



2019

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Recommended Citation

Roddis JK, Holloway I, Bond C, Galvin KT. Acquiring knowledge prior to diagnosis: A grounded theory of patients' experiences. *Patient Experience Journal*. 2019; 6(1):10-18. doi: 10.35680/2372-0247.1317.

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Acquiring knowledge prior to diagnosis: A grounded theory of patients' experiences

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Abstract

This research aimed to explore and explain how people make sense of long-term health conditions. Using purposive and theoretical sampling within a grounded theory design, experiences of thrombophilia and asthma were explored. The article focuses on information gained by patients before diagnosis and how this contributes to their understanding. The study adopted a constructivist grounded theory approach, generating a theory of how individuals adapt to their long-term condition. Ethical approval was sought from the NHS and the institution at which the research was conducted. Data were collected through semi-structured interviews, with sixteen participants who had provided informed consent. Individuals with long-term conditions frequently gain knowledge about their condition before diagnosis, through clinical encounters, from friends, family or acquaintances, by linking specific symptoms to a particular condition, or through experiencing ongoing symptoms. Knowledge gained before the point of diagnosis enables individuals to become informed about their condition. Some of this knowledge may be accurate, some may be specific to them as individuals and some of it may be misunderstood or coincidentally linked to their condition. However, patients will use and rely on this knowledge, particularly in the absence of evidence to the contrary. Healthcare professionals may wish to talk through patients' understanding of their condition at the point of diagnosis, in order to identify and correct misunderstandings and provide information of which patients are unaware. They could also use the opportunities offered at medication and other review touchpoints to review patients' knowledge and understanding.

Keywords

Patient experience, qualitative methods, long-term condition, thrombophilia, asthma, pre-diagnosis, patient knowledge

Introduction

This paper will specifically consider one of the major findings of a wider study (previously reported in Roddis, Holloway, Bond and Galvin¹), concerning how patients acquired knowledge and information about their condition before being formally diagnosed. The overall purpose of this research was to explore and explain how people make sense of long-term health conditions. Through the use of both purposive and theoretical sampling within a grounded theory design, experiences of individuals with thrombophilia and asthma were explored.

Thrombophilia is a long-term condition which increases the individual's risk of having a blood clot (thrombus), due to either inherited or acquired factors. This risk is further increased by events such as immobility, long-haul flights, pregnancy and some medications. Patients may be advised to make lifestyle changes, prescribed short-term treatment (for example, to reduce their risk when flying) or prescribed ongoing treatment in order to reduce their risk of having a clot. Asthma is a long-term condition characterised by inflammation of the lungs, which leads to

symptoms of shortness of breath, chest tightness, wheezing and coughing. It can be aggravated by factors such as pollution, infection, exercise, pollen, moulds and fungi amongst others, and a heightened emotional state may also trigger an exacerbation. It is usually treated through a combination of preventer medication (often corticosteroid inhalers, potentially with additional medication) and reliever inhalers to reduce symptoms. Both these conditions were examined because they can be life-threatening, and potentially lethal if undiagnosed and untreated. Conversely, the two conditions can have a minimal effect on one's life on a day-to-day basis; this is the reason they were selected for consideration in the study.

The original research was conducted by undertaking interviews with individuals affected by one of the two conditions. Analysis involved using a grounded theory approach. Themes were identified in the data. These were then grouped into categories before the parameters of the categories were identified. A provisional theory was developed. This was repeated with each set of data in an iterative manner.

Whilst the wider study developed a model of how individuals with a long-term condition can achieve well-being, this paper focuses on the knowledge gained by these patients before diagnosis.

More than 15 million people in England are affected by long-term health conditions². Several studies have shown that the preferred sources of information on long-term conditions, including asthma, are healthcare professionals³⁻⁷, although they may rate different information as being of importance when compared with patients^{8,9}. Professionals do not always wish to provide detailed information, due to concerns that this may cause anxiety or repeat visits from patients, and could undermine their judgement in prescribing medication¹⁰. Individuals with long-term conditions such as asthma gain information from other people, including support groups and family members^{6,7,11,12}, though this can result in misconceptions and misunderstandings⁹. Healthcare providers have been demonstrated to hold different health beliefs and values when compared with patients, particularly in the areas of meaning of illness and of working in partnership with one another¹³.

The internet is often trawled to search for information¹⁴⁻¹⁷ and may be of particular use where patients feel they are not receiving enough information from health professionals¹⁵. However, information found online may be confusing or written in technical language and therefore not easily understood^{16,18,19}. Patients using internet discussion boards considered themselves to be responsible for the management of their condition, but valued working in partnership with doctors²⁰. Discussion boards provided support and information²¹. However, patients became distressed by others' stories, and the boards led to misinformation and misunderstandings²².

Thus, information is acquired from a number of sources, and is of varying degrees of use. Several studies have demonstrated that healthcare professionals are a preferred source of information, but their views of what is necessary may differ from that of patients. Another source is the internet, which is convenient with regard to time and place, allows individuals to gain information, and may support decision-making, though there are a number of recognised problems with its use. Information and experiences are shared within families and with others accessing support groups. Risks include the potential for this to be incorrect and perpetuate inaccuracies.

Whilst the literature demonstrates the variety of sources used to gain information about long-term conditions, few studies differentiate between the knowledge gained before a diagnosis has been reached, and that sought or gained following a diagnosis. One of the few studies to do so is that by Attfield, Adams and Blandford²³, who found that patients will look for information before consulting a

healthcare professional, in order to determine whether they should see a doctor and in preparation for the clinical encounter. The findings of the current study confirm that those with long-term conditions may gain knowledge before receiving a diagnosis.

Methods

A constructivist grounded theory approach enabled the development of a theory about the way in which the participants made sense of their long-term condition (a full description of the methods can be found in Roddis, Holloway, Bond and Galvin¹). This type of grounded theory contends that knowledge and meaning is constructed and reconstructed by individuals and society, rather than being discovered²⁴. Meaning, process and interaction are emphasised²⁵, revealing the meaning people attach to having and adapting to a long-term condition, and the effect this has on their sense of self.

Following the tenets of grounded theory, theoretical sampling – sampling that follows up emerging concepts – indicated that certain ideas ought to be revisited after the initial interviews. The original research topic, the perspectives of people with thrombophilia, was decided upon as, unlike many chronic conditions considered in the literature, this condition can lead to ill-health and occasional life-threatening illness. It does not, however, appear to change people's lives significantly, in contrast to those illnesses which Charmaz²⁶ describes as causing the self to become lost. Asthma was selected as a second comparative condition due to its similarity in this regard.

An initial literature search was undertaken at the start of this research, as is usual in qualitative studies, with a view to identifying gaps in the existing knowledge and to place the research in context²⁷. Further literature of relevance was identified according to, and used in dialogue with, the study findings.

An iterative approach was adopted to data collection and analysis²⁸ and, as stated, emergent concepts were followed up through theoretical sampling. This is a method of sampling whereby the researcher recruits participants according to their potential contribution to the concepts emerging from the data. A fundamental element of grounded theory research, it permits the further development and explication of categories. Study participants were recruited via two local hospitals and a national charity which works with people who have suffered from blood clots. Concepts which had arisen were followed up by exploring the perspectives of people with asthma. Although difficult to achieve²⁵, saturation has been attempted by stopping data collection only when the concepts and categories relevant to the research aim had been explored, and no further ideas important to the emerging theory had arisen.

Semi-structured interviews²⁹ with sixteen individuals were used to collect data. These were undertaken either face-to-face, in the homes or workplaces of participants, on University premises, or by telephone, and became increasingly structured as the research progressed and concepts gained clarity. Ethical approval was gained from the University together with the NHS Research Ethics Service (reference 08/H0201/87). Permission was received from the charity to advertise the study on its closed Facebook page. In advance of the interview(s), participants gave written informed consent to participate in the study. They were also asked to confirm, at the beginning of each interview, that they were still willing to go ahead. All interviews were recorded and transcription was carried out by the main researcher (JR). At this point, any identifying features, including names and places, were removed from the transcripts. The researcher adhered to ethical guidelines of qualitative research throughout the study.

Data were analysed using constant comparison²⁸. The researchers first code the data, where possible using the participants' own words²⁵. They compare data across, between and within interviews and assign similar concepts the same or a similar code²⁵. Concepts are then grouped into categories, containing more than one code, and the properties of the categories are identified²⁵. Finally, links between categories are identified and described²⁵. This was repeated until saturation had been reached.

Results

The findings of this study demonstrate that patients frequently seek out information and start to learn about their long-term condition before receiving a final diagnosis. They may acquire knowledge from a range of sources, including healthcare professionals, family members, and experience, the latter being of particular importance. Each source will enable the individual to gain a different level of understanding of the condition. The wider study showed that there is a process engaged with by individuals, consisting of the phases 'gaining knowledge' and 'living with a long-term condition', and that patients who have knowledge of their condition, make informed decisions and accept the condition can live with it¹. The findings also revealed that some others do not adapt to or integrate their condition fully into their life¹. For these patients, a long-term condition represents a burden, attracting their attention and creating worry. Well-being is less likely to be possible for these individuals¹.

The main sources of knowledge identified are considered below, with a specific focus on where patients learn about their condition before receiving a final diagnosis.

Limited understanding: Information from healthcare professionals

Some participants in this study were advised by a healthcare professional, before undergoing a diagnostic test, that they might have thrombophilia. This group were unlikely to have a known family history of thrombosis; as a result, this was the first time they had learned of thrombophilia.

For example, one man had had a blood clot, and subsequently been warned that he might have thrombophilia, and that it was hereditary. As far as he knew, no-one else in his family had experienced thrombosis and he had not expected others to have a positive result; he thought if they also had the condition, they would, like him, have been hospitalised.

I didn't really expect anybody else in the family to have had it because I think naturally I was thinking, well you know I've just spent 10 days in hospital getting this looked at. If anybody else has had it surely they would have gone through the same sort of thing as well (Unique Reference Number P093)

Another man was also the first in his family to have been diagnosed with thrombophilia. He had suffered from a blood clot some years prior to being advised that he may have a form of hereditary thrombophilia, and consequently being tested for the condition.

For these people, knowledge of thrombophilia was at this point based on the experience of having a clot, their beliefs that family members had not had any related symptoms, and the information provided by healthcare professionals, which included a label for their condition. They had experienced symptoms which led them to consult a medical practitioner, and which led to information from the healthcare professional that they may have the condition.

Similarly, some individuals affected by asthma learned that they might have the condition when they consulted a healthcare professional. One individual's words offered an example of this:

It was getting quite sort of keeping me awake at night and I was really struggling sometimes, so that's when I went to the doctor's erm and they sort of listened to my chest and they said I think it's more, you know, it's not just a cold, it's possibly asthma here. It sounds your, you know, chest sounds very tight and wheezy (P142)

Thus, individuals found out that they had a long-term condition through consulting a healthcare professional about symptoms, which led the professional to suspect a particular condition. The pathway between patients learning from a healthcare professional that they may have a long-term condition and a confirmed diagnosis was usually straightforward. Much of their learning occurred

after a diagnosis had been confirmed. Some individuals will experience surprise in finding out that they could have a long-term condition, particularly where there is an inherited component to the illness. Patients at this stage have little experience of their condition, and may not be aware of their information needs, it is therefore not possible to say whether or not these are met.

Learning about the condition vicariously: A positive test result for a family member

Some patients, particularly those whose condition has a genetic element, begin to learn about their condition from family members. Knowledge about thrombophilia existing within their family, and the illness it can cause, can be acquired through discussion amongst family members and through individuals' own experiences of their relative's illness.

One participant learned that thrombophilia existed in her family when her sister was diagnosed, whilst another woman's father had experienced a deep vein thrombosis when she was ten years old, and he was subsequently diagnosed with the condition. She had later also been diagnosed when she had a clot in her teens.

It all started with my dad I guess ... he, when he was 38, had pretty much three DVTs at once 'cause he refused to go to the hospital ... and they worked out that he had thrombophilia (P112)

When they discovered that they might be at risk from thrombophilia, these participants were not sure that they were also affected. They knew only that the condition existed in their family and that it was possible that they too might have it. However, they learned from their own experiences, in terms of any symptoms they had themselves experienced to date and the process they went through to confirm that they also had the condition. They also learned from the experiences of affected family members.

As a result of their own and family members' experiences of thrombophilia, the narratives of these individuals were less straightforward than those who learned of the condition from a healthcare professional. There was often a time period between learning of the condition in a family member and their own diagnosis, during which patients learned about the condition. This vicarious learning informs an individual's approach to their own diagnosis and their management of the condition, including where the knowledge gained is medically inaccurate.

Developing an understanding: Linking symptoms and diagnosis

Some individuals had made a link between the symptoms they experienced, and the possibility that they might have a condition relating to the blood. Those with inherited forms of thrombophilia often linked their own symptoms

to those experienced by family members. Symptoms thought to be related to thrombophilia included clots (deep vein thrombosis or pulmonary embolism), non-thrombotic symptoms such as painful legs and varicose veins, or other blood-related issues, particularly stroke. Some individuals sought medical advice about the perceived links, and a variety of responses were received.

For example, one woman had been prompted by a friend's experience of deep vein thrombosis into making links with her painful legs and the varicose veins she suffered, and with her mother's strokes and emboli. As a result, she consulted her GP.

I've always had very, very erm achy legs and varicose legs and I said erm, you know, I was worried because I was talking to somebody and they said oooh you know I've, I've got a clot in my leg and I thought, oh gosh, I don't like the sound of that. So it got me worried, concerned about you know my mother, what she had, went to the doctor (P081)

Another participant had suffered two thromboses herself and was aware of two members of her family who had also had blood clots. Whilst this led to a test for thrombophilia, this was incorrectly deemed negative. Some time later, her sister received a positive test result for thrombophilia, prompting the participant to undergo further testing. This confirmed that she did indeed have an inherited form of the condition.

She started spontaneously having clots in her arms and then she had a clot in her leg and then of course she mentioned to her doctor, oh my sister's, my mum died of one, my sister's had them and they went, oooh now that's interesting, so they tested her and she had Factor V ... they tested me and I've got it too (P111)

As a number of years had passed between this woman's initial, incorrect diagnosis and her sister's positive thrombophilia diagnosis, the individual was aware that something was causing blood clots in her family. She therefore spent some time tentatively learning about this 'thing', and the illness it caused in the form of thromboses.

Those with thrombophilia were not the only participants to link their own symptoms to those experienced by others; individuals with asthma also did this. One participant self-diagnosed his asthma by comparing his symptoms with those of his wife, who was known to have the condition.

My wife has asthma and she has the puffers and I have symptoms that she recognises and when I use her puffer the symptoms go away (P147)

Thus, some individuals linked their symptoms to those of others, and as a result recognised that they might be affected by a particular condition. This was based on

personal belief rather than information from others and was frequently based on perception rather than medical fact. For example, one woman linked her friend's thrombophilia with her mother's emboli and strokes; strokes are not necessarily caused by thrombophilia. As a result, this group of individuals held beliefs which were based on medically incorrect knowledge and used these to inform their approach to their condition. The journey between recognising that they may have some kind of long-term condition and receiving a diagnosis varied between patients. For some, the journey was relatively straightforward. Others struggled to gain a diagnosis despite their symptoms clearly indicating a particular condition was present. For these patients, the journey often involved further illness and thus experiential learning.

Making sense of the condition: Experiences before diagnosis

A number of participants had had their condition for a period of time before they were able to receive a diagnosis. Although they were unable to label the condition and did not realise they had it, they learned about it, experienced symptoms, consulted healthcare professionals and changed their lifestyles during this time. In particular, they found out about the condition when experiencing illness.

Subsequent to diagnosis, they reflected on their experiences and recognised not only symptoms, but also the responses of healthcare professionals, and changes they had made as a result of their condition. Participants with thrombophilia had reflected on their experiences of having had clots (diagnosed and undiagnosed as such) and the consequent effects. One individual, for example, had experienced symptoms of blood clots which had gone undiagnosed for a significant time period.

It's taken like 39 years for them to decide that that's what I've got, having had problems for 20 years of that time (P121)

Before being advised that she had thrombophilia, another had been told of several reasons for the clot she had suffered, saying:

At that time, because they were trying to think, oh it's a freak incident, you know. Oh, they tried saying I was overweight which is ironic as I wasn't because I was 100lbs less than I am today... They were trying to say oh, you must have an unhealthy lifestyle. I don't smoke. Oh, you must be on birth control. I'm not on birth control. (P143)

Whilst they waited for a diagnosis, individuals with thrombophilia experienced symptoms and learned about how the condition affected them. They spoke of the insights they had gained into the attitudes of healthcare professionals towards their illness, including occasions when clots were dismissed as one-off incidents or were

blamed on lifestyle, or where symptoms were dismissed altogether and thrombosis went undiagnosed. The knowledge individuals acquired whilst experiencing their undiagnosed condition remained with them, and they discussed this during interviews even where it had taken place a number of years previously. Thus these experiences contributed to the participants' knowledge of their condition, despite often occurring before it had been given a name.

Both those with thrombophilia and those with asthma spoke of their experiences during the time before diagnosis took place. However, individuals with thrombophilia tended to discuss long periods during which they had blood clots, experienced symptoms and the reactions of healthcare professionals and gained knowledge about the condition. Following diagnosis, those with asthma reflected on their experiences and suggested that they believed they had had a mild form for some time. For instance, two participants indicated that they had had something which affected their breathing, with one saying:

When I went in it all sort of clicked that I should probably have been on inhalers before that 'cause there's a few times I'd been wheezing and er seem a bit strange to, you know, myself and family and so on and so forth (P145)

For these people, the feeling that there was something different about their breathing was generally dismissed for a time, until they felt ill enough to seek medical advice and were diagnosed with asthma, at which point it became apparent that they were not merely unfit. Tentative learning thus took place by individuals reflecting on their pre-diagnosis symptoms and making meaning of these at a later date. Asthma may be more recognisable and capable of self-diagnosis by the lay person due to its frequency and the likelihood that most people will have heard of the condition before their own diagnosis.

Patients whose experiences of their condition prior to diagnosis helped them to make sense of the condition were the ones who underwent the longest and most complex journey. These individuals gradually realised that there might be a link between repeated occurrences of particular events, particularly clots and wheezing. Their knowledge remained with them, even once they had received a biomedical explanation for their illness, and strongly informed their management of their condition post-diagnosis. These patients, particularly those with thrombophilia, were most likely to have experienced what might be described as poor care, in that their concerns and illness had often been dismissed, and this contributed to their views of healthcare professionals once they had received a diagnosis.

Discussion

Individuals with a long-term condition often begin to gather information and learn about this before they receive a diagnosis. Kralik, Brown and Koch³⁰ describe how, across different studies, the diagnosis itself was a memorable event but one considered infrequently in the literature. They do not, however, discuss the importance of the stage before diagnosis, particularly with regard to the knowledge gained at this time, for those with a long-term condition³⁰.

The literature supports the possibility that patients may begin to learn about and adapt to their conditions before being diagnosed. Individuals affected by glaucoma, for instance, had started to notice their failing eyesight, though they were not aware of the cause, and had, in many instances, begun to adapt by, for example, improving household lighting³¹. Whilst Green, Siddall and Murdoch³¹ consider the experience of being diagnosed, they do not explore explicitly the knowledge gained by patients prior to their diagnosis. Those affected by dementia began to learn about their condition before being diagnosed, though, as with those with glaucoma, they may attribute the effects of the condition to other reasons³². Whilst patients with pulmonary arterial hypertension often had to wait some time for a diagnosis, they adapted to their condition and thus began to gain knowledge about it³³.

The concept of awareness is relevant to this study. Several authors have discussed awareness in connection with illnesses which have an inherited component³⁴⁻³⁸. Geelen, Van Hoyweghen and Horstman³⁹ identified the concept of “becoming aware of a familial disease” (p.1754) for familial hypertrophic cardiomyopathy. They found that individuals recognised the condition by linking their own symptoms to those experienced by others, or were informed of a possible family illness by health professionals, in the latter case either in conjunction with a family history or in isolation. This confirms the routes identified in the current study. The study by Geelen, Van Hoyweghen and Horstman³⁹ does not however identify the importance of information gained, either through personal or family experiences, at this pre-diagnostic stage. Hunt, Jordan and Irwin⁴⁰ used mixed methods to investigate the contribution made by medical consultations on patients’ constructions of their illness. They found that prior constructs persisted even after consultation with a doctor. Although patients understood and remembered the diagnosis given, they maintained their previous ideas about what was wrong with them. These two sets of constructs were then integrated to offer a reason for their symptoms. This is confirmed by the findings of Taïeb, Bricou, Baubet et al.⁴¹, which identified that beliefs about the causes of illness included some which were congruent with the biomedical model together with some which were not, demonstrating that there may be discrepancies

between the explanations offered by a healthcare professional and patients’ constructs. Similarly, those with thrombophilia had identified multiple causes for their thrombosis, including stress and surgery, prior to receiving their diagnosis⁴².

Patients are unlikely to gain a large amount of medical information before being diagnosed. The exception will be those patients who are advised by a healthcare professional that a particular condition is suspected. In this instance, the information provided has its basis in socially constructed medical knowledge^{43,44} and is reconstructed by the individual receiving the information. In contrast, other patients may gain information from family members and acquaintances, including from the internet; their constructs are based on both their own and others’ experiences. Those who link symptoms to a particular diagnosis or have lived with a condition for some time before diagnosis are likely to have had a range of experiences from which they have learnt. Johannsson, Ekebergh and Dahlberg⁴⁵ also point to the experience of ‘falling ill’ and how patients discern that something is not right and further begin to unwillingly accept adjustment following diagnosis, but at the same time experience relief at explanation of symptoms. This present study indicates that first hand experiences in particular, including those which occur before diagnosis, enable patients to get to know their condition in a personally meaningful way and that ‘falling ill’ seems to be central to learning rather than information passed on by others.

Whilst the constructs developed at this stage may or may not be accurate, they will contribute to the knowledge held by that individual in relation to the condition, and these constructs and beliefs will be at least partially maintained following diagnosis and the related biomedical explanation. They will form a fundamental part of patients’ experiences of their long-term condition and, when amalgamated with biomedical constructs, they will be used by patients to manage their condition and influence how they adapt to it. The work by Charmaz²⁶ provides an example of how patients’ social constructions of their health condition can contribute to a changed concept of the self, though the current study indicates that not all patients experience such a significant change.

Practice Implications

Individuals’ reactions to their long-term condition and its treatment are based on information and both their own and others’ perceived experiences, some of which may have been gained before diagnosis. Some of their knowledge is likely to be based on information found on the internet, which will be of varying quality and accuracy. This knowledge and the constructs on which it is based may not conform to the advice offered by health professionals. It is important for healthcare professionals

to understand that not all of the knowledge held by a patient about their condition will be biomedically correct, and that it will not all have been acquired from a healthcare professional. However, this knowledge is of value to the patient, as it can be used to support their management of their condition. At the point of diagnosis, it may be useful for practitioners to recognise the potential for patients to have learned about their condition before this point, and to take some time to talk through with patients their existing thoughts about their condition and where these ideas have come from. In doing so, it could be possible to identify and correct misunderstandings, and to provide information that is missing in the patient's understanding of their condition. This is particularly important where patients have gone undiagnosed for a period of time.

Beyond this, consultations for medication and other reviews linked to the condition may be useful touchpoints at which healthcare professionals could find it useful to discuss with the patients their understanding and knowledge. This may bring to light further instances of knowledge held by these individuals, based on their tentative prior learning, which may affect their approach to managing their condition.

Limitations

This study is limited by being based solely in England, where healthcare is funded through taxation, meaning that access to care and treatments are free at the point of delivery, and widely available. Access to care and treatments is not reliant on insurance provision or the patient's ability to pay. As a result, participants' accounts did not consider such factors as paying for their treatment, the costs of insurance and so on. Had the study been undertaken in another jurisdiction, it is likely that factors such as access to care, treatments and testing, and their affordability, would have been discussed more frequently. Therefore, consideration of the constructivist aspect of this study, locating the findings in a time, place and culture, is important for anyone outside the UK.

The qualitative nature of the project meant that a small number of people were interviewed. Problems with recruitment through the NHS led to three access routes and to a combination of interview modes; it is not possible to say with certainty that the same data would have been collected had all interviews been undertaken using the same mode. However, consideration of the data collected through the different interview modes suggests that the quality of the data does not significantly differ, and this is supported by the literature⁴⁶.

Conclusion

Some people will not learn about their long-term condition before being diagnosed; this includes individuals who were diagnosed at a very young age, and those who had no previous awareness or experience of their condition, for example when there was no reason to believe the condition could affect them, or when other illnesses had led to the premature death of members of previous generations.

Others go through a phase of tentative learning where they become conscious of something which causes their symptoms. They are unlikely to be able to name this. Although unconfirmed at this stage, ideas and impressions will begin to form in their minds about the condition. These constructs might not be medically correct; however, they will form part of the knowledge built up by individuals about their condition. Patients will draw upon social constructions of their health condition as they gain further knowledge, as they develop strategies to manage it within their day-to-day life, and as their sense of self adapts or changes to take account of their condition.

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