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Treatment delay within the patient journey of people with KS:

a retrospective qualitative multiple-case study.

Exemplaar Korsakov Kenniscentrum d.d. 10 mei 2021

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Nederlandstalige Samenvatting

Uit de literatuur is bekend dat chronisch alcoholisme een stoornis is met een laag behandelingspercentage als gevolg van de sociaaleconomische status en de leefomstandigheden van mensen met een chronische alcoholverslaving. Tot op heden is geen gericht retrospectief onderzoek verricht naar factoren, in het zorgtraject van mensen met een chronische alcoholverslaving leidend tot het syndroom van Korsakov, die mogelijk voor vertragingen in de behandeling hebben gezorgd.

Ons onderzoek was een retrospectief verkennend multipel casestudie onderzoek. De dataverzameling richtte zich op 14 casussen, zijnde de *patient journey* van 14 patiënten met Korsakov, die zijn opgenomen in verschillende gespecialiseerde woonvoorzieningen voor langdurige zorg. De *patient journey* startte vanaf het eerste moment dat professionele zorg noodzakelijk werd geacht en eindigde op het moment van opname in een gespecialiseerde woonvoorziening voor langdurige zorg en behandeling.

Proces mapping is gebruikt om een beeld te vormen van de *patient journey* en thematische analyse om terugkerende thema's binnen de *patient journey* te zoeken.

Drie terugkerende thema's kwamen uit de data naar voren: het gebrek aan kennis over het syndroom van Korsakov, de versnippering van de zorg en de wachtlijsten, en het ontbreken van specialistische thuiszorg.

Het gebrek aan kennis over het syndroom van Korsakov komt naar voren bij zowel familieleden, huisartsen, artsen in algemene ziekenhuizen en thuiszorg medewerkers. De belangrijke rol die de huisarts heeft, viel hierbij op. Wij concluderen dat huisartsen meer kennis over het syndroom van Korsakov nodig hebben om Korsakov te kunnen herkennen, om te weten welke interventie nodig is en wat de beste plaats is om mensen met Korsakov naartoe te verwijzen.

Het tweede thema is de gefragmenteerde zorg en het bestaan van wachtlijsten. Geïntegreerde zorg blijkt nodig wanneer een gecoördineerd pakket aan zorg nodig is. Patiënten met een chronische alcoholstoornis of het syndroom van Korsakov hebben zowel geestelijke als lichamelijke zorg nodig. Wij stellen voor om speciale case managers Korsakov op te leiden, zodat de continuïteit van de zorg voor mensen met Korsakov gewaarborgd wordt. Deze casemanagers zouden verantwoordelijkheid moeten dragen voor het gehele zorgtraject: het volgen van de patiënt en het zorgen voor de juiste vervolgstappen in het traject. Toekomstig onderzoek kan zich richten op de rol van deze case managers Korsakov.

Thuiszorg is het laatste thema dat in de *patient journey* naar voren komt. De patiënt met Korsakov moet thuis gespecialiseerde zorg krijgen. Wij stellen voor om thuiszorgmedewerkers op te leiden met kennis van de verzorging en behandeling van patiënten met Korsakov. De huidige opleiding voor thuiszorgmedewerkers besteedt mogelijk niet genoeg aandacht aan de zorg en behandeling van mensen met Korsakov. Hier ligt een aandachtpunt voor de opleiders van thuiszorgmedewerkers.

Door het blootleggen van deze drie thema's in de *patient journey*, hopen wij een bijdrage te leveren aan het verbeteren van het zorgtraject van mensen met een chronische alcoholverslaving en patiënten met Korsakov, zodat tijdig en op de juiste manier behandeld kan worden.

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Introduction

In 2016, the harmful use of alcohol resulted in some 3 million deaths (5.3% of all deaths) worldwide and 132.6 million disability-adjusted life years. The effects of alcohol consumption on mortality are greater than those of tuberculosis (2.3%), HIV/AIDS (1.8%), diabetes (2.8%), hypertension (1.6%), digestive diseases (4.5%), road injuries (2.5%) and violence (0.8%). The highest per capita consumption of alcohol (10 litres or more) is observed in the WHO European Region (1).

For many patients, alcohol use disorders are chronic, recurring conditions involving multiple treatment cycles, abstinence, and relapse (2). Mc Kay (2011) described several factors that interfere with the delivery of continuing care, among other things funding problems for extended treatment and the fact that patients are reluctant to receive care (2).

Alcohol use disorders (AUDs) are among the mental disorders with the lowest treatment rate. In high-income countries, 10 % or less of the people fulfilling the diagnostic criteria receive treatment (3-5). Given that alcohol is one of the most important risk factors for morbidity and mortality in Europe and AUDs account for significant shares of disease burden in Europe, increasing treatment engagement should be a public health priority (6-9).

In the Netherlands, 8,5 % of the population drinks excessive, and 8.5% is a heavy drinker (10). The number of patients (of all ages) that have been treated for alcohol poisoning in an Accident and Emergency department continues to rise. In 2018, an estimated 6,300 patients have been treated for this condition, in addition to another 17,700 people who have been treated for an injury after an accident or violence while being under the influence of alcohol. Both estimates are subject to under-reporting; the actual harm is more significant.

Chronic alcoholism can cause neurocognitive dysfunction such as Wernicke's encephalopathy (WE) and the longer-term manifestation of thiamine deficiency known as Korsakoff's syndrome (KS) (11). KS is predominantly characterised by global amnesia, and in more severe cases, also by cognitive and behavioural dysfunction. In addition, they have a wide variety of comorbid problems: somatic, psychiatric, behavioural, and functional issues are common (12). For a definition of KS, see Figure 1.

Definition Korsakoff's Syndrome (13)

"KS is a largely irreversible residual syndrome, caused by severe thiamine deficiency and occurring after incomplete recovery from a Wernicke encephalopathy, predominantly in the context of alcohol abuse and malnutrition, characterized by an abnormal mental state in which episodic memory is affected out of all proportion to other cognitive functions in an otherwise alert and responsive patient, whose psychological make-up may be further distinguished by executive dysfunction, flattened affect, apathy, lack of illness insight, and possibly by fantastic confabulations in the early stage."

Figure 1. *Definition Korsakoff's Syndrome*

The incidence and prevalence of KS are difficult to determine; in the Netherlands, it is estimated at 8,000 - 10,000. This estimate is related to the number of heavy and excessive drinkers. Because most of them avoid care, they have not been officially diagnosed. About 1,350 people are, however, admitted to specialised residential facilities for long-term care and treatment. Here, residents receive care that is fully adapted to their situation after the diagnosis of Korsakov is made. The average age at admission is around 50 years (14). Studies on the incidence of KS in other parts of the world are lacking altogether (11).

Treatment delay is the best explanation for the progression of WE to KS (13). There are some known reasons for this treatment delay, such as the socioeconomic status of alcoholics and their living conditions (13). People with KS are not aware of their illness and consequently do not have any care demands; they are usually brought into contact with professional healthcare through an intervening family carer (15).

It seems interesting to gain insight into the factors in the patient journey of patient with KS that are responsible for the treatment delay, besides socioeconomic status and living conditions, to get some clues for the reduction of treatment delay. The term ‘patient journey’ refers to understanding the experiences and the processes the patient goes through during the course of the disease and treatment and is used to focus and improve the processes around patient care (16). The patient journey has been studied in some medical conditions, such as Parkinson’s disease (17), Locked-in syndrome (18), Pertussis (19) and Rheumatoid arthritis (20,21) (16). We have not been able to identify any publication of the patient journey of patients with KS.

The main question guiding this research reads as follows: Which themes can be identified within the patient journey of people with KS to explain treatment delay, which ultimately resulted in developing the Korsakoff’s syndrome?

Aim

This study aims to reduce treatment delay for people with KS by generating knowledge about the patient journey from the first moment that professional care was deemed necessary until the time of admission into a specialised residential facility for long-term care and treatment.

Methods

Design

A retrospective exploratory multiple-case study was conducted. In retrospective studies, the outcome of interest has already occurred in each individual by the time the participant is enrolled.

This study is a multiple-case study that involves studying multiple cases simultaneously to generate a still broader appreciation of a particular issue (22). It is an established research design used extensively in various disciplines, particularly in the social sciences (23). In multiple-case studies, several cases are carefully selected. This offers the advantage of allowing comparisons to be made across several cases. This approach is well suited for studying the patient journey and gave us practical and valuable tools to analyse our data.

Participants

Data collection focused on 14 cases, being the patient journey of 14 patients with KS, already admitted in a specialised residential facility for long-term care. We used the strategy of typical case sampling for purposefully selecting our information-rich cases (24). With the cooperation of key informants in the network of the Korsakoff Knowledge Centre (KKC), we had access to various residential facilities for people with KS. The KKC aims at developing knowledge, practice, and skills in the broadest possible sense for people with KS.

Criteria for inclusion of the 14 patients were: they had a family member or representative who was willing to tell us about their knowledge of the patient journey of their family member/client, and they probably could give more information about former professionals who were involved in the patient journey of this patient. In all 14 cases, we included the perspectives of patients (n =8), family or volunteer caregivers (n=14), and healthcare professionals (n=34) (Table 1).

Case nr.	Female/male patient (number||duration interview*)	Family or volunteer caregiver (number||duration interview)	Healthcare Professional (number||duration interview)	Total interviews per case
001	Male (001-01||26)	Brother (001-02 || 50)	Nurse-in-charge (001-03||40) Elderly Care Physician (001-04||40) Social worker (001-05||44) General Practitioner (001-06||25) Cognitive behaviourist therapist (001-07||29)	7
002	Female (002-01||23)	Daughter (002-02||39)	Elderly Care Physician (002-03||43) Home care worker (002-04||34) Cognitive behaviourist therapist (002-05||73)	5
003	Male (003-01)	Daughter (003-02||55)	Nurse-in-charge (003/004-03||38) Social worker (003/004-04||62)	3
004	Male (004-01)	Daughter (004-02||20)		1

005	Male (005-01‖15)	Sister (005-02‖74)	Coordinating Nurse (005-03‖41) Clinical Psychologist (005-04‖28) Salvation Army employee (005-05‖28) Social Worker (005-06‖44) Nurse-in-charge (005-07‖19)	7
006	Female (006-01‖15)	Son (006-02‖40)		2
007	Male (007-01‖42)	Brother-in-law (007-02‖94)	Nurse-in charge (007-03‖59) Elderly Care Physician (007-04‖63) Mental Health Care Social Worker (007-05‖62)	5
008	Male (008-01‖66)		Nurse-in-charge (008-02‖59) Social Worker (008-03‖53) Mental Health Care Social Worker (008-04‖67) Care-Coordinator Rehab (008-05‖49)	5
009	Male (009-01)	Girlfriend (009_02‖57)	Representative (009-03‖30)	2
010	Male (010-01)	Daughter (010-02‖89)		1
011	Male (011-01‖57)	Trustee (011-02‖41)		2
012	Male (012-01‖57)			1
013	Male (013-01)	Daughter (013-02‖44)		1
014	Male (014-01)	Daughter (014-02‖55) Spouse (014-03‖62)		2
015	Additional interviews without being linked to a specific patient	Daughter (015-02‖44)	Care-Coordinator (015-03‖50) Judge (015-04‖24) Specialised Korsakoff Nurse (015-05‖39) Psychologist (015-06‖31) Director KKC (015-07‖57) Specialised Korsakoff Nurse (015-08‖48) Specialised Korsakoff Nurse (015-09‖45) Specialised Korsakoff Nurse (015-10‖61) Social Worker (015-11‖26) Nurse in General Hospital (015-12‖38) Home care worker (015-13‖33)	12
Total	8 (301 min)	14 (723 min)	34 (1.523 min)	56 (2.547 min)

**duration interview in minutes*

***Table 1**. General overview of the cases: people with KS and the interviewees*

Due to the COVID-19 virus, not all patients and caregivers could be interviewed because the residential facilities were not accessible for researchers. This is also the reason that ‘case 015’ was added. Case 15 contained additional interviews with professionals and one daughter who were not involved in any specific case. Nurse-in-charge (003//004) and social worker (003//004) are the same persons in case 003 and 004. Both the nurse-in-charge as the social worker discussed two patients’ journeys in one interview. All other interviews concerned the experiences with the patient journey of one of the patients suffering from KS.

Data collection

A qualitative semi-structured interview approach was used, using open-ended questions and with the participant encouraged to elaborate on any points of the patient journey. The interviews took place from February 2019 through May 2020. Respondents were asked to recall the patient journey of a specific patient before admission to the specialised residential facility for long-term care (25). Individual interviews were held at the place of preference of the interviewees. Due to the COVID-19 virus, some interviews took place using online chat/video programs such as Teams and Zoom or by phone, depending on the participants’ preference.

First, interviews were held with patients and healthcare professionals in the residential facilities. Then the family members/representatives were interviewed after being approached by the healthcare professional of the residential facility, whether it was agreed that the investigator could contact them. After that, we used snowball sampling, a recruitment method that employs research into participants’ social networks to access specific populations (26). Snowball sampling is often used when the population under investigation is ‘hidden’. In this study, the particular populations were healthcare professionals who could know the patient’s journey of one specific patient because of their role during this patient journey.

The time needed for data collection could be reduced by allotting students to investigate different cases. The interview approach resulted in interviews of different lengths with a range from 15 to 94 minutes. The interviews were audiotaped and transcribed for analysis. This allowed the interviewers to concentrate on their conversation strategy and making focused field notes. Interviews were conducted and transcribed by student-researchers under the supervision of a senior researcher to ensure consistency and accuracy (27).

Ethics

All interviews were treated confidentially and anonymously. No formal medical-ethical approval was required according to the Dutch Act of Medical Research Involving Human Beings. However, we obtained permission from the participating residential facilities. All participants received a letter containing information about the study and the contact details of the student researchers and supervisor to gain further details. Participation was voluntary. At the beginning of the interviews, all participants gave their oral or written consent to participate. All transcribed interview data were kept anonymous, and participants were assigned a non-identifiable code to ensure privacy.

Data analysis

In this multiple-case study, the student researchers made a detailed description of each case before considering the emerging similarities and differences in cross-case comparisons by the senior researcher (23).

The case study approach to qualitative analysis constitutes a specific way of collecting, organising, and analysing data; in that sense, it represents an analysis process. The purpose is to gather comprehensive, systematic, and in-depth information about each case of interest. The analysis process results in a product: a case study.

We used process mapping to understand the patient journey. Process mapping is a way to understand the patient journey; it can be used to identify and characterises value and non-value steps in the patient pathway through care (28).

The data analysis began with analysing the interviews from the individual case studies, which was discussed with the senior researcher. All individual student researchers (n=6) wrote a research report, which was part of their bachelor’s thesis (29-34). They visualised the patient journey using a flow diagram (see, for example, case 007 and 008 in Figure 2).

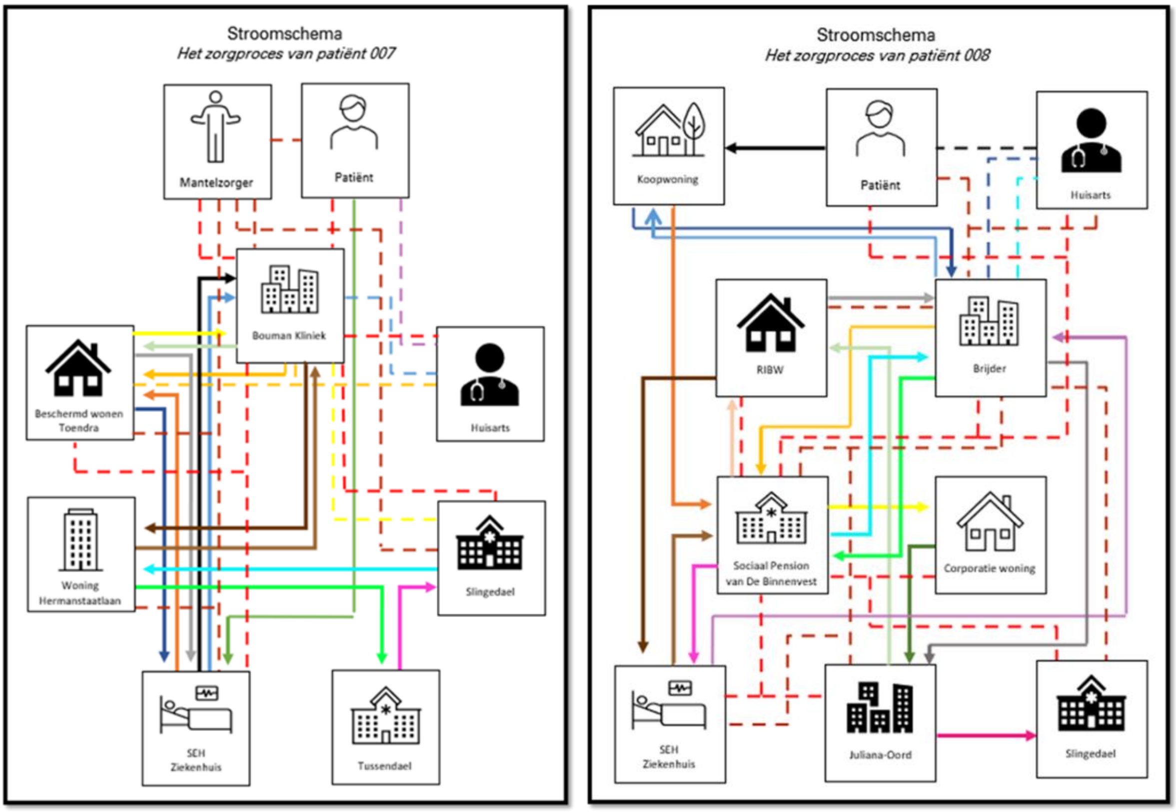

Figure 2. *The patient journey of patient 007 and 008.*

The six research reports and corresponding data included all the information for subsequent analysis. The 14 case studies were compared and contrasted by the senior researcher: information was edited, redundancies were sorted out, parts were fitted together, and the case record was organised for ready access chronologically and topically. Thematic analysis (TA) was used to search for recurring themes. TA is a method for systematically identifying, organising, and offering insight into patterns of meaning (themes) across a data set. Through focusing on meaning across a data set, TA allows the researcher to see and make sense of collective or shared meanings and experiences (35).

Results

The results described in this paper focus on the cross-case comparison.

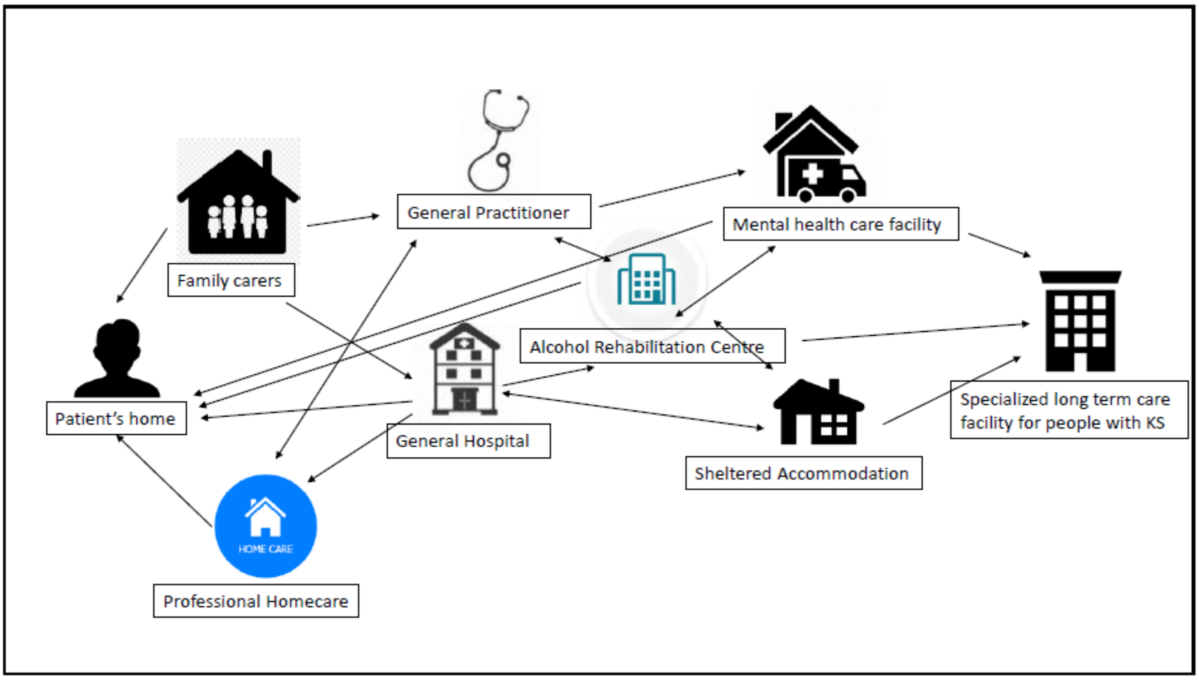

Figure 3. *The cross-case patient journey of patients with KS.*

In the next section, the overall patient journey, as mapped in figure 3, is chronologically described. After that, the qualitative description of themes found in the overall patient journey of people with KS follows.

The patient journey of patients with KS

The beginning of the patient journey is characterised by a traumatic event in the life of the patient, for example, a divorce (003; 007), repudiation by the family due to pregnancy (004), the death of a family member (005, 006) or a rehousing (013). Sometimes the drinking started as a habit at a very young age (007). During the period of chronic alcoholism, a family member often contacted the general practitioner (GP). The GP did not always recognise the problem because patients lack insight into their illness and are reluctant to receive care. If the GP did acknowledge the problem, most of them tried to arrange professional home care. However, this was difficult to arrange because most patients were reluctant to receive care. As a result, the patients were mentally and physically deteriorating in their homes.

Over time, most patients ended up in the general hospital, often the emergency department, due to physical problems. This could be a pneumonia (007), a fall which caused broken limbs (004; 005; 007; 009; 010) or a delirium (001; 002; 003; 008; 011; 013; 014). When a physical problem was the indication for hospital admission, often no care was offered for the existing alcohol problem.

After discharge from the hospital, the majority of patients went back home without further care. Continuation of the old life characterised by alcohol abuse, further deterioration of mental and physical health, and dignity loss was the result. During this time, the GP, the professional home carers, or family members tried to give the best possible care. This home period almost always ended up in another hospital admission.

The moment the chronic alcohol problem was recognised, it often resulted in an admission to an alcohol rehabilitation centre for detoxification. After that, patients went, for a short period, to a specialised institution with a diagnosis setting for these patients (001; 006; 010), a mental health care institution (005; 007;009; 014) or a temporary sheltered home (008). Finally, all patients came home again.

This circle has been run several times: home, hospital, alcohol rehabilitation centre, home (for example 001, three times; 002, two times; 007, four times; 008 three times; 011 six times). That’s why these patients are often called revolving-door patients.

Finally, when the diagnosis of KS was made, patients still had to go a long way to get admitted to a specialised Korsakoff residential facility for long term care. Some patients first ended up in sheltered housing (005; 006; 007; 008), a mental health care institution (007; 009; 010; 014) or a nursing home for the elderly (001; 002; 004).

Qualitative description of reoccurring themes in the patient journeys of people with KS

Data analysis revealed three reoccurring themes: the lack of knowledge of KS, the fragmentation of care/waiting lists, and the ack of specialistic home care.

1. Lack of Knowledge of the Syndrome

Respondents experienced a lack of knowledge about KS during the patient journey. Family members describe that they had no knowledge of KS whatsoever and did not even know about the existence of this syndrome. After the diagnosis of KS, they still had no clue what to expect.

> "I did not know that chronic alcoholism could end up in KS. I never heard of it. If I had known, maybe we could have arranged the proper care on time." (013_02)

Not only do family members experience a knowledge gap, they also notice a lack of knowledge among health care providers about KS. Our respondents frequently mentioned the lack of knowledge among home care workers and GP's.

> "The home care professionals were very kind, but they did not know what to do. They told us, 'please call the GP because we do not know what to do'. Their knowledge and experience with patients with KS are limited. (…) Their knowledge should have been better, for example, with regard to vitamin intake. They did not know that was necessary [thiamine intake]. And I seriously wonder if the GP had this knowledge." (002_02)

> "It is not easy to find your way, especially when you are young and do not have any experiences with healthcare. I thought the GP could help me, but even he had never heard of a specialised care institution for people with KS. So, he could not help me either. This was very stressful. I felt alone and did not know where to go to." (003_02)

> "I asked the GP to come by, but he said we had to come to his practice. Of course, my client did not want to do that—end of the conversation. Only when things are going terribly wrong and someone ends up in the hospital care is given. (…) A GP sees people only shortly. Maybe in the old days, the GP had a kind of family relationship

> with his patients. Nowadays, it is far from that. Especially not in Amsterdam. The general practices are too big, with too many different GP's." (015_03)

> "A GP can sometimes be very reluctant to offer help and actually cannot properly assess how serious the situation is, resulting in patients ending up in the care system too late. We have experienced this several times." (003 / 004_03)

As a result of the GP's lack of knowledge, our respondents experienced a lack of responsibility of the GP. According to our respondents, the GP did not know that the patient himself usually does not have a request for care and consequently will not come to the GP's practice.

> "The GP did not want to do anything. He told me that people could only visit him voluntarily. Of course, my father did not want to do that." (003_02)

> "My brother still lived at home where he frequently collapsed. At a certain point, it went seriously wrong. I called the GP. The GP went to my brother's house, but my brother did not open the door. The GP just left without doing anything. He took no responsibility." (005-02)

A GP (001_06) mentioned the reasons for his lack of knowledge. He described that GPs have little knowledge and experience with KS because they do not meet many patients in their practices with this syndrome and therefore have difficulty recognising it. It is a rare syndrome. As described before, patients with KS lack insight into their illness and are reluctant to receive care. So, it is difficult for the GP to get in touch with the patient and arrange care.

> "I did not have any patient with KS last year. So, it is sporadic. As a GP, I see 2400 patients a year. (…) As a GP, I react to the care demands of people. I am not visiting people without a request. (…) When I suspect something is wrong, I contact the professional home care organisation or mental health care organisation who can deliver ambulatory care. I do not have any experience with KS; it is something a specialist has to handle." (001_06)

Our respondents also mentioned the lack of knowledge regarding the KS of healthcare professionals working in general hospitals. Often, the general hospital is the first place where professional care is given to the patient, mainly in the emergency department due to calling 112 or by a GP’s referral. The general hospital has a crucial role in diagnosing Wernicke’s encephalopathy (WE) in time to prevent KS.

> “They [the doctors] do not have any knowledge of KS. Many emergency departments have never seen someone with WE closely. As a result, they do not recognise WE and do not signal it. The behaviour is often attributed to being drunk. (…) Geriatric specialists and other healthcare professionals have a lack of education about this syndrome.” (020_01; 020_02)

> “When my friend ended up in the hospital, the doctor saw that something was wrong. He thought my friend was behaving strangely. My friend was agitated and anxious. […] This complicated the process of making a correct diagnosis. (009_02)

2. Fragmentation of care and waiting lists

Our respondents indicated that the Dutch Health Insurance Act has cut back too much mental health care capacity, resulting in long waiting lists for everything: intake, diagnosis, and admission to a suitable, specialised institution.

> “A situation like Mrs M’s you encounter at most once a year. (…) You have to deal with long waiting lists. Long waiting lists for the intake, a long waiting list for psychological examination and a long waiting list for admission in a good institution.” (002_03)

> “We do get people from which we suspect it is a KS, but after this suspicion, they have to be examined by our psychodiagnostic department, which again has very long waiting lists. That is a problem. (…)” (001_04)

> “The waiting lists for specialised Korsakov residential facilities are long. When we have a spot available, there are already ten applicants in line. There seem to be more and

> more patients with KS. We should expand because we need more beds. Now they are placed in non-specialist wards because we don’t have room.” (015_03)

Our respondents told us that the fragmentation in care results in patients not receiving the right care in a timely manner.

> “There are institutions where a diagnosis is made, and there are institutions where people with KS can live, but there is a gap in between. Because you can only receive a referral for a long-term care institution once you have been diagnosed, so, you can only join the waiting list once you have received the indication.” (008_04)

> “Well, then 112 was called immediately, and he was admitted to the general hospital. He stayed there for four weeks. Yes, he spent four weeks in the hospital because there was no place for him anywhere in the system at all. The hospital helped us searching for a good place to stay for him. Eventually, that happened after four weeks. He ended up at a nursing home.” (003_02)

> “And when you call the GP, he refers to the acute mental health care service because my father was in a crisis. The acute mental health care service referred back to the GP. Ultimately, the police had to take him off the street and put him in custody for a while. They released him when he was more down to earth. Nothing changed in his situation.” (006_02)

3. Lack of specialistic homecare

Patients with Korsakov syndrome, revolving-door patients, return home at different points in their patient journey. They return home after a detoxification period, when the physical problem is treated in the general hospital, or when specialistic long-term care is not available. In the home situation, they do not receive the specialised care they need. The care given in the home situation is provided by nurses who are not trained for this kind of care.

> “He had an acute WE when he was admitted in the general hospital. He was there for a week. Then they let him go; he was allowed to go home with intensive home care. (…) That was a little drama, and that care was finished very quickly. They did not know how to handle him and even forgot to give him his medicine.” (001_02)

> “Another reason patients with KS are sent home, again and again, is because they need specialistic care that most care institutions cannot provide. Most care admission is focused on short-term care while people with KS need long term care” (011_02)

> “Often, home care organisations are already involved. (…) But at one point, they get stuck in good intentions but cannot offer the right care. They call us with questions like ‘the patient does not want to do anything, ‘we don’t know what to do’, or ‘what care exactly is needed?’ "(008_05)

Discussion

To identify themes that may explain the treatment delay of patients with KS, in addition to the already existing knowledge about the influence of socio-economic status and living conditions, we generated knowledge about the patient journey of 14 patients with KS. The experiences of patients, family carers and professionals during the patient journey shed light on three important themes: 1) the lack of knowledge of KS, 2) fragmented care and waiting lists, and 3) the lack of specialistic home care.

The lack of knowledge about KS was identified with both family and professionals dealing with this patient group. The role of the general practitioner (GP) was particularly notable in this regard. The GP has a significant role at the very start of the patient journey. He is the one who has to refer the patient to the appropriate care services. The GP sees patients with a chronic alcohol use disorder or KS only sporadically in his practice. Firstly, because it is a rare disorder, and secondly, these patients are not aware of their illness and consequently do not have any care demands (15). This complicates the GP’s ability to make a timely and proper diagnosis.

These findings are in line with results in the existing literature. GPs are in an excellent position to identify vulnerable patients' socio-medical problems on time and provide targeted help to prevent homelessness and premature death due to chronic alcohol addiction (36). GPs can serve as a junction point to specialised care (39). However, GP's need more knowledge to recognise chronic alcoholism and KS, to know what intervention is necessary and where to refer to. In the early 1990s, a large-scale World Health Organization study in primary care centres in 14 countries (including 7 European countries) showed that primary care physicians recognised only about 50% of mental disorders(37), and alcohol use disorders were no exception (38).

To better recognise these disorders, Probst ea. suggested more regular monitoring of patients' alcohol consumption and offering brief interventions for individuals with mild alcohol use disorders to improve their health and reduce societal harm (39,40).

The second theme was fragmented care and the existence of waiting lists. Waiting lists appear to exist at many points in the patient journey: for being diagnosed, for doing an intake, and for final placement in an institution. Not being diagnosed in time results in KS because WE is misdiagnosed or its treatment with thiamine is inadequate (41).

One of the biggest problems in this context is that people with chronic alcohol addiction or already KS have physical and mental problems. As a result, they often fall between two stools. The addiction treatment services cannot deal with the mental health problems, and mental healthcare cannot deal with the addiction problems. It seems that the fragmentation in care is a bottleneck.

Fragmentation can lead to diminished knowledge of KS. This is in line with research of Minkman. Minkman described that fragmentation of health care is an effect of three major driving forces in health care development: decentralisation of care, sub-specialisation in health care which leads to diminished knowledge of closely related specialities, and the professional organisation which take personal responsibility for health care decisions (42). Integrated care is required when a coordinated set of services is needed, as in patients with a chronic alcohol disorder or KS, to cover the full range of the patient’s demands, both mental and physical problems (43).

The development of chains of care can support integrated care. Åhgren ea. defined the chain of care as ‘coordinated activities within health care, linked together to achieve a qualitative final result for the patient (44). A chain of care often involves several responsible authorities and medical providers’. A system, in this sense, is a set of elements interacting to achieve a shared aim (44).

This shared aim can be achieved by transcending responsibilities. Previously, I wrote about the responsibilities of healthcare professionals (45). Health care might improve if professional not only reason from their own perspective but try to transcend their own professional responsibility to connect with the other actors’ perspective on responsibility. I have referred to this as ‘transcending responsibility’, which asks for a re-examination of assumptions, and values, critical thinking and new creativity (45).

This is in line with Åhgren ea., who focused on the personal responsibility taken in health care by physicians, nurses, and other personnel (44). They independently take decisions regarding the treatment of patients without looking at the problems as a total package. This is in line with our study. Our respondents said that patients who ended up in the hospital due to a physical problem received no attention for their addiction problem because that was not the reason for their admission. They were sent back home as soon as the physical problem gave the physicians reason to do so.

The lack of knowledge of KS and the fragmented care and waiting lists resulted in patients not receiving the proper care at the right time and throwbacks to a former stage in the patient journey; patients were sent home again without specialist care. To ensure the continuation of care, we propose to train special case managers Korsakov. They should remain in charge of the entire care pathway, the patient journey, following the patient and ensuring the appropriate next steps in the pathway. Up till now, it is rare to have one single person with responsibility for the entire treatment process and corresponding decision-making power. We recommend focusing future research on the role of these case managers Korsakov.

Home care is the last theme to be addressed in the patient journey. The patient must be offered specialised care at home. We suggest training home care workers with knowledge of the care and treatment of patients with KS. Current training for home care workers may not pay enough attention to the care and treatment of people with KS. We suggest that there might be extra attention for this. Future research on this topic is necessary.

We sincerely hope that by uncovering these three themes in the patient journey, we can contribute to improving the clinical practice for patients with KS and reduce treatment delay.

Conclusion

Our analysis suggests that increasing the knowledge about KS plays an essential role in reducing treatment delay for patients with KS. The lack of knowledge of family members, GP's, healthcare professionals in general hospitals, and home care workers requires our attention. The part played by the GP is crucial because GP's have the first contact with the patient and his/her family. There is a need to find ways to organise coordinated care for patients with KS.

We suggest that Korsakov case managers with specialised knowledge might play a significant role in this process, following the patient from the start of the patient journey and ensure that the appropriate next steps in the pathway are taken. This might improve the care and diminish treatment delays for this specific group of patients.

Limitations/strength of the research

Two potential limitations to this study should be addressed. Firstly, although the interviews were carefully and critically evaluated, interpretation of the interview data depends on the individual skills and interpretation of the researchers themselves.

Secondly, recruitment through key clinicians may have produced an atypical sample of patients. The selection of other patients and carers might have yielded different outcomes. However, the method of case sampling was deliberately chosen to be able to study the patient journey. Case study research has sometimes been criticised for lacking scientific rigour and providing little basis for generalisation. We are aware that this diminished the possibility to generalise the data to other groups.

The reliability of this kind of study lies in the recognition of others. When healthcare professionals and family members recognise the presented data, the knowledge gained from this study may serve as a basis for discussion and raising awareness (45-46).

The strength of this study lies in the fact that 56 interviews were conducted. Patients, family and health care professionals provided a wealth of thick description and highlighted multiple viewpoints relating to the patient journey of the 14 patients. The fact that there were 14 separate cases to analyse made it possible to reliably establish a pattern in the trajectory of these cases.

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