

A discourse approach to patient expertise in the management of invisible illnesses

Un enfoque de discurso sobre la experiencia del paciente en el manejo de enfermedades invisibles

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Abstract

Invisible illnesses, which are not outwardly visible, encompass mental, cognitive, and physical conditions that impair daily activities. Promoting self-management for patients living with these chronic conditions has been the central aim of healthcare systems around the world. Through an analysis of medical consultations with student patients at a university healthcare facility in Chile, we propose a framework that identifies the themes, sub-themes, and indexes that embody the identity work of expert patients with invisible chronic health conditions. The study explores the complexity of the resources and doctor-patient alignments used to perform patient expertise in natural interactions and the key role of experiential knowledge in the self-diagnosis and the management of invisible illnesses.

Keywords: discourse analysis, patient expertise, self-management, medical consultations, invisible conditions, university students

Resumen

Las discapacidades invisibles, que no son evidentes a simple vista, abarcan condiciones mentales, cognitivas y físicas que dificultan las actividades diarias. Promover la autogestión de estas enfermedades crónicas ha sido el objetivo central de los sistemas sanitarios de todo el mundo. Analizando las consultas médicas con estudiantes que son pacientes en un centro de salud universitario en Chile, proponemos un marco que identifica los temas, subtemas e índices que encarnan el trabajo identitario de pacientes expertos con enfermedades crónicas invisibles. El artículo explora la complejidad de los

recursos y las alineaciones médico-paciente que se utilizan para construir la experiencia del paciente en interacciones naturales y el papel central del conocimiento experiencial en el autodiagnóstico y el manejo de enfermedades invisibles.

Palabras clave: análisis del discurso, experiencia del paciente, autogestión, consultas médicas, enfermedades invisibles, estudiantes universitarios

INTRODUCTION

A patient-centred approach to care is nowadays a worldwide priority in healthcare. Modern healthcare systems and institutions undertake initiatives which encourage patients to take control of their health and increase their ability to self-manage their conditions, implementing expert patient programmes and policies designed to improve patients' self-management (see, e.g., Sanderson & Angouri, 2013). Most notably, when patients suffer from chronic illnesses or disabilities, they are expected to be actively involved in making decisions about the treatment and management of their conditions (e.g., Connor et al., 2012; Newman et al., 2004). The rapid advancements in information and communication technologies, such as the internet or mass media, facilitate patients' empowerment by providing easier access to health information (e.g., Prestin & Chou, 2014). As a result, the patient becomes, to different extents, an expert who may question and challenge the traditional positioning of the doctor in a medical consultation. Therefore, the way patients interactively manage and negotiate liability and illness with doctors becomes an interesting topic of academic research within discourse studies.

1. Theoretical framework

Knowledge negotiated by patients has most often been described as lay expertise (e.g., Williams, 2014) and has been juxtaposed with professional expertise, embracing scientific and clinical knowledge. In general terms, expertise is related to having or to acquiring knowledge (Sarangi, 2010). Expert patients are considered to be capable of taking responsibility for their condition and taking care of themselves, managing various dimensions of self-care. According to the Chilean Ministry of Health, they are expected to know how to take medicines, adapt or change their eating and exercise habits, be able to identify the symptoms, and respond appropriately to them, and also manage the social and emotional impact of the disease, dealing with their daily roles and activities as well as negative emotions (Ministerio de Salud, 2018). More specifically, patient expertise is grounded in the lived experience of their condition and it often goes beyond the specialised and technical knowledge of the medical professional (Prior, 2003). This experiential knowledge (Baillergeau & Duyvendak, 2016), which is a prerequisite for one's self-construction as a legitimate expert patient, can later be shared with healthcare systems (Sanderson & Angouri, 2013).

However, the negotiation process of expertise between healthcare specialists and patients in medical consultations is a much more complex issue. As noted by Bellander and Ladquvist (2020, p. 2), analyses of patients' practices "point to the tensions between professional expertise and patient expertise due to increased complexity as to what counts as pertinent knowledge, what channels are considered reliable and viable, and how knowledge is distributed among different actors" (see also Groth et al., 2016).

Furthermore, patients frequently resist the expertise claimed by professionals (e.g., Cicourel, 1999; Koenig, 2011) or challenge the identities that the medical system projects upon them (Sanderson & Angouri, 2013; Sowińska, 2022). Finally, even though patient knowledge cannot be considered on a par with medical knowledge (cf. Edgar, 2005), expert patients often integrate medical knowledge into their lived experience (using domain-specific language and technical knowledge as well as medical reasoning to endorse their beliefs), while sharing knowledge on health issues (Bellander & Landqvist, 2020; Sarangi, 2001). This, in turn, as pointed out by Connor et al. (2012), is related to patients with high agency, who take responsibility for the management of their condition.

Much has been discussed in the literature about professional expertise (e.g., Sarangi & Clarke, 2002), the patient perspective on the enactment of expertise as part of their self-identity in medical consultations has largely been neglected. This paper addresses this gap and focuses on the discursive resources used when constructing expertise and performance of patient expertise in invisible chronic disabilities in doctor-patient interactions. Invisible disabilities, which are common in modern societies, refer to "mental and physical conditions that are not immediately noticeable by an observer" and the choice to disclose the disability rests with the person (Matthews & Harrington, 2000, p. 405). They often include chronic physical conditions, such as diabetes; cognitive conditions, such as ADHD; or mental disorders, such as depression and anxiety. In this paper, the umbrella term 'invisible conditions' is used to refer to both invisible disabilities and chronic illnesses. Taking the framework proposed by Sanderson and Angouri (2013) as a starting point, we explore the resources for constructing expertise and performance of expertise in medical consultations with student patients with self-reported invisible conditions. The study shows how these patients discursively work to understand and manage their disability, while also negotiating their expert stance with the doctor.

2. Data and methods

The paper is part of a larger research project on the role of university students' discourse with invisible disabilities in doctor-patient communication (Sowińska & Pezoa, 2023). We examined 9 medical consultations videotaped at the health centre

(*Área de Salud*) of a higher education institution in the northern region of Chile, between December 2018 and March 2019. The health centre is part of the General Direction of Student Affairs (*Dirección General Estudiantil*)—an institution in charge of reviewing and improving student services in the areas of health, entertainment, sport, arts, and culture. Chile has a two-tier public private healthcare system, with around 18% of the population privately insured. It should be noted that the public insurance managed by the government (i.e., *Fonasa*) is underfunded and poorly-equipped to provide care for most of the population, especially for those who have a low income and are chronically ill or disabled (Crispi et al., 2020). The university provides health care services for students regardless of their medical insurance.

The recruitment procedure was conducted by the health centre and the program advisor of the School of English of the same institution, who invited all students to participate in this project either directly or through an official recruitment announcement. The study was approved by the university ethical committee (Protocol 041/2018 - Report 042b/2018). All participants gave their written informed consent for videotaping their consultations. The data collection was interrupted by two student strikes in 2019 firstly, due to the feminist movement and then to civil protests and, secondly, by the COVID-19 pandemic that led to the closure of the university.

The participants were three male and six female students between 19 and 28 years old, who self-identified as having hidden disabilities. The participants in this study included three students with depression, one student with diabetes, one student with a mixed headache syndrome and personality disorder, and 4 students without a diagnosis who constantly presented a variety of physical and mental symptoms for at least a year. In particular, during the consultations, these students reported: chronic fatigue, high cholesterol level, digestive problems, headaches, panic attacks, fainting, memory lapses, chronic diarrhoea, vertigo, nausea, cold sore, dandruff, tachycardia, low mood, and anxiety.

The interviews lasted from 15 minutes to 50 minutes and were conducted by two general practitioners (GPs). No other observers were present during the consultations. It should be noted that the GPs were occasional doctors for the majority of the student patients, rather than their long-term treating doctors. Because these illnesses are invisible, in other words, their symptoms are not easily observable by the doctor, the specialist depends and relies to a large extent on what patients tell them they feel in order to build the clinical case. Such invisible conditions are also often chronic (e.g., diabetes and depression), which means that the patient has a history of living with the illness, of consulting different doctors in search of better help, and of managing it. Moreover, for patients, the management of a chronic illness involves engaging in health-related decision-making processes on a daily basis (see e.g., Greenhalgh, 2009).

All of this increases the likelihood of patients in becoming experts of their own illness and also developing an authoritative voice when it comes to making decisions regarding their health. Most student patients reported having a long history of symptoms and despite many medical visits, they had not been diagnosed properly or they had not received the right treatment.

The original data in Spanish were first transcribed verbatim and subject to a thematic analysis, which allowed to capture broader themes and subthemes related to expertise construction in the data (cf. Sowińska & Pezoa, 2023). In particular, data displaying patient expertise was coded, taking the framework presented in Sanderson and Angouri (2013) as a starting point and adapting it to our dataset and findings. The framework was adapted in terms of sub-themes and indexes used to construct and perform expertise: it features experiential knowledge as one of the major resources of constructing expertise, and does not discuss the sub-themes and indexes absent in our data (such as access to institutional resources). We first coded data extracts relevant to our research aim and grouped similar indexes to form themes. The themes, sub-themes, and indexes of expertise identified in our data are presented in Table 1 and discussed in the following section. Then we further probed the results with a more fine-grained discourse analysis of extracts illustrating expertise negotiation, different facets of expert patient identity and resources drawn upon. For this purpose, the most representative quotations were selected and translated into English.

3. Results

In this section, excerpts from medical consultations were examined with the aim of describing how patient expertise is constructed and enacted in the interaction. In particular, the analysis centres on two major themes that constitute the identity work of patients with invisible chronic illnesses, namely, resources of constructing expertise and the performance of expertise. In the framework for invisible chronic illnesses, we propose, here (see Table 1), there are three major resources for constructing expertise that the student patients employ: domain-specific knowledge, experiential knowledge, and the ability to self-manage. More specifically, in order to build themselves as experts, the student patients used technical/medical terminology (e.g., medication names or medical terms to name conditions), displayed laboratory test literacy, and talked about the aetiology of their conditions. They also often admitted to acquiring knowledge through investigating and reading about their conditions.

Experiential knowledge is incorporated into our framework as another dimension (i.e., a sub-theme) of expertise. Accordingly, patients' experiential knowledge involved the following indexes: self-knowledge/self-awareness, i.e., recognising signs and symptoms, recognizing social triggers or related events and experiences. This involved, for instance, not being able to take medicines during university exams,

drawing on previous visits to specialists and a chronology of related events as well as the ability to process information about risks. In fact, of the nine participating students, eight reported managing their hidden conditions by themselves, whether by self-medicating, i.e., taking pills whenever they saw fit, or by self-treating (Sowińska & Pezoa, 2023). Thus, finally, the ability to self-manage encompasses the following indexes: self-control to avoid symptoms, pacing, monitoring illness, and seeking help.

These resources serve as the basis on which the patient claims expertise and also on which the doctor projects expertise on the patient (see theme 'performance of expertise' in Table 1). While claiming expertise of invisible illnesses, student patients actively engage in self-diagnosis. Self-diagnosis is an integral part of the clinical consultations explored in this study because it allows patients to display the ownership of their illness. Patients who put forward their own self-diagnosis may regard the consultation as an opportunity through which to seek a second expert opinion (cf. Sarangi, 2001).

In this light, many student patients presented themselves as experts on their condition and they either self-diagnosed during the consultation or provided domain-specific and/or experiential explanations for their symptoms. Example 1 serves to illustrate these points of our analysis (see Appendix for the original examples in Spanish).

Example 1

Context: The patient suffers from multiple conditions (chronic fatigue, high-level cholesterol, digestive problems, and anaemia). He reported in the interview that he does not have the right diagnosis.

1. GP: What about concentration, how is it to study?
2. Is it still hard for you to study?
3. P: Yes, that's also improved lately, concentration, clarity,
4. but, of course, I also have less umm + less energy.
5. It's just that I'm also, I also have some problems,
6. for example, I am now with some anaemia, so I'm a little short on +
7. GP: Yes, it's a little bit at the limit, yes [looking at lab results].
8. P: Right, so, that also influences that I am a bit slower.
9. GP: Are you taking the medication the doctor prescribed?
10. P: She prescribed two, for cholesterol and for +
11. GP: For the anaemia.
12. P: The one for cholesterol, I will not take it, and the other one +
13. I + I haven't + decid- I would like to +
14. GP: So you are not taking any medication.

15. P: No
16. GP: Why?
17. P: I am not concerned about cholesterol so much.
18. GP: Did she [the other doctor] tell you that you had 406?
19. P: Yes, yes she told me.
20. GP: And do you know how much is normal?
21. P: Normal is like 200 and something, but that doesn't worry me.
22. GP: That is very high!
23. P: Yes, I know.
24. GP: And you are not worried about that? Why not?
25. P: Because cholesterol is not like... It doesn't reveal that much...
26. Besides, that is only the result of total cholesterol, which is not really
27. measured... calculated... And also... besides, that was one exam
28. [the numbers] may vary from one exam to another,
29. for instance, the second one shows that the level decreased.
30. GP: [it dropped] to 362
31. P: It lowered to what is good cholesterol, as they say, the HDL is still high
32. triglycerides are low, so I don't get it.
33. GP: The bad thing is that LDL cholesterol is what forms plaques in your
34. arteries,
35. forms plaques in your viscera, it's the LDL and it's super high [giggles
36. nervously].
37. P: The other levels are also high, so also without seeing them quickly
38. they aren't high either, so the other tests say that yes
39. there is a deficit in the blood, I mean, it is a case of anaemia.
40. GP: What explanation do you give to that?
41. P: They are not, umm, the other levels are normal and, in general,
42. I eat things that are rather healthy, I don't drink alcohol, I don't smoke.
43. I don't have bad habits so...
44. GP: You can do everything right and still have anaemia.
45. You can do everything right and still have high cholesterol.
46. P: No, no.
47. I am not referring to that.
48. The anaemia, of course there is something
49. there and there is a problem and I want to correct it.
50. The cholesterol thing, if I have all the other levels, I am fine.
51. That's what I mean, that does not concern me +
52. I think that having the other levels [looking] good is more important than
53. the other.
54. GP: What other?

54. P: The other, well, what I was saying, eating healthy things, not smoking,
55. not drinking, resting well, having good habits... compared to a number.
56. GP: Who says? Who says that?
57. P: Anyway.
58. GP: Do you study all this?
59. You read a lot?
60. P: I just know, I read about it.
61. GP: And did you stop taking the medications from one day to the next?
62. How long have you not taken them?
63. P: Since the summer.

First and foremost, the example illustrates how multidimensional and dynamic lay expertise may be as the patient indexes his expertise in multiple ways to support his decision of not complying with the medication prescribed (lines 12-15 and 61-63). The patient builds his case and his patient identity by drawing on domain-specific knowledge acquired by himself, which he clarifies towards the end of the example upon the doctor's direct inquiry (lines 56-60), and his previous experiences with other doctors. This allows the patient to be able to display what we will call here his laboratory test literacy, skilful, though inaccurate, interpretations of lab results (lines 6, 21, 25-29, 31-32, 36-38, and 40), to use technical language and to engage in decision-making processes regarding his illness (not to adhere to specific treatment).

Moreover, as the patient manages the discussion topics of the medical consultation and repeatedly challenges the doctor's suggestions (e.g., lines 21, 23, and 40-46), the latter seems to provide explicit (lines 22 and 24) and implicit (lines 33-35) evaluations of the patient's health condition as a way to persuade the patient to see the evidence her way. This happens amidst a series of turns in which the doctor asks a good number of evaluative questions (e.g., line 24), not particularly designed to elicit symptoms, but rather to elicit the patient's opinion regarding his condition. By doing this, the doctor provides the interactional 'space' for the development of the patient's case (Barone & Lazzaro-Salazar, 2015a). This seems to prompt the patient to make judgements about the relevance and suitability of the prescribed treatment (lines 12-21 and 54-55), displaying his own ability to self-manage his conditions as he justifies his non-compliance with the suggested treatment path (of the current and previous doctors).

Most notably, as the patient draws on domain-specific language and knowledge to build his case in support of not treating his conditions, he also seems to instrumentally use his identity positioning as a resource to the same end. Thus, at different points in the conversation, he expresses his lack of concern for treating two of the conditions he reported (high cholesterol and anaemia) (lines 17, 21, and 50), constructing himself

as a calm and reflexive expert patient. He even mirrors conversational structures that may be more commonly associated to the doctor's positioning in clinical consultations, to the point that he provides his own diagnosis (line 38). Nonetheless, even though he is seemingly trying to construct his expertise from an evidence-based perspective, which is strongly advocated by modern medicine (Lazzaro-Salazar, 2020), he is doing this by drawing on inaccurate interpretations of the lab tests and other medical information, which may certainly lead to the inappropriate management of the patient's conditions. Towards the end of the conversation the patient's answers to the doctor's questions are elusive and do not reveal the source that feeds into the patient's expertise.

One further way in which the patients in this study also constructed themselves as experts is by drawing on their experiential knowledge of their illness. As Example 2 illustrates, self-knowledge and self-awareness prove to be vital in the construction of patients' expertise in this study.

Example 2

Context: The student patient was diagnosed with depression with suicidal ideation. She reports having panic attacks, memory lapses, and fainting.

64. GP: Ok, now let's go back to this year.
65. Now do you already feel that you are going to start feeling the same, yes?
66. P: Yes, the thing is that for a while now I can feel when it is going to
67. happen, as I already know my limit of stress or worries that I feel
68. or say "I either relax or it will happen again".
69. The thing is that most of the time the routine does not allow you to relax
70. or step aside and clear up.
71. GP: It's difficult, and even more so at university

The patient in this example presents herself as a source of experiential knowledge, in particular displaying the kind of self-knowledge that allows her to notice, recognise, and evaluate her symptoms and what provokes them (i.e., high levels of stress and stressful situations). In other words, her expertise is based on the kind of self-awareness that allows her to identify the moment when her symptoms may start to appear (lines 3-4); she knows her limits and she is aware of the circumstances which may impair her control over the symptoms (i.e., stress or worries, line 4).

It is also interesting to note that in this example both the doctor and the patient avoid mentioning the patient's condition by name and instead it is implicitly referred to. In this exchange, the doctor initiates the turn and the patient aligns with the implicit construction of her condition. The patient then talks about the symptoms as if she were in complete control of them, as if changing them were in her power if she

just relaxes. The view that the management of a chronic illness depends almost exclusively on patients and their ability to self-control to avoid symptoms is very often associated with discourses of blame, which often burdens the patient with the responsibility for their own health management and outcomes (Walton & Lazzaro-Salazar, 2015). This often happens because it is assumed that: 1) the patient is an expert of their condition, 2) the chronic illness was triggered by the patient's own doing (e.g., bad eating habits), and that (since it is a long-term disease) patients need to learn to manage it (e.g., Ravn et al., 2016). Possibly aligning with these ideological assumptions, the patient in this extract presents herself as an expert on her own illness, taking full responsibility not only for identifying the symptoms, but also for knowing how to manage them (line 5). However, when the time comes for her to admit that she is having a hard time managing them, she distances herself from the situation using impersonal constructions (lines 6-7). This, in turn, may also allow her to distance herself from any feelings of blame and failure imposed on chronic patients.

A similar case is presented in Example 3 below. The patient's self-knowledge and awareness allows her to recognise initial signs and symptoms of her dizziness (lines 5-6) and to control those symptoms (line 3). This example also provides a further instance in which the patient resists the doctor's medication plan (see Example 1), yet it offers an alternative way of dealing with this disagreement.

Example 3

Context: The patient reports suffering from vertigo and migraine since the beginning of her studies and admits to being diagnosed with depression by a university psychologist.

1. P: I get dizzy but now I know what that is.
2. GP: Ok.
3. P: I can try to control it.
4. GP: Hmmmm (...)
5. P: I feel like + an avalanche is coming towards me,
6. and my anxiety works against me.
7. GP: Yeah + and they never gave you treatment for that dizziness?
8. P: No (...)
9. P: I stayed like that because then I ended up coming to the psychologist
10. around the middle of the year and they had already diagnosed me with +.
11. They told me that I was one step away from having depression.
12. GP: Ok.
13. P: And then I started taking like sertraline.
14. GP: Ok.
15. P: And clonazepam to sleep.

16. GP: Ok.
17. P: Like for a month or two + the clonazepam and sertraline
18. I finished taking them now in December (...)
19. GP: Ok.
20. P: And she [the treating psychologist] told me that she was going to
21. gradually stop them, because she had told me before that she wanted to
22. stop them and I said no, because I was in an evaluation period and +
23. I thought I was unable to stop them.
24. GP: Of course, if you were in a period of stress it's not recommended at that
25. time to do th-
26. P: Yes, then later I gradually stopped them
27. by November or December, I was already at half a pill
28. and then I stopped taking them.

In response to the doctor's query regarding whether she had been medicated by her previous doctor (line 7), the patient supports her negative response (line 8) with the fact that it was only towards the middle of that year that she was diagnosed by a psychologist (lines 9-11) and that she started taking medicine (lines 13, 15, and 17-18). However, the patient disagreed with the medication plan proposed by the psychologist (lines 20-21) based on her own assessment of the risks involved when considering her health status and the life events that characterised the period when she should have stopped taking her medicine (lines 22-23). The doctor agrees and aligns with the patient's decision (lines 24-25), validating patient expertise, and the patient then draws on her knowledge of medication doses and of ways to self-pace her medication (lines 26-28) to continue elaborating her clinical case. That helps the patient build her expert stance in relation to how she manages her health. All in all, in this example, the patient's risk assessment plays a pivotal role in her management of a chronic condition and is fundamentally based on the social events that characterise her life reality at the time.

The relevance of social triggers of conditions is also made evident in other interviews. Thus, while in Examples 1 to 3 patients' self-knowledge is mostly related to recognising signs and symptoms, Example 4 shows how the patient is able to recognise the influence of social factors on the development of his chronic condition. Moreover, this example also illustrates how patients often simultaneously use a combination of experiential knowledge and knowledge acquired through reading and studying to build their case and expertise in support of their health decisions.

Example 4

Context: In the interview, the patient reports suffering from anxiety and panic attacks.

1. GP: Tell me, more or less, why are you here? What happened to you?
2. P: Ok, I'm going to start from the year 2017.
3. P: At that time, I approached the psychologist at the DGE [which stands for
4. *Dirección General Estudiantil*; Engl. General Student Directorate].
5. Umm I think that it all started with the fact that during all that year.
6. It was the hardest year for me emotionally.
7. I suffered like, many changes, like a + [silence].
8. GP: Like there were things that marked you?
9. P: Of course, some things... There were some incidents in the family, etc.
10. But what marked me the most was the death of my grandmother,
11. and, of course, I approached the psychologist and everything +,
12. but because it was the end of the semester I couldn't continue.
13. GP: Mmm yeah so at that time you consulted your psychologist for
14. for rather a mourning.
15. P: Yes [...]
16. It was the first semester of that year.
17. P: But I found myself overwhelmed,
18. and at that time it wasn't clear what I really had.
19. So that same year I began to investigate by myself what I had.
20. GP: Ok.
21. P: I began to relate what I felt along with what I was reading,
22. so that year I discovered that I suffered from a lot of anxiety.
23. GP: Ok.
24. P: Anxiety, anxiety and later also depression.
25. GP: That was what you discussed with the psychologist, wasn't it?
26. P: We didn't get to talk about those issues,
27. but I felt that, what we were going to end up with that,
28. that in the end it was going to be like the diagnosis of anxiety, etc.
29. GP: But in the end it was like only your own study.
30. P: Right.

The patient presents himself as a source of experiential knowledge drawing on a chronology of his lived experiences and, as in Example 1, third party interactions to evaluate his health status. In particular, he begins this exchange by providing the timeframe for the events he will describe (line 2) and by sharing his experience of his encounters with another professional (lines 3-4, 11, and 26). The doctor helps to elaborate the case as she makes clarifying comments (lines 13-14) and questions (line 25). The patient's experience with a previous psychologist is intertwined with accounts of how he felt during that period of time (lines 5-6, 12, and 17), and the life events that the patient identifies as triggers of his health condition (i.e., incidents in the family and death of his grandmother in lines 9-10).

As the conversation develops and the patient reflects on the different time periods that constitute his chronology of events and health accounts (lines 2, 5, 12, 16, and 18-19), he seems to emphasize the fact that his condition has become chronic. However, his experiential knowledge alone and skilfulness in identifying the triggers of his health condition are not enough to allow the patient to self-diagnose. Thus, to make up for his initial inability to self-diagnose (see line 18), he resorts to his own health literacy skills and resources, framing his self-diagnosis as a ‘discovery’ based on his readings and close examination of his symptoms (line 21). He further supports his self-diagnosis (line 24) by sharing his own judgement and assessment of his encounters with the previous psychologist (line 26) and what the patient seems to think the previous psychologist would have concluded from his case (see hypothetical diagnosis in lines 26-28).

This example then shows how patients’ expertise may be constructed in interrelated ways by drawing on two kinds of resources, namely, their experiential knowledge and the knowledge that they have acquired through searching and reading on the matter, to reach their self-diagnosis (see also Example 1). In Example 4, in particular, to achieve the former, the patient performs expertise by revisiting his own trajectory of self-diagnosis (see Example 3), by displaying his self-awareness when he reflects on related events and how these affected his health status, and by evaluating his experiences with relevant others.

Making these evaluations and being able to monitor their conditions in the ways described above, e.g., identifying social triggers of illness seem to afford the student patients the epistemic right (as in Lindström & Karlsson, 2016; e.g., Haw et al., 2018) to make decisions in terms of which professional they turn to for help and when they do so, to use their own resources (often a combination of online material and self-assessment of symptoms) to self-diagnose and to make treatment decisions. This all works to display these patients’ apparent control over their condition and, thus, to assert psychological ownership of their illness, which involves their sense of identity, responsibility and perceived capacity to control their condition (Karnilowicz, 2011).

DISCUSSION AND CONCLUSION

This paper contributes to research on medical consultations with university students with invisible disabilities by exploring the resources used for the enactment and negotiation of patient expertise in the patient’s interaction with the doctor from the perspective of discourse analysis.

As the analysis has shown, patient expertise was mainly constructed by drawing on domain-specific language and knowledge, mostly experiential knowledge, and by displaying the ability to self-manage. Among the expert activities performed by

patients that emerged in the analysis were: self-medication, treatment decisions, use of domain-specific language to discuss their condition and medication details, recall of doses, providing domain-specific and/or experiential explanations for their symptoms, and self-diagnosing.

The study highlights the central role of experiential knowledge in self-diagnosis and the management of invisible illness. Experiential knowledge, involving self-knowledge, i.e., recognising signs and symptoms, and recognizing social triggers or related events and experiences, goes beyond using clinical evidence and experiences of living with a condition as proposed in previous studies (e.g., Mazanderani et al., 2012) to encompass also other spheres of patients' control. In the context of our study, there are interesting findings about the combination of experiential knowledge and domain-specific knowledge, acquired through reading and researching about the condition that the patients drew on to reach a self-diagnosis (e.g., Example 4). Nonetheless, even when both kinds of knowledge are used as resources by most patients in this study, experiential knowledge seems to play a more vital role in building their clinical case. This finding is congruent with Bellander and Ladnqvist's (2020) study of epistemic communities online, which highlights the relevance of patient expert knowledge and confirms that knowledge arising from a patient's own experience and observations needs only some of the medical data. As can be seen in most examples analysed here, not only are accounts of experiential knowledge more extensive in the interviews recorded, patients' health experiences are also the foundations on which they start building their illness trajectories and start making sense of their condition. Thus, even when patients mostly claim to have reached a self-diagnosis once they studied and did some reading on the issue, diagnosis and medication decisions are made only after evaluating the information gathered against their experiences of their condition.

In this light, our data shows that the way patients draw on their experiential knowledge to build their expert self in interaction is much more complex and relevant than originally made out to be in studies examining the discursive construction of expert stances of chronic patients. For instance, in the framework proposed by Sanderson and Angouri (2013), experiential knowledge was included as an index rather than as a sub-theme in categories such as 'monitoring illness' (as part of the sub-theme 'ability to self-manage') and 'formalization of experiential knowledge' (in the 'expertise claimed by patient' sub-theme). However, we believe this consideration does not fully attest to the role of patients' self-knowledge/self-awareness as a vital resource in their construction of an expert self, and psychological ownership and empowerment over their condition (consider Kingod et al., 2017).

The patients tend to resist the treatment path or negotiate their treatment with doctors in rather rigid ways. The doctors' treatment decisions were often undermined and challenged (Example 1 and Example 3). This may be explained by the fact that both previous and current treating doctors seem to be occasional doctors to these patients, which may also explain why patients seem to approach the medical consultation with a clear idea of, for instance, their diagnosis. Yet, although some of the excerpts analysed may point at a clash between 'expert' (professional) expertise and patient expertise, a medical consultation does not seem to be about creating a dichotomy of patient versus medical experts (cf. Bellander & Landqvist, 2020). Rather, patients' lived experience in managing invisible and often chronic illnesses (due to the inefficiency of the healthcare system in their case) seems to have afforded them the epistemic right to adopt an active role towards making decisions about medication and treatment (cf. Koenig, 2011). Patients actively claim ownership over the trajectories of their illness (Example 1), and their experiential (Example 3) and acquired knowledge of it (Example 4). As a result, these patients often seem to feel in a strong position to negotiate their expertise and the management of their health decisions with the specialist.

Despite the fact that the student patients often sought professional advice, it is interesting to note how the doctor in most of these exchanges projected expertise on patients, by providing interactional space for patients to claim their expertise of the invisible condition by asking questions that aligned with the patients' orientation in the conversation, and by allowing more conversational time for patients to develop this. This finding is congruent with Pawelczyk and Talarczyk's (2018) study, which demonstrates how the therapist and the patient interactionally engage in co-constructing the patient's expertise, and how the therapist downgrades her epistemic position and bolsters the patient's voice as expert to accomplish the session's therapeutic goals. From a very practical perspective, challenging patients' expert stances in medical interactions may be counterproductive for doctors as this may affect doctor-patient relations and trust, and may have a negative impact on patient compliance. Besides, doctors may value patients' input as part of the medical consultation.

Finally, although the self-management of a chronic illness is the goal of a myriad of healthcare strategies of modern medicine, in the case of the patients with invisible conditions the perceived lack of appropriate treatment and follow-up schemes on the part of the public healthcare system (Télez et al., 2020) as well as perceived lack of understanding of the condition seems to compel them to take control over their own illness and self-manage it. As previous research has shown, when people suffer from conditions difficult to pin down and treat, and medical visits do not bring any positive results, patients tend to resort to their own coping strategies (e.g., Sowińska &

Czachowski, 2018). However, the fact that patients present themselves as knowledgeable and experts of their own condition does not mean this knowledge is always accurate. The danger of engaging in the self-management of an illness that was not diagnosed, supported and guided by the healthcare system in the first place (but rather developed by the patient alone) is that the patient may be ill-informed and thus may be basing their expertise on inaccurate information and inappropriate assumptions. This, in turn, may result in patients' non-adherence to treatment and/or self-medication, as it was shown in Example 1, which often does not lead to the successful treatment of chronic conditions. In fact, patients may well be ill-informed depending on the source on which they draw to gain further insights into their invisible illness.

Table 1. Themes, sub-themes and indexes of patient expertise.

Themes	Sub-themes	Indexes
Resources of constructing expertise	Domain-specific knowledge	<ul style="list-style-type: none"> • Use of medication names • Use of medical terms to refer to illness or condition • Recall of doses • Knowledge of aetiology • Laboratory test literacy
	Experiential knowledge	<ul style="list-style-type: none"> • Self-knowledge/self-awareness (e.g. recognizing signs and symptoms, recognizing social triggers of illness) • Drawing on previous visits to specialists • Chronology of related events • Assessing information against experience of illness/condition and assessing risk
	Ability to self-manage	<ul style="list-style-type: none"> • Self-control to avoid symptoms • Pacing • Monitoring illness • Seeking help
Performance of expertise	Expertise claimed by patient	<ul style="list-style-type: none"> • Revisiting trajectories of self-diagnosis • Recognition of technical knowledge • Psychological ownership of illness • Taking responsibility for treatment decisions
	Expertise projected on patient	<ul style="list-style-type: none"> • Expectation of compliance / adherence to treatment plan • Formalisation (validation) of experiential knowledge • Interactional 'space' to develop patient's case/narrative

Note: adapted from Sanderson & Angouri, 2013.

Transcription conventions

YES capitals for emphasis

[...] clarification

(...) deleted parts

- cut off word
- ! for emphasis
- ? question mark
- + short pauses
- “” inner dialogue

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APPENDIX

Example 1

Médico General (MG): En la concentración, ¿Cómo está para estudiar? ¿Te cuesta estudiar?

Paciente (P): Sí, también he mejorado últimamente, de la concentración, de la claridad, pero claro también tengo menos, eh... menos energía. Es que ahí igual, tengo algunos problemas por ejemplo igual estoy con cierta anemia entonces me falta un poco el...

MG: a ver...está un poquito en el borde, sí.

P: Claro, entonces eso también influye en un poco más lento.

(...)

MG: ¿Te estás tomando el medicamento que te dejó la doctora?

P: Me dejó para el colesterol y otro... para la anemia.

M: Para la anemia.

P: El del colesterol no me lo tomaré, el otro aún no lo necesito.

MG: ¿O sea no estás tomando el medicamento?

P: No.

MG: ¿Por qué?

P: El colesterol no me preocupa tanto.

MG: ...te dijo que tenías 406?

P: sí, si me dijo.

MG: ¿y sabes cuánto es lo normal?

P: ¿Normal?, como 200 y algo...pero no me preocupa.

M: eso es muy alto.

P: Sí, lo sé.

M: ¿no te preocupa... porque no te preocupa?

P: Porque el colesterol tampoco es que diga tanto, además esa es solamente la cifra del colesterol total, igual ni siquiera es que sea medido en cada grado. Además, es que ese fue un examen y entre exámenes puede variar. Por ejemplo, en el segundo dice que igual bajó.

MG: a 362

P: Bajó, a lo que es el colesterol bueno como se dice, el LDL igual esta alto. Los triglicéridos están bajo entonces no cacho.

MG: Lo que es malo, que es el LDL, que es el que forma placas en tus arterias, que forman placas en tus vísceras, es el LDL y está súper alto.

P: Es que los otros también están altos, entonces también sin verlos rápido, pero tampoco son elevados. Entonces, los otros análisis dicen que si, en la sangre hay un déficit, el tema de la anemia.

MG: ¿Qué explicación le das a eso?

P: Tampoco son, eh, los otros están mal, normales y en general también como cosas que son más bien saludables, no bebo alcohol, no fumo, entonces...

Puedes hacer todo bien y aun así tener anemia. Puedes hacer todo bien y aun así tener el colesterol alto.

P: No, no. Si no voy a eso. Lo de la anemia, claro hay algo ahí y hay algún problema y quiero corregirlo. Lo del colesterol, por si tengo todos los otro estoy bien, a eso le digo, a eso no me preocupa...Creo que, tener lo otro bien es más importante que lo otro.

MG: ¿Qué otro?

P: Lo otro. Bueno lo que decía, comer cosas saludables, no fumar, no beber, descansar bien, tener buenos hábitos, a que una cifra.

MG: ¿Quién dice eso? ¿Todo eso lo estudias? ¿lees mucho?

P: Igual sé, leí sobre eso.

MG: Ya

P: Obviamente no soy un experto, pero igual sé sobre eso.

MG: ¿Dejaste de tomar los medicamentos de un día para otro? ¿Cuánto tiempo no los has tomado?

P: Desde el verano.

Example 2

MG: Ya, ahora volvamos a este año. Ahora ya sientes que te vas a empezar a sentir igual, ¿eso?

P: Sí, el tema es que de un tiempo a esta parte ya presiento cuando me va a dar, como que ya sé mi límite de estrés o de preocupaciones que ya siento o digo: o me relajo o me va a volver a dar. El tema es que muchas veces la rutina a uno no permite relajarte o hacerte al lado y despejarte.

MG: Difícil, y más en la universidad.

Example 3

P: ...me vuelve el vértigo, pero ya sé que es eso...

MG: Ya...

P: Puedo intentar controlarlo...

MG: Mhm...

P: Pero es como que siento que... una avalancha viene hacia mí y mi ansiedad me juega en contra.

MG: Ya... ¿y nunca te dejaron tratamiento para esos vértigos?

P: No. (...)

P: Me quede con eso, porque después igual termine viniendo como a mitad de año a la psicóloga y ya me habían diagnosticado con, me dijeron que estaba a un paso de tener el cuadro de depresión...

MG: Ya...

P: Y ahí me empezaron a tomar pastillas, empecé a tomar como sertralina...

MG: Ya...

P: Y clonazepam para dormir...

MG: Ya...

P: Cómo por un mes o dos meses el clonazepam y la sertralina la termine de tomar ahora en diciembre. (...)

P: Y ella me dijo que me las iba a ir sacando paulatinamente, porque me había dicho anteriormente que me las quería sacar y yo le dije que no, porque estaba en tiempos de pruebas y... y no me encontraba como apta para que me las sacara...

MG: Claro sí, si estabas en periodo de estrés no es recomendable en ese momento hacer el...

P: Sí, entonces después me las fue sacando paulatinamente, ya en noviembre o diciembre ya estaba como con la mitad de una pastilla y ya después dejé de tomarla...

Example 4

MG: cuéntame más o menos, qué es o que te hace consultar. ¿Qué te pasó?

P: No...es que...voy a partir por el año 2017, que es cuando yo me acerqué aquí donde la psicóloga de la DGE, ehh yo creo que todo partió por el tema de que todo ese año, fue como el año más fuerte para mí en el tema emocional, porque sufrí varios cambios, así como...

MG: ¿así como que hubo cosas que te marcaron?

P: claro, algunos, hubieron algunos incidentes en la familia, etc., pero lo que más me dejó marcado fue la muerte de mi abuela y claro me acerque a la psicóloga y todo... pero por tema de fin de semestre no pude seguir continuando.

MG: Mmmm, ya, entonces tú esa vez consultaste a la psicóloga por, más por un luto.

P: Claro

MG: Fue después de tu abuela. ¿Fue mucho tiempo después?

P: Mira, no fue tanto, fue al principio del año, fue el primer semestre de ese año. Pero yo me vi muy atochado y en ese tiempo no estaba claro de lo que yo tenía realmente, entonces yo en ese mismo año empecé por las mías a investigar, lo que yo tenía, empecé a relacionar lo que yo sentía junto con lo que yo iba leyendo entonces yo ese año descubrí que sufría de mucha ansiedad.

MG: Ya

P: ansiedad, ansiedad y después junto con la depresión.

MG: ¿eso fue lo que manejaste con la psicóloga o no?

P: esos temas no los alcanzamos a hablar, pero yo sentía que eso, a lo que íbamos a terminar que al final iba a ser como el diagnóstico de ansiedad, etc.

MG: pero al final fue como un estudio tuyo nomas

P: Claro.