

Title

Receiving a diagnosis of Pernicious Anaemia: exploring experiences of relationships with health professionals.

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Objectives:

Pernicious Anaemia (PA) is a chronic condition caused by vitamin B12 deficiency. This is a qualitative study using interpretative phenomenological analysis (IPA); which aimed to explore the patients lived experience of diagnosis and treatment.

Methods:

Eleven semi-structured interviews were conducted with PA patients, these covered participants' diagnostic and treatment journeys, the responses of others to their diagnosis and the role health professionals have played in their medical care. Interviews were analysed for recurrent themes using IPA.

Results:

Three superordinate themes were identified: 'The struggle to achieve a diagnosis', 'The significance of a diagnosis' and 'Battling for sufficient treatment'. Participants were dissatisfied with their medical care due to diagnostic delay, insufficient treatment and poor relationships with their health professionals. Many experienced, anticipated, and internalized stigma, which led to a reduced quality of life and withdrawal from the medical profession.

Discussion:

Participants' interactions with their health professionals hindered their adaptation to their condition this affected their psychological and physical wellbeing. Increased

clinician awareness of stigma in the PA population symptoms and effective patient-centred communication is required

Pernicious Anaemia (PA) is a chronic condition that stems from an inability to absorb and use vitamin B12 [1]. The condition is prevalent in 0.1% of the general population and is more frequently diagnosed in older adults (1.9%) [1]. Common symptoms of PA are fatigue, memory loss and difficulty maintaining concentration [2]. PA is treated via regular intramuscular injections of hydroxocobalamin (1000 ug) [3]. However, many patients report that they experience a recurrence of symptoms by the end of this treatment interval [4]. PA patients experience lengthy diagnostic journeys (of up to two years); this is problematic as diagnosis is an important event in the course of a chronic illness that can validate the patient's experience and provide meaning [4, 5].

Published literature into the patient experience of PA remains sparse; existing research is principally focused on investigating aetiology [1, 6, and 7]. Healthcare providers have also expressed a need for increased investigation into the patient experience [8] and it is important to establish how individuals with PA deal with a condition that has a complex diagnostic trajectory. This study used interpretative phenomenological analysis (IPA) to capture the lived experience individuals who have received a diagnosis of PA.

Method

This study gained ethical approval from the School of Sport & Health Sciences at XXXXX. As an interpretative phenomenological analysis (IPA) was employed, purposive sampling was used to select participants who had a range of perspectives and experiences of PA. Eligible participants were aged between 18 and 75 years, English speaking with a formal diagnosis of PA. Participant demographics can be found in Table 1. Eleven participants were recruited from an advert hosted on the

Pernicious Anaemia Society's (PAS) website and social media page. The demographics of this group represent the varied backgrounds of those with PA.

[Table 1 here]

Semi-structured interviews explored participant's experience of diagnosis and treatment. Interview durations ranged from 27 to 65 minutes. All interviews were audio recorded and transcribed verbatim. Transcripts were analysed using IPA. IPA concerns itself with entering the life-world of the participant regarding their social and personal perspectives and experiences through the comprehensive analysis of an individual's accounts [9]. As such it is idiographic in nature, and deals with small sample sizes. During analysis clusters of themes were developed then analysed in relation to all transcripts. Clusters of themes were developed then analysed in relation to all transcripts. Recurrence of themes was determined if they appeared in at least half of other transcripts and if so, superordinate themes constructed (Smith, 2011). Three superordinate themes were identified

Results

The struggle to achieve a diagnosis

All participants expressed dissatisfaction with their diagnostic journey; this lengthy process was characterised by a deterioration in physical and psychological health. The challenge of gaining diagnosis resulted in strained relationships with health professionals. On the onset of the condition it was common for PA symptoms to be attributed to other causes such as lifestyle:

'... I kept saying to my consultant that I was exhausted, and I couldn't speak, and that I was really forgetful and that-, he just told me to basically "have a coffee...once you find you're doing exercise, once you eat better then you'll be fine". But I was actually really physically fit at the time... I think it probably took me three goes at telling this to him... at the last one, I was literally crying.' [Grace]

There was also experience of misdiagnosis; five participants reported that they had received an initial diagnosis of depression. Patients were frequently told that their symptoms were 'in their head'. This suggestion that symptoms were psychosomatic was often viewed as a judgement of sanity.

'I mean there were days that I couldn't get out of bed, literally couldn't get out of bed, um, and it would be a nice day like today, and you're lying there and you're thinking "I've gotta get up, I've gotta get up", but you physically cannot get out of bed. You're so, so tired. And th-, and then you know when you go and tell them it's just "well you're depressed". No I'm not depressed! I'm not depressed at all! (Sighs).' [Daphne]

Madison described the necessity of writing a list of her symptoms to legitimise her experience to her doctor. Many interviewed stated that disbelief of symptom severity had led to a series of visits to health care providers, and in some cases caused the patient to begin to question their own illness experience.

'Maybe it's because they get so many people who have B12 deficiencies all coming in telling them they're tired, because that's what I felt like. I felt like I was just another person with a- with a bad back... "Oh here we go again, another person who's tired", you know... they just made my self-confidence a little bit less in a sense of maybe I was just, you know, not imaging it but I'm being silly and- and I'm being a bit of aa hypochondriac maybe.' [Rebecca]

All participants described lengthy diagnostic journeys; this was evident even if their symptoms were acknowledged as having a physical cause from the outset. Susie was transferred between hospital departments and met with multiple clinicians. She struggled to find a medical professional who was able to make sense of her symptoms.

'... what it felt like is, you know if you go into a supermarket, if you imagine it, there's someone standing in each aisle, and all they know is bread, and you have to ask about bread when you're in the bread aisle and you ask about beans in the bean aisle and so on. To be honest, it feels like that. No one looks at the big picture. Um, I mean the neurologist did loads of tests, but he was a multiple sclerosis man, and I think, you know, if you haven't got MS, don't darken my door. The endocrinologist was your diabetes man... This pernicious anaemia, B12 deficiency, call it what you will, doesn't quite fit with anyone...' [Susie]

The significance of a diagnosis

Despite the lengthy diagnostic journey all participants valued receiving the diagnosis of PA. Diagnosis prompted them to adapt and 'move on' with their health, having a label for their symptoms legitimised the illness to themselves and others

'... it made me feel justified in myself as to why I was feeling that way... it makes me feel like I'm not going insane because I- it was really upsetting me

because I was thinking “no, I was 30 years old and I was feeling like this”. All my friends thought I was boring. So, now, it makes me feel better. I don’t think it makes anybody else understand it though.’ [Grace]

Despite the personal significance of diagnosis many patients felt that they had insufficient information to adequately understand PA. Recognition that PA had an impact on daily life was important to developing supportive and meaningful relationships. However, all participants encountered at least one health professional who placed low or no significance on the impact of PA.

‘... I almost felt like, PA wasn’t important to them... it was insignificant to the day, in their day. Like they’ve got more pushing things to do... I was coming out there flabbergasted... and I think with it feeling like that, I felt, I don’t know, I felt like I didn’t want to make another appointment because I thought they would just look at me and think I was just being- wasting their time”.’ [Rebecca]

This trivialisation had a negative impact on the patient-health professional relationship. Many patients felt abandoned, this struggle to be taken seriously lead to a loss of faith in the health-care system. Post diagnosis there was a decreased reliance on health professionals with individuals beginning to seek alternative sources of health information. For some, this was a consequence of the negative experiences in Primary Care. Charities such as PAS and social media support groups were a popular sources of alternative support

Seeking sufficient treatment

Each participant reported their current PA treatment was insufficient. A need for replacement B12 was evident through a ‘lull’ towards the end of their treatment cycle where symptoms would return. Florence described her experience during her twelve week treatment cycle

‘... before I have an injection I’m really tired. I have a really dry mouth... bad pain, awful pain in my legs and my um, shoulders...I’m less inclined to do anything because I’m just so tired, but when I have the injection, it feels like I’ve got a boost of energy. For about- for about a week or so but then I can feel it going again. And then after about 2 weeks my mouth goes dry, and I’ll think “oh here we go”. And then it is a vicious circle.’ [Florence]

Health professionals' adherence to British National Formulary (BNF) treatment guidelines for PA was a cause of grievance. Nine participants described how strict adherence to guidelines had a negative impact on their treatment. Daphne described that guidelines led to their treatment being rigid rather than person centred.

'... I wasn't getting any better at all. Um, I asked the GP for injections more frequently, they said "no, it was only allowed every three months, the guidelines were only three-monthly and that was perfectly adequate".'
[Madison]

' Oh, when I went to have my injection once, um, one of the nurses actually threw the B12 away because I was a day early. So rather than giving me the injection a day early, by their reckoning it's on a three-month basis, she threw it away, and she sent me home to come back the next day and, and that's a really just sort of about sums it up really. It's, no I got- I got no faith at all when it comes to this disease.' [Daphne]

Participants claiming treatment insufficiency were often viewed as obsessing over Their condition and scrounging for treatment. This such attitude was encountered by Susie:

'... I was given a telephone appointment, um, and he [general practitioner] rang me and I said "oh I- I wanted like more B12 injections", you know, and- and he just said... "the NHS is not here to help you feel better". And I said "no it doesn't make me feel- I'm not saying it makes me feel better, happier. I'm saying that I've been really ill and I've started to feel better and I'm frightened of that slipping backwards again, and I'm asking for more B12 injections" and he said "no, that is not what the NHS is here for".' [Susie]

Susie's encounter with her GP left her feeling misunderstood and judged, with her request for more treatment made to feel shameful. The majority of participants expressed the need for PA treatment be a symptom-led, however the concept of individual variability was rarely acknowledged within health settings. Most participants expressed desire to collaboratively manage their treatment. When this was not forthcoming from health professionals they often began to withdraw from this relationship.

'Um, I'm almost at the point now that I don't want to go to the doctor, I just manage t myself now. Um, it's probably not good because if anything else needs checking then it will get missed.' [Gwen]

Madison was desperate to have control over her own health and began self-injecting B₁₂. Self-injection of B₁₂ although outside of current treatment guidelines was common within the sample with seven participants engaging in the behaviour. Some participants concealed this self-injecting from their health professionals due to expectations of negative encounters, while others openly disclosed their actions. Matthew experienced first-hand the responses of his health professionals to his self-injecting:

'... I made a mistake because the nurse said to me "I bet you really need this jab, you're looking forward to it" and I said "no actually I'm okay, I feel okay because I had one four weeks ago" and she then refused to uh, to treat me, and got really upset because I was self-injecting and I was um, I was doing something wrong...' [Matthew]

Matthew's self-injecting was subject to disdain and he was made to feel shameful. Like many other participants, despite his initial unease and uncertainty at administering his own injections, Matthew felt forced into self-injecting when efforts to collaboratively manage his treatment were unsuccessful. This lack of understanding and trust between participant and health professional led to a diminished relationship, with participants expressing fears of negative treatment from their health professionals.

Discussion

This exploratory study is the first to document the lived experiences of the PA patient. Analysis of participants' accounts revealed dissatisfaction with medical care. Reasons included perceived diagnostic delay, de-legitimisation of illness experience and ineffective treatment. All participants described experiences that had led to strained relationships with health professionals. Many interviewed had been told their symptoms were 'in their head' or the consequence of modern living. Similar to what is seen in other chronic conditions; fatigue, poor concentration and headaches were trivialised and viewed to be a consequence of demanding roles and long working hours [10]. Research suggests that health professionals are more likely to give

psychosomatic explanations for health concerns to females than males [11] yet participants in this study did not consider gender to play a role in their experiences.

Most participants interviewed had experienced an initial misdiagnosis; this fits with a UK survey of patient experiences of PA which found that many are originally diagnosed with anxiety and depression [4]. In other chronic illnesses, diagnostic delay frequently leads to further health complications and poorer health outcomes [12]. An additional risk of late diagnosis of PA is that patients face irreversible neurological damage or death if deficiency becomes too severe [13]. Late diagnosis can also impact on the psychological adjustment to chronic conditions [14]. Whilst participants in this study perceived diagnostic delay to be a result of health professionals' disregard for wellbeing; the insidious nature of PA and its unspecific symptom presentation makes it difficult to diagnosis. This alongside inconsistencies in diagnostic testing play a role in the extended diagnostic journey [13,15].

Those interviewed placed great importance on their PA diagnosis, but found that the majority of "others" make light of the condition's impact. This made participants feel nervous about returning to their health professionals to discuss treatment, and many anticipated negative interactions. These descriptions are in line with previous research into stigma within the PA population [16]. This found the patient group perceived the condition to be stigmatised. Levels of anticipated stigma positively correlated with reported symptoms of anxiety and depression [16]. Participants felt that their current treatment regime was insufficient at managing PA symptoms. This supports survey data which found that 64% of respondents were dissatisfied with how their PA was being managed [4]. Patients felt that their continued presence of symptoms was viewed as malingering.

Some participants felt obligated to seize control of their treatment, the majority of these decided to begin to self-administer vitamin B12. The risks associated with self-administering vitamin B₁₂ are unknown, an increased frequency of vitamin B12 injections has yet to prove dangerous and is considered minimally toxic [6]. The individuals interviewed purchased hydroxocobalamin from overseas (either in person or online), this raises concerns around patient safety as the treatment is not prescribed or managed by a Health Service. Those that did "self-treat" their PA

experienced stigmatising encounters and were often considered to be non-compliant or chastised for their actions. For this reason, many patient concealed their self-treatment from their health professionals.

This study holds several limitations. Firstly, the use of the Pernicious Anaemia Society as the source of recruitment may have biased findings as individuals who have experienced or perceived problems in their medical care may be more likely to join the support group (17). Secondly, some individuals were declined from participation due to the requirement of having a formal PA diagnosis. As found in this study, many participants struggled achieving a diagnosis of PA, and therefore this inclusion criterion prevented such individuals whom were currently experiencing difficult diagnostic journeys from sharing their views. To conclude, the phenomenological approach used in this study allowed for an in-depth exploration of PA patients healthcare journeys, and has uncovered many areas, which require attention. The findings from this study can be used to increase clinicians' awareness into the impact a diagnosis of PA has on the patient. Further research is required from both quantitative and qualitative methodologies to understand the patient's experiences in more depth.

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