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After encounters: Revealing patients' unseen work through their pathways to care

Abstract

160 words

Research has long since focused on the notion of access and the trajectory towards a healthcare encounter but has neglected what happens to patients *after* these encounters. This paper shifts attention to what happens after healthcare encounters to develop a more nuanced understanding of how patients from a diverse range of backgrounds make sense of medical advice and how they mix this knowledge with other forms of information to make decisions about what to do next. This approach reveals significant unseen, unrecognised and unacknowledged work that patients undertake. Drawing on 160 in-depth interviews across four European countries the paper problematizes the notion of access; expands the definition of 'decision partners'; and reframes the medical encounter as a journey, where one encounter leads to the next. Decentring the professional from the healthcare encounter allows us to understand why patients take particular pathways to care and how resources might be more appropriately leveraged to support both patients and professionals along this journey.

Word Count: 7,972

Introduction

Previous research on healthcare seeking in diverse geographical areas has long since focussed on notions of 'access' and 'barriers' to services. However, little research has specifically explored and conceptualised what happens *after* a healthcare encounter. Rather than addressing

barriers to access, in this paper we pay close attention to what patients do after an encounter with a medical professional to re-frame how we think about accessing healthcare and its outcomes. We specifically focus on encounters with biomedical professionals. Our approach avoids conceptualising the patient as responsible for overcoming barriers to access and their health outcome, for example by getting appropriate information, or learning the local language. By shifting the focus to what happens after the encounter, the actions of both the patient *and* the professional are brought into analysis. By examining how a diverse range of patients make sense of, and act upon, advice reveal the large amount of work that patients undertake along their healthcare journey which remains unseen, unrecognised and unacknowledged when encounters with professionals are placed at the centre of analysis.

Focusing attention on what happens after the healthcare encounter (rather than the trajectory to an initial encounter) reveals how patients commit time, energy and resources to understanding and resolving their health concern. Understanding what happens after medical encounters might help to ensure resources are better placed to care for patients along their healthcare journeys.

This paper argues that exploring what happens after a healthcare encounter provides a deeper understanding of two areas. First, as mentioned above, the approach explores and disentangles the work that patients engage in after encounters reveals practical issues that prevent patients adhering to treatment plans, for example payment problems with insurance schemes or prescriptions, or lack of knowledge, information or distrust about prescriptions or treatment. Second, and perhaps more importantly, this perspective reveals how patients make sense of biomedical knowledge within the broader context of other understandings and beliefs and how different knowledge, understanding and beliefs are all used together to make decisions about treatment and care. By attending to the decisions that patients make after they have received health advice including who they turn to and why, and how they make sense of the advice

received in relation to other forms and advice and knowledge, we get a more informed and nuanced perspective of how resources are deployed. This could be applied to analysing healthcare-seeking behaviours and encounters with welfare services more generally.

Literature review: after medical encounters

Research on the patient-professional encounter has mainly focused on how diverse populations access professional medical care providers (Bowen 2001; DeVoe et al 2007; Gulliford et al 2002) and how patients and professionals communicate within the encounter (Park 2011; Dean et al 2017). Clinical psychologists, public health professionals and sociologists of health have explored professional communication skills and relationship-building between patient and professionals *within* medical encounters, particularly the implications of interpreters and other ‘third parties’ including family members as part of the encounter (Laidsaar-Powell et al 2013). Recently, notions of the ‘patient centred’ encounter and ‘shared decision making’ in medical encounters have gained currency. These approaches go a long way to acknowledging the complexities of patient-professional relationships and the uncertainty of the encounter. However, they do not fully address what happens after the medical encounter.

Clayman et al’s (2017) research argues that the time after the encounter is crucial both in the short term where patients reflect on decisions, seek information and choose whether or not to adhere to treatment plans and in the longer term where patients make new appointments and take action with their clinician’s knowledge. Clayman et al. term this ‘person-centered decision making’. However, this model intrinsically imagines the patient as operating within the biomedical sphere in all interactions concerned with their health; thereby masking the wide range of strategies that patients deploy that may fall outside of biomedicine. Patients may combine many different approaches and seek information and support from a much broader

range of sources than this model identifies (see Phillimore et al. forthcoming) Focussing on the actions after encounters reveals the extent of their work and provides a fuller understanding of patient experiences and decision-making.

Research that seeks to understand health information seeking is also primarily focused on the time before or during the medical encounter and not how patients seek information about their health afterwards (Kontos 2011; Rooks et al. 2012; Mendes 2017). Research attending to what happens after an encounter has often been restricted to understanding ‘second opinions’ (Goldman et al 2009; Greenfield et al 2012; Gross et al 2017; Moumjid et al 2007; Payne et al 2014). The research conducted on ‘second opinions’ has acknowledged that they are not always sought from medical professionals, but only recognises holistic therapies as complementary (Sutherland et al 1994; Tam et al 2005) thereby not recognising strategies that might be employed beyond complementary medicine (Cant and Sharma 2004).

Some research has come closer to linking healthcare seeking behaviour with the medical encounter by looking at families and the way that parents try to care for the health of their children through ‘family health work’. This approach recognises a crucial problem with the drive towards greater health literacy and ‘autonomy’ over care. Nichols et al. (2016) suggest that the healthcare system is only interested in information-seeking and patient autonomy insofar as it supports patients' engagement with the systems' existing practices, frames of validity and service pathways. People who are unable to demonstrate health knowledge and work that support existing systemic processes cannot effectively use what they know and already do, to support their children's health and wellness. Thus only a proportion of the unseen family health work is legitimated by healthcare professionals.

In contrast to the majority of the scholarly work undertaken in this research area, our approach does not conceive encounters as isolated incidents and but rather part of a patient journey

(Green et al. 2014). To think about the encounter as one discrete event mirrors the viewpoint of the health professional: when a patient leaves their consulting room professionals' have accomplished their work, until the next encounter. However, for patients, their work is often just beginning. They undertake a process of making sense of what has happened and what they should do next. The end of one healthcare encounter can be (and often is) the beginning of the next. Crucially, the next encounter is not necessarily with a biomedical health provider.

We argue that, in addition to previous research that has focused upon patients' search for second opinions (Gross et al 2017); through models of 'patient centredness' (Rivadeneira 2000); or 'shared decision making' (Makoul 2006; Hassink 2017; Unruh 2008) that the time after the encounter should take account of a broader range of factors. This approach reveals the diverse strategies patients employ to address health concerns including turning to the third sector, self-treatment, online advice and treatment, religious healing, transnational health-seeking and holistic therapy etc. Rather than a neat loop that leads from one professional encounter to the next (Clayman et al 2017), we argue healthcare journeys should be conceived of as constellations with various nodes where patients draw on a wide range of professional and lay advice (Green et al. 2014). For patients, this advice may not necessarily all sit within a conception of a biomedical explanation for their health concern as is often assumed in research delimited to biomedical conceptions and priorities.

Second, the potentially disruptive and risky nature of healthcare encounters gains a different salience when viewed from the perspective of what happens after the encounter. The meanings made after the encounter are potentially more important for the patient than the encounter itself, as suggested by the widely used concept of biographical disruption (Bury 1982). Health professionals control of encounters and privileged access to knowledge (Poteat et al. 2013) influences the strategies available to patients. By focusing on actions after the encounter, we

can gain a greater understanding of how the potential for repetition or rupture are negotiated in a history of encounters, and the diverse strategies that patients deploy.

The lay referral network (Freidson 1974) has long been seen as crucial to patients' decision to take their symptoms to a professional, but the time period after the healthcare encounter may be more crucial than the time before it. By taking this perspective we can place health professionals' knowledge and advice within an appropriate context for the patients' understanding of their health concern. Shifting the focus towards what happens after the biomedical encounter, including but also beyond the biomedical sphere, has practical implications, for example adherence to treatment plans, thinking differently about how to leverage information technology and how to use the internet to harness medical professionals' advice rather than undermine it.

Methods

Setting and sample

This research took place across four different countries: Germany, Portugal, Sweden and the United Kingdom. In total, 160 residents from 8 neighbourhoods (on average 20 per neighbourhood) were interviewed.

We aimed to produce meaningful comparative data on the experiences of residents across the eight case study locations in four European welfare states. Following Green and colleagues (2014) a narrative approach was selected in order to achieve a contextualised understanding of residents' healthcare-seeking behaviour, as 'narratives provide an analytic opportunity for exploring the links between structure and experience and between explanation and action' Williams (2004: 289). Narratives are crucial analytical devices (Rosaldo 1989) and 'stories are

inherently analytic, and ... in the sequence of reasoning, analysis has narrative form' (Narayan 2002: 8). We focus on in-depth accounts of residents' experiences in each of the four welfare states when solving their health concerns

First, we asked questions to gain an understanding of the subjective meaning that interviewees placed on health and 'staying healthy'. This enabled us to place the narratives in their wider context through residents' experiences, perspectives and standpoints as explained in the interview. Second, we asked questions such as 'what do you normally do if you have a health concern?' and encouraged interviewees to provide narrative accounts of their journey through a particular health concern which we termed 'timeline questions'. These involved asking interviewees to describe their healthcare journey, identifying the people, places and things that they used to orientate this journey and what each of these provided in terms of information support, shifting expectations or perceptions of care. For example, we asked 'Since you were living in this area when were you last ill or had a health worry and felt you needed to get some help?'

For each health concern we gained detailed information regarding what the interviewee did and why, the temporality of the health issue and events within the healthcare journey and exactly who was spoken to and why, what they suggested and how it made the interviewee feel or act. We also prompted interviewees as to whether they used the internet or consulted informal, alternative or complementary medicine, used faith based or transnational approaches.

Our starting point for recruitment was specific neighbourhoods in each country in order to include people from a wide variety of backgrounds. We used maximum variation (heterogeneity) sampling to ensure diversity in the composition of the sample in each country in terms of their age, gender, ethnic and linguistic backgrounds, and to ensure the inclusion of participants from majority and minority populations. This approach is a form of comparison-

focused sampling that selects cases to compare and contrast to learn about the factors that explain similarities and differences. The method involves purposefully picking a wide range of cases to enable variation on dimensions of interest for two purposes. First to document the diversity of experiences, and second to identify important common patterns that appear across the diversity in the research sample to cut through the ‘noise’ of variation (Patton 1990: 267). Our sample included residents from a wide variety of countries of origin, ethnicities, immigration statuses, life stages and faiths. The core shared aspects that emerged, despite these many intersecting axes of difference hold increased authenticity and validity because they are not the result of a pre-determined characteristic or a particular interest in a pre-defined group of informants. All interviews were digitally recorded and then transcribed.

Analysis

Through interviews we were able to construct a detailed and nuanced picture of how residents sought (or not) to solve a health concern and their subjective understandings of this process. This approach is innovative because it starts from the health concern (self-defined) and all the steps that lead to solving it rather than an interaction with a health professional. The methodology does not privilege or assume that visiting a health professional is at the heart of solving a health concern. But the methodology does allow us to identify the obstacles and barriers that patients encountered and when possible, how they overcame them.

Data were coded using a systematic thematic analysis approach (Guest 2011) to identify the key issues and moments raised by respondents. This involved interpretive code-and-retrieve methods wherein the data were transcribed and read by the research team who together identified codes and then undertook an interpretative thematic analysis. A standard and share coding frame was then developed and all interviews for each country were coded using this

common framework. The authors then analysed each of the health concerns and traced what happened before, during and after an encounter. From this analysis, it emerged that how residents made sense of the information provided by medical professionals was a crucial element of making decisions about their health concern. The work undertaken after a medical encounter emerged as a key defining moment in the trajectories of residents' health seeking journey. All interviews were then analysed for instances of the work 'after encounters'.

Ethical permission from the relevant local committees was obtained. We identified respondents by approaching people on the streets, connecting with local NGOs and using our researchers' social networks. We explained the nature and purpose of the research first verbally, then when individuals expressed an interest in participating, gave them an information form and the opportunity to ask questions. Interviews were then arranged at a time and place of the respondents choosing and in the language of their choice. Interviewees and interviewers signed consent forms which emphasised interviewees' option to withdraw from the interview at any time. All names used in this paper are pseudonyms (for complete list of interviewees please see appendix).

Problematizing the notion of 'access to health'

The importance of considering what happens after a healthcare encounter is underlined by the observation even some respondents who enjoyed what they considered was a positive healthcare encounter, nonetheless contended with practical issues afterwards in terms of difficulty in following treatment plans. A range of issues and challenges to accessing health resources were revealed by focusing specifically on what happens after an encounter with a medical professional. These include problems of interpretation and confusion after the encounter; costs of accessing prescribed medication; use of alternative medication; self-

treatment; and transnational health seeking among other actions. These insights reveal how patients make sense of medical advice and how they mix this knowledge with other forms of information specifically that there are various barriers at work in respect of making sense of medical advice but what emerges as most important is accessing health resources.

For example, Aminah, a 23 year old Syrian asylum seeker living in Sweden, had a vaginal yeast infection and was very embarrassed about visiting the doctor. Eventually, she asked a friend who reassured her it was a normal problem and that she should visit the drop-in clinic. She said the medical encounter itself went well however, Aminah confronted problems after obtaining the medication becoming confused because the medication she was prescribed had a picture of a foot on it. At this point what had been a good encounter was thrown into uncertainty. She was not sure what to do and said, of the doctor *'she gave me a cream for like, there was a foot on it. I was like "Is this for like feet?"'*

At this point Aminah decided to return to the doctor to check the medication. She continued

I was like, I told her, to the doctor "I just want to make sure of something, is this the right thing you gave me?" and she was like "Yeah, its like" she called the pharmacy man and she asked him, they talked a little bit and she told me like it's alright, it's the same thing. But I was thinking, I know it might be the same problem but I was like a bit scared because, you know, the feet are things that you put something on the outside, you know.

Moreover, the way that the doctor understood her confusion when she returned to check the medication increased her trust and confidence in health care professionals.

Yeah, it was very nice, she was very nice and I liked the thing they understood what happened, because when I told her that this happened, like this itchy thing happened

before, I told her like yeah, it was because I took Augmentin, and she said "Yes exactly, it happens!" because it was a bit embarrassing and, you know, to have this kind of illness and she was like "It's OK, it's normal and it happens when you get this antibiotic thing".

Her encounter did not end when she received her prescription. Her concern was easily dealt with but her experience highlights the importance of the stages after the medical encounter itself that discussions around a strict frame on access to health may not capture. She also felt reassured because the doctor told her it was not her fault, she had not 'done' anything wrong but this was a common problem with antibiotics. It is also important to take the country context into account. ~~This encounter took place in Sweden where it may be easier to make a follow-up appointment than it is with a doctor in Portugal.~~

The issue of cost also emerged for our interviewees but there were markedly differences between countries. In the UK and Sweden cost did not emerge as a problem for patients. However, in Germany accessing prescriptions or care that fell outside health insurance schemes or in Portugal where there are no health insurance schemes, was a problem despite relatively easy access to professional healthcare and positive descriptions of the healthcare encounter itself. For example, migrants with uncertain legal status often found clinics where they were able to receive professional health advice. However, problems arose for these interviewees after their healthcare encounter when they considered their treatment options. For example Nagette, a 38 year old Nigerian hair stylist living in Germany, had a pain in her lower abdomen. She did not have a legal status in Germany but found a doctor who would examine her. She was diagnosed with fibroids and offered an operation but wanted to wait until she had her legal status so that she had a hospital card. In the meantime she states

I went to Africa there's one of my brother's wife is a nurse... so she said there's a, there's a native medicine and it's English medicine too but this native medicine, if I'm drinking it, it will be drying, drying it... so it like it's melting it. So I said okay, so I started drinking the medicine before I come back to Europe. So when I came back I went for check-up they said, "It's just tiny, tiny".

Her friend subsequently found her a local gynaecologist who would see her despite her legal status. She went to the gynaecologist without money for treatment so she is continuing to treat her condition with herbs.

So she (gynaecologist) now gave me other doctor number. I should call and I said okay. So, I didn't go. I didn't go because I said eh... I was not having money... because if I go, it's going to be money. So I just decide okay, let me wait, meanwhile I was expecting very soon my visa will come out so I can get hospital card everything so that I can so... It wasn't the way I expect it. So the stress was now... over me, I said okay... So that is why since then I have not been there, ja.

Nagette could access the doctor, trusted them and received the information she needed. However after her encounter in discussion with friends she finds an alternative treatment to see her through until she can formally access biomedical treatment.

For patients like Nagette, focusing only on health 'access' does not capture the full range of challenges that she encounters. Shifting the focus to after encounters brings issues regarding treatment and care into the analysis. The issue of cost did not just emerge for migrants with uncertain legal status. For example, Mona's daughter was born unsighted. Mona, a 37 year old Syrian architect with refugee status in Germany, had many successful encounters with health professionals who recommended specialist therapies for her daughter. However, these therapies were not covered by her health insurance. After the encounter Mona engaged in long

discussions with her relatives for support and financial assistance so she could afford the special therapies for her daughter.

The after encounter approach demonstrates the limited lens of 'access' and how much is masked when the focus of inquiry is only on biomedical encounters within one country rather than following the patient across a wide range of healthcare strategies and countries. Transnational health-seeking becomes important because to address communication barriers; lack of local support and the cost of some procedures and prescriptions. For example Maher, a 27 year old single man from Syria without residency rights in Sweden, injured his hand. His experience demonstrates how lack of knowledge about eligibility and barriers between emergency and secondary care have consequences despite a seemingly smooth initial medical encounter. He accessed A&E and received sutures for his hand injury, an initial experience he describes as positive. However, he cannot receive follow-up care for his injury so engaged in transnational health-seeking after the medical encounter.

I went to the hospital and I had my papers and everything and then they sutured my hand but they gave me a paper and told me to go the country where I came from in order to do an operation there. So I went to the country where I came from, and it didn't work... I had to go to Turkey in order to do an operation on my hand. This has hurt me a lot.

Following his discharge from hospital Maher travelled first to Germany but was unable to receive treatment there because *'I don't know anyone there so in order for me to access health care there, it would at least take me a week or so... I don't know anyone and I can't speak the language so I had to leave immediately to Turkey from there'*. Subsequently he travelled to Turkey where his friends paid the cost of a private hospital and private care. This protracted journey to care began in a Swedish hospital where he experienced no initial barrier to access.

Examining what happens after a healthcare encounter is vital to shed light on the amount of work that Maher undertook and the range of resources and advice he employed that did not relate to his initial encounter in Sweden. This section has shown how important a range of other influences and resources, in addition to what we might term ‘access to care’ are required for patients to gain an appropriate resolution to a health problem.

Revealing unseen work: extending the notion of ‘decision partners’

In addition to problematizing the notion of access in medical encounters, paying close attention to what patients do after an encounter reveals the range of resources that many patients deploy. In particular, we highlight three points in this section: first, the differential use, role and rationale of decision partners; second, the differential use of internet ~~healthcare encounter~~; and third, the implications of using a wide range of decision partners for adherence to formally prescribed treatment plans.

Many respondents sought reassurance and advice after healthcare encounters. This search for comfort and support has been termed consulting with ‘decision partners’ (Clayman et al 2017), referring to family members or close friends. We found that advice and reassurance was sought after the encounter from a wider social network, including yoga teachers, library staff, language teachers and NGO employees. Decision partners had somewhat fuzzy roles. Individuals who were medically trained but were also family members, for example a sister who was a nurse, were described as the most trusted advisors. The current literature on ‘decision partners’ does not acknowledge the combination of roles that some decision partners hold (Wenzel et al. 2015; Scholl 2011; Shin et al. 2013). The comfort provided by these individuals stemmed from having a long-standing personal and familial relationship who could offer support and knowledge to enable individuals to reflect on the outcomes of the encounter.

A case in point is Isabela, a 33 year old single woman from Brazil living in Portugal who began to lose her hair. Isabela undertook a large amount of work to try to solve this health concern after a private consultation with a dermatologist that did not address her concerns:

He didn't even ask me for any blood test and he only asked me to be calm and prescribed me a sedative and later I did a research about what it was as I don't take any medicine, but that time I was very nervous. So I bought it, and I had to take 2 per day and I used to take only half. But then I thought I should be doing wrong to take half than to take nothing'

Her dissatisfaction during the first encounter extended to the treatment she was offered. Although she did begin the treatment she did not follow the prescription.

didn't feel anything... so I started looking to enrol in a healthcare center. Because I came to Portugal with my PB4, this is a document that Brazilian use to show that the person is entitled to have healthcare, but when I went to enrol myself there in the healthcare center, they had little information about that document, they didn't even want to enrol me, it was very complicated, I was attended badly.

Isabela's perceived legal status impeded her from gaining a second opinion from a medical professional. Simultaneously she also discussed her condition with her yoga teacher.

My Yoga master indicated me a doctor of Chinese medicine, who is an acupuncturist. She was excellent as she was recommended by the one whom I had a trust and I had a discount too and I started doing this since October and I started getting better with acupuncture.

While attending the acupuncture, Isabela sought new ways to resolve the barriers to formal medical provision.

I searched for the citizen office and there Viviane [a volunteer] helped me (laughter) and started to go with me... they did not understand the dual citizenship situation and did not even know how to enrol me. I also had another problem with my healthcare card which was not the same European healthcare card, it was an Italian healthcare card valid till January 2015 and it was about to expire. He wanted to enrol me in healthcare center under the validity. It was so confusing, so I had to redo my card, to then I solved this documentation problem. We even went to the social security office, and look, even at the last consultation that I had, I went there with 5-6 documents because I do not know which one is correct and which one they are going to accept. I always take my passport because I do not know whether they will accept my Driving license which is Portuguese. It depends a lot on the person who attends me, they never understand my situation and what my number is.

While Isabela tried to resolve her access situation her condition deteriorated so she decided to fly to Brazil to seek treatment. She saw a private dermatologist, had tests and was diagnosed with diffuse alopecia areata. With this diagnosis Isabela returned to Portugal having finally gained access to the public health system with the aid of an NGO and began attending regular medical appointments. At the time of the interview she was seeing a dermatologist in the Portuguese public hospital. These actions foreground how the different professional medical knowledge she gathered while attempting to address her condition is made sense of relationally between the patient and many different people including health professionals in Brazil and Portugal, a Portuguese NGO and other health interlocutors such as her yoga teacher, an acupuncturist, and her mother who is a pharmacist. After Isabela's initial medical consultation which she described as deeply dissatisfying her pathway to care crossed different services, countries and continents. Isabela's case also demonstrates how these issues intertwine and may compound each other, such as bureaucratic barriers impeding access to care and the dismissal

of her problem as minor by biomedical professionals. Moreover, Isabela exemplifies how medical knowledge from one health professional provides only one form of understanding deployed by patients to make sense of their condition. It is by no means the only (and may not be the most valued) knowledge that they use to make decisions about their health care for example Isabela's yoga teacher recommended an acupuncturist and after disappointing encounters with health professionals she focuses much of her attention on complementary therapies. Paying attention to the work that patients undertake after an encounter reveals the diverse strategies they engage in with a range of different actors or 'decision partners' to gain comfort and reassurance (Clayman et al 2017). This section has demonstrated how different strategies inter-relate and affect each other.

Luis, a 28 year old salesman from Spain, living in the United Kingdom noted that he always Skypes his uncle, a doctor in Spain, when he needs health advice. Following a football injury Luis said

I went home, I took the bus and went home and then from home I sat down and I tried to stand up and I couldn't so... I have an uncle who is a doctor he knows everything! He said you should go to the hospital and get the liquid out and everything should be fine.

Crucially, his uncle does not have particular knowledge about sports injuries but he trusts him the most in relation to his healthcare 'He is a cardiologist. He is the cleverest person I know'.

Luis' case is an example that was replicated across all our case study countries regardless of the particularities or availability of their national health services. Residents trusted and depended on medical professionals within their own family even where they had no knowledge of the local healthcare system. These decision partners were used across the range of residents from high-income professionals who had been born and lived in the same country, to those

who had recently arrived and had no previous contact with healthcare there. Our findings indicate that patients seek out information that they value, but that the substantiation of this information intrinsically relies on the social relationship. Respondents turned to these family members after they had visited a health professional in a bid to better understand their health concern and the best course of action for them to follow. Crucially, trust appeared more important than specific medical knowledge.

Technology appeared to be used in a similar way as decision partners (and also a form of care) after encounters. Recent patient decision-making research has been dominated by the role of internet searches (Murray 2003) with online health information-seeking related to the patient – professional encounter (Tan 2017), but there has been little research that examines the role of the internet in finding information after the encounter. Searching the internet can have positive and negative repercussions for treatment plans (finding supportive forums on the internet or through gaining contradictory opinions that undermine adherence to treatment or cast doubt on professional opinion).

Some respondents with chronic conditions had no support network, a situation they described as leaving them isolated and anxious. One way they managed such feelings was through searching the internet to assuage the shock and rupture of a serious diagnosis. For example, Serena, a 36 year old student in the UK, was diagnosed with a brain aneurysm which brought about panic attacks. She describes the reaction to her condition by health professionals ‘they told me to go home and have a bottle of wine’. Her inability to access the information she wanted in that initial encounter left her feeling distressed causing. In order to make sense of the information she received in the encounter she sought advice in internet chat rooms and forums. Communication technologies are often used to contact online medical specialists for advice and to access information to inform decision-making.

Use of the internet after encounters could lead to prescribed treatment plans being abandoned. For example, Elsa, a 60-year-old Colombian shop owner living in Portugal, stopped taking medication for heavy menstrual bleeding after she read the list of side-effects on the internet. Insufficient explanation of dosage and side-effects by health professionals is one of many reasons why respondents sought information after a biomedical encounter.

This section has explored the differential use, role and rationale of decision partners. Our findings indicate that it was commonplace to consult a wide variety of decision partners after a biomedical encounter. Trust was of clear importance when sourcing advice from decision partners, including engaging in transnational activity and formal and informal provision. Crucially, trust appeared to be more important than specific medical knowledge possessed by such partners. In addition, this section has foregrounded the differential use of internet following healthcare encounter. Such technology was used to contact specialists for advice and to access information that could inform decision-making. This latter point has implications for adherence to formally prescribed treatment plans.

Conclusion: After encounters and ways forward

In this paper we used the medical encounter as the starting point, rather than the end point of the analysis representing a significant departure from previous perspectives shedding new light on how we envisage the patient-professional relationship and the nature of health seeking. This paper has shown that actions undertaken by patients following an encounter shape their engagement with treatments and medication. Our timeline analyses have revealed the amount of unseen work that people embark on after they have engaged with a health professional, providing a nuanced perspective through which to consider patients behaviours.

Crucially, medical advice is just one of many different types of knowledge that patients engaged with to make sense of their health concern after the initial encounter. Our findings have implications for both policy and practice on healthcare seeking. First, given the importance of the internet as a resource it is possible to acknowledge how such technology could be harnessed to provide support after an encounter through biomedical professionals providing links to key information that they perhaps do not have time to share. This information could be offered in multiple languages. Second, we highlight how a wide range of decision partners shape post-encounter responses and actions which can support patients to make sense of their health concern and treatment. We also show that a multiplicity of advice is sought simultaneously and that actions are frequently guided by trusting relationships. Third, we demonstrate how initial encounters are inextricably linked to later events while highlighting how encounters which patients see as unsatisfactory appear to push some patients to use alternative services, and even cross countries and continents in search of a resolution.

The importance of the after-encounter emerged because of the study's innovative and rigorous methodology. Through taking a narrative approach to data collection focusing upon processes of healthcare seeking we were able to construct a detailed and nuanced picture of how people sought (or not) to solve a health concern and their subjective understandings of processes. Our approach is novel because it starts from the self-definition of health concern, accounting for all the steps that lead to solving it rather than an interaction with one or more type of service, condition or social group. The methodology does not privilege or assume that visiting a health professional is at the heart of addressing a health concern, on the contrary, it is only one possible step. Thus we argue that future research seeking to understand access to healthcare services should take into account the entire process of healthcare seeking. This might include pre-encounter interactions and actions as well as those that occur after the encounter is they are to understand the nature of actions which shape patient behaviours.

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Appendix 1 – Table of respondents

Age	M or F	Ethnicity	Languages	Legal status
30-44	M	Asian	Punjabi	Naturalised
45-59	F	Asian	Gujrati	Naturalised
60-79	M	Asian	Hindi	Naturalised
30-44	F	Asian	Cantonese	Native
18-29	M	White	Russian	EU national
60-79	F	Asian	Mandarin	Naturalised
18-29	M	White	Spanish	EU National
18-29	F	White	N.D.*	Native
60-79	M	White	N.D.	Native
18-29	M	White	French	Native
18-29	F	White	Swedish	EU national
18-29	F	Asian	Arabic	N.D.
60-79	F	White	None	Naturalised
30-44	F	Mixed	French	EU national
60-79	M	White	German	Native

45-59	M	Asian	Cantonese	Naturalised
30-44	F	Mixed	Spanish	Native
18-29	F	Asian	Mandarin	Asylum Seeker
30-44	F	White	Polish	EU national
60-79	M	Asian	Malay	Naturalised
45-59	F	African/Caribbean	Arabic	N.D.
60-79	F	White	Swedish	N.D.
18-29	M	Asian	Arabic	N.D.
45-59	F	N/A	Somali	N.D.
60-79	M	Other	Swedish	N.D.
30-44	M	White	Swedish	N.D.
18-29	M	N/A	Tigrinya	N.D.
45-59	F	White	Russian	N.D.
30-44	M	Asian	Arabic	N.D.
60-79	F	White	Swedish	N.D.
80+	F	Asian	Persian	N.D.
45-59	F	African/Caribbean	English	N.D.
60-79	F	Asian	Persian	N.D.
45-59	F	Asian	Swedish	N.D.
30-44	M	White	Swedish	N.D.
80+	M	Asian	English	N.D.
30-44	M	White	Swedish	N.D.
30-44	F	N.D.	German	Permanent Leave
30-44	F	African/Caribbean	German	Temporary Leave
30-44	F	N.D.	German	Permanent Leave
30-44	F	African/Caribbean	English	Temporary Leave
45-59	F	N.D.	German	Permanent Leave
45-59	F	African/Caribbean	Arabic	Permanent Leave
30-44	F	Asian	Turkish	EU national
60-79	M	N.D.	German	Permanent Leave
18-29	M	Other	German	Refugee
60-79	F	African/Caribbean	French	Permanent Leave
30-44	M	Other	Bulgarian	EU national
30-44	M	African/Caribbean	German	Permanent Leave
30-44	M	African/Caribbean	French	Temporary Leave
30-44	F	N.D.	Bulgarian	EU national
30-44	F	African/Caribbean	German	Permanent Leave
30-44	F	N.D.	German	Permanent Leave
30-44	F	Asian	Arabic	Permanent Leave
45-59	M	N.D.	German	Permanent Leave
30-44	F	N.D.	German	Permanent Leave
45-59	M	N.D.	German	Permanent Leave
80+	F	African/Caribbean	None	Naturalised
45-59	M	Asian	Punjabi	Naturalised

30-44	F	Asian	Vietnamese	Naturalised
18-29	M	Asian	Urdu	Naturalised
60-79	M	Asian	Urdu	Naturalised
30-44	F	Mixed	N.D.	Native
60-79	M	African/Caribbean	N.D.	Naturalised
60-79	M	Mixed	Urdu	EU national
18-29	M	Asian	Bengal	Native
45-59	F	Asian	N.D.	Naturalised
60-79	M	White	English	Native
45-59	F	White	Bosnian	N.D.
45-59	F	African/Caribbean	None	Native
30-44	F	African/Caribbean	French	Naturalised
60-79	M	African/Caribbean	German	Naturalised
30-44	M	White	None	Native
18-29	M	Asian	Turkish	Naturalised
45-59	F	African/Caribbean	Swahili	Naturalised
30-44	M	African/Caribbean	French	Naturalised
18-29	M	African/Caribbean	Arabic	Refugee
45-59	F	N.D.	Portuguese	Native
45-59	M	N.D.	Portuguese	Native
30-44	F	N.D.	Portuguese	Permanent Leave
30-44	M	N.D.	Spanish	Native
60-79	F	N.D.	Portuguese	Permanent Leave
30-44	F	N.D.	Portuguese	Native
30-44	M	N.D.	Creole	Permanent Leave
30-44	M	N.D.	Hindi	Permanent Leave
60-79	F	N.D.	Portuguese	Permanent Leave
30-44	M	N.D.	Portuguese	Native
30-44	F	N.D.	Portuguese	Native
30-44	F	N.D.	Portuguese	Native
30-44	M	N.D.	Portuguese	Native
30-44	M	N.D.	Portuguese	Native
45-59	M	N.D.	Portuguese	Native
45-59	F	N.D.	N.D.	Native
18-29	M	N.D.	Spanish	Native
30-44	M	N.D.	Spanish	Native
45-59	F	N.D.	Portuguese	Native
60-79	F	N.D.	Portuguese	Native
18-29	F	N.D.	Nepali	Temporary Leave
30-44	F	N.D.	Nepali	Temporary Leave
30-44	F	N.D.	Portuguese	EU national
45-59	F	N.D.	Portuguese	Native
60-79	F	N.D.	Portuguese	Native
60-79	F	N.D.	Portuguese	Permanent Leave

45-59	M	N.D.	Portuguese	Naturalised
18-29	M	N.D.	Bengali	Temporary Leave
60-79	F	N.D.	Portuguese	Native
80+	F	N.D.	Portuguese	Native
80+	F	N.D.	Portuguese	Native
30-44	F	N.D.	Punjabi	Temporary Leave
45-59	F	N.D.	Punjabi	Permanent Leave
18-29	M	N.D.	Portuguese	Native
45-59	M	N.D.	Portuguese	Temporary Leave
18-29	F	N.D.	Bengali	Temporary Leave
30-44	F	N.D.	Portuguese	Permanent Leave
30-44	F	N.D.	Italian	EU national
30-44	F	N.D.	Portuguese	Permanent Leave
18-29	M	N.D.	Spanish	Temporary Leave
45-59	M	N.D.	Spanish	EU national
45-59	F	N.D.	Chinese	Permanent Leave
18-29	M	N.D.	Creole	Undocumented
30-44	F	N.D.	Punjabi	Undocumented
30-44	M	N.D.	Punjabi	Undocumented
30-44	M	N.D.	German	Undocumented
30-44	M	N.D.	German	Permanent Leave
30-44	F	White	German	Permanent Leave
45-59	F	N.D.	German	Permanent Leave
30-44	M	N.D.	Spanish	Temporary Leave
18-29	F	N.D.	Arabic	Undocumented
18-29	F	N.D.	German	Permanent Leave
45-59	F	N.D.	German	Permanent Leave
45-59	M	N.D.	German	Permanent Leave
60-79	M	Asian	Arabic	Permanent Leave
30-44	F	African/Caribbean	English	Temporary Leave
60-79	M	Asian	Tamil	Permanent Leave
60-79	M	N.D.	German	Permanent Leave
45-59	M	Asian	German	Permanent Leave
30-44	F	White	German	Permanent Leave
80+	F	N.D.	German	Permanent Leave
45-59	F	N.D.	German	Permanent Leave
80+	M	N.D.	German	Permanent Leave
45-59	F	N.D.	German	Permanent Leave
45-59	F	N.D.	German	Permanent Leave
30-44	F	White	Swedish	N.D.
18-29	M	Asian	Swedish	N.D.
18-29	F	African/Caribbean	Swedish	N.D.
80+	M	White	Swedish	N.D.
80+	F	White	Finnish	N.D.

60-79	F	African/Caribbean	Somali	N.D.
45-59	F	African/Caribbean	Somali	N.D.
80+	M	White	Swedish	N.D.
60-79	F	White	Swedish	N.D.
45-59	M	African/Caribbean	Swedish	N.D.
18-29	M	Other	Swedish	N.D.
30-44	F	White	Swedish	N.D.
45-59	F	Asian	Arabic	N.D.
60-79	F	Asian	Arabic	N.D.
45-59	F	White	Swedish	N.D.
18-29	F	Asian	N.D.	N.D.
30-44	M	Asian	N.D.	N.D.