucinations and delusions, but it can also present itself with symptoms such as thought disorganisation or apathy,[6]. The duration of untreated psychosis, i.e. the period between onset of symptoms and initiation of appropriate treatment, has been associated with poorer general outcomes,[7]. These manifest themselves as reduced likelihood of remission, poorer social functioning and cognitive impairment,[8,9]. In middle and high-income countries several factors playing a role in a prolonged DUP have been identified such as stigma,[10,11,12], the financial situation of the patient,[11,13], illness awareness,[11,13,14], perception,[13], distance to care facilities,[15],and knowledge of mental illnesses,[14]. Several countries have conducted research into country-specific factors and have begun to design and test interventions to reduce the DUP,[16].

In Suriname, a middle-income country, limited evidence on psychosis is available. The most recent study on the incidence of schizophrenic disorders has been conducted in 2005 and showed an incidence of 1.77 per 10.000,[17]. Healthcare is highly centralised, with only one psychiatric hospital located in the capital city Paramaribo. A study researching the equity in healthcare in Suriname reported the use of secondary healthcare to be lower in the rural interior compared with coastal areas,[18]. Studies in Africa found reasons for low access to mental healthcare related to cultural views on causes of disease and noted people visiting informal health care settings first, before reporting to a hospital,[19]. Another recent study found that traditional medicine could contribute to a delay of starting appropriate treatment,[13]. Suriname is a country in which traditional medicine is widely practised and large parts of the population still rely on these traditional healers in both urban and rural areas. Research in Suriname has shown that within traditional medicine, psychiatric diseases such as depression and anxiety are considered a social imbalance or to have spiritual causes,[20]. These alternate explanations of disease,

amongst other factors, alter help seeking behaviour of patients and their pathway to care, which seems to be of great importance in psychotic disorders.

Therefore, the aim of this study is to explore the duration of untreated psychosis among Surinamese patients and its influencing factors using the perspectives from patients, their families and first line health care professionals in Suriname.

METHODS

Setting, study design and participants

In Suriname, the mental healthcare system is not evenly distributed between rural and urban areas,[21]. It is highly centralised with only one psychiatric hospital based in the capital city Paramaribo, the so-called 'Psychiatric Centre of Suriname' or 'PCS'. In addition to this psychiatric hospital, there is one outpatient clinic of the PCS based in Nieuw-Nickerie. With only 10 psychiatrists in place, this calculates to 1 psychiatrist per 56.000 population in the country,[22]. To put this into perspective, the Netherlands has a calculated 1 psychiatrist per 4.636 population,[23]. General practitioners (GPs) are the first line of care in the formal health care system. We conducted semi-structured interviews between February 2019 and April 2019 among patients, family members and GPs. Patients were eligible for inclusion if they (i) signed the informed consent form; (ii) were diagnosed with a psychotic disorder; and (iii) were aged between 16 to 65 years of age. Patients were excluded for participation if they (i) had mental retardation or (ii) had a known drug-induced psychosis. For family members and GPs no inclusion or exclusion criteria were formulated.

Sampling and materials

Eligible patients were selected based on purposive sampling in order to aim at a heterogeneous group of participants concerning area of living and estimated DUP known by PCS. Patients were recruited from various regions in Suriname, namely Paramaribo, Moengo (East), Nieuw-Nickerie (West) and Brownsweg (South). The patients were recruited based on the inclusion criteria and contacted by a psychiatrist working in the PCS. A convenience sample of family members was used. If patients brought a family member to an interview, this family member was also approached for participation in the study. In case patients were visited at home for an interview and a family member was present and willing to participate, this member was interviewed and included in the study as well. Also, a convenience sample for the general practitioners was used. General practitioners were telephonically approached (by RN) and asked for participation, and if they were willing to participate they were included. In total 8 general practitioners were approached for participation in the study. The interviewing process continued until saturation appeared and when no new themes emerged.

A first draft of the topic list was developed by the research team, using topics from previous studies on the Cultural Formulation Interview,[24],and the McGill Illness Narrative Interview (MINI),[25]. Thereafter, it was discussed with PCS healthcare professionals (psychiatrists and nurses) for further improvement and clarification of language, cultural appropriateness and focus on known factors that would be relevant for the research question. This ensured that every factor associated with DUP, insights in the care pathway, and cultural factors would be addressed and understandable to the participants. Patients were interviewed about their first episode of psychosis and the topics covered were based on the predicted factors which could influence the DUP. The GP interviews focused on their knowledge of and experience with psychotic disorders. Semi-structured interviews were conducted by (AvB, MdL, LK, MP) in Dutch (the official language of Suriname), with the presence of a nurse from the PCS when possible for any language and communication problems. Conducting an interview took on average 30-45 minutes. When patients were only able to speak their local dialect then a nurse would translate. This was the case for five (n=5) out of 27 patient interviews and one (n=1) out of 14 family interviews. Doctor interviews were all conducted in Dutch. All interviews were tape recorded and transcribed verbatim.

Patient and public involvement

Patients were first involved in the research process at the stage of conducting the interviews. The research question was developed based on Surinamese health workers their experiences with patients with psychosis presenting late to their practice, and their subsequent suspicion of the presence of long DUP in Suriname. Experiences from participants, together with themes from previous research, formed the baseline for this study's outcome measures. Patients and public were not involved in the design, recruitment or assessment of burden of the study. Patient participation was by means of partaking in interviews. Research results were shared with the Psychiatric Centre Suriname. Participants who showed interest in the study results were recommended to check in with their practising physician upon conclusion of the study.

Data analysis

Whilst conducting and transcribing interviews, data analysis was performed simultaneously. The transcribed interviews were analysed according to thematic analysis,[26]. In order to ensure reliability, the first four transcripts were independently coded by at least two researchers using a combined inductive and deductive approach. These findings were discussed in order to create a set of codes the four researchers mutually agreed on, and to develop the initial codebook. Subsequently, all other transcripts were coded individually by a researcher. Thereafter another member of the study team reviewed this coding, adding comments and highlighting possibly overlooked codes. Then discussion

followed between the researchers who did coding for that interview. The analysis was considered finished when two researchers reached a consensus. The initial codebook was revised based on coding of the subsequent transcripts. When new codes emerged during analysis, these were added to the codebook and previously finished analyses of transcript were scanned for these newly found codes. Thereafter, the data were refined into themes and subthemes, which was then put into a database. A separate document contained any relevant, supporting quotations.

Ethics

Ethical approval was obtained from the Ministry of Public Health in Suriname (VG 20-18). All patients and their families signed an informed consent form prior to the interviews and were informed that participation was voluntary. They were made aware of their right to withdraw from the study at any point and that interviews would be processed anonymously and used for scientific purpose. If participants were unable to write and/or read, they received oral explanation of the study and gave oral consent.

RESULTS

Socio-demographics

In total 33 patients were approached for an interview, of which five patients were excluded due to having drug-induced psychosis (n=3), mental retardation (n=1) and because of a language barrier which could not be overcome (n=1). Socio-demographic characteristics of one (n=1) patient were collected through a family interview, because the patient was not able to participate. A total of 13 family members and 8 general practitioners were included. Sociodemographic characteristics are shown in Table 1. Patients had an equal gender distribution and a median age of 39 (IQR 31 – 48) years. Most patients lived in the capital city Paramaribo. The majority of patients indicated to have multiple ethnicities, and generally, Indian and Creole were the most common. The predominant religion was Christianity and Hinduism. Most patients were single and lived with their family. The most commonly reached educational level was secondary education. Unemployment was high and most earned under 2000 SRD (€240) per month. The median DUP (n=2 unknown) was 4 months (IQR: 1 – 36) and the median onset of first symptoms (n=1 unknown) was 60 months ago (IQR: 19 – 132). Mainly mothers were interviewed, with a median age of 53 (IQR:48 – 58) years. The majority of GPs were males, with a median age of 47 (IQR: 41.5 – 56) years and they were mainly based in Paramaribo and West-Suriname (table 1). Values were marked ‘unknown’ in case they could not be reliably retrieved from the interview nor from the medical file.

Table 1 Socio-demographic factors of participants

Variable	Patient Frequency, n (%)	Family Frequency, n (%)	General Practitioner Frequency, n (%)
Age: median,[IQR]	39,[17]*	53,[10]****	47,[14.5]
Gender			
Male	14 (50%)	4 (31%)	7 (88%)
Female	14 (50%)	9 (69%)	1 (12%)
Ethnicity			
Indian	6 (21%)	6 (46%)	-
Creole	3 (11%)	3 (23%)	-
Mixed**	2 (7%)	0	-
Javanese	4 (14%)	3 (23%)	-
Marron	5 (18%)	0	-
Indigenous	0	0	-
Jewish	0	0	-
Chinese	0	0	-
Caucasian	0	0	-
Multiple ethnicities	7 (25%)***	1 (8%) *****	-
Unknown	1 (4%)	0	-
Place of living			
Paramaribo	16 (58%)	7 (54%)	-
East Suriname	4 (14%)	2 (15%)	-
West Suriname	4 (14%)	4 (31%)	-
South Suriname	4 (14%)	0	-
Religion			
Christianity	13 (46%)	4 (31%)	-
Hinduism	7 (25%)	6 (46%)	-
Islam	4 (14%)	3 (23%)	-
No religion	3 (11%)	0	-
Unknown	1 (4%)	0	-
Relationship status			
Single	15 (54%)	3 (23%)	-
In a relationship	7 (25%)	2 (15%)	-
Married	2 (7%)	6 (46%)	-
Divorced	3 (10%)	0	-
Widowed	0	1 (8%)	-
Unknown	1 (4%)	1 (8%)	-
Children			
Yes	11 (39%)	-	-
No	14 (50%)	-	-

Unknown	3 (11%)	-	-
Living situation			
With family	20 (71%)	-	-
With partner	1 (4%)	-	-
Alone	1 (4%)	-	-
Unknown	6 (21%)	-	-
Educational level			
No education	1 (4%)	-	-
Primary	8 (28%)	-	-
Secondary	15 (53%)	-	-
Higher	3 (11%)	-	-
Unknown	1 (4%)	-	-
Work status			
Employed	9 (32%)	-	-
Unemployed	19 (68%)	-	-
Monthly income			
0 – 999 SRD	19 (67%)	-	-
1000 – 1999 SRD	7 (25%)	-	-
2000 – 4999 SRD	1 (4%)	-	-
>5000 SRD	0	-	-
Unknown	1 (4%)	-	-
(100 SRD ≈ 12 EUR)			
Relation to patient			
Partner (married)	-	1 (8%)	-
Mother	-	7 (53%)	-
Father	-	2 (15%)	-
Sibling	-	1 (8%)	-
Aunt	-	1 (8%)	-
Adoption mother	-	1 (8%)	-
Location of GP practice			
Paramaribo	-	-	4 (50%)
East Suriname	-	-	0
West Suriname	-	-	3 (38%)
South Suriname	-	-	1 (12%)

*Patient 29 had been older than 62 for years already but didn't know birth date, there was no file. We assigned patient age 62.
*One patient was included in the study based on the story the family told, they did not specify age and therefore this patient was not included in the calculations for age.
**Mixed was not further specified.
***Multiple ethnicities for patients included the following combinations: Creole-Indigenous-Jewish-Mixed. Creole-Indigenous-Mixed. Creole -Caucasian-Mixed. Indian-Chinese-Javanese-Caucasian. Indian-Creole (2x). Indian-Jewish-Chinese.
**** Age of 3 family members unknown.
***** Multiple ethnicities for family included the following combination: Creole-Indigenous-Jewish-Mixed.

Using the perspectives of patients, their family members and GPs, we identified various factors related to the duration of untreated psychosis. According to participants, presentation of symptoms and illness awareness, help seeking behaviour and alternative medicine, social support and stigma, and financial and practical factors are important topics.

Presentation of symptoms and poor illness awareness

The onset of psychosis was characterised by a wide variety of symptoms. According to patients and family members, hallucinations and disturbed and confused thoughts are the most common first symptoms of a psychosis.

Patient 1: 'I saw things.. on the tv, what I wasn't allowed to see and hear. And I also heard things.. and in my thoughts. I thought differently about things.. I wanted to have my own thoughts. I had thoughts about things that weren't true.'

Nearly half of the patients also presented with aggressive behaviour and agitation. According to a few patients, symptoms of paranoia, sleep disturbance and abnormal motor behaviour were present. Depressive or suicidal thoughts were hardly mentioned.

Patient 4: 'It was a sudden outburst (..) that I suddenly became aggressive at home.'

Patient 12: 'The delusions got worse and worse and worse, there were several conspiracies playing in my head and eh I thought people were planning things against me.'

According to GPs, patients most frequently present with hallucinations, disturbed and confused thoughts and aggressive behaviour as symptoms of psychosis. They elaborated on disturbed behaviour and indicated seeing a wide range including disobedience, confusion, destruction of property, self-neglect, wandering outside all day, blackmailing and aggression.

GP 6: 'Aggressive behaviour yes, usually family members come and tell me that a brother or, or, or an uncle suddenly behaves aggressively.'

The majority of patients expressed that they realised they experienced unusual things, such as hearing voices or behaving aggressively. However they mostly did not seem to associate these experiences to an illness, as they had difficulties realising that their behaviours were abnormal manifestations or that it fell

under the scope of a medical problem. Only a few patients associated their symptoms to having an illness.

Patient 18: 'I never thought of seeking help for voices.'

Researcher: 'Why do you think that it lasted so long until you (..) got help?'
Patient 5: 'Because first I had to think whether it was normal or abnormal.'

Most of the patients and family members believed there was a supernatural explanation to the symptoms as they reported the cause of a psychosis to be the cause of a spell or the devil. As there were people from different cultures involved in this study, these supernatural causes varied widely corresponding to patients their culture or religion. For example, Christians would often mention God or the devil whereas indigenous people would attribute their symptoms to spirits that could do something to you, or even possess you (Winti). GPs too acknowledged that most patients often hold cultural beliefs as primary cause for their symptoms.

Patient 14: 'Some people will say, who tell me that it is the Winti (spirit) *from that family.' 'I still talk a language that I do not understand (..) so that is the Winti.'*

Patient 1: 'I thought it's just one of those things they put on you, people in Suriname we believe people put something on you so I thought that was it. I didn't know it was just my illness.' 'Yes, that is Voodoo.'

Family 18: 'We thought it were attacks of the devil.'

While some patients attributed their symptoms to other mental or physical factors such as stress and head trauma, a few patients indicated to be completely unaware of their condition at the time.

Patient 10: 'I was (ill) because I was stressed. I stressed a lot.'

Family members reported that they noticed changes in the behaviour of their relatives, and that they associated these changes to an illness. It should be mentioned that participants would also use 'illness' for problems outside of the medical scope. It was rare that neither the family nor other people noticed something was wrong or different about the patient.

Family 7: 'I could see he was sick, you know? As a mother, you know?'

GP 1: 'Usually the mentors tell us that the patient has been acting strange for a while.'

Help seeking behaviour

The majority of patients and their family members reported to have visited a traditional healer for alternative care, and this was mainly the first line of care. In Suriname, there is a great variety in who can be classified as a 'traditional healer'. Traditional healers that were repeatedly mentioned by participants of our study were: *Pandits, Babas* (Hindu culture); *Lukuman, Bonuman* (Indigenous culture); *Church priests* (Christian religion). Some patients indicated they visited a traditional healer multiple times or went to multiple different healers.

Researcher: 'Why did you first go to the Lukuman (traditional healer)*?'*
Patient 16: 'Because that.. these things spiritual things. (..) This cannot be treated at the general practitioner.'

Researcher: 'How many different people (traditional healers) did you visit in those 4 years?'
Patient 6: 'Almost four'.

The second most common first place to seek help was at the GP. Generally, nearly half of the study population saw a GP before receiving treatment at the psychiatric hospital. Most GPs stated that they had been trained in medical school on how to recognise psychotic symptoms and that they would immediately refer patients who present to their clinic with these symptoms. Overall it was mainly the family that decided on where help should be sought. In a few of these cases, aggressive behaviour was a clear indication for the family that the patient needed immediate medical attention. In the end, in a great majority of cases the family decided to visit a psychiatrist.

Patient 26: 'They (parents) said ehm, you are confused, go to the doctor.'

Researcher: 'Who decided to go to the GP?'
Patient 16: 'My mother and my grandmother.'

Interestingly, some traditional healers also recommended consulting a psychiatrist according to patients and family members.

Patient 7: 'That Pandit said you must go to the doctor.'

Stigma and social support

Many participants indicated that there was a negative perception of psychosis and other psychiatric illnesses in society and many patients did not share their problem outside of their families. Often, the Surinamese people would use descriptive words as 'crazy' when referring to someone with a mental illness. Patients expressed fear of being labelled in a negative way.

Researcher: 'What was for you the main reason not to go to the GP?'
Patient 8: 'That was it, that people will find me crazy.'

Researcher: 'Do people view you differently?'
Patient 24: 'Yes a few of them.'
Researcher: 'Yes? How do they see it?'
Patient 24: 'How should I say it (..), like a madman.'

Around half of the study population indicated that stigma was not present within the family and reported to feel supported by their families. If patients were willing to share their problems, the main first place to do so was with someone within their family. Sharing their problem with outsiders would commonly be done after the patient had already received treatment. Patients noted that family support was often a key component in getting them to seek and receive help. Family members also played a big role in helping patients to stick to their treatment. GPs too emphasised the importance of family support for treatment initiation and continuation.

Family 18: 'Now when she got these things, I have really, I really did not at all think about getting crazy or being crazy, no (..). But thinking that she is crazy? No, I have not at all thought that.'

Patient 6: 'I have also told my nieces (..) they said; you did the right thing getting help at the Baba (traditional healer)*. (..) They just want to support you.'*

Family 7: 'I go with him, (..), every time he has to come, I come along.'

Interviewees also reported a specific stigma on the Psychiatric Centre in Paramaribo. Commonly, it is perceived as a place for mad or crazy people.

Patient 1: 'My brother and my mother have said at school I should not tell anything to everybody that I.. am under treatment at the PCS. Because then they will treat you different or so.'

GP 1: 'They just don't want to go to the PCS, yes. Because fairly it is seen as a madhouse.'

Financial and practical factors around mental health services

Most patients were insured prior to seeking help, most commonly with basic insurance. Basic insurance covers psychiatric care in Suriname. In those that did not have insurance prior to their symptoms, it was clear that this led to a delay in receiving appropriate treatment. When asked, costs did not seem to keep participants from seeking help. Only very rarely costs were mentioned as an issue for seeking healthcare.

Family 16: 'We didn't have to pay for it. He has an insurance card.'

Researcher: 'Have you ever doubted whether to seek help because it costs so much money?'
Patient 14: 'No I have never doubted.'

Family 7: 'He had no things, no thing-card.'
Nurse: 'Insurance card.'
Family 7: 'Insurance yes. Then I had to wait a long time (..) three months or so.'

None of the interviewees reported any problem with distance to the GP and none mentioned having any difficulty getting help at the GP. The interviewed GPs agreed with this finding and said distance to them was not an issue for patients. Patients living in rural areas did mention that in the past it would be difficult to go to the PCS, situated in Paramaribo, but nowadays it is possible for them to receive psychiatric care through their GPs.

Patient 4: 'What happened to me, I make time to come to the PCS so for me the distance is no longer important. What is important is I have found help, it is good for me. The distance doesn't matter anymore.'

GP 4: 'The distance I would not say (..) now with these developments we have enough GPs where they can go.'

DISCUSSION AND CONCLUSION

This study aimed to explore the duration of untreated psychosis among Surinamese patients and related factors using the perspectives from patients, their families and first line health care professionals in

Suriname. The median DUP was 4 months. Main emerging themes included poor illness awareness, use of alternative medicine, stigma and family support. Patients and families had difficulty recognising symptoms as an illness and would attribute these to supernatural causes, resulting in a delay before contacting a general practitioner or psychiatrist. Significant stigma and fear of being labelled 'crazy' also contributed to a delay in help-seeking, as it withheld people from talking openly about their symptoms. Good family support was associated with a shorter period of time lost before seeing a healthcare professional and often it was the family who took initiative to look for help. Other factors such as financial resources, accessibility to health care facilities and knowledge of psychiatric illness amongst GPs were investigated too, but were found to be of less significant relevance to DUP.

One important and recurrent finding was the finding that patients and families attributed symptoms to external, predominantly supernatural, causes. These non-medical explanatory models of psychosis have been found previously in non-western countries,[27]. Social, cultural and religious explanations were encountered and were thought to influence pathway to care,[27]. Likewise, a study in Malawi,[28],found the socio-cultural explanation of witchcraft and spirit possession to be dominant and determinant for subsequent help-seeking. In our study, the most common first place to seek help was traditional medicine, with GP practices following second. Generally, the use of traditional medicines is common in many households in Suriname,[29]. From these results, a relationship between this cultural explanation and alternative medicine as first place to seek help is evident. Various studies in countries with rich cultural history see similar results,[28,30,31]. Many patients who reported seeing a traditional healer before seeing a medical specialist, were also the ones who had a longer DUP. A cross-sectional study in South Africa found similar results for contact with traditional healers and DUP,[30]. Burns,[32],too reported an association between alternative medicine and long DUP. There have been promising attempts to set up collaborations between traditional healers and general healthcare,[33,34],or at educating traditional healers for recognising mental diseases,[35]. However, these studies are still juvenile and such a study in Suriname has yet to be performed.

We found that in particular family relations played a major role in social support, help-seeking behaviour and treatment initiation and continuation. Many family members are closely involved in decision-making on the patient's behalf and could therefore be of vital influence on a patients' duration of untreated psychosis. Correspondingly, a US study found patients with stronger family relations to have a shorter DUP compared with individuals who had a more troubled relationship with their families,[36]. In their study, a key component in a strong relationship included open communication, a factor which emerged during our interviews too. Another study from China also found family members misjudging the patients' disease to be the main cause for treatment delay,[37], again emphasising the importance of family in final decision-making. Family members appear to be the most common initiators in seeking care and to

be decision-makers regarding treatment,[30,31]. The social context including family seems to be a promising topic for further research and future interventions aimed at reducing DUP.

General stigma seemed to be a barrier for patients to talk about their symptoms and seek help, a finding consistent with previous studies,[38]. Recently, Kular,[12],has found stigma on mental illnesses significantly lengthening DUP. GPs in our study attributed treatment delay to stigma too. Psychosis is still misunderstood and people are afraid of receiving the label 'crazy'. Correspondingly, we found the Psychiatric Centre in Paramaribo was seen as a place for mad people.

The study is prone to significant recall bias, since all data was gathered through interviews and stories were told in retrospect. The time of onset of first symptoms ranged from 1986 to 2017, from which the recall bias is apparent. During transcript analysis, contradictory information was occasionally found between patients' and their families' stories or between a narrative and the medical file. As there was only one moment of contact, there was no opportunity to clarify contradictory information with the interviewee. In these cases, information from the medical file and subsequently the families' story was deemed more accurate than the patients' story. If conflicting themes occurred within the same transcript, for example a patient indicating throughout the interview that they were both aware and not aware of their symptoms, both themes were marked as present in the results. This might have led to certain themes being over- or underexposed in this research. Additionally, it was difficult to determine DUP for some patients due to inconsistencies between patient- and family stories and the medical file. Finally, a selection bias is possible since participants were specifically chosen to create a diverse population.

Strengths of the study were access to patient files to minimise bias for date of admission, onset of symptoms and DUP. Another significant strength is the presence of local nurses during the interviews to overcome language barriers between researcher and interviewee, improving quality of collected data. The inclusion of GPs strengthens the study by adding a different, medical viewpoint. Furthermore, stories from patients confirmed by family members ensured more reliable data. Lastly, the study design ensured a broad geographical spread for data collection, strengthening the scope to which results can be applied.

In conclusion, multiple factors were found to be related to DUP, of which poor illness awareness, alternative medicine, perceived stigma and social support were predominant. Many other factors were explored, including accessibility to healthcare facilities and financial factors. The importance of factors such as the use of alternative medicine, stigma and family support provide a reflection of the Surinamese society and results of our study facilitate better understanding of this specific population. Knowledge about these country-specific factors can be used as supportive material for measures taken to reduce

DUP in Suriname in the future. In concordance with the WHO Traditional Medicine Strategy,[39], collaboration between traditional healers and the general healthcare system would be a significant step forward and should be pursued.

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Conflicts of interests

The authors declare no conflict of interests.

Contributorship

AvB, MdL, MP and LK initiated this study in collaboration with WV and RN. AvB, MdL, MP, LK, WV and JdZ prepared the research plan and interview templates in the Netherlands. RN and RD were responsible for the ethical approval and provision of appropriate research facilities in Suriname. AvB, MdL, MP and LK performed, transcribed and analysed interviews in Suriname under supervision of RN, WV and JdZ. Nurses Saakie, Moestadjap, Dameri and Gadjri provided useful assistance during interviews. AvB, MdL, MP and LK drafted a first manuscript for the University of Groningen. AvB and JdZ drafted the final manuscript for publication. All authors are responsible for and involved in the project and have critically revised the manuscript. All authors have read and approved the final manuscript.

Data sharing statement

All data relevant to the study are included in the article.

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Duration of untreated psychosis and pathways to care in Suriname: a qualitative study among patients, relatives and general practitioners.

Atousa van Beek[1], Janine de Zeeuw[2], Menno de Leeuw[1], Mia Poplawska[1], Lise Kerkvliet[1], Rudi Dwarkasing[3], Randhir Nanda[3], Wim Veling[4]

Affiliations:

1. University of Groningen, University Medical Center Groningen, Department of Medical Sciences, Groningen, The Netherlands

2. University of Groningen, University Medical Center Groningen, Department of Health Sciences, Groningen, Global Health Unit, The Netherlands

3. Psychiatric Centre Suriname, Paramaribo, Suriname

4. University of Groningen, University Medical Center Groningen, Department of Psychiatry, Groningen, The Netherlands

Correspondence to J. de Zeeuw: j.de.zeeuw@umcg.nl

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Psychosis, duration of untreated psychosis, Global mental health, qualitative study

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ABSTRACT

Purpose Psychosis is a severe mental health problem and is responsible for poor health outcomes, premature mortality and morbidity, especially in low- and middle-income countries. The duration of untreated psychosis (DUP), that is the time period between onset of symptoms until initiation of appropriate treatment by a healthcare professional, is one of the main determinants for successful treatment in western settings. This study aims to explore the factors related to the DUP among Surinamese patients using the perspectives from patients, their families and first-line healthcare professionals in Suriname.

Methods Semi-structured interviews were conducted with patients having a history of psychosis, family members and general practitioners between February 2019 and April 2019 in Suriname. Interviews were tape-recorded and transcribed verbatim. Data was analysed using a thematic analysis for which an inductive and deductive approach was applied.

Results In total, 28 patients, 13 family members and 8 general practitioners were interviewed. Five patients were excluded from the study. A median DUP of 4 months was found (IQR 1–36). Identified themes related to DUP included presentation of symptoms and illness awareness, help seeking behaviour and alternative medicine, social support and stigma, financial and practical factors.

Conclusion Multiple factors were related to DUP, of which poor illness awareness, traditional medicine, stigma and social support were predominant. Poor illness awareness and use of alternative medicine were related to a longer DUP. Stigma was often an obstacle for patients and their families. Social and family support was important in helping patients to get medical help sooner. Other explored factors including financial and practical factors did not contribute to DUP.

Strengths and limitations of this study

- Collaboration with local nurses during interviews to overcome language and cultural barriers
- Incorporating views from different population groups; patients, family and general practitioners
- Retrospective study design prone to recall bias
- Selection bias due to purposive sampling

INTRODUCTION

Globally, mental and addiction disorders caused 7% of all global burden of disease measured in DALY's and 19% of all years lived with disability in 2016,[1], along with a percentage of 16% of the world population being affected by mental disorders,[1]. People with mental health disorders are at high risk for disabilities and mortality,[2], stigma and discrimination,[3]. In most countries, especially low- and middle-income countries, health systems are inadequately designed to manage mental health problems,[2,4]. An alarming 76-85% of people with severe mental disorders in low- and middle-income countries do not have access to proper mental healthcare,[2].

One such severe mental disorder, schizophrenia, affects over 21 million people worldwide. The global incidence of schizophrenia is 1.5 per 10.000,[5],and the global burden of schizophrenia alone accounts for 1.7% of YLD's,[4]. Psychotic symptoms are a core feature of schizophrenia, which is characterised by sensory and/or cognitive disturbances. It has a broad clinical presentation with most prominently symptoms such as hallucinations and delusions, but it can also present itself with symptoms such as thought disorganisation or apathy,[6]. The duration of untreated psychosis, i.e. the period between onset of symptoms and initiation of appropriate treatment by a healthcare professional, has been associated with poorer general outcomes,[7]. These manifest themselves as reduced likelihood of remission, poorer social functioning and cognitive impairment,[8,9]. In middle and high-income countries several factors playing a role in a prolonged DUP have been identified such as stigma,[10,11,12], the financial situation of the patient,[11,13], illness awareness,[11,13,14], perception,[13], distance to care facilities,[15],and knowledge of mental illnesses,[14]. Studies in Africa found reasons for low access to mental healthcare related to cultural views on causes of disease and noted people visiting informal health care settings first, before reporting to a hospital,[16]. Another recent study found that traditional medicine could contribute to a delay of starting appropriate treatment,[13]. Several countries have conducted research into country-specific factors and have begun to design and test interventions to reduce the DUP,[17].

In Suriname, a middle-income country, limited evidence on psychosis is available. The most recent study on the incidence of schizophrenic disorders was conducted in 2005 and showed an incidence of 1.77 per 10.000,[18]. Healthcare is highly centralised, with only one psychiatric hospital located in the capital city Paramaribo. A study researching the equity in healthcare in Suriname reported the use of secondary healthcare to be lower in the rural interior compared with coastal areas,[19]. Suriname is a country in which traditional medicine is widely practised and large parts of the population still rely on these traditional healers in both urban and rural areas. Research in Suriname has shown that within traditional medicine, psychiatric diseases such as depression and anxiety are considered a social imbalance or to have spiritual causes,[20]. These alternate explanations of disease, amongst other factors, alter help seeking behaviour of patients and their pathway to care, which seems to be of great importance in psychotic disorders.

Therefore, the aim of this study is to explore the factors related to the duration of untreated psychosis among Surinamese patients using the perspectives from patients, their families and first line health care professionals in Suriname.

METHODS

Setting, study design and participants

In Suriname, the healthcare system is not evenly distributed between rural and urban areas,[21]. It is highly centralised with only one psychiatric hospital based in the capital city Paramaribo, the so-called 'Psychiatric Centre of Suriname' or 'PCS'. In addition to this psychiatric hospital, there is one outpatient clinic of the PCS based in Nieuw-Nickerie. With only 10 psychiatrists in place, this calculates to 1 psychiatrist per 56.000 population in the country,[22]. To put this into perspective, the Netherlands has a calculated 1 psychiatrist per 4.636 population,[23]. General practitioners (GPs) are the first line of care in the formal health care system. We conducted semi-structured interviews between February 2019 and April 2019 among patients, family members and GPs. Patients were eligible for inclusion if they (i) signed the informed consent form; (ii) were diagnosed with a psychotic disorder; and (iii) were aged between 16 to 65 years of age. Patients were excluded for participation if they (i) had mental retardation or (ii) had a known drug-induced psychosis. For family members and GPs no inclusion or exclusion criteria were formulated.

Sampling and materials

Patients were recruited from various regions in Suriname, namely Paramaribo, Moengo (East), Nieuw-Nickerie (West) and Brownsweg (South). The patients, known by the PCS to have a history of psychosis, were recruited based on the inclusion criteria and contacted by psychiatrists working in the PCS (mainly RN). Eligible patients were selected based on purposive sampling in order to aim at a heterogeneous group of participants concerning area of living and estimated DUP. A convenience sample of family members was used. If patients brought a family member to an interview, this family member was also approached for participation in the study. In case patients were visited at home for an interview and a family member was present and willing to participate, this member was interviewed and included in the study as well. Also, a convenience sample for the general practitioners was used. General practitioners were telephonically approached (by RN) and asked for participation, and if they were willing to participate they were included. In total 8 general practitioners were approached for participation in the study. The interviewing process continued until saturation appeared and when no new themes emerged.

A first draft of the topic list was developed by the research team, using topics from previous studies and using the Cultural Formulation Interview,[24],and the McGill Illness Narrative Interview (MINI),[25] as the

foundation of our interview design. Thereafter, it was discussed with PCS healthcare professionals (psychiatrists and nurses) for further improvement and clarification of language, cultural appropriateness and focus on known factors that would be relevant for the research question. This ensured that every factor associated with DUP, insights in the care pathway, and cultural factors would be addressed and understandable to the participants. DUP was defined as the time period between onset of symptoms until initiation of appropriate treatment by a healthcare professional. Onset of symptoms was defined as the first manifestation of symptoms as reported by the patient or their family, irrespective of illness awarenessPatients were interviewed about their first episode of psychosis and the topics covered were based on the predicted factors which could influence the DUP. The GP interviews focused on their knowledge of and experience with psychotic disorders. Semi-structured interviews were conducted by (AvB, MdL, LK, MP) in Dutch (the official language of Suriname), with the presence of a nurse from the PCS when possible for any language and communication problems. When patients were only able to speak their local dialect then a nurse would translate. This was the case for five (n=5) out of 27 patient interviews and one (n=1) out of 14 family interviews. Doctor interviews were all conducted in Dutch. All interviews were tape recorded and transcribed verbatim. Interview templates for the original and revised patient and family interview (Supplementary File 1 and 2) and general practitioner interview (Supplementary File 3) translated into English can be found in the supplementary materials.

Patient and public involvement

Patients were first involved in the research process at the stage of conducting the interviews. Experiences from participants, together with themes from previous research, formed the baseline for this study's outcome measures. Patients and public were not involved in the design, recruitment or burden of the study. Research results were shared with the Psychiatric Centre Suriname. Participants who showed interest in the study results were recommended to check in with their practising physician upon conclusion of the study.

Data analysis

Whilst conducting and transcribing interviews, data analysis was performed simultaneously. The transcribed interviews were analysed according to thematic analysis,[26]. In order to ensure reliability, the first four transcripts were independently coded by at least two researchers using a combined inductive and deductive approach. These findings were discussed in order to create a set of codes the four researchers mutually agreed on, and to develop the initial codebook. Subsequently, all other transcripts were coded individually by a researcher. Thereafter another member of the study team reviewed this coding, adding comments and highlighting possibly overlooked codes. Then discussion followed between the researchers who did coding for that interview. The analysis was considered finished when two

researchers reached a consensus. The initial codebook was revised based on coding of the subsequent transcripts. When new codes emerged during analysis, these were added to the codebook and previously finished analyses of transcript were scanned for these newly found codes. Thereafter, the data were refined into themes and subthemes, which was then put into a database. A separate document contained any relevant, supporting quotations.

Ethics

Ethical approval was obtained from the Ministry of Public Health in Suriname (VG 20-18). All patients and their families signed an informed consent form prior to the interviews and were informed that participation was voluntary. They were made aware of their right to withdraw from the study at any point and that interviews would be processed anonymously and used for scientific purpose. If participants were unable to write and/or read, they received oral explanation of the study and gave oral consent.

RESULTS

Socio-demographics

In total 33 patients were approached for an interview, of which five patients were excluded due to having drug-induced psychosis (n=3), mental retardation (n=1) and because of a language barrier which could not be overcome (n=1). Socio-demographic characteristics of one (n=1) patient were collected through a family interview, because the patient was not able to participate. A total of 13 family members and 8 general practitioners were included. Sociodemographic characteristics are shown in Table 1. Patients had an equal gender distribution and a median age of 39 (IQR 31 – 48) years. Most patients lived in the capital city Paramaribo. The majority of patients indicated to have multiple ethnicities, and generally, Indian and Creole were the most common. The predominant religion was Christianity and Hinduism. Most patients were single and lived with their family. The most commonly reached educational level was secondary education. Unemployment was high and most earned under 2000 SRD (€240) per month. The median DUP (n=2 unknown) was 4 months (IQR: 1 – 36) and the median onset of first symptoms (n=1 unknown) was 60 months ago (IQR: 19 – 132). Mainly mothers were interviewed, with a median age of 53 (IQR:48 – 58) years. The majority of GPs were males, with a median age of 47 (IQR: 41.5 – 56) years and they were mainly based in Paramaribo and West-Suriname (table 1). Values were marked ‘unknown’ in case they could not be reliably retrieved from the interview nor from the medical file.

Table 1 Socio-demographic factors of participants

Variable	Patient Frequency, n (%)	Family Frequency, n (%)	General Practitioner Frequency, n (%)
Age: median,[IQR]	39,[17]*	53,[10]****	47,[14.5]
Gender			
Male	14 (50%)	4 (31%)	7 (88%)
Female	14 (50%)	9 (69%)	1 (12%)
Ethnicity			
Indian	6 (21%)	6 (46%)	-
Creole	3 (11%)	3 (23%)	-
Mixed**	2 (7%)	0	-
Javanese	4 (14%)	3 (23%)	-
Marron	5 (18%)	0	-
Indigenous	0	0	-
Jewish	0	0	-
Chinese	0	0	-
Caucasian	0	0	-
Multiple ethnicities	7 (25%)***	1 (8%) *****	-
Unknown	1 (4%)	0	-
Place of living			
Paramaribo	16 (58%)	7 (54%)	-
East Suriname	4 (14%)	2 (15%)	-
West Suriname	4 (14%)	4 (31%)	-
South Suriname	4 (14%)	0	-
Religion			
Christianity	13 (46%)	4 (31%)	-
Hinduism	7 (25%)	6 (46%)	-
Islam	4 (14%)	3 (23%)	-
No religion	3 (11%)	0	-
Unknown	1 (4%)	0	-
Relationship status			
Single	15 (54%)	3 (23%)	-
In a relationship	7 (25%)	2 (15%)	-
Married	2 (7%)	6 (46%)	-
Divorced	3 (10%)	0	-
Widowed	0	1 (8%)	-
Unknown	1 (4%)	1 (8%)	-
Children			
Yes	11 (39%)	-	-
No	14 (50%)	-	-
Unknown	3 (11%)	-	-
Living situation			
With family	20 (71%)	-	-

With partner	1 (4%)	-	-
Alone	1 (4%)	-	-
Unknown	6 (21%)	-	-
Educational level			
No education	1 (4%)	-	-
Primary	8 (28%)	-	-
Secondary	15 (53%)	-	-
Higher	3 (11%)	-	-
Unknown	1 (4%)	-	-
Work status			
Employed	9 (32%)	-	-
Unemployed	19 (68%)	-	-
Monthly income			
0 – 999 SRD	19 (67%)	-	-
1000 – 1999 SRD	7 (25%)	-	-
2000 – 4999 SRD	1 (4%)	-	-
>5000 SRD	0	-	-
Unknown	1 (4%)	-	-
(100 SRD ≈ 12 EUR)			
Relation to patient			
Partner (married)	-	1 (8%)	-
Mother	-	7 (53%)	-
Father	-	2 (15%)	-
Sibling	-	1 (8%)	-
Aunt	-	1 (8%)	-
Adoption mother	-	1 (8%)	-
Location of GP practice			
Paramaribo	-	-	4 (50%)
East Suriname	-	-	0
West Suriname	-	-	3 (38%)
South Suriname	-	-	1 (12%)

*Patient 29 had been older than 62 for years already but didn't know birth date, there was no file. We assigned patient age 62.
*One patient was included in the study based on the story the family told, they did not specify age and therefore this patient was not included in the calculations for age.
**Mixed was not further specified.
***Multiple ethnicities for patients included the following combinations: Creole-Indigenous-Jewish-Mixed. Creole-Indigenous-Mixed. Creole -Caucasian-Mixed. Indian-Chinese-Javanese-Caucasian. Indian-Creole (2x). Indian-Jewish-Chinese.
**** Age of 3 family members unknown
***** Multiple ethnicities for family included the following combination: Creole-Indigenous-Jewish-Mixed

Using the perspectives of patients, their family members and GPs, we identified various factors related to the duration of untreated psychosis. According to participants, presentation of symptoms and illness

awareness, help seeking behaviour and alternative medicine, social support and stigma, and financial and practical factors are important topics.

Presentation of symptoms and poor illness awareness

The onset of psychosis was characterised by a wide variety of symptoms. According to patients and family members, hallucinations and disturbed and confused thoughts are the most common first symptoms of a psychosis.

Patient 1: 'I saw things.. on the tv, what I wasn't allowed to see and hear. And I also heard things.. and in my thoughts. I thought differently about things.. I wanted to have my own thoughts. I had thoughts about things that weren't true.'

Nearly half of the patients also presented with aggressive behaviour and agitation. According to a few patients, symptoms of paranoia, sleep disturbance and abnormal motor behaviour were present. Depressive or suicidal thoughts were hardly mentioned (table 2).

Patient 4: 'It was a sudden outburst (..) that I suddenly became aggressive at home.'

Patient 12: 'The delusions got worse and worse and worse, there were several conspiracies playing in my head and eh I thought people were planning things against me.'

According to GPs, patients most frequently present with hallucinations, disturbed and confused thoughts and aggressive behaviour as symptoms of psychosis. They elaborated on disturbed behaviour and indicated seeing a wide range including disobedience, confusion, destruction of property, self-neglect, wandering outside all day, blackmailing and aggression.

GP 6: 'Aggressive behaviour yes, usually family members come and tell me that a brother or, or, or an uncle suddenly behaves aggressively.'

The majority of patients expressed that they realised they experienced unusual things, such as hearing voices or behaving aggressively. However they mostly did not seem to associate these experiences to an illness, as they had difficulties realising that their behaviours were abnormal manifestations or that it fell under the scope of a medical problem. Only a few patients associated their symptoms with having an illness.

Patient 18: 'I never thought of seeking help for voices.'

Researcher: 'Why do you think that it lasted so long until you (..) got help?'
Patient 5: 'Because first I had to think whether it was normal or abnormal.'

Most of the patients and family members believed there was a supernatural explanation to the symptoms as they reported the cause of a psychosis to be the cause of a spell or the devil. As there were people from different cultures involved in this study, these supernatural causes varied widely corresponding to patients' their culture or religion. For example, Christians would often mention God or the devil whereas indigenous people would attribute their symptoms to spirits that could do something to you, or even possess you (Winti). GPs too acknowledged that most patients often hold cultural beliefs as the primary cause for their symptoms.

Patient 14: 'Some people will say, who tell me that it is the Winti (spirit) *from that family.' 'I still talk a language that I do not understand (..) so that is the Winti.'*

Patient 1: 'I thought it's just one of those things they put on you, people in Suriname we believe people put something on you so I thought that was it. I didn't know it was just my illness.' 'Yes, that is Voodoo.'

Family 18: 'We thought it were attacks of the devil.'

While some patients attributed their symptoms to other mental or physical factors such as stress and head trauma, a few patients indicated to be completely unaware of their condition at the time.

Patient 10: 'I was (ill) because I was stressed. I stressed a lot.'

Family members reported that they noticed changes in the behaviour of their relatives, and that they associated these changes to an illness. It should be mentioned that participants would also use 'illness' for problems outside of the medical scope. It was rare that neither the family nor other people noticed something was wrong or different about the patient.

Family 7: 'I could see he was sick, you know? As a mother, you know?'

GP 1: 'Usually the mentors tell us that the patient has been acting strange for a while.'

Table 2. Presenting symptoms reported by participants

Presenting symptoms	Frequency, n (%)
Disturbed and confused thoughts	17 (61%)
Abnormal motor behaviour	6 (21%)
Hallucinations	22 (79%)
Agitation or aggression	12 (43%)
Delusion or paranoia	9 (32%)
Sleep disturbances	8 (29%)
Depressive or suicidal thoughts	1 (4%)

Presenting symptoms as times reported (n, %) by patients or their family. Multiple symptoms could apply to one patient. Presenting symptoms mentioned by both patient and family are counted as one.

Help seeking behaviour

The majority of patients and their family members reported to have visited a traditional healer for alternative care, and this was mainly the first line of care. In Suriname, there is a great variety in who can be classified as a 'traditional healer'. Traditional healers that were repeatedly mentioned by participants of our study were: *Pandits, Babas* (Hindu culture); *Lukuman, Bonuman* (Indigenous culture); *Church priests* (Christian religion). Some patients indicated they visited a traditional healer multiple times or went to multiple different healers.

Researcher: 'Why did you first go to the Lukuman (traditional healer)*?'*
Patient 16: 'Because that.. these things spiritual things. (..) This cannot be treated at the general practitioner.'

Researcher: 'How many different people (traditional healers) did you visit in those 4 years?'
Patient 6: 'Almost four'.

The second most common first place to seek help was at the GP. Generally, 46% of the study population saw a GP before receiving treatment at the psychiatric hospital. Most GPs stated that they had been trained in medical school on how to recognise psychotic symptoms and that they would immediately refer patients who present to their clinic with these symptoms. Overall it was mainly the family that decided on where help should be sought. In a few of these cases, aggressive behaviour was a clear indication for the family that the patient needed immediate medical attention. In the end, in a great majority of cases the family decided to visit a psychiatrist.

Patient 26: 'They (parents) said ehm, you are confused, go to the doctor.'

Researcher: 'Who decided to go to the GP?'
Patient 16: 'My mother and my grandmother.'

Interestingly, some traditional healers also recommended consulting a psychiatrist according to patients and family members.

Patient 7: 'That Pandit said you must go to the doctor.'

Stigma and social support

Many participants indicated that there was a negative perception of psychosis and other psychiatric illnesses in society and many patients did not share their problem outside of their families. Often, the Surinamese people would use descriptive words as 'crazy' when referring to someone with a mental illness. Patients expressed fear of being labelled in a negative way.

Researcher: 'What was for you the main reason not to go to the GP?'
Patient 8: 'That was it, that people will find me crazy.'

Researcher: 'Do people view you differently?'
Patient 24: 'Yes a few of them.'
Researcher: 'Yes? How do they see it?'
Patient 24: 'How should I say it (..), like a madman.'

Around half of the study population indicated that stigma was not present within the family and 89% of participants reported to feel supported by their families. If patients were willing to share their problems, the main first place to do so was with someone within their family. Sharing their problem with outsiders would commonly be done after the patient had already received treatment. Patients noted that family support was often a key component in getting them to seek and receive help. Family members also played a big role in helping patients to stick to their treatment. GPs too emphasised the importance of family support for treatment initiation and continuation.

Family 18: 'Now when she got these things, I have really, I really did not at all think about getting crazy or being crazy, no (..). But thinking that she is crazy? No, I have not at all thought that.'

Patient 6: 'I have also told my nieces (..) they said; you did the right thing getting help at the Baba (traditional healer)*. (..) They just want to support you.'*

Family 7: 'I go with him, (..), every time he has to come, I come along.'

Interviewees also reported a specific stigma on the Psychiatric Centre in Paramaribo. Commonly, it is perceived as a place for mad or crazy people.

Patient 1: 'My brother and my mother have said at school I should not tell anything to everybody that I.. am under treatment at the PCS. Because then they will treat you different or so.'

GP 1: 'They just don't want to go to the PCS, yes. Because fairly it is seen as a madhouse.'

Financial and practical factors around mental health services

Most patients were insured prior to seeking help, most commonly with basic insurance. Basic insurance covers psychiatric care in Suriname. In those that did not have insurance prior to their symptoms, it was clear that this led to a delay in receiving appropriate treatment. When asked, costs did not seem to keep participants from seeking help. Only very rarely costs were mentioned as an issue for seeking healthcare.

Family 16: 'We didn't have to pay for it. He has an insurance card.'

Researcher: 'Have you ever doubted whether to seek help because it costs so much money?'
Patient 14: 'No I have never doubted.'

Family 7: 'He had no things, no thing-card.'
Nurse: 'Insurance card.'
Family 7: 'Insurance yes. Then I had to wait a long time (..) three months or so.'

None of the interviewees reported any problem with distance to the GP and none mentioned having any difficulty getting help at the GP. The interviewed GPs agreed with this finding and said distance to them was not an issue for patients. Patients living in rural areas did mention that in the past it would be difficult to go to the PCS, situated in Paramaribo, but nowadays it is possible for them to receive psychiatric care through their GPs.

Patient 4: 'What happened to me, I make time to come to the PCS so for me the distance is no longer important. What is important is I have found help, it is good for me. The distance doesn't matter anymore.'

GP 4: 'The distance I would not say (..) now with these developments we have enough GPs where they can go.'

DISCUSSION AND CONCLUSION

This study aimed to explore the duration of untreated psychosis among Surinamese patients and related factors using the perspectives from patients, their families and first line health care professionals in Suriname. The median DUP was 4 months. Main emerging themes included poor illness awareness, use of alternative medicine, stigma and family support. Patients and families had difficulty recognising symptoms as an illness and would attribute these to supernatural causes, resulting in a delay before contacting a general practitioner or psychiatrist. Significant stigma and fear of being labelled 'crazy' also contributed to a delay in help-seeking, as it withheld people from talking openly about their symptoms. Good family support was associated with a shorter period of time lost before seeing a healthcare professional and often it was the family who took initiative to look for help. Other factors such as financial resources, accessibility to health care facilities and knowledge of psychiatric illness amongst GPs were investigated too, but were found to be of less significant relevance to DUP.

One important and recurrent finding was the lack of illness awareness amongst the participants and their communities. Many patients and families attributed symptoms to external, predominantly supernatural, causes. These non-medical explanatory models of psychosis have been found previously in non-western countries,[27]. Social, cultural and religious explanations were encountered and would often influence pathway to care,[27]. Likewise, a study in Malawi,[28],found the socio-cultural explanation of witchcraft and spirit possession to be dominant and determinant for subsequent help-seeking. In our study, the most common first place to seek help was traditional medicine, with GP practices following second. Generally, the use of traditional medicines is common in many households in Suriname,[29]. From these results, a relationship between this cultural explanation and alternative medicine as first place to seek help is evident. Various studies in countries with rich cultural history see similar results,[28,30,31]. Many patients who reported seeing a traditional healer before seeing a medical specialist, were also the ones who had a longer DUP. A cross-sectional study in South Africa found similar results for contact with traditional healers and DUP,[30]. Burns,[32],too reported an association between alternative medicine and long DUP. There have been promising attempts to set up collaborations between traditional healers

and general healthcare,[33,34],or at educating traditional healers for recognising mental diseases,[35]. However, these studies are still juvenile and such a study in Suriname has yet to be performed.

We found that in particular family relations played a major role in social support, help-seeking behaviour and treatment initiation and continuation. Many family members are closely involved in decision-making on the patient's behalf and could therefore be of vital influence on a patients' duration of untreated psychosis. Correspondingly, a US study found patients with stronger family relations to have a shorter DUP compared with individuals who had a more troubled relationship with their families,[36]. In their study, a key component in a strong relationship included open communication, a factor which emerged during our interviews too. Another study from China also found family members misjudging the patients' disease to be the main cause for treatment delay,[37], again emphasising the importance of family in final decision-making. Family members appear to be the most common initiators in seeking care and to be decision-makers regarding treatment,[30,31]. The social context including family seems to be a promising topic for further research and future interventions aimed at reducing DUP.

General stigma seemed to be a barrier for patients to talk about their symptoms and seek help, a finding consistent with previous studies,[38]. Recently, Kular,[12],has found stigma on mental illnesses significantly lengthening DUP. GPs too attributed treatment delay to stigma. Psychosis is still misunderstood and people are afraid of receiving the label 'crazy'. Correspondingly, we found the Psychiatric Centre in Paramaribo was seen as a place for mad people.

The study is prone to significant recall bias, since all data was gathered through interviews and stories were told in retrospect. The time of onset of first symptoms ranged from 1986 to 2017, from which the recall bias is apparent. During transcript analysis, contradictory information was occasionally found between patients' and their families' stories or between a narrative and the medical file. As there was only one moment of contact, there was no opportunity to clarify contradictory information with the interviewee. In these cases, information from the medical file and subsequently the families' story was deemed more accurate than the patients' story. If conflicting themes occurred within the same transcript, for example a patient indicating throughout the interview that they were both aware and not aware of their symptoms, both themes were marked as present in the results. This might have led to certain themes being over- or underexposed in this research. Additionally, it was difficult to determine DUP for some patients due to inconsistencies between patient- and family stories and the medical file. Finally, a selection bias is likely since participants were specifically chosen to create a diverse population.

Strengths of the study were access to patient files to minimise bias for date of admission, onset of symptoms and DUP. Another significant strength is the presence of local nurses during the interviews to overcome language barriers between researcher and interviewee, improving quality of collected data.

The inclusion of GPs strengthens the study by adding a different, medical viewpoint. Furthermore, stories from patients confirmed by family members ensured more reliable data. Lastly, the study design ensured a broad geographical spread for data collection, strengthening the scope to which results can be applied.

In conclusion, multiple factors were related to DUP, of which poor illness awareness, alternative medicine, perceived stigma and social support were predominant. Many other factors were explored, including accessibility to healthcare facilities and financial factors. The importance of factors such as the use of alternative medicine, stigma and family support provide a reflection of the Surinamese society and results of our study facilitate better understanding of this specific population. Knowledge about these country-specific factors can be used as supportive material for measures taken to reduce DUP in Suriname in the future. In concordance with the WHO Traditional Medicine Strategy,[39], collaboration between traditional healers and the general healthcare system would be a significant step forward and should be pursued.

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Conflicts of interests

The authors declare no conflict of interests

Contributorship

AvB, MdL, MP and LK initiated this study in collaboration with WV and RN. AvB, MdL, MP, LK, WV and JdZ prepared the research plan and interview templates in the Netherlands. RN and RD were responsible for the ethical approval and provision of appropriate research facilities in Suriname. AvB, MdL, MP and LK performed, transcribed and analysed interviews in Suriname under supervision of RN, WV and JdZ. AvB,

MdL, MP and LK drafted a first manuscript for the University of Groningen. AvB and JdZ drafted the final manuscript for publication. All authors are responsible for and involved in the project and have critically revised the manuscript. All authors have read and approved the final manuscript.

Data sharing statement

All data relevant to the study are included in the article or as supplementary material.

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Interview with patient

General

1. Age: ...
2. Gender:
    - Female
    - Male
    - Other, ...
3. Ethnicity: ...
4. Place of birth: ...
5. Religion:
    - No
    - Yes
        - Christian
        - Jewish
        - Muslim
        - Hindu
        - Buddhist
        - Other, ...
6. Relationship status: ...
7. Children:
    - No
    - Yes, … children
8. Living situation:
    a. Single
    b. Partner
    c. Married
9. Educational level:
    - Primary (age 12)
    - Secondary (high school, age 17)
    - Tertiary
10. Employment: ...
11. Monthly income:
    - 0-2000 SRD
    - 2000-5000 SRD
    - 5000-10000 SRD
    - More than 10000 SRD

Introduction

Firstly, we would like to thank you for being here and for being part of this research. Before we start we would like to introduce ourselves. Our names are [Menno de Leeuw] [Atousa van Beek] [Mia Poplawska] [Lise Kerkvliet] and we are medical students from the Netherlands. For our studies we have set up this research here. For our research we will be looking into experiences and difficulties encountered from people who have had psychosis, such as yourself. Therefore, we are very glad that you are willing to share your story with us.

We would like to understand the problems or difficulties that you experienced in the past. We want to know your experience. We will ask some questions about the period that you were having difficulties and how you were dealing with them. Just as a reminder we would like to let you know that this interview will be recorded. Only people involved in the study such as ourselves will be able to access these recordings.

Please remember there are no right or wrong answers, and that everything you say will be confidential and treated anonymously. You do not have to answer any questions you are not comfortable with.
If at any point something we say or ask is unclear, do not hesitate to ask a question about it.

Do you have any questions for us?
Then we would like to get started.

Initial illness narrative

1. People often understand their problems in their own way, which may be similar to or different from how doctors describe the problem. How would you describe the problem you had?
    a. What troubled you the most about your problem?
2. At a certain point, you may have noticed that something was different from normal. When did you experience changes or difficulties for the first time?
    a. Can you describe the changes or difficulties you first noticed?
    b. Did you notice any changes or difficulties yourself, or did someone else notice this?
    c. Did someone else notice at all that you behave differently or had difficulties?
    d. At that time, what did you think of of the changes and difficulties?
        i. Did you understand the seriousness?
        ii. Did you understand that you were unwell?
3. I would like to know more about your experience with your first changes and difficulties. Can you think of anything that changed in your life at that time? Examples can be: a lot of stress, loss of a loved one or a break-up.
    a. Did you use drugs for pleasure at that time?
    b. Did you receive any medication prescribed by a doctor at that time?

Prototype narrative

1. In the past, have you ever had a health problem that you consider similar to your current health problem?
2. Did a person in your family ever experience a health problem similar to yours?

Explanatory model narrative

1. A lot of people have their own thoughts about their health problem. I would like to know something about what you thought at that moment.
    a. What did you think was happening to you?
    b. What did you think was the cause of your health problem?
2. Family members may also have their own thoughts about someone's health problem. I would like to know what they thought of yours at that moment.
    a. What do others in your family, friends, or in your community think was causing your problem?

Past help seeking

1. People all react differently to problems like yours. What did you first do when you realised you had a health problem?
2. When did you first try and find help? What made you decide to do so?
3. Did anything prevent you from getting the help you need?
4. Often, people look for help from many different sources, including different kinds of doctors, helpers, or healers. In the past, what kinds of treatment, help, advice, or healing have you sought for your health problem?
    a. What types of treatments were helpful?
    b. What types of treatments were not helpful?
    c. [If not mentioned traditional healing]. A lot of people with health problems similar to yours go to a traditional healer.
        i. Did you also go to a traditional healer?
5. Who decided to contact professional medical help? E.g. was it you or a family member who reached out.
6. Could you tell us more about how you felt when you talked with the medical professional?

Accessibility to care

1. I would like to ask a few questions about the nearest health clinic.
    a. How far is it from you?
    b. How long does it take for you to get there?
    c. How do you get there?
    d. Are there any reasons you can't get there? Possibilities could be that you can't leave the house, no time due to work, family does not agree or the cost.

2. Sometimes doctors and patients misunderstand each other because they come from different backgrounds or have different expectations.
    a. Have you ever been concerned about this?
    b. Did you face this problem when seeking help from a doctor?
3. What do you think of medical services? Do you have the feeling they could help you with your health problem?

Role of cultural identity

1. People have different backgrounds or identity's. Me for example, value my family and my place of birth very much. How is that in your case?
    a. For you, what are the most important aspects of your background or identity?
2. Sometimes also, being from a particular background or having a certain identity can cause problems. In my case, being from a certain part in The Netherlands, stereotypes can sometimes give people wrong ideas about who I am.
    a. Are there any aspects of your background or identity that are causing other concerns or difficulties for you?

Stigma

1. Does your family have an opinion regarding seeking medical treatment?
    a. Is this opinion influenced by their culture?
2. A health problem like yours can be misunderstood by many people without knowledge about psychosis for example.
    a. Do you feel that people treat or look at your differently since you've had mental health problems? By people we mean for example your religious community, friends or family?

Costs

1. How do you pay for your medical treatment?
2. Did you ever think twice about contacting medical services because of the costs?
3. If you have insurance, does it cover all costs regarding your illness?

Social support

1. Speaking about health problems may give relief for some people. It is sometimes nice to get something off your chest. Is this for you also the case? Or don't you share anything with anybody?
    a. Did you share your problems with your friends or family?
    b. Did your family or friends suggested or offered you any kind of help for your health problem?
    c. Are there any kinds of support that make your problem better, such as support from family, friends, or others?

Other

1. …
2. ...

For example, the communities you belong to, the languages you speak, where you or your family are from, your race or ethnic background, your gender or sexual orientation, or your faith or religion.

Interview with family

General

1. Age: ...
2. Gender:
    - Female
    - Male
    - Other, ...
3. Ethnicity: ...
4. Place of birth: ...
5. Religion:
    - No
    - Yes
        - Christian
        - Jewish
        - Muslim
        - Hindu
        - Buddhist
        - Other, ...
6. Relationship status: ...
7. How are you related to the patient?: ...

Introduction

Firstly, we would like to thank you for being here and for being part of this research. Before we start we would like to introduce ourselves. Our names are [Menno de Leeuw] [Atousa van Beek] [Mia Poplawska] [Lise Kerkvliet] and we are medical students from the Netherlands. For our studies we have set up this research here. For our research we will be looking into experiences and difficulties encountered from people who have had or know someone with psychosis, such as yourself. Therefore, we are very glad that you are willing to share your story with us.

We would like to understand the problems or difficulties that you experienced in the past. We want to know your experience. We will ask some questions about the period that your family member was having difficulties and what your view on this was. Just as a reminder we would like to let you know that this interview will be recorded. Only people involved in the study such as ourselves will be able to access these recordings.

Please remember there are no right or wrong answers, and that everything you say will be confidential and treated anonymously. You do not have to answer any questions you are not comfortable with.
If at any point something we say or ask is unclear, do not hesitate to ask a question about it.

Do you have any questions for us?

Then we would like to get started.

Initial illness narrative

1. Can you describe *(name of patient)* before they became ill?
2. At a certain point, you may have noticed that something was different from normal. When did you notice that *(name of patient)* changed or had some difficulties for the first time?
    a. Can you describe the changes or difficulties you first noticed?
    b. At that time, what did you think of of the changes and difficulties?
        i. Did you understand the seriousness?
        ii. Did you understand that they were unwell?
3. I would like to know more about the period when you first noticed changes in *(name of patient)*. Can you think of anything that changed in their life at that time? Examples can be: a lot of stress, loss of a loved one or a break-up.
    a. Did they use drugs for pleasure at that time?
    b. Did they receive any medication prescribed by a doctor at that time?
4. Can you describe what happened in the period after *(name of patient)* was diagnosed?
5. How were you involved when *(name of patient)* was unwell or had difficulties? Was there for example something you could do to help him/her?

Prototype narrative

1. Did a person in your family ever experience a health problem similar to *(name of patient)*?

Explanatory model narrative

1. A lot of people have their own thoughts about the reasons for a health problem. I would like to know something about what you thought about your family member at that moment.
    a. What did you think was happening to him/her?
    b. What did you think was the cause of his/her health problem?
2. We would like to know about your experience after you found out (name of patient) was ill.
    a. What effect did the diagnosis have on you?
    b. How did you cope with it?

Past help seeking

1. People all react differently when a family member becomes ill. What did you first do when you realised they had a health problem?
2. Did you talk to him/her about trying to find help? Can you explain how this went?

Care

1. Did *(name of patient)* attend the first doctor appointments or didn't they want to talk to a medical professional?

2. What did you think of the first medical professionals that helped your family member?
3. What do you think of medical services? Do you have the feeling they could help with his/her health problem?

Costs

1. Were you involved in paying *(name of patient)* his/her medical treatment?
2. Did you ever think twice about contacting medical services for *(name of patient)* because of the costs?

Other

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Interview patient

General

- Age: ...
- Gender:
    - Female
    - Male
    - Other, ...
- Ethnicity: ...
- Place of birth: ...
- Religion:
    - No
    - Yes
        - Christianity
            - RK
            - Volle evangelie
            - EBGC
            - Adventiat
        - Jewish
        - Muslim
        - Hinduism
        - Buddhism
        - Other, ...
- Relationship status:
    - None
    - Yes
- Children:
    - No
    - Yes, … children
- Living status:
    - Single
    - Living together
    - Married
    - Divorced
    - Widow
- Education:
    - Primary - Gewoon lager Onderwijs (G.L.O.)
    - Secondary - Voortgezet Onderwijs op Junioren Niveau (V.O.J.)
    - Tertiary - Voortgezet onderwijs voor Senioren (V.O.S.)
- Current employment: ...

- Monthly income:
  - 0-1000 SRD
  - 1000-2000 SRD
  - 2000-5000 SRD
  - 5000-10000 SRD
  - More than 10000 SRD

Introduction

Firstly, we would like to thank you for being here and for being part of this research. Before we start we would like to introduce ourselves. Our names are [Menno de Leeuw] [Atousa van Beek] [Mia Poplawska] [Lise Kerkvliet] and we are medical students from the Netherlands. For our studies we have set up this research here. For our research we will be looking into experiences and difficulties encountered from people who have had psychosis, such as yourself. Therefore, we are very glad that you are willing to share your story with us.

We would like to understand the problems or difficulties that you experienced in the past. We want to know your experience. We will ask some questions about the period that you were having difficulties and how you were dealing with them. Just as a reminder we would like to let you know that this interview will be recorded. Only people involved in the study such as ourselves will be able to access these recordings.

Please remember there are no right or wrong answers, and that everything you say will be confidential and treated anonymously. You do not have to answer any questions you are not comfortable with.
If at any point something we say or ask is unclear, do not hesitate to ask a question about it.

Do you have any questions for us?
Then we would like to get started.

Initial illness narrative

1. People often understand their problems in their own way, which may be similar to or different from how doctors describe the problem. How would you describe the problem you had?
   a. What troubled you the most about your problem?
2. At a certain point, you may have noticed that something was different from normal. When did you experience changes or difficulties for the first time?
   a. Can you describe the changes or difficulties you first noticed?
   b. Did you notice any changes or difficulties yourself, or did someone else notice this?
   ~~c. Did someone else notice at all that you behave differently or had difficulties?~~
   d. At that time, what did you think of the changes and difficulties?

i. **When did your family or your friends express difficulties when interacting with you?**
ii. **Did you understand the seriousness?**
    1. **Did you know that you were ill at that time?**
iii. **What kind of thoughts went through your head?**
iv. **Were you yourself under the impression that something was going on?**

3. I would like to know more about your experience with your first changes and difficulties. Can you think of anything that changed in your life at that time? ~~Examples can be: a lot of stress, loss of a loved one or a break-up.~~
    a. Did you use drugs for pleasure at that time?
    b. Did you receive any medication prescribed by a doctor at that time?
    c. Did you have any physical complaints or illnesses at that time?

Prototype narrative

1. In the past, have you ever had a health problem that you consider similar to your current health problem?
2. Did a person in your family ever experience a health problem similar to yours?
    a. Is there someone in your family with psychiatric illness, who you'd call crazy or has problems with thinking?
    b. Has anyone in your family ever been treated in the PCS?

Explanatory model narrative

1. A lot of people have their own thoughts about their health problem. I would like to know something about what you thought at that moment.
    a. What did you think was happening to you?
    b. What did you think was the cause of your health problem?
2. Family members may also have their own thoughts about someone's health problem. I would like to know what they thought of yours at that moment.
    a. What do others in your family, friends, or in your community think was causing your problem?

Past help seeking

1. People all react differently to problems like yours. What did you first do when you realised you had a health problem?
2. When did you first try and find help? What made you decide to do so?
    a. Whose idea was it to find help?
3. Why did you not go to the GP in the first place?
4. Why did you not go to the PCS in the first place?
5. Did anything prevent you from getting the help you need?

6. Often, people look for help from many different sources, including different kinds of doctors, helpers, or healers. In the past, what kinds of treatment, help, advice, or healing have you sought for your health problem?
    a. What types of treatments were helpful?
    b. What types of treatments were not helpful?
    c. [If not mentioned traditional healing]. A lot of people with health problems similar to yours go to a traditional healer.
        i. Did you also go to a traditional healer?
        ii. Did you think the help you received from the traditional healer actually helped you at that time?
7. Who decided to contact professional medical help? E.g. was it you or a family member who reached out.
~~8. Could you tell us more about how you felt when you talked with the medical professional?~~
9. What did you know about the PCS at that time?
    a. What was your view on the PCS?
10. What did your family know about the PCS at that time?
    a. What was their view on the PCS?

Accessibility to care

1. I would like to ask a few questions about the nearest health clinic.
    a. How far is it from you?
    ~~b. How long does it take for you to get there?~~
    c. How do you get there?
    d. Is it difficult for you to get to the GP/PCS?
    e. Are there any reasons you can't get there? Possibilities could be that you can't leave the house, no time due to work, family does not agree or the cost.
2. Sometimes doctors and patients misunderstand each other because they come from different backgrounds or have different expectations.
    a. Have you ever been concerned about this?
    ~~b. Did you face this problem when seeking help from a doctor?~~
~~3. What do you think of medical services? Do you have the feeling they could help you with your health problem?~~

~~**Role of cultural identity**~~

~~1. People have different backgrounds or identity's. Me for example, value my family and my place of birth very much. How is that in your case?~~
    ~~a. For you, what are the most important aspects of your background or identity?~~
~~2. Sometimes also, being from a particular background or having a certain identity can cause problems. In my case, being from a certain part in The Netherlands, stereotypes can sometimes give people wrong ideas about who I am.~~

~~a. Are there any aspects of your background or identity that are causing other concerns or difficulties for you?~~

Stigma

1. Does your family have an opinion regarding seeking medical treatment?
   ~~a. Is this opinion influenced by their culture?~~
2. A health problem like yours can be misunderstood by many people without knowledge about psychosis for example.
   a. Do you feel that people treat or look at your differently since you've had mental health problems? By people we mean for example your religious community, friends or family?

Costs

1. How do you pay for your medical treatment?
2. Did you ever think twice about contacting medical services because of the costs?
3. If you have insurance, does it cover all costs regarding your illness?
   a. Were you insured at the time your problems started?
   b. Were you insured before going to the PCS?

Social support

1. Speaking about health problems may give relief for some people. It is sometimes nice to get something off your chest. Is this for you also the case? Or don't you share anything with anybody?
   a. Did you share your problems with your friends or family?
   b. Did your family or friends suggested or offered you any kind of help for your health problem?
   c. Are there any kinds of support that make your problem better, such as support from family, friends, or others?

Other

1. **If you look back on that period of time, how much time do you think was in between your first symptoms and the first time you got to the PCS?**
2. **When was the first time you visited the PCS?**

Interview with family

General

1. Age: ...
2. Gender:
    - Female
    - Male
    - Other, ...
3. Ethnicity: ...
4. Place of birth: ...
5. Religion:
    - No
    - Yes
        - Christian
        - Jewish
        - Muslim
        - Hindu
        - Buddhist
        - Other, ...
6. Relationship status: ...
7. How are you related to the patient?: ...

Introduction

Firstly, we would like to thank you for being here and for being part of this research. Before we start we would like to introduce ourselves. Our names are [Menno de Leeuw] [Atousa van Beek] [Mia Poplawska] [Lise Kerkvliet] and we are medical students from the Netherlands. For our studies we have set up this research here. For our research we will be looking into experiences and difficulties encountered from people who have had or know someone with psychosis, such as yourself. Therefore, we are very glad that you are willing to share your story with us.

We would like to understand the problems or difficulties that you experienced in the past. We want to know your experience. We will ask some questions about the period that your family member was having difficulties and what your view on this was. Just as a reminder we would like to let you know that this interview will be recorded. Only people involved in the study such as ourselves will be able to access these recordings.

Please remember there are no right or wrong answers, and that everything you say will be confidential and treated anonymously. You do not have to answer any questions you are not comfortable with.
If at any point something we say or ask is unclear, do not hesitate to ask a question about it.

Do you have any questions for us?

Then we would like to get started.

Initial illness narrative

1. Can you describe *(name of patient)* before they became ill?
2. At a certain point, you may have noticed that something was different from normal. When did you notice that *(name of patient)* changed or had some difficulties for the first time?
    a. Can you describe the changes or difficulties you first noticed?
    b. At that time, what did you think of the changes and difficulties?
        i. Did you understand the seriousness?
            1. Did you understand they were ill at that time?
        ii. Did you understand that they were unwell?
3. I would like to know more about the period when you first noticed changes in *(name of patient)*. Can you think of anything that changed in their life at that time? Examples can be: a lot of stress, loss of a loved one or a break-up.
    a. Did they use drugs for pleasure at that time?
    b. Did they receive any medication prescribed by a doctor at that time?
4. Can you describe what happened in the period after *(name of patient)* was diagnosed?
5. How were you involved when *(name of patient)* was unwell or had difficulties? Was there for example something you could do to help him/her?

Prototype narrative

1. Did a person in your family ever experience a health problem similar to *(name of patient)*?

Explanatory model narrative

1. A lot of people have their own thoughts about the reasons for a health problem. I would like to know something about what you thought about your family member at that moment.
    a. What did you think was happening to him/her?
    b. What did you think was the cause of his/her health problem?

~~2. We would like to know about your experience after you found out (name of patient) was ill.~~

~~a. What effect did the diagnosis have on you?~~

~~b. How did you cope with it?~~

Past help seeking

1. People all react differently when a family member becomes ill. What did you first do when you realised they had a health problem?
    a. What was the first place where (name patient) sought help?
    b. Were you involved in this?
2. Did you talk to him/her about trying to find help? Can you explain how this went?

Care

1. Did *(name of patient)* attend the first doctor appointments or didn't they want to talk to a medical professional?
    a. **What was the advice you got from the GP?**
    b. **Was (name patient) referred to the PCS immediately?**
2. ~~What did you think of the first medical professionals that helped your family member?~~
3. ~~What do you think of medical services? Do you have the feeling they could help with his/her health problem?~~

Costs

1. Were you involved in paying *(name of patient)* his/her medical treatment?
2. Did you ever think twice about contacting medical services for *(name of patient)* because of the costs?

Other

1. **If you look back on that period of time, how much time do you think was in between your relative's (patient) first symptoms and the first time they got to the PCS?**
2. **When was the first time your relative visited the PCS?**

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Interview physician

General

1. Age: …
2. Gender:
    - Female
    - Male
    - Other, …
3. Occupation: …
4. Years in occupation: …

Introduction

Firstly, we would like to thank you for being here and for being part of this research. Before we start we would like to introduce ourselves. Our names are [Menno de Leeuw] [Atousa van Beek] [Mia Poplawska] [Lise Kerkvliet] and we are medical students from the Netherlands. For our studies we have set up this research here. For our research we will be looking into experiences and difficulties encountered from people who have had psychosis, but also the opinions of the patient's family and treating physicians. Therefore, we are very glad that you are willing to share your story with us.

We would like to understand more about the possible reasons for a long Duration of Untreated Psychosis (DUP) and how we could help to reduce this. We decided to define this time as the time between the patient presenting with symptoms and receiving treatment from a healthcare professional.

We want to know more about your experience with treating patients with psychosis. We might ask some specific questions about (patient) but will mainly take a more wide-scale approach.

Just as a reminder we would like to let you know that this interview will be recorded. Only people involved in the study such as ourselves and dr. Nanda and dr. Veling will be able to access these recordings. Everything we talk about today will be confidential and treated anonymously.

Do you have any questions for us?

Then we would like to get started.

Psychosis

1. How many patients presenting with psychosis do you see on a yearly basis (estimate)?
2. What are the most common symptoms you see among your patients presenting with psychosis?

3. Patients can wait a long time before presenting to a doctor with their psychotic symptoms.
    a. How long do patients usually wait before seeing you?
    b. In your experience, what are reasons for a long DUP (duration of untreated psychosis – waiting a long period of time before seeing a doctor)
        i. Do you think distance is an important factor?
        ii. Do you think costs are an important factor?
        iii. Do you think the absence of social support is an important factor?
        iv. Do you think a low educational level is an important factor?
        v. Do you think a lack of knowledge (patient) is an important factor?
        vi. Do you think a lack of self-awareness is an important factor?
        vii. Do you think that searching for alternative medicine is an important factor?
        viii. Do you think that stigma is an important factor? (mental health, the pcs)
4. Based on your experience and knowledge, what are the most common causes of psychosis among your patients?
    a. Perspective of the patient
    b. Perspective of the physician

Knowledge of physicians about psychosis

1. How were you trained to recognise (symptoms of) psychosis?

Actions by physicians regarding psychosis

1. Could you tell us what you do when you see a patient with symptoms of psychosis for the first time
2. What causes you to refer a patient to a psychiatrist?
3. Do patients generally see you first when they have symptoms or do they go to the pcs directly?

Traditional and alternative medicine

1. What is your view on traditional medicine?
2. Do you often see patients (with psychotic symptoms) who have first visited traditional healer before seeing you?
3. Do you have contact with traditional healers? Do you collaborate with them?

Other

1. From the data we collect via these interviews we are going to try and produce a product to help shorten the DUP. For this, we would really like to know what you believe, as a professional, is needed to improve the time before your patients receive treatment?

a. Do you think it will be useful to offer a short educational programme about psychosis for GPs?
b. Do you think it will be useful to make a short video which informs people about what a psychosis is, how to recognise it and where to go for help?

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Duration of untreated psychosis and pathways to care in Suriname: a qualitative study among patients, relatives and general practitioners.

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Duration of untreated psychosis and pathways to care in Suriname: a qualitative study among patients, relatives and general practitioners.

Atousa van Beek[1], Janine de Zeeuw[2], Menno de Leeuw[1], Mia Poplawska[1], Lise Kerkvliet[1], Rudi Dwarkasing[3], Randhir Nanda[3], Wim Veling[4]

Affiliations:

1. University of Groningen, University Medical Center Groningen, Department of Medical Sciences, Groningen, The Netherlands
2. University of Groningen, University Medical Center Groningen, Department of Health Sciences, Groningen, Global Health Unit, The Netherlands
3. Psychiatric Centre Suriname, Paramaribo, Suriname
4. University of Groningen, University Medical Center Groningen, Department of Psychiatry, Groningen, The Netherlands

Correspondence to J. de Zeeuw: j.de.zeeuw@umcg.nl

Key words

Psychosis, duration of untreated psychosis, Global mental health, qualitative study

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ABSTRACT

Purpose Psychosis is a severe mental health problem and is responsible for poor health outcomes, premature mortality and morbidity, especially in low- and middle-income countries. The duration of untreated psychosis (DUP), that is the time period between onset of symptoms until initiation of appropriate treatment by a healthcare professional, is one of the main determinants for successful treatment in western settings. This study aims to explore the factors related to the DUP among Surinamese patients using the perspectives from patients, their families and first-line healthcare professionals in Suriname.

Methods Semi-structured interviews were conducted with patients having a history of psychosis, family members and general practitioners between February 2019 and April 2019 in Suriname. Interviews were tape-recorded and transcribed verbatim. Data was analysed using a thematic analysis for which an inductive and deductive approach was applied.

Results In total, 28 patients, 13 family members and 8 general practitioners were interviewed. Five patients were excluded from the study. A median DUP of 4 months was found (IQR 1–36). Identified themes related to DUP included presentation of symptoms and illness awareness, help seeking behaviour and alternative medicine, social support and stigma, financial and practical factors.

Conclusion Multiple factors were related to DUP, of which poor illness awareness, traditional medicine, stigma and social support were predominant. Poor illness awareness and use of alternative medicine were related to a longer DUP. Stigma was often an obstacle for patients and their families. Social and family support was important in helping patients to get medical help sooner. Other explored factors including financial and practical factors did not contribute to DUP.

Strengths and limitations of this study

- Collaboration with local nurses during interviews to overcome language and cultural barriers
- Incorporating views from different population groups; patients, family and general practitioners
- Retrospective study design prone to recall bias
- Selection bias due to purposive sampling

INTRODUCTION

Globally, mental and addiction disorders caused 7% of all global burden of disease measured in DALY's and 19% of all years lived with disability in 2016,[1], along with a percentage of 16% of the world population being affected by mental disorders,[1]. People with mental health disorders are at high risk for disabilities and mortality,[2], stigma and discrimination,[3]. In most countries, especially low- and middle-income countries, health systems are inadequately designed to manage mental health problems,[2,4]. An alarming 76-85% of people with severe mental disorders in low- and middle-income countries do not have access to proper mental healthcare,[2].

One such severe mental disorder, schizophrenia, affects over 21 million people worldwide. The global incidence of schizophrenia is 1.5 per 10.000,[5], and the global burden of schizophrenia alone accounts for 1.7% of YLD's,[4]. Psychotic symptoms are a core feature of schizophrenia, which is characterised by sensory and/or cognitive disturbances. It has a broad clinical presentation with most prominently symptoms such as hallucinations and delusions, but it can also present itself with symptoms such as thought disorganisation or apathy,[6]. The duration of untreated psychosis, i.e. the period between onset of symptoms and initiation of appropriate treatment by a healthcare professional, has been associated with poorer general outcomes,[7]. These manifest themselves as reduced likelihood of remission, poorer social functioning and cognitive impairment,[8,9]. In middle and high-income countries several factors playing a role in a prolonged DUP have been identified such as stigma,[10,11,12], the financial situation of the patient,[11,13], illness awareness,[11,13,14], perception,[13], distance to care facilities,[15], and knowledge of mental illnesses,[14]. Studies in Africa found reasons for low access to mental healthcare related to cultural views on causes of disease and noted people visiting informal health care settings first, before reporting to a hospital,[16]. Another recent study found that traditional medicine could contribute to a delay of starting appropriate treatment,[13]. Several countries have conducted research into country-specific factors and have begun to design and test interventions to reduce the DUP,[17].

In Suriname, a middle-income country, limited evidence on psychosis is available. The most recent study on the incidence of schizophrenic disorders was conducted in 2005 and showed an incidence of 1.77 per 10.000,[18]. Healthcare is highly centralised, with only one psychiatric hospital located in the capital city Paramaribo. A study researching the equity in healthcare in Suriname reported the use of secondary healthcare to be lower in the rural interior compared with coastal areas,[19]. Suriname is a country in which traditional medicine is widely practised and large parts of the population still rely on these traditional healers in both urban and rural areas. Research in Suriname has shown that within traditional medicine, psychiatric diseases such as depression and anxiety are considered a social imbalance or to have spiritual causes,[20]. These alternate explanations of disease, amongst other factors, alter help seeking behaviour of patients and their pathway to care, which seems to be of great importance in psychotic disorders.

Therefore, the aim of this study is to explore the factors related to the duration of untreated psychosis among Surinamese patients using the perspectives from patients, their families and first line health care professionals in Suriname.

METHODS

Setting, study design and participants

In Suriname, the healthcare system is not evenly distributed between rural and urban areas,[21]. It is highly centralised with only one psychiatric hospital based in the capital city Paramaribo, the so-called 'Psychiatric Centre of Suriname' or 'PCS'. In addition to this psychiatric hospital, there is one outpatient clinic of the PCS based in Nieuw-Nickerie. With only 10 psychiatrists in place, this calculates to 1 psychiatrist per 56.000 population in the country,[22]. To put this into perspective, the Netherlands has a calculated 1 psychiatrist per 4.636 population,[23]. General practitioners (GPs) are the first line of care in the formal health care system. We conducted semi-structured interviews between February 2019 and April 2019 among patients, family members and GPs. Patients were eligible for inclusion if they (i) signed the informed consent form; (ii) were diagnosed with a psychotic disorder; and (iii) were aged between 16 to 65 years of age. Patients were excluded for participation if they (i) had intellectual disability or (ii) had a known drug-induced psychosis. For family members and GPs no inclusion or exclusion criteria were formulated.

Sampling and materials

Patients were recruited from various regions in Suriname, namely Paramaribo, Moengo (East), Nieuw-Nickerie (West) and Brownsweg (South). The patients, known by the PCS to have a history of psychosis, were recruited based on the inclusion criteria and contacted by psychiatrists working in the PCS (mainly RN). Eligible patients were selected based on purposive sampling in order to aim at a heterogeneous group of participants concerning area of living and estimated DUP. A convenience sample of family members was used. If patients brought a family member to an interview, this family member was also approached for participation in the study. In case patients were visited at home for an interview and a family member was present and willing to participate, this member was interviewed and included in the study as well. Also, a convenience sample for the general practitioners was used. General practitioners were telephonically approached (by RN) and asked for participation, and if they were willing to participate they were included. In total 8 general practitioners were approached for participation in the study. The interviewing process continued until saturation appeared and when no new themes emerged.

A first draft of the topic list was developed by the research team, using topics from previous studies and using the Cultural Formulation Interview,[24], and the McGill Illness Narrative Interview (MINI),[25] as the

foundation of our interview design. Thereafter, it was discussed with PCS healthcare professionals (psychiatrists and nurses) for further improvement and clarification of language, cultural appropriateness and focus on known factors that would be relevant for the research question. This ensured that every factor associated with DUP, insights in the care pathway, and cultural factors would be addressed and understandable to the participants. DUP was defined as the time period between onset of symptoms until initiation of appropriate treatment by a healthcare professional. Onset of symptoms was defined as the first manifestation of symptoms as reported by the patient or their family, irrespective of illness awareness. The treatment initiated by healthcare professionals is based on international evidence-based guidelines. Patients were interviewed about their first episode of psychosis and the topics covered were based on the predicted factors which could influence the DUP. The GP interviews focused on their knowledge of and experience with psychotic disorders. Semi-structured interviews were conducted by (AvB, MdL, LK, MP) in Dutch (the official language of Suriname), with the presence of a nurse from the PCS when possible for any language and communication problems. When patients were only able to speak their local dialect then a nurse would translate. This was the case for five (n=5) out of 27 patient interviews and one (n=1) out of 14 family interviews. Doctor interviews were all conducted in Dutch. All interviews were tape recorded and transcribed verbatim. Interview templates for the original and revised patient and family interview (Supplementary File 1 and 2) and general practitioner interview (Supplementary File 3) translated into English can be found in the supplementary materials.

Patient and public involvement

Patients were first involved in the research process at the stage of conducting the interviews. Experiences from participants, together with themes from previous research, formed the baseline for this study's outcome measures. Patients and public were not involved in the design, recruitment or burden of the study. Research results were shared with the Psychiatric Centre Suriname. Participants who showed interest in the study results were recommended to check in with their practising physician upon conclusion of the study.

Data analysis

Whilst conducting and transcribing interviews, data analysis was performed simultaneously. The transcribed interviews were analysed according to thematic analysis,[26]. In order to ensure reliability, the first four transcripts were independently coded by at least two researchers using a combined inductive and deductive approach. These findings were discussed in order to create a set of codes the four researchers mutually agreed on, and to develop the initial codebook. Subsequently, all other transcripts were coded individually by a researcher. Thereafter another member of the study team reviewed this coding, adding comments and highlighting possibly overlooked codes. Then discussion followed between

the researchers who did coding for that interview. The analysis was considered finished when two researchers reached a consensus. The initial codebook was revised based on coding of the subsequent transcripts. When new codes emerged during analysis, these were added to the codebook and previously finished analyses of transcript were scanned for these newly found codes. Thereafter, the data were refined into themes and subthemes, which was then put into a database. A separate document contained any relevant, supporting quotations.

Ethics

Ethical approval was obtained from the Ministry of Public Health in Suriname (VG 20-18). All patients and their families signed an informed consent form prior to the interviews and were informed that participation was voluntary. They were made aware of their right to withdraw from the study at any point and that interviews would be processed anonymously and used for scientific purpose. If participants were unable to write and/or read, they received oral explanation of the study and gave oral consent.

RESULTS

Socio-demographics

In total 33 patients were approached for an interview, of which five patients were excluded due to having drug-induced psychosis (n=3), intellectual disability (n=1) and because of a language barrier which could not be overcome (n=1). Socio-demographic characteristics of one (n=1) patient were collected through a family interview, because the patient was not able to participate. A total of 13 family members and 8 general practitioners were included. Sociodemographic characteristics are shown in Table 1. Patients had an equal gender distribution and a median age of 39 (IQR 31 – 48) years. Most patients lived in the capital city Paramaribo. The majority of patients indicated to have multiple ethnicities, and generally, Indian and Creole were the most common. The predominant religion was Christianity and Hinduism. Most patients were single and lived with their family. The most commonly reached educational level was secondary education. Unemployment was high and most earned under 2000 SRD (€240) per month. The median DUP (n=2 unknown) was 4 months (IQR: 1 – 36) and the median onset of first symptoms (n=1 unknown) was 60 months ago (IQR: 19 – 132). Mainly mothers were interviewed, with a median age of 53 (IQR:48 – 58) years. The majority of GPs were males, with a median age of 47 (IQR: 41.5 – 56) years and they were mainly based in Paramaribo and West-Suriname (table 1). Values were marked ‘unknown’ in case they could not be reliably retrieved from the interview nor from the medical file.

Table 1 Socio-demographic factors of participants

Variable	Patient Frequency, n (%)	Family Frequency, n (%)	General Practitioner Frequency, n (%)
Age: median,[IQR]	39,[17][1]	53,[10][4]	47,[14.5]
Gender			
Male	14 (50%)	4 (31%)	7 (88%)
Female	14 (50%)	9 (69%)	1 (12%)
Ethnicity			
Indian	6 (21%)	6 (46%)	-
Creole	3 (11%)	3 (23%)	-
Mixed[2]	2 (7%)	0	-
Javanese	4 (14%)	3 (23%)	-
Marron	5 (18%)	0	-
Multiple ethnicities	7 (25%)[3]	1 (8%)[5]	-
Unknown	1 (4%)	0	-
Place of living			
Paramaribo	16 (58%)	7 (54%)	-
East Suriname	4 (14%)	2 (15%)	-
West Suriname	4 (14%)	4 (31%)	-
South Suriname	4 (14%)	0	-
Religion			
Christianity	13 (46%)	4 (31%)	-
Hinduism	7 (25%)	6 (46%)	-
Islam	4 (14%)	3 (23%)	-
No religion	3 (11%)	0	-
Unknown	1 (4%)	0	-
Relationship status			
Single	15 (54%)	3 (23%)	-
In a relationship	7 (25%)	2 (15%)	-
Married	2 (7%)	6 (46%)	-
Divorced	3 (10%)	0	-
Widowed	0	1 (8%)	-
Unknown	1 (4%)	1 (8%)	-
Children			
Yes	11 (39%)	-	-
No	14 (50%)	-	-
Unknown	3 (11%)	-	-
Living situation			
With family	20 (71%)	-	-
With partner	1 (4%)	-	-
Alone	1 (4%)	-	-
Unknown	6 (21%)	-	-
Educational level			

No education	1 (4%)	-	-
Primary	8 (28%)	-	-
Secondary	15 (53%)	-	-
Higher	3 (11%)	-	-
Unknown	1 (4%)	-	-
Work status			
Employed	9 (32%)	-	-
Unemployed	19 (68%)	-	-
Monthly income			
0 – 999 SRD	19 (67%)	-	-
1000 – 1999 SRD	7 (25%)	-	-
2000 – 4999 SRD	1 (4%)	-	-
>5000 SRD	0	-	-
Unknown	1 (4%)	-	-
(100 SRD ≈ 12 EUR)			
Relation to patient			
Partner (married)	-	1 (8%)	-
Mother	-	7 (53%)	-
Father	-	2 (15%)	-
Sibling	-	1 (8%)	-
Aunt	-	1 (8%)	-
Adoption mother	-	1 (8%)	-
Location of GP practice			
Paramaribo	-	-	4 (50%)
East Suriname	-	-	0
West Suriname	-	-	3 (38%)
South Suriname	-	-	1 (12%)

1 Patient 29 had been older than 62 for years already but didn't know birth date, there was no file. We assigned patient age 62.
1 One patient was included in the study based on the story the family told, they did not specify age and therefore this patient was not included in the calculations for age.
2 Mixed was not further specified.
3 Multiple ethnicities for patients included the following combinations: Creole-Indigenous-Jewish-Mixed. Creole-Indigenous-Mixed. Creole -Caucasian-Mixed. Indian-Chinese-Javanese-Caucasian. Indian-Creole (2x). Indian-Jewish-Chinese.
4 Age of 3 family members unknown
5 Multiple ethnicities for family included the following combination: Creole-Indigenous-Jewish-Mixed

Using the perspectives of patients, their family members and GPs, we identified various factors related to the duration of untreated psychosis. According to participants, presentation of symptoms and illness awareness, help seeking behaviour and alternative medicine, social support and stigma, and financial and practical factors are important topics.

Presentation of symptoms and poor illness awareness

The onset of psychosis was characterised by a wide variety of symptoms. According to patients and family members, hallucinations and disturbed and confused thoughts are the most common first symptoms of a psychosis.

Patient 1: 'I saw things.. on the tv, what I wasn't allowed to see and hear. And I also heard things.. and in my thoughts. I thought differently about things.. I wanted to have my own thoughts. I had thoughts about things that weren't true.'

Nearly half of the patients also presented with aggressive behaviour and agitation. According to a few patients, symptoms of paranoia, sleep disturbance and abnormal motor behaviour were present. Depressive or suicidal thoughts were hardly mentioned (table 2).

Patient 4: 'It was a sudden outburst (..) that I suddenly became aggressive at home.'

Patient 12: 'The delusions got worse and worse and worse, there were several conspiracies playing in my head and eh I thought people were planning things against me.'

According to GPs, patients most frequently present with hallucinations, disturbed and confused thoughts and aggressive behaviour as symptoms of psychosis. They elaborated on disturbed behaviour and indicated seeing a wide range including disobedience, confusion, destruction of property, self-neglect, wandering outside all day, blackmailing and aggression.

GP 6: 'Aggressive behaviour yes, usually family members come and tell me that a brother or, or, or an uncle suddenly behaves aggressively.'

The majority of patients expressed that they realised they experienced unusual things, such as hearing voices or behaving aggressively. However they mostly did not seem to associate these experiences to an illness, as they had difficulties realising that their behaviours were abnormal manifestations or that it fell under the scope of a medical problem. Only a few patients associated their symptoms with having an illness.

Patient 18: 'I never thought of seeking help for voices.'

Researcher: 'Why do you think that it lasted so long until you (..) got help?'
Patient 5: 'Because first I had to think whether it was normal or abnormal.'

Most of the patients and family members believed there was a supernatural explanation to the symptoms as they reported the cause of a psychosis to be the cause of a spell or the devil. As there were people from different cultures involved in this study, these supernatural causes varied widely corresponding to patients' their culture or religion. For example, Christians would often mention God or the devil whereas indigenous people would attribute their symptoms to spirits that could do something to you, or even possess you (Winti). GPs too acknowledged that most patients often hold cultural beliefs as the primary cause for their symptoms.

Patient 14: 'Some people will say, who tell me that it is the Winti (spirit) *from that family.' 'I still talk a language that I do not understand (..) so that is the Winti.'*

Patient 1: 'I thought it's just one of those things they put on you, people in Suriname we believe people put something on you so I thought that was it. I didn't know it was just my illness.' 'Yes, that is Voodoo.'

Family 18: 'We thought it were attacks of the devil.'

While some patients attributed their symptoms to other mental or physical factors such as stress and head trauma, a few patients indicated to be completely unaware of their condition at the time.

Patient 10: 'I was (ill) because I was stressed. I stressed a lot.'

Family members reported that they noticed changes in the behaviour of their relatives, and that they associated these changes to an illness. It should be mentioned that participants would also use 'illness' for problems outside of the medical scope. It was rare that neither the family nor other people noticed something was wrong or different about the patient.

Family 7: 'I could see he was sick, you know? As a mother, you know?'

GP 1: 'Usually the mentors tell us that the patient has been acting strange for a while.'

Table 2. Presenting symptoms reported by participants

Presenting symptoms	Frequency, n (%)
Disturbed and confused thoughts	17 (61%)

Abnormal motor behaviour	6 (21%)
Hallucinations	22 (79%)
Agitation or aggression	12 (43%)
Delusion or paranoia	9 (32%)
Sleep disturbances	8 (29%)
Depressive or suicidal thoughts	1 (4%)

Presenting symptoms as times reported (n, %) by patients or their family. Multiple symptoms could apply to one patient. Presenting symptoms mentioned by both patient and family are counted as one.

Help seeking behaviour

The majority of patients and their family members reported to have visited a traditional healer for alternative care, and this was mainly the first line of care. In Suriname, there is a great variety in who can be classified as a 'traditional healer'. Traditional healers that were repeatedly mentioned by participants of our study were: *Pandits, Babas* (Hindu culture); *Lukuman, Bonuman* (Afro-American culture); *Chamans* (Indigenous culture); *Church priests* (Christian religion). Some patients indicated they visited a traditional healer multiple times or went to multiple different healers.

Researcher: 'Why did you first go to the Lukuman (traditional healer)*?'*
Patient 16: 'Because that.. these things spiritual things. (..) This cannot be treated at the general practitioner.'

Researcher: 'How many different people (traditional healers) did you visit in those 4 years?'
Patient 6: 'Almost four'.

The second most common first place to seek help was at the GP. Generally, 46% of the study population saw a GP before receiving treatment at the psychiatric hospital. Most GPs stated that they had been trained in medical school on how to recognise psychotic symptoms and that they would immediately refer patients who present to their clinic with these symptoms. Overall it was mainly the family that decided on where help should be sought. In a few of these cases, aggressive behaviour was a clear indication for the family that the patient needed immediate medical attention. In the end, in a great majority of cases the family decided to visit a psychiatrist.

Patient 26: 'They (parents) said ehm, you are confused, go to the doctor.'

Researcher: 'Who decided to go to the GP?'

Patient 16: 'My mother and my grandmother.'

Interestingly, some traditional healers also recommended consulting a psychiatrist according to patients and family members.

Patient 7: 'That Pandit said you must go to the doctor.'

Stigma and social support

Many participants indicated that there was a negative perception of psychosis and other psychiatric illnesses in society and many patients did not share their problem outside of their families. Often, the Surinamese people would use descriptive words as 'crazy' when referring to someone with a mental illness. Patients expressed fear of being labelled in a negative way.

Researcher: 'What was for you the main reason not to go to the GP?'

Patient 8: 'That was it, that people will find me crazy.'

Researcher: 'Do people view you differently?'

Patient 24: 'Yes a few of them.'

Researcher: 'Yes? How do they see it?'

Patient 24: 'How should I say it (..), like a madman.'

Around half of the study population indicated that stigma was not present within the family and 89% of participants reported to feel supported by their families. If patients were willing to share their problems, the main first place to do so was with someone within their family. Sharing their problem with outsiders would commonly be done after the patient had already received treatment. Patients noted that family support was often a key component in getting them to seek and receive help. Family members also played a big role in helping patients to stick to their treatment. GPs too emphasised the importance of family support for treatment initiation and continuation.

Family 18: 'Now when she got these things, I have really, I really did not at all think about getting crazy or being crazy, no (..). But thinking that she is crazy? No, I have not at all thought that.'

Patient 6: 'I have also told my nieces (..) they said; you did the right thing getting help at the Baba (traditional healer)*. (..) They just want to support you.'*

Family 7: 'I go with him, (..), every time he has to come, I come along.'

Interviewees also reported a specific stigma on the Psychiatric Centre in Paramaribo. Commonly, it is perceived as a place for mad or crazy people.

Patient 1: 'My brother and my mother have said at school I should not tell anything to everybody that I.. am under treatment at the PCS. Because then they will treat you different or so.'

GP 1: 'They just don't want to go to the PCS, yes. Because fairly it is seen as a madhouse.'

Financial and practical factors around mental health services

Most patients were insured prior to seeking help, most commonly with basic insurance. Basic insurance covers psychiatric care in Suriname. In those that did not have insurance prior to their symptoms, it was clear that this led to a delay in receiving appropriate treatment. When asked, costs did not seem to keep participants from seeking help. Only very rarely costs were mentioned as an issue for seeking healthcare.

Family 16: 'We didn't have to pay for it. He has an insurance card.'

Researcher: 'Have you ever doubted whether to seek help because it costs so much money?'
Patient 14: 'No I have never doubted.'

Family 7: 'He had no things, no thing-card.'
Nurse: 'Insurance card.'
Family 7: 'Insurance yes. Then I had to wait a long time (..) three months or so.'

None of the interviewees reported any problem with distance to the GP and none mentioned having any difficulty getting help at the GP. The interviewed GPs agreed with this finding and said distance to them was not an issue for patients. Patients living in rural areas did mention that in the past it would be difficult to go to the PCS, situated in Paramaribo, but nowadays it is possible for them to receive psychiatric care through their GPs.

Patient 4: 'What happened to me, I make time to come to the PCS so for me the distance is no longer important. What is important is I have found help, it is good for me. The distance doesn't matter anymore.'

GP 4: 'The distance I would not say (..) now with these developments we have enough GPs where they can go.'

DISCUSSION AND CONCLUSION

This study aimed to explore the duration of untreated psychosis among Surinamese patients and related factors using the perspectives from patients, their families and first line health care professionals in Suriname. The median DUP was 4 months. Main emerging themes included poor illness awareness, use of alternative medicine, stigma and family support. Patients and families had difficulty recognising symptoms as an illness and would attribute these to supernatural causes, resulting in a delay before contacting a general practitioner or psychiatrist. Significant stigma and fear of being labelled 'crazy' also contributed to a delay in help-seeking, as it withheld people from talking openly about their symptoms. Good family support was associated with a shorter period of time lost before seeing a healthcare professional and often it was the family who took initiative to look for help. Other factors such as financial resources, accessibility to health care facilities and knowledge of psychiatric illness amongst GPs were investigated too, but were found to be of less significant relevance to DUP.

One important and recurrent finding was the lack of illness awareness amongst the participants and their communities. Many patients and families attributed symptoms to external, predominantly supernatural, causes. These non-medical explanatory models of psychosis have been found previously in non-western countries,[27]. Social, cultural and religious explanations were encountered and would often influence pathway to care,[27]. Likewise, a study in Malawi,[28], found the socio-cultural explanation of witchcraft and spirit possession to be dominant and determinant for subsequent help-seeking. In our study, the most common first place to seek help was traditional medicine, with GP practices following second. Generally, the use of traditional medicines is common in many households in Suriname,[29]. From these results, a relationship between this cultural explanation and alternative medicine as first place to seek help is evident. Various studies in countries with rich cultural history see similar results,[28,30,31]. Many patients who reported seeing a traditional healer before seeing a medical specialist, were also the ones who had a longer DUP. A cross-sectional study in South Africa found similar results for contact with traditional healers and DUP,[30]. Burns,[32], too reported an association between alternative medicine and long DUP. There have been promising attempts to set up collaborations between traditional healers and general healthcare,[33,34], or at educating traditional healers for recognising mental diseases,[35]. However, these studies are still juvenile and such a study in Suriname has yet to be performed.

We found that in particular family relations played a major role in social support, help-seeking behaviour and treatment initiation and continuation. Many family members are closely involved in decision-making

on the patient's behalf and could therefore be of vital influence on a patients' duration of untreated psychosis. Correspondingly, a US study found patients with stronger family relations to have a shorter DUP compared with individuals who had a more troubled relationship with their families,[36]. In their study, a key component in a strong relationship included open communication, a factor which emerged during our interviews too. Another study from China also found family members misjudging the patients' disease to be the main cause for treatment delay,[37], again emphasising the importance of family in final decision-making. Family members appear to be the most common initiators in seeking care and to be decision-makers regarding treatment,[30,31]. The social context including family seems to be a promising topic for further research and future interventions aimed at reducing DUP.

General stigma seemed to be a barrier for patients to talk about their symptoms and seek help, a finding consistent with previous studies,[38]. Recently, Kular,[12], has found stigma on mental illnesses significantly lengthening DUP. GPs too attributed treatment delay to stigma. Psychosis is still misunderstood and people are afraid of receiving the label 'crazy'. Correspondingly, we found the Psychiatric Centre in Paramaribo was seen as a place for mad people.

The study is prone to significant recall bias, since all data was gathered through interviews and stories were told in retrospect. The time of onset of first symptoms ranged from 1986 to 2017, from which the recall bias is apparent. During transcript analysis, contradictory information was occasionally found between patients' and their families' stories or between a narrative and the medical file. As there was only one moment of contact, there was no opportunity to clarify contradictory information with the interviewee. In these cases, information from the medical file and subsequently the families' story was deemed more accurate than the patients' story. If conflicting themes occurred within the same transcript, for example a patient indicating throughout the interview that they were both aware and not aware of their symptoms, both themes were marked as present in the results. This might have led to certain themes being over- or underexposed in this research. Additionally, it was difficult to determine DUP for some patients due to inconsistencies between patient- and family stories and the medical file. Finally, a selection bias is likely since participants were specifically chosen to create a diverse population.

Strengths of the study were access to patient files to minimise bias for date of admission, onset of symptoms and DUP. Another significant strength is the presence of local nurses during the interviews to overcome language barriers between researcher and interviewee, improving quality of collected data. The inclusion of GPs strengthens the study by adding a different, medical viewpoint. Furthermore, stories from patients confirmed by family members ensured more reliable data. Lastly, the study design ensured a broad geographical spread for data collection, strengthening the scope to which results can be applied.

In conclusion, multiple factors were related to DUP, of which poor illness awareness, alternative medicine, perceived stigma and social support were predominant. Many other factors were explored, including accessibility to healthcare facilities and financial factors. The importance of factors such as the use of alternative medicine, stigma and family support provide a reflection of the Surinamese society and results of our study facilitate better understanding of this specific population. Knowledge about these country-specific factors can be used as supportive material for measures taken to reduce DUP in Suriname in the future. In concordance with the WHO Traditional Medicine Strategy,[39], collaboration between traditional healers and the general healthcare system would be a significant step forward and should be pursued.

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Conflicts of interests

The authors declare no conflict of interests

Contributorship

AvB, MdL, MP and LK initiated this study in collaboration with WV and RN. AvB, MdL, MP, LK, WV and JdZ prepared the research plan and interview templates in the Netherlands. RN and RD were responsible for the ethical approval and provision of appropriate research facilities in Suriname. AvB, MdL, MP and LK performed, transcribed and analysed interviews in Suriname under supervision of RN, WV and JdZ. AvB, MdL, MP and LK drafted a first manuscript for the University of Groningen. AvB and JdZ drafted the final manuscript for publication. All authors are responsible for and involved in the project and have critically revised the manuscript. All authors have read and approved the final manuscript.

Data sharing statement

All data relevant to the study are included in the article or as supplementary material.

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Interview with patient

General

1. Age: ...
2. Gender:
    - Female
    - Male
    - Other, ...
3. Ethnicity: ...
4. Place of birth: ...
5. Religion:
    - No
    - Yes
        - Christian
        - Jewish
        - Muslim
        - Hindu
        - Buddhist
        - Other, ...
6. Relationship status: ...
7. Children:
    - No
    - Yes, … children
8. Living situation:
    a. Single
    b. Partner
    c. Married
9. Educational level:
    - Primary (age 12)
    - Secondary (high school, age 17)
    - Tertiary
10. Employment: ...
11. Monthly income:
    - 0-2000 SRD
    - 2000-5000 SRD
    - 5000-10000 SRD
    - More than 10000 SRD

Introduction

Firstly, we would like to thank you for being here and for being part of this research. Before we start we would like to introduce ourselves. Our names are [Menno de Leeuw] [Atousa van Beek] [Mia Poplawska] [Lise Kerkvliet] and we are medical students from the Netherlands. For our studies we have set up this research here. For our research we will be looking into experiences and difficulties encountered from people who have had psychosis, such as yourself. Therefore, we are very glad that you are willing to share your story with us.

We would like to understand the problems or difficulties that you experienced in the past. We want to know your experience. We will ask some questions about the period that you were having difficulties and how you were dealing with them. Just as a reminder we would like to let you know that this interview will be recorded. Only people involved in the study such as ourselves will be able to access these recordings.

Please remember there are no right or wrong answers, and that everything you say will be confidential and treated anonymously. You do not have to answer any questions you are not comfortable with.
If at any point something we say or ask is unclear, do not hesitate to ask a question about it.

Do you have any questions for us?
Then we would like to get started.

Initial illness narrative

1. People often understand their problems in their own way, which may be similar to or different from how doctors describe the problem. How would you describe the problem you had?
    a. What troubled you the most about your problem?
2. At a certain point, you may have noticed that something was different from normal. When did you experience changes or difficulties for the first time?
    a. Can you describe the changes or difficulties you first noticed?
    b. Did you notice any changes or difficulties yourself, or did someone else notice this?
    c. Did someone else notice at all that you behave differently or had difficulties?
    d. At that time, what did you think of of the changes and difficulties?
        i. Did you understand the seriousness?
        ii. Did you understand that you were unwell?
3. I would like to know more about your experience with your first changes and difficulties. Can you think of anything that changed in your life at that time? Examples can be: a lot of stress, loss of a loved one or a break-up.
    a. Did you use drugs for pleasure at that time?
    b. Did you receive any medication prescribed by a doctor at that time?

Prototype narrative

1. In the past, have you ever had a health problem that you consider similar to your current health problem?
2. Did a person in your family ever experience a health problem similar to yours?

Explanatory model narrative

1. A lot of people have their own thoughts about their health problem. I would like to know something about what you thought at that moment.
    a. What did you think was happening to you?
    b. What did you think was the cause of your health problem?
2. Family members may also have their own thoughts about someone's health problem. I would like to know what they thought of yours at that moment.
    a. What do others in your family, friends, or in your community think was causing your problem?

Past help seeking

1. People all react differently to problems like yours. What did you first do when you realised you had a health problem?
2. When did you first try and find help? What made you decide to do so?
3. Did anything prevent you from getting the help you need?
4. Often, people look for help from many different sources, including different kinds of doctors, helpers, or healers. In the past, what kinds of treatment, help, advice, or healing have you sought for your health problem?
    a. What types of treatments were helpful?
    b. What types of treatments were not helpful?
    c. [If not mentioned traditional healing]. A lot of people with health problems similar to yours go to a traditional healer.
        i. Did you also go to a traditional healer?
5. Who decided to contact professional medical help? E.g. was it you or a family member who reached out.
6. Could you tell us more about how you felt when you talked with the medical professional?

Accessibility to care

1. I would like to ask a few questions about the nearest health clinic.
    a. How far is it from you?
    b. How long does it take for you to get there?
    c. How do you get there?
    d. Are there any reasons you can't get there? Possibilities could be that you can't leave the house, no time due to work, family does not agree or the cost.

2. Sometimes doctors and patients misunderstand each other because they come from different backgrounds or have different expectations.
    a. Have you ever been concerned about this?
    b. Did you face this problem when seeking help from a doctor?
3. What do you think of medical services? Do you have the feeling they could help you with your health problem?

Role of cultural identity

1. People have different backgrounds or identity's. Me for example, value my family and my place of birth very much. How is that in your case?
    a. For you, what are the most important aspects of your background or identity?
2. Sometimes also, being from a particular background or having a certain identity can cause problems. In my case, being from a certain part in The Netherlands, stereotypes can sometimes give people wrong ideas about who I am.
    a. Are there any aspects of your background or identity that are causing other concerns or difficulties for you?

Stigma

1. Does your family have an opinion regarding seeking medical treatment?
    a. Is this opinion influenced by their culture?
2. A health problem like yours can be misunderstood by many people without knowledge about psychosis for example.
    a. Do you feel that people treat or look at your differently since you've had mental health problems? By people we mean for example your religious community, friends or family?

Costs

1. How do you pay for your medical treatment?
2. Did you ever think twice about contacting medical services because of the costs?
3. If you have insurance, does it cover all costs regarding your illness?

Social support

1. Speaking about health problems may give relief for some people. It is sometimes nice to get something off your chest. Is this for you also the case? Or don't you share anything with anybody?
    a. Did you share your problems with your friends or family?
    b. Did your family or friends suggested or offered you any kind of help for your health problem?
    c. Are there any kinds of support that make your problem better, such as support from family, friends, or others?

Other

1. …
2. ...

For example, the communities you belong to, the languages you speak, where you or your family are from, your race or ethnic background, your gender or sexual orientation, or your faith or religion.

Interview with family

General

1. Age: ...
2. Gender:
    - Female
    - Male
    - Other, ...
3. Ethnicity: ...
4. Place of birth: ...
5. Religion:
    - No
    - Yes
        - Christian
        - Jewish
        - Muslim
        - Hindu
        - Buddhist
        - Other, ...
6. Relationship status: ...
7. How are you related to the patient?: ...

Introduction

Firstly, we would like to thank you for being here and for being part of this research. Before we start we would like to introduce ourselves. Our names are [Menno de Leeuw] [Atousa van Beek] [Mia Poplawska] [Lise Kerkvliet] and we are medical students from the Netherlands. For our studies we have set up this research here. For our research we will be looking into experiences and difficulties encountered from people who have had or know someone with psychosis, such as yourself. Therefore, we are very glad that you are willing to share your story with us.

We would like to understand the problems or difficulties that you experienced in the past. We want to know your experience. We will ask some questions about the period that your family member was having difficulties and what your view on this was. Just as a reminder we would like to let you know that this interview will be recorded. Only people involved in the study such as ourselves will be able to access these recordings.

Please remember there are no right or wrong answers, and that everything you say will be confidential and treated anonymously. You do not have to answer any questions you are not comfortable with.
If at any point something we say or ask is unclear, do not hesitate to ask a question about it.

Do you have any questions for us?

Then we would like to get started.

Initial illness narrative

1. Can you describe *(name of patient)* before they became ill?
2. At a certain point, you may have noticed that something was different from normal. When did you notice that *(name of patient)* changed or had some difficulties for the first time?
    a. Can you describe the changes or difficulties you first noticed?
    b. At that time, what did you think of of the changes and difficulties?
        i. Did you understand the seriousness?
        ii. Did you understand that they were unwell?
3. I would like to know more about the period when you first noticed changes in *(name of patient)*. Can you think of anything that changed in their life at that time? Examples can be: a lot of stress, loss of a loved one or a break-up.
    a. Did they use drugs for pleasure at that time?
    b. Did they receive any medication prescribed by a doctor at that time?
4. Can you describe what happened in the period after *(name of patient)* was diagnosed?
5. How were you involved when *(name of patient)* was unwell or had difficulties? Was there for example something you could do to help him/her?

Prototype narrative

1. Did a person in your family ever experience a health problem similar to *(name of patient)*?

Explanatory model narrative

1. A lot of people have their own thoughts about the reasons for a health problem. I would like to know something about what you thought about your family member at that moment.
    a. What did you think was happening to him/her?
    b. What did you think was the cause of his/her health problem?
2. We would like to know about your experience after you found out (name of patient) was ill.
    a. What effect did the diagnosis have on you?
    b. How did you cope with it?

Past help seeking

1. People all react differently when a family member becomes ill. What did you first do when you realised they had a health problem?
2. Did you talk to him/her about trying to find help? Can you explain how this went?

Care

1. Did *(name of patient)* attend the first doctor appointments or didn't they want to talk to a medical professional?

2. What did you think of the first medical professionals that helped your family member?
3. What do you think of medical services? Do you have the feeling they could help with his/her health problem?

Costs

1. Were you involved in paying *(name of patient)* his/her medical treatment?
2. Did you ever think twice about contacting medical services for *(name of patient)* because of the costs?

Other

2019, Suriname Research. Menno de Leeuw, Atousa van Beek, Mia Poplawska, Lise Kerkvliet.

Interview patient

General

- Age: ...
- Gender:
    - Female
    - Male
    - Other, ...
- Ethnicity: ...
- Place of birth: ...
- Religion:
    - No
    - Yes
        - Christianity
            - RK
            - Volle evangelie
            - EBGC
            - Adventiat
        - Jewish
        - Muslim
        - Hinduism
        - Buddhism
        - Other, ...
- Relationship status:
    - None
    - Yes
- Children:
    - No
    - Yes, … children
- Living status:
    - Single
    - Living together
    - Married
    - Divorced
    - Widow
- Education:
    - Primary - Gewoon lager Onderwijs (G.L.O.)
    - Secondary - Voortgezet Onderwijs op Junioren Niveau (V.O.J.)
    - Tertiary - Voortgezet onderwijs voor Senioren (V.O.S.)
- Current employment: ...

- Monthly income:
  - 0-1000 SRD
  - 1000-2000 SRD
  - 2000-5000 SRD
  - 5000-10000 SRD
  - More than 10000 SRD

Introduction

Firstly, we would like to thank you for being here and for being part of this research. Before we start we would like to introduce ourselves. Our names are [Menno de Leeuw] [Atousa van Beek] [Mia Poplawska] [Lise Kerkvliet] and we are medical students from the Netherlands. For our studies we have set up this research here. For our research we will be looking into experiences and difficulties encountered from people who have had psychosis, such as yourself. Therefore, we are very glad that you are willing to share your story with us.

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If at any point something we say or ask is unclear, do not hesitate to ask a question about it.

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Then we would like to get started.

Initial illness narrative

1. People often understand their problems in their own way, which may be similar to or different from how doctors describe the problem. How would you describe the problem you had?
   a. What troubled you the most about your problem?
2. At a certain point, you may have noticed that something was different from normal. When did you experience changes or difficulties for the first time?
   a. Can you describe the changes or difficulties you first noticed?
   b. Did you notice any changes or difficulties yourself, or did someone else notice this?
   ~~c. Did someone else notice at all that you behave differently or had difficulties?~~
   d. At that time, what did you think of the changes and difficulties?

i. **When did your family or your friends express difficulties when interacting with you?**
ii. **Did you understand the seriousness?**
    1. **Did you know that you were ill at that time?**
iii. **What kind of thoughts went through your head?**
iv. **Were you yourself under the impression that something was going on?**

3. I would like to know more about your experience with your first changes and difficulties. Can you think of anything that changed in your life at that time? ~~Examples can be: a lot of stress, loss of a loved one or a break-up.~~
    a. Did you use drugs for pleasure at that time?
    b. Did you receive any medication prescribed by a doctor at that time?
    c. Did you have any physical complaints or illnesses at that time?

Prototype narrative

1. In the past, have you ever had a health problem that you consider similar to your current health problem?
2. Did a person in your family ever experience a health problem similar to yours?
    a. Is there someone in your family with psychiatric illness, who you'd call crazy or has problems with thinking?
    b. Has anyone in your family ever been treated in the PCS?

Explanatory model narrative

1. A lot of people have their own thoughts about their health problem. I would like to know something about what you thought at that moment.
    a. What did you think was happening to you?
    b. What did you think was the cause of your health problem?
2. Family members may also have their own thoughts about someone's health problem. I would like to know what they thought of yours at that moment.
    a. What do others in your family, friends, or in your community think was causing your problem?

Past help seeking

1. People all react differently to problems like yours. What did you first do when you realised you had a health problem?
2. When did you first try and find help? What made you decide to do so?
    a. Whose idea was it to find help?
3. Why did you not go to the GP in the first place?
4. Why did you not go to the PCS in the first place?
5. Did anything prevent you from getting the help you need?

6. Often, people look for help from many different sources, including different kinds of doctors, helpers, or healers. In the past, what kinds of treatment, help, advice, or healing have you sought for your health problem?
    a. What types of treatments were helpful?
    b. What types of treatments were not helpful?
    c. [If not mentioned traditional healing]. A lot of people with health problems similar to yours go to a traditional healer.
        i. Did you also go to a traditional healer?
        ii. Did you think the help you received from the traditional healer actually helped you at that time?
7. Who decided to contact professional medical help? E.g. was it you or a family member who reached out.
~~8. Could you tell us more about how you felt when you talked with the medical professional?~~
9. What did you know about the PCS at that time?
    a. What was your view on the PCS?
10. What did your family know about the PCS at that time?
    a. What was their view on the PCS?

Accessibility to care

1. I would like to ask a few questions about the nearest health clinic.
    a. How far is it from you?
    ~~b. How long does it take for you to get there?~~
    c. How do you get there?
    d. Is it difficult for you to get to the GP/PCS?
    e. Are there any reasons you can't get there? Possibilities could be that you can't leave the house, no time due to work, family does not agree or the cost.
2. Sometimes doctors and patients misunderstand each other because they come from different backgrounds or have different expectations.
    a. Have you ever been concerned about this?
    ~~b. Did you face this problem when seeking help from a doctor?~~
~~3. What do you think of medical services? Do you have the feeling they could help you with your health problem?~~

~~**Role of cultural identity**~~

~~1. People have different backgrounds or identity's. Me for example, value my family and my place of birth very much. How is that in your case?~~
    ~~a. For you, what are the most important aspects of your background or identity?~~
~~2. Sometimes also, being from a particular background or having a certain identity can cause problems. In my case, being from a certain part in The Netherlands, stereotypes can sometimes give people wrong ideas about who I am.~~

~~a. Are there any aspects of your background or identity that are causing other concerns or difficulties for you?~~

Stigma

1. Does your family have an opinion regarding seeking medical treatment?
   ~~a. Is this opinion influenced by their culture?~~
2. A health problem like yours can be misunderstood by many people without knowledge about psychosis for example.
   a. Do you feel that people treat or look at your differently since you've had mental health problems? By people we mean for example your religious community, friends or family?

Costs

1. How do you pay for your medical treatment?
2. Did you ever think twice about contacting medical services because of the costs?
3. If you have insurance, does it cover all costs regarding your illness?
   a. Were you insured at the time your problems started?
   b. Were you insured before going to the PCS?

Social support

1. Speaking about health problems may give relief for some people. It is sometimes nice to get something off your chest. Is this for you also the case? Or don't you share anything with anybody?
   a. Did you share your problems with your friends or family?
   b. Did your family or friends suggested or offered you any kind of help for your health problem?
   c. Are there any kinds of support that make your problem better, such as support from family, friends, or others?

Other

1. **If you look back on that period of time, how much time do you think was in between your first symptoms and the first time you got to the PCS?**
2. **When was the first time you visited the PCS?**

Interview with family

General

1. Age: ...
2. Gender:
    - Female
    - Male
    - Other, ...
3. Ethnicity: ...
4. Place of birth: ...
5. Religion:
    - No
    - Yes
        - Christian
        - Jewish
        - Muslim
        - Hindu
        - Buddhist
        - Other, ...
6. Relationship status: ...
7. How are you related to the patient?: ...

Introduction

Firstly, we would like to thank you for being here and for being part of this research. Before we start we would like to introduce ourselves. Our names are [Menno de Leeuw] [Atousa van Beek] [Mia Poplawska] [Lise Kerkvliet] and we are medical students from the Netherlands. For our studies we have set up this research here. For our research we will be looking into experiences and difficulties encountered from people who have had or know someone with psychosis, such as yourself. Therefore, we are very glad that you are willing to share your story with us.

We would like to understand the problems or difficulties that you experienced in the past. We want to know your experience. We will ask some questions about the period that your family member was having difficulties and what your view on this was. Just as a reminder we would like to let you know that this interview will be recorded. Only people involved in the study such as ourselves will be able to access these recordings.

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If at any point something we say or ask is unclear, do not hesitate to ask a question about it.

Do you have any questions for us?

Then we would like to get started.

Initial illness narrative

1. Can you describe *(name of patient)* before they became ill?
2. At a certain point, you may have noticed that something was different from normal. When did you notice that *(name of patient)* changed or had some difficulties for the first time?
    a. Can you describe the changes or difficulties you first noticed?
    b. At that time, what did you think of the changes and difficulties?
        i. Did you understand the seriousness?
            1. Did you understand they were ill at that time?
        ii. Did you understand that they were unwell?
3. I would like to know more about the period when you first noticed changes in *(name of patient)*. Can you think of anything that changed in their life at that time? Examples can be: a lot of stress, loss of a loved one or a break-up.
    a. Did they use drugs for pleasure at that time?
    b. Did they receive any medication prescribed by a doctor at that time?
4. Can you describe what happened in the period after *(name of patient)* was diagnosed?
5. How were you involved when *(name of patient)* was unwell or had difficulties? Was there for example something you could do to help him/her?

Prototype narrative

1. Did a person in your family ever experience a health problem similar to *(name of patient)*?

Explanatory model narrative

1. A lot of people have their own thoughts about the reasons for a health problem. I would like to know something about what you thought about your family member at that moment.
    a. What did you think was happening to him/her?
    b. What did you think was the cause of his/her health problem?

~~2. We would like to know about your experience after you found out (name of patient) was ill.~~

~~a. What effect did the diagnosis have on you?~~

~~b. How did you cope with it?~~

Past help seeking

1. People all react differently when a family member becomes ill. What did you first do when you realised they had a health problem?
    a. What was the first place where (name patient) sought help?
    b. Were you involved in this?
2. Did you talk to him/her about trying to find help? Can you explain how this went?

Care

1. Did *(name of patient)* attend the first doctor appointments or didn't they want to talk to a medical professional?
    a. **What was the advice you got from the GP?**
    b. **Was (name patient) referred to the PCS immediately?**
2. ~~What did you think of the first medical professionals that helped your family member?~~
3. ~~What do you think of medical services? Do you have the feeling they could help with his/her health problem?~~

Costs

1. Were you involved in paying *(name of patient)* his/her medical treatment?
2. Did you ever think twice about contacting medical services for *(name of patient)* because of the costs?

Other

1. **If you look back on that period of time, how much time do you think was in between your relative's (patient) first symptoms and the first time they got to the PCS?**
2. **When was the first time your relative visited the PCS?**

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Interview physician

General

1. Age: …
2. Gender:
    - Female
    - Male
    - Other, …
3. Occupation: …
4. Years in occupation: …

Introduction

Firstly, we would like to thank you for being here and for being part of this research. Before we start we would like to introduce ourselves. Our names are [Menno de Leeuw] [Atousa van Beek] [Mia Poplawska] [Lise Kerkvliet] and we are medical students from the Netherlands. For our studies we have set up this research here. For our research we will be looking into experiences and difficulties encountered from people who have had psychosis, but also the opinions of the patient's family and treating physicians. Therefore, we are very glad that you are willing to share your story with us.

We would like to understand more about the possible reasons for a long Duration of Untreated Psychosis (DUP) and how we could help to reduce this. We decided to define this time as the time between the patient presenting with symptoms and receiving treatment from a healthcare professional.

We want to know more about your experience with treating patients with psychosis. We might ask some specific questions about (patient) but will mainly take a more wide-scale approach.

Just as a reminder we would like to let you know that this interview will be recorded. Only people involved in the study such as ourselves and dr. Nanda and dr. Veling will be able to access these recordings. Everything we talk about today will be confidential and treated anonymously.

Do you have any questions for us?

Then we would like to get started.

Psychosis

1. How many patients presenting with psychosis do you see on a yearly basis (estimate)?
2. What are the most common symptoms you see among your patients presenting with psychosis?

3. Patients can wait a long time before presenting to a doctor with their psychotic symptoms.
    a. How long do patients usually wait before seeing you?
    b. In your experience, what are reasons for a long DUP (duration of untreated psychosis – waiting a long period of time before seeing a doctor)
        i. Do you think distance is an important factor?
        ii. Do you think costs are an important factor?
        iii. Do you think the absence of social support is an important factor?
        iv. Do you think a low educational level is an important factor?
        v. Do you think a lack of knowledge (patient) is an important factor?
        vi. Do you think a lack of self-awareness is an important factor?
        vii. Do you think that searching for alternative medicine is an important factor?
        viii. Do you think that stigma is an important factor? (mental health, the pcs)
4. Based on your experience and knowledge, what are the most common causes of psychosis among your patients?
    a. Perspective of the patient
    b. Perspective of the physician

Knowledge of physicians about psychosis

1. How were you trained to recognise (symptoms of) psychosis?

Actions by physicians regarding psychosis

1. Could you tell us what you do when you see a patient with symptoms of psychosis for the first time
2. What causes you to refer a patient to a psychiatrist?
3. Do patients generally see you first when they have symptoms or do they go to the pcs directly?

Traditional and alternative medicine

1. What is your view on traditional medicine?
2. Do you often see patients (with psychotic symptoms) who have first visited traditional healer before seeing you?
3. Do you have contact with traditional healers? Do you collaborate with them?

Other

1. From the data we collect via these interviews we are going to try and produce a product to help shorten the DUP. For this, we would really like to know what you believe, as a professional, is needed to improve the time before your patients receive treatment?

a. Do you think it will be useful to offer a short educational programme about psychosis for GPs?
b. Do you think it will be useful to make a short video which informs people about what a psychosis is, how to recognise it and where to go for help?

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