A Vicious Cycle of Access to Excluded Medicines: Evidence from a Qualitative Study

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Abstract

Aim: Medications procured through out-of-pocket payments from abroad are often more expensive compared to local treatment options, and the process is further prolonged even when medications are brought in. This situation generates a vicious cycle for both those with purchasing power and those without. This study aims to examine the challenges associated with accessing medications procured from abroad and to provide stakeholders with evidence-based solutions to these challenges.

Method: This study was conducted using a qualitative content analysis method with complaints of 68 patients in Türkiye about challenge to access their medications. Visual analyses were conducted using the MAXQDA program.

Results: The most frequently encountered themes in patient statements are "victimization," "communication issues", "delays in medicine supply," and "addressing authorities to politicians." Patients with genetic disorders, dermatological conditions, those undergoing transplants, as well as individuals suffering from cancer, neurological diseases, cardiovascular issues, rheumatological conditions, and psychiatric or addiction-related disorders reported that delays in medication supply hindered their treatments or forced them to discontinue them. Additionally, patients indicated ongoing communication problems with foreign drug supply units, expressing difficulties in accessing medications and frustration due to their inability to receive treatment.

Conclusion: In seeking solutions to these issues, they often held authorities and politicians accountable. This finding highlights the need for a more effective communication network between drug supply units and patients. A new system or reorganization of the current system is necessary to quickly address patient needs and make processes more understandable. Patients have expressed concerns about a lack of information regarding drug supply abroad.

Keywords: Access to medication, affordability, MAXQDA, Türkiye.

Kapsamdışı İlaçlara Erişimin Kısır Döngüsü: Nitel Bir Çalışmadan Elde Edilen Kanıtlar

Öz

Amaç: Yurtdışından cepten ödemelerle temin edilen ilaçlar, yerel tedavi seçeneklerine kıyasla genellikle daha pahalıdır ve ilaçlar getirildiğinde bile süreç daha da uzar. Bu durum, hem satın alma gücü olanlar hem de olmayanlar için bir kısır döngü yaratır. Bu çalışma, yurtdışından temin edilen ilaçlara erişimle ilgili zorlukları incelemeyi ve paydaşlara bu zorluklara kanıta dayalı çözümler sunmayı amaçlamaktadır.

Yöntem: Bu çalışma, Türkiye'de ilaçlara erişimde zorluklarla ilgili 68 hastanın şikayetleriyle nitel içerik analizi yöntemi kullanılarak gerçekleştirilmiştir. Görsel analizler MAXQDA programı kullanılarak yapılmıştır.

Bulgular: Hasta ifadelerinde en sık karşılaşılan temalar "mağduriyet", "iletişim sorunları", "ilaç tedarikindeki gecikmeler" ve "yetkili ve politikacıları adres gösterme"dir. Genetik bozuklukları, dermatolojik rahatsızlıkları, organ nakli geçirenleri, kanser, nörolojik hastalıklar, kardiyovasküler sorunlar, romatolojik rahatsızlıklar ve psikiyatrik veya bağımlılıkla ilgili bozukluklardan muzdarip hastalar, ilaç tedarikindeki gecikmelerin tedavilerini engellediğini veya kesintiye uğramaya zorladığını bildirmişlerdir. Ek olarak,

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hastalar yabancı ilaç tedarik birimleriyle devam eden iletişim sorunlarını belirtmiş, ilaçlara erişimde zorluklar yaşadıklarını ve tedavi alamadıkları için hayal kırıklığı yaşadıklarını ifade etmişlerdir.

Sonuç: Bu sorunlara çözüm arayışında, genellikle yetkilileri ve politikacıları sorumlu tutmuşlardır. Bu bulgu, ilaç tedarik birimleri ile hastalar arasında daha etkili bir iletişim ağına duyulan ihtiyacı vurgulamaktadır. Hasta ihtiyaçlarını hızlı bir şekilde karşılamak ve süreçleri daha anlaşılır hale getirmek için yeni bir sistem veya mevcut sistemin yeniden düzenlenmesi gerekmektedir. Hastalar, yurt dışından ilaç tedarikiyle ilgili bilgi eksikliği konusunda endişelerini dile getirmişlerdir.

Anahtar Sözcükler: İlaç erişimi, satın alınabilirlik, MAXQDA, Türkiye.

Introduction

The high cost of certain medications that are unavailable in the country, along with disruptions in the supply chain, complicates access to these medications[1]. Access-related issues concerning medications create a complex process in some countries, continuing to disadvantage both patients and their caregivers[2,3]. Medications procured through out-of-pocket payments from abroad are often more expensive compared to local treatment options, and the process is further prolonged even when medications are brought in. This situation generates a vicious cycle for both those with purchasing power and those without[4–6]. Particularly in the procurement of certain life-saving medications that are not available in every country, such as those for cancer, neurology, transplantation, and cardiovascular diseases, communication issues may arise between patients and the institutions providing these medications[7].

Bureaucratic barriers related to the supply chain of medications, along with poorly managed processes, hinder patients from receiving the medications they need in a timely manner. Especially concerning is the prolonged waiting times that can negatively impact the course of a patient's illness, adversely affecting their treatment processes[6,8]. The importation of medications from abroad has become problematic not only in terms of cost but also due to legal regulations and communication deficiencies with overseas medication procurement units[6,9]. Communication challenges extend the procurement process for the medications that patients require, leading to disruptions in their treatment regimens[10,11].

The communication deficiencies of overseas medication procurement units directly lead to delays in the procurement process of medications[12,13]. Communication issues result in the untimely arrival of necessary medications for patients, causing disruptions in their treatment processes[14,15]. Furthermore, bureaucratic barriers and legal regulations associated with importing medications from abroad further extend patients' treatment times[16]. Therefore, addressing the challenges faced in obtaining medications from overseas is critically important for the improvement of Türkiye's healthcare system. By tackling this issue, evidence-based policies can be developed. The evidence generated from this analysis emerges as a global concern that should also be considered in health policy[17].

This study aims to examine the challenges associated with accessing medications procured from abroad and to provide stakeholders with evidence-based solutions to these challenges. Through this research, it seeks to offer policymakers the necessary evidence to reevaluate and restructure the procurement process for medications that are

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imported into Türkiye and are not covered by reimbursement. Focusing on the research question "What are the main difficulties experienced by patients in Türkiye in the process of obtaining medicines from abroad and what are the related solutions?", this study aims to offer concrete suggestions for a new supply chain model for medicines supplied from abroad.

Material and Methods

Research Design

This study was conducted using a qualitative content analysis (QCA) method to examine complaints from some patients in Turkiye about not being able to access their medications, which are prescribed by a doctor and must be obtained out-of-pocket from abroad[18].

Participant Profile, Selection and Sampling

The participants consist of 68 patients or patient representatives who have problems accessing medication despite paying out of pocket, who share their problems with documents through a website established to complain, and who provide detailed information such as medication information, why they could not get their medication, etc. Since all complaints on the website where the participants reported their complaints were included in the research, no sample selection was made[19].

Inclusion, Exclusion Criteria and Keywords

The inclusion criteria were determined as having a complaint made visible to everyone on the website set up for complaints, complaints of patients who paid for their medicine out of pocket, and complaints about accessing medicines abroad prescribed by a doctor. The exclusion criteria were selected as complaints about accessing medicines domestically and complaints about pharmacies. The relevant website was searched with the keywords “Turkish Pharmacists Association Overseas Medicines”, “Turkish Pharmacists Association Overseas Medicine Supply”, “Turkish Pharmacists Association Telephone” and “Turkish Pharmacists Association Overseas Pharmacists Association”.

Data Collection, Coding and Theming Processes

The patients' complaints were scanned on the website using defined keywords, resulting in a total of 218 complaints. After removing those unrelated to foreign drugs and local pharmacies, 110 complaints remained. From these, 40 duplicates were eliminated, leaving 70 complaints. Two of these were excluded as they had been removed from the website, resulting in 68 patient complaints for examination.

Each complaint was transferred to a Word document, which were then read and categorized into themes based on the types of inaccessible drugs. Main and sub-codings were determined by a single researcher after obtaining expert opinion on the subject. The documents were subsequently uploaded to their respective themes. After a second review, main and subcodes were established. The main and subcodes, and themes were transferred to an Excel file, and the document contents were then uploaded to the relevant main and subcodes in the MAXQDA 2022 program[20].

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Data Analysis

The data were analyzed in two stages. In the first stage, the data collected through keywords were transferred to individual Word documents for each patient. The data were then sorted based on their relevance to the subject. The extracted content underwent observational analysis, leading to the identification of themes, codes, and subcodes, which were documented in an Excel file[21]. In the second stage, the organized documents were imported into the MAXQDA program. The documents were categorized into themes within the program, and the relevant content was reviewed and assigned to the appropriate themes, main codes, and subcodes. After the assignments were completed, visual analyses were conducted using the MAXQDA 2022 program for a more in-depth evaluation[20].

The Role of the Researcher and Ethical Statement

In this study, the role of the researcher is objective. Because it is stated that the role of the researcher in qualitative research is to try to reach the feelings and thoughts of the participants[22]. However, since the contents previously declared by the participants were examined in this study, the researcher adopted a completely objective attitude and a possible bias originating from the researcher was avoided. Therefore, since the researcher maintained his independence, no ethical violations were made. Since the data were secondary, no ethics committee approval was obtained for this research.

Reliability and Validity

The study was conducted based on the validity criteria suggested by[23], focusing on the reliability, appropriateness, auditability, and confirmability of qualitative research. The data comprised 68 distinct patient complaints that were categorized into predefined themes and codes. The necessary number of responses for each theme and code was met, ensuring the reliability of the data prior to analysis. The results were validated by checking whether the complaints articulated by individual participants were also mentioned by others. To further ensure the validity of the findings, an examination was conducted to determine if the comments and support messages associated with each complaint were contributed by different individuals. The data collection and analysis processes were carried out by an experienced qualitative researcher, and each step was meticulously documented. To enable readers and stakeholders to verify the findings, participants' statements were included in the visuals.

Permission to Reproduce Material from other Source

Since the questions and all other materials in this study were prepared by the author, no permission was obtained. No material from any other source was used.

Results

The frequency distribution of codes in patient complaints is shown in Figure 1. In Figure 1, codes that occur frequently in patient statements are shown in larger font sizes, while less frequent codes are shown in smaller font sizes. Accordingly, the most frequent codes in patient statements are "be victimized", "communication problems", "delays in supply of medicines", and "addressing authorities and politicians", respectively.

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Figure 1. Code cloud

Patient complaints regarding the theme of access to genetic disease medications are shown with the codes in Figure 2. For this theme, patients talked intensively about the delays in supply of medicines and the grievances they experienced. Patients emphasized that they could not receive treatment or had to stop treatment due to delays in drug supply for their genetic diseases (Figure 2). In fact, for genetic disease drug theme, P4 and P14 patients' statements regarding drug supply delays are as follows:

"I have been unable to obtain my vital medication, which I need to take four times a day, for the past 86 days. Due to an exorbitant price difference for my previous medication, I switched to an alternative that my doctor approved. However, I have been facing difficulties in obtaining medication for the last few years, particularly during my applications at the end of the year." (P4)

"I deposited the money, but it has been three months and my medicine has not arrived from abroad. My condition is very bad and I have to use my medicine daily. When I call, they keep telling me different things. They victimize people and I am helpless because my medicine is not available here." (P14)

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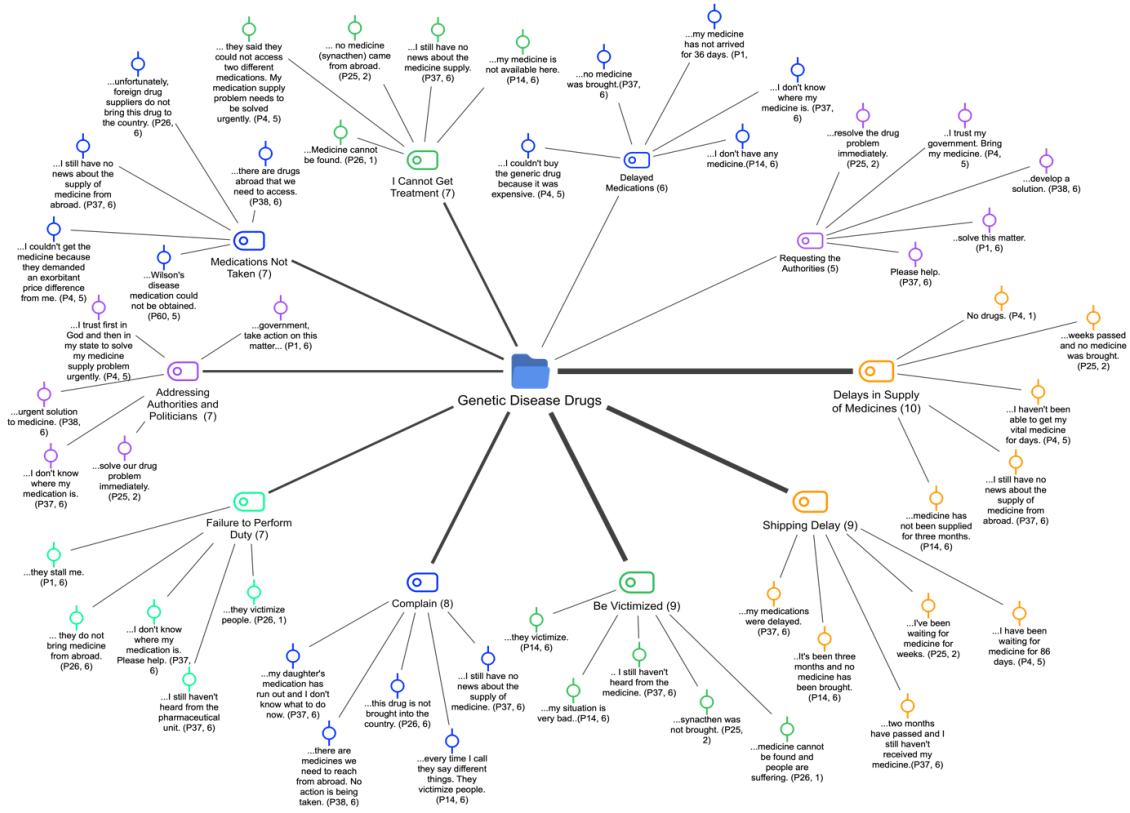
Figure 2. Participant statements regarding the theme of genetic disease drugs single-case model



In the theme of access to dermatology drugs, patients expressed their complaints with the codes in Figure 3. For this theme, patients frequently expressed the communication problems they experienced during drug supply. Patients stated that they constantly experienced communication problems with the foreign drug supply unit during drug supply for dermatology diseases (Figure 3). The communication problems experienced regarding drug supply are reflected in the statements of patients P5, P6 and P8 as follows:

"The Turkish Pharmacists' Association cannot supply the medicine called Dapsone, which my father, who has a skin disease, has been using regularly for a year. The phone lines they provide are always busy and they throw me off the line every time." (P5)

"Since we have just switched to the Tebeos system, we naturally have questions about the integration. The customer representatives provided to help us solve our problems have not answered our calls or responded to us for a week." (P6)

"I call frequently, but I can't get any information. My disease is progressing day by day, and I want this injustice resolved." (P8)

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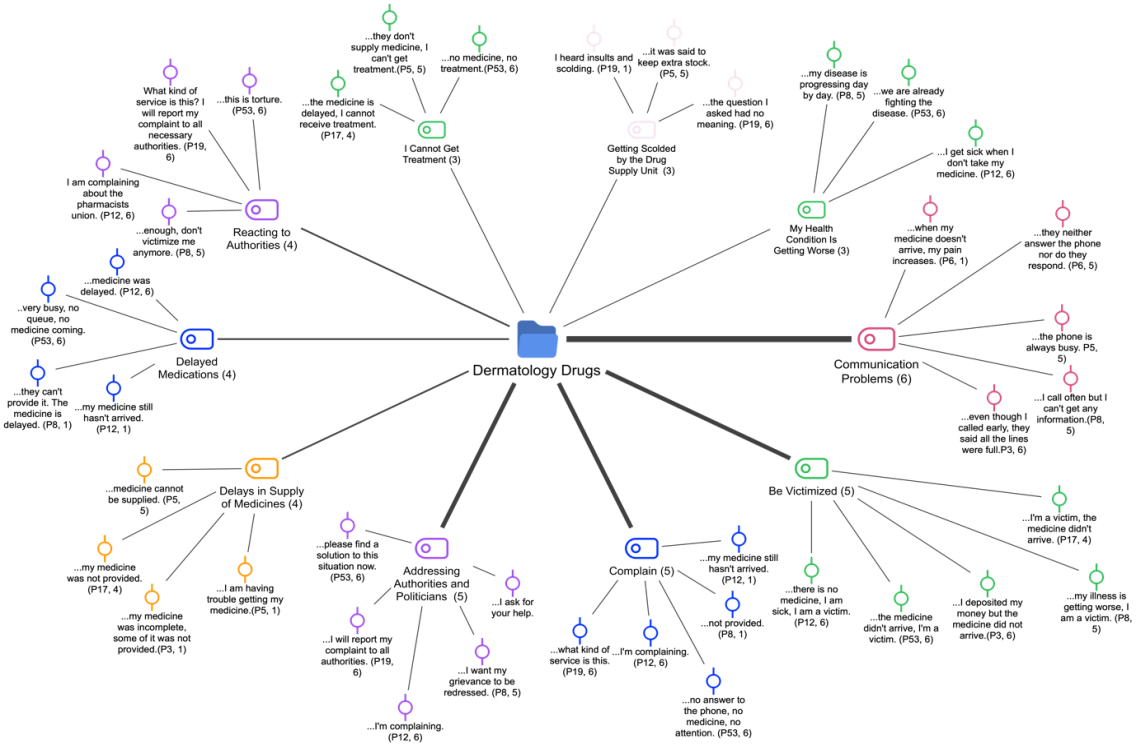
Figure 3. Participant statements on the dermatology drug access theme single-case model



In the theme of access to psychiatry and addiction drugs, patients expressed their complaints with the codes in Figure 4. Patients stated that they were heavily victimized due to the supply of psychiatric and addiction medications and that the reason for this victimization was the authorities and politicians (Figure 4). The statements of patients coded P13 and P32 on the subject are as follows:

"We are incredibly victimized and I will continue to complain everywhere and file a lawsuit, whatever it takes. My patient's illness has also progressed." (P13)

"Although we applied for the epilepsy medication that we had previously brought from abroad through the drug supply unit in March and sent the shipping fee they requested in Euros, we never received the medication. No information is given, my child is a victim, we are experiencing a drug shortage. We want it to be resolved as soon as possible." (P32)

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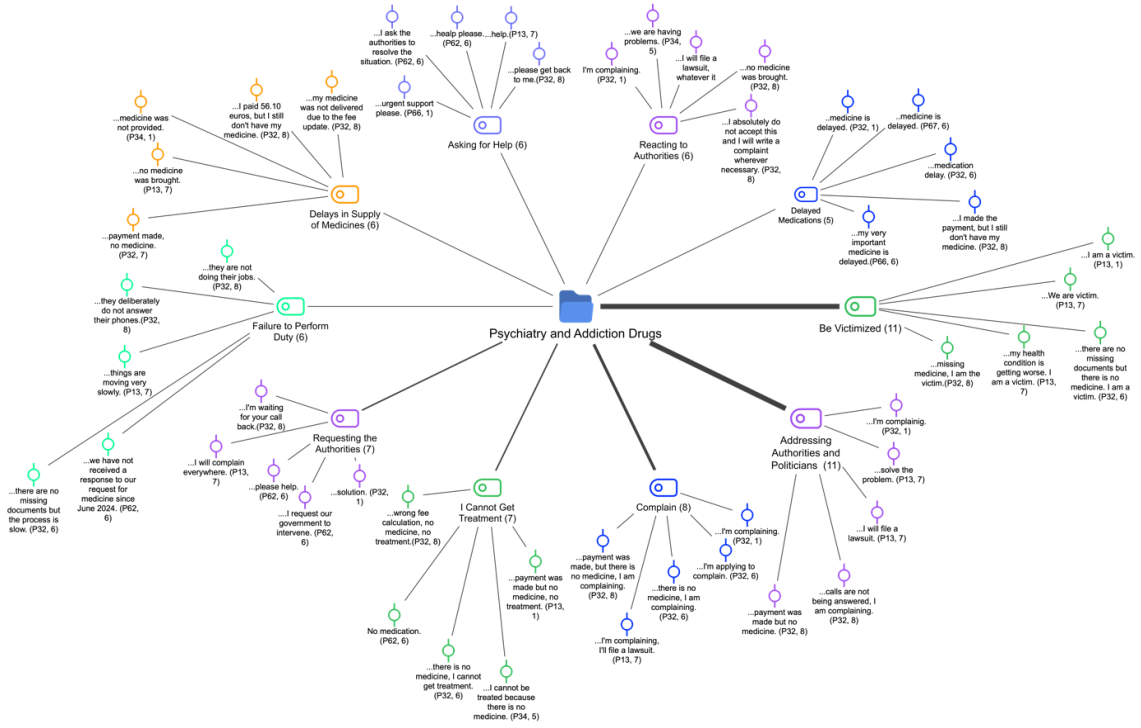
Figure 4. Participant statements on the psychiatry and addiction drugs access theme single-case model



In the theme of access to transplant drugs, patients expressed their complaints with the codes in Figure 5. Patients frequently mentioned authorities and politicians for access to transplant drugs (Figure 5). Patients P20 and P21 expressed their situation on the subject as follows:

"Pegasys, which is used the most by many patients, is not available anywhere and there is no equivalent; we are a victim. It is not included in the scope of foreign drug supply. Please help find it again. The return of this drug will be a remedy for many people's problems." (P20)

"I paid 3,634 euros for 12 medicines. I use one a week and it is enough for me for 3 months but I cannot afford to buy it. Unfortunately, it is very expensive and the price per unit is 303 euros. Most people cannot afford this without government support. At least accept that we pay the exchange rate determined by the government for imported medicines." (P21)

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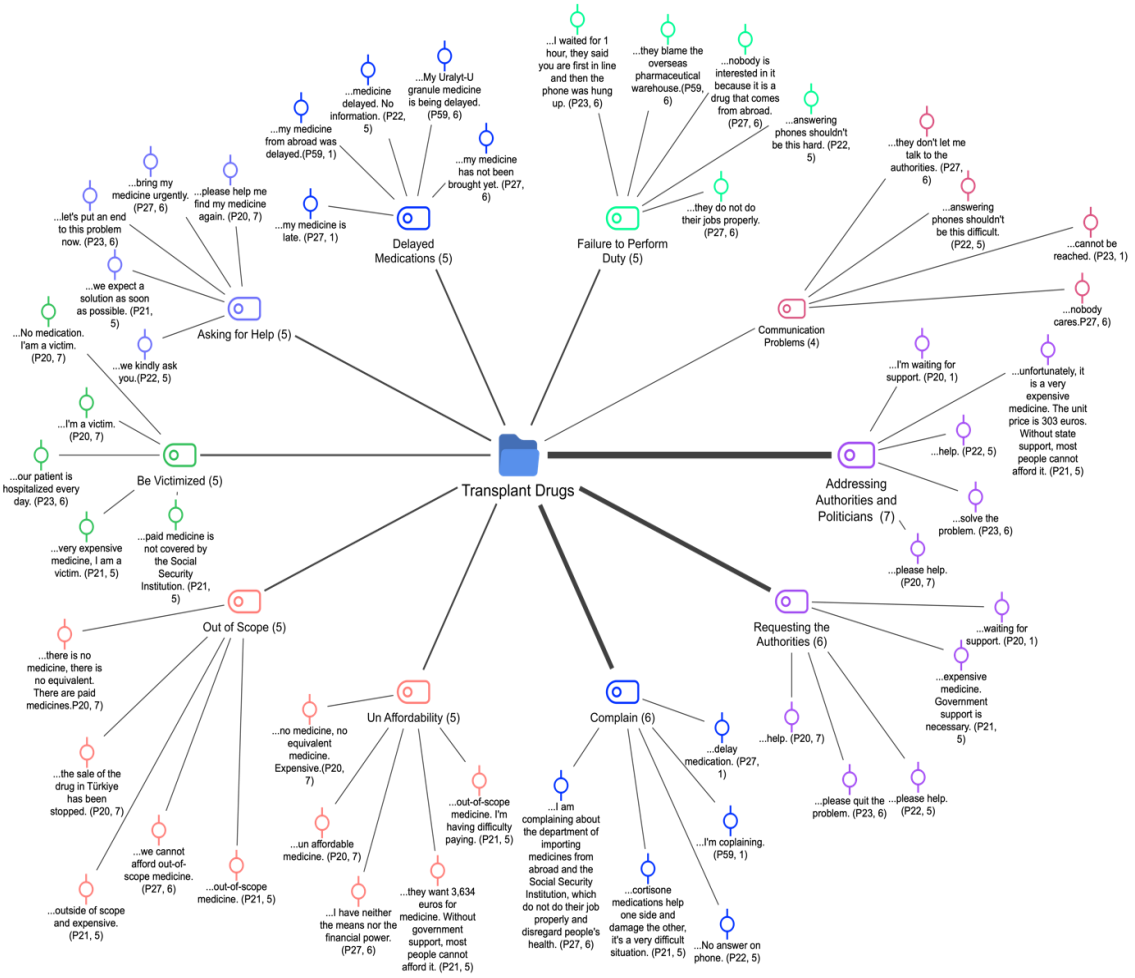
Figure 5. Participant statements on the transplant drugs access theme single-case model



In the theme of access to cancer and neurology, patients expressed their complaints with the codes in Figure 6. Patients expressed intensely that they were unable to access cancer and neurological disease treatment and that they were suffering because of this (Figure 6). Patients P16 and P33 expressed their situation on the subject as follows:

"We applied for medicine abroad for my brother who has cancer and paid the fee. When we made the payment in Euros, we were told that the medicine would arrive within 1 to 6 weeks. It has been three months, even a day is very important to us, but today I learned that there is no medicine. We are victims." (P16)

"I can't get the medicine. I have to pay for the medicine. I'm a victim." (P33)

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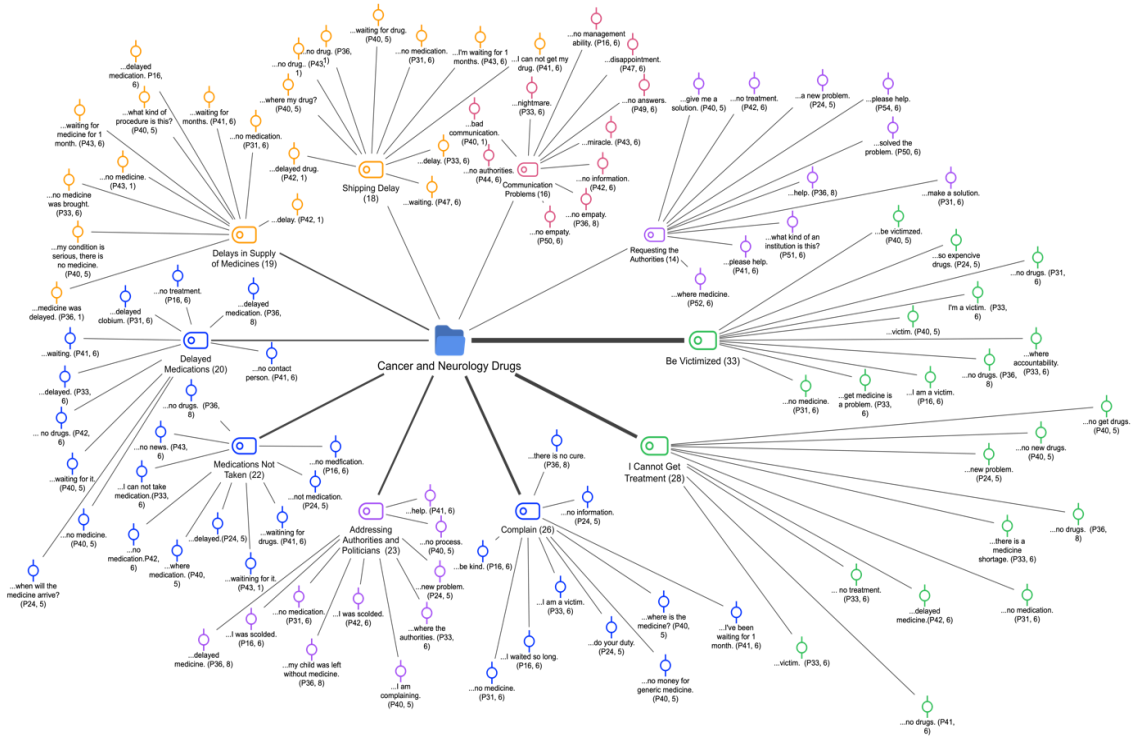
Figure 6. Participant statements on the cancer and neurology drugs access theme single-case model



In the theme of access to heart drugs, patients expressed their complaints with the codes in Figure 7. Patients frequently stated that they had communication problems regarding access to heart medication and were unable to obtain information on the subject (Figure 7). Patients coded P28, P45 and P48 reported the following statements regarding access to heart medication.

"Is it that hard to answer that phone? I've been calling for 3 days and no one is answering." (P28)

"The prescription I gave for the second treatment has not arrived yet. I call on the phone, if they answer, I introduce myself and ask about my medicine. They say it will come. I have been waiting for 20 days, my treatment date is passing, I have become a victim." (P45)

"We requested medicine from abroad. We paid for it. It's been 5 months and still no response. We can't even reach them to meet. Will they call back when the patient dies? We definitely can't reach them with their numbers. We are waiting for a solution. Our patient is in bad condition and I think he will die before the medicine arrives. Shame on them, they don't even call back." (P48)

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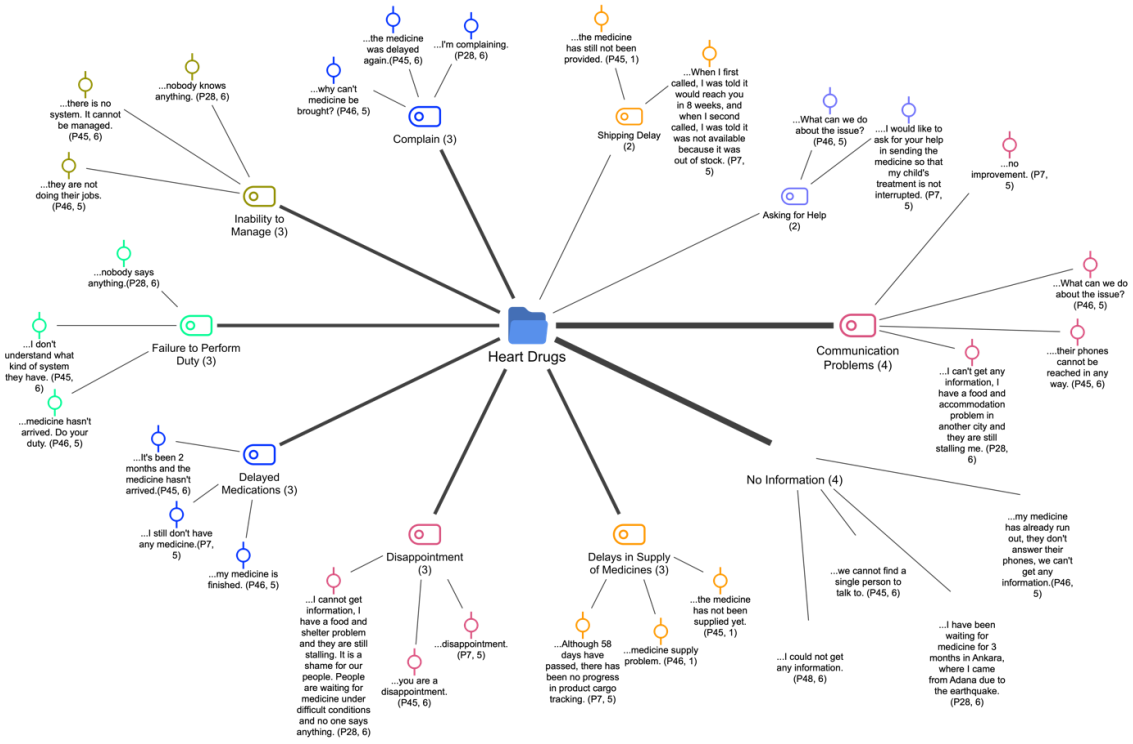
Figure 7. Participant statements on the heart drugs access theme single-case model



In the theme of access to rheumatology drugs, patients expressed their complaints with the codes in Figure 8. Patients frequently stated that they had communication problems regarding access to rheumatology medications and that they viewed authorities and politicians as responsible for the issue (Figure 8). Patients coded P11 and P15 reported the following statements regarding access to rheumatology medications.

"We applied for injections. However, our injections have not arrived for almost 3 months. My baby is 10 months old and we need these injections very much. His seizures are relentless and my child is in a very bad condition. Please let our medicines come now, my baby is very sick. I ask you to help." (P11)

"I have been waiting for medicine for three weeks. How long will this situation continue? Enough is enough. It is extremely tiring and sad to face this situation every time. We want to pay for medicine and get it. Every three months we have to apply with anxiety about whether the medicine will be available or not. Even though three weeks have passed, we are still waiting for medicine. I wonder who will take responsibility for this situation. I don't even want to think about what our citizens who are in a more difficult situation have to do. The state's failure to control the exchange rate is also making it difficult for us economically." (P15)

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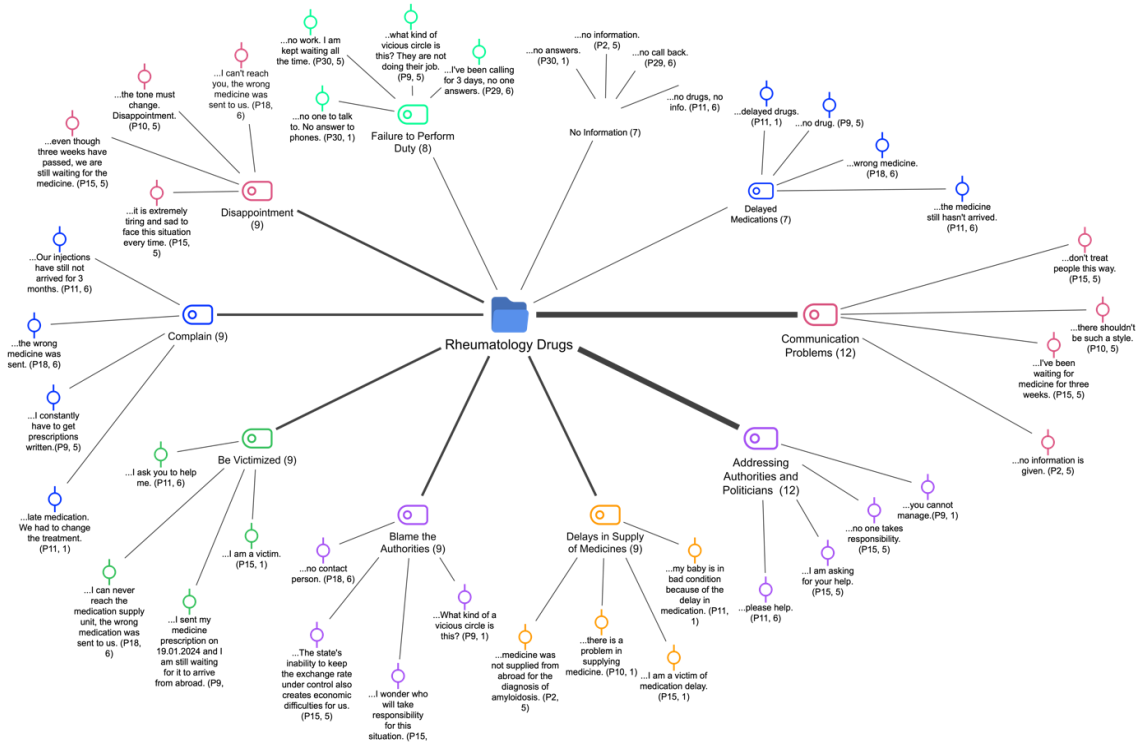
Figure 8. Participant statements on the rheumatology drugs access theme single-case model



Discussion

Access to medications procured from abroad continues to be a significant issue for patients in Türkiye. According to the research findings, patients have expressed concerns regarding the challenges they face in accessing medications, highlighting that communication problems and delays in the procurement process adversely affect their treatment journeys. In particular, delays in obtaining genetic medications complicate patients' access to treatment or may lead them to discontinue their therapies[4,17]. This situation has become a matter that raises questions about the effectiveness of the healthcare system. In fact, studies on the subject report that access problems related to medicines are a problem in all low, middle and high-income countries from time to time and that this indicates a lack of a health system[6,24].

The communication problems encountered by patients in obtaining medications for dermatological conditions highlight the deficiencies in the operations of the foreign drug procurement units. These communication issues prevent patients from accessing the information they need, consequently prolonging their treatment processes[6,10]. In addition, the grievances experienced by patients undergoing psychiatric and addiction treatment reflect the challenges associated with the procurement of medications for this group. Patients are calling on authorities and healthcare professionals to address these issues[25]. A report published in 2024 on the subject offers solutions and strategies specifically addressing the vicious cycle of drug access. It provides evidence that

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communication and supply problems exist in drug access and that these can be resolved through methods such as patient-centered communication[26].

Another notable point in the research is the difficulties encountered in the procurement of medications for cancer and neurological diseases. Patients have expressed that these access deficiencies pose a serious threat to their health. These findings highlight the necessity for a review of health policies and the need to make the medication supply system more effective[27–29]. Additionally, communication issues in accessing cardiac and rheumatology medications are another significant factor negatively impacting patients' treatment processes[30,31]. A comprehensive report on access to medicines in OECD countries found that many new medicines, often targeting small populations, enter the market at very high prices, creating challenges for both payers and patients[32]. In this context, recommendations can be made to increase the economic value of medicines in countries, facilitate incentives for pharmaceutical Research and Development, and facilitate government subsidies for pharmaceuticals. These recommendations are anticipated to address issues related to access to medicines.

Lack of communication in the supply of medicines abroad restricts patients' access to the information they need and therefore paves the way for the extension of their treatment processes. In addition, patients receiving psychiatric and addiction treatment experience serious grievances due to the difficulties they experience in obtaining medicines in this group. This situation negatively affects not only the physical health of the patients but also their mental health. Similar studies have also demonstrated that individuals experiencing medication access issues experience physical, mental, and social well-being[1,33,34]. In this context, the study is consistent with other studies in the literature and yields similar results.

Patients' complaints about access to transplant medicines are also striking. Patients who stated that they think that the authorities and politicians are not taking enough steps in this regard stated that this situation seriously victimizes them. In general, access problems experienced for cancer, neurological diseases and rheumatology medicines are also among the important factors that restrict patients' treatment processes. Communication problems frequently experienced in accessing heart medicines increase patients' concerns about their treatment processes and this situation reinforces their distrust of the authorities.

As a result, problems experienced in the access of medicines supplied from abroad constitute a significant challenge for the healthcare system in Türkiye. It is obvious that communication processes need to be improved and authorities need to take effective responsibility in order to eliminate the grievances experienced by patients. Restructuring health policies by taking these problems into account may help reduce the difficulties experienced by patients during the treatment process.

Limitations

This study was conducted under some limitations. Therefore, the results should be evaluated according to these limitations. One of these limitations is the lack of generalization that arises from the nature of the qualitative study. Another important limitation is that the limitations based on patient statements were reported. Because

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there may be some difference between the subjective judgments of the patients and what is actually experienced. However, considering these limitations, it is thought that this study will attract the attention of politicians by presenting a problem and providing solution suggestions. Considering these limitations, it is recommended that future studies be conducted using the same methodology and coding across different patient groups. This will provide evidence on the challenges faced by different populations regarding access to medicines abroad and the strategies needed to address these challenges.

Conclusion

This finding highlights the need for a more effective communication network between drug supply units and patients. A new system or reorganization of the current system is necessary to quickly address patient needs and make processes more understandable. Patients have expressed concerns about a lack of information regarding drug supply abroad. Authorities should implement tools like brochures, websites, and mobile apps to provide timely information.

Support programs should be developed for vulnerable groups, such as psychiatric and addiction patients, to minimize their suffering during treatment. Emergency procedures for supplying vital medications, like those for cancer and heart diseases, should be established, ensuring timely delivery. Additionally, training for personnel on patient challenges is essential, fostering empathy to improve communication.

Current policies must be regularly reviewed and updated to prevent supply delays, especially for genetic drugs and rare diseases. Patients seek transparency and speed in drug supply processes to avoid interruptions in their treatment. This emphasizes the need for health policies to reflect actual patient needs. Persistent communication issues erode patients' trust in health services, making it crucial to resolve these problems swiftly. Patients stress the accountability of authorities in forming health policies and advocate for system improvements, underscoring the importance of their involvement in healthcare management. Delays in drug supply can have lasting impacts on health, highlighting the necessity for continuity in health services.

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