



## Article

# “I Just Stay in the House So I Don’t Need to Explain”: A Qualitative Investigation of Persons with Invisible Disabilities

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**Abstract:** Research has shown that persons with disabilities continually face discrimination. More research attention has focused on individuals’ experiences of visible disability, despite evidence that there are higher numbers worldwide of people with invisible disabilities. As such, persons with invisible disabilities can feel under-represented in disability literature. A qualitative study was conducted to address this. Twenty-five persons with an invisible disability were recruited to take part in focus groups and interviews aimed at understanding the lived experience of invisible disability on social life and within the workplace. Data were analyzed using Braun and Clarke’s reflexive thematic analysis, identifying themes of (1) Incongruity between looking and feeling, (2) The impact of others, (3) Adaptation, (4) Talking about disability, (5) (Un)supported and (un)accepted, and (6) Discrimination/legislation. The findings indicate that the language, attitudes and behaviour of others are important to support inclusion in the social and working lives of those with invisible disabilities. Persons without a disability should be willing to talk about disability, see the strengths of those with an invisible disability and be mindful of language used around visibility. Suggestions relating to what we can do to be better support those with an invisible disability in society are discussed.

**Keywords:** invisible disabilities; hidden disabilities; invisible illness; social life; working life; society



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## 1. Introduction

Given that more than one billion people worldwide are registered disabled and disability has become part of the human condition, almost everyone will experience long- or short-term impairment at some point during their lifetime [1]. As a result of ageing, increasing survivorship from disease, and better treatment regimens, more people have disabilities than ever before [2]. The United Kingdom Equality Act (2010) defines disability as “a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on ability to do normal daily activities”. Disabilities can impact a person’s vision, movement, thinking, memory, learning, communicating, hearing, mental health and social relationships. Disability is therefore an umbrella term that covers impairments, activity limitations, and participation restrictions [1]. Thus, experiencing a health condition can have an impact upon how an individual interacts with their environment [3].

The United Nations’ 2030 Agenda for Sustainable Development pledges that no one is left behind, and argues that full and equal participation of persons with disabilities is critical. Thus, to achieve the Sustainable Development Goals by 2030, more understanding of disability discourse and research is needed. The context in which the current study is set (Scotland, United Kingdom) also supports this mission. The Scottish Government have introduced legislation to protect the rights and welfare of persons with disabilities in Scotland; for example, the Equality Act (2010) and the Equality and Human Rights Commission. These aim to remove barriers which may stop individuals enjoying equal

access to full citizenship, and to allow persons with disabilities freedom, dignity, choice and control over their lives.

Within disability research and campaigning, visible disabilities often take priority over invisible disabilities [4]. Visibility is commonly used as a marker of disability existence by those around the individual, meaning that those with invisible disabilities (also referred to as hidden disabilities, non-apparent disabilities and sometimes invisible illnesses) often go unnoticed or are not believed about their difficulties [5]. According to the Invisible Disabilities Association (n.d.), invisible disabilities refer to a range of symptoms such as debilitating pain, fatigue, dizziness, cognitive dysfunctions, brain injuries, learning differences, mental health disorders and hearing and vision impairments. Invisible disability is therefore a physical, mental or neurological impairment that cannot be seen but may impact upon a person's movements, senses, activities and day-to-day life [6,7]. Fleischer and Zames [8] argue that the number of persons with invisible disabilities is larger than those with visible disabilities, and although they comprise a large portion of the disability community, those with invisible disabilities may be under-represented within research.

Indeed, research has tended to focus on the impact of having a visible disability, indicating that persons with visible disabilities often experience social constraints, such as restricted employment, education, housing, etc., and poorly designed environments, which exacerbate disablement [9]. In addition, evidence demonstrates that those with visible disabilities such as cerebral palsy and Down syndrome may experience negative attitudes and stigmatization from others [10–12]. Zheng et al. [2] examined public attitudes towards disability and reported that discrimination was common. In addition, it can be difficult for the individual to decide whether to disclose their disability [13]. As the boundary between disabled and non-disabled is less clear for those with invisible disabilities, the possibility to pass as not having a disability is more likely than when the individual has a visible disability [14]. This can have a negative impact upon self-concept and identity, as the individual must continually decide when and where to disclose the disability [15,16], which in turn can lead to discrimination. This is despite policy that legally protects persons with disabilities from discrimination across the world (e.g., Americans with Disability Act, 2020; Equality Act, 2010; United Nation Convention on the Rights of Persons with Disabilities, 2007).

### *1.1. Invisible Disability in the Social Context*

Given that invisible disabilities can be difficult to detect due to their lack of visual representation, those with an invisible disability tend to report experiencing different challenges and societal barriers to inclusion than those with visible disabilities [17–20]. For example, navigating the social context can be difficult for persons with invisible disabilities. Although there is limited research examining the social impact of having an invisible disability, research examining disability in general has found that persons with disabilities can be perceived to be incapable of achieving in the same way as those without disabilities in domains such as relationships and maturity. These negative beliefs towards disability directly impact upon the successful inclusion of persons with a disability into the community, contributing to their stigmatization [21,22].

Relevant to invisible disability, Stone [18] found that participants who had experienced a hemorrhagic stroke were reluctant to attend social events because they were easily misunderstood and believed they did not meet others' expectations of acceptable sociability. Further, others have found that persons with invisible disabilities are at risk of experiencing more discrimination, isolation, and anxiety in social situations than those with visible disabilities [23]. The lack of visibility of invisible disabilities and, thus, the ability to "pass" as not having a disability can make it more challenging for both the individual and others to understand the disability [24]. Fitzgerald [6] argued that telling those with invisible disabilities that "they look well" can be frustrating for the individual, as the external appearance does not match internal reality.

### 1.2. Invisible Disability in the Employment Context

Not having a marker of disability can mean the needs of those with invisible disabilities are not identified, therefore leading to exclusion in specific environments, such as the workplace. Research examining disclosure of invisibility in the workplace has suggested there may be negative consequences; such as stigmatization from employers and colleagues [25–30]. Given the nature of the disability, a request for an accommodation may result in negative reactions from colleagues because it may be perceived as differential or even preferential treatment [18]. Research has also suggested that accommodations for persons with invisible disabilities are likely to be viewed more negatively than accommodations made for those with visible disabilities in the workplace [31]. Again, because the disability cannot be seen, co-workers may believe the individual is ‘faking it’ to get desired perks [18]. Such research is important given that it identifies mechanisms which might drive exclusion in the workplace. However, there is a need for more research which provides a platform for persons with invisible disabilities to share their lived experience in both social and employment contexts.

### 1.3. Current Study

In order to achieve a sustainable future, more research which examines experiences of inclusion of persons with invisible disabilities is critical. Despite this, limited research has examined experiences of having an invisible disability in social and employment contexts. Most research that focuses on invisible disability tends to examine students’ educational experiences [32,33] or parental perspectives [34,35]. However, more focus is needed on adults with an invisible disability in the community. The extent to which such lived experience varies as a function of the visual representation of disability is unknown and so it is important to talk to, and hear from, individuals themselves, in their own words, talking about their lives. Although none of the research team identify as having a pervasive invisible disability, they each have friends and family members who do, and thus understand that although each life and thus experience is different, there are commonalities that are apparent and which warrant further investigation to shed more light on living with an invisible disability. Therefore, this paper aims to qualitatively explore this, by asking the question, “What is the lived experience of invisible disability?”.

## 2. Materials and Methods

### 2.1. Theoretical Framework

The project adopted a phenomenological approach to data collection, in that it was concerned with understanding participants’ lived experiences of the world. This allows for the elicitation of a wide range of views, perspectives, and understandings of an issue, providing a unique insight into (particularly) sensitive topic areas [36]. Phenomenology values how people perceive the “same” experiences from different perspectives, and so is appropriate to underpin an investigation such as the current project. Specifically, this study adopts a social constructionist approach to analysis, positing that jointly constructed understandings of the world form the basis for shared assumptions about reality [37]. The approach conceptualises identity as a form of social action rather than a psychological construct [38]: we cannot assume that we have knowledge of individuals that goes on beyond what we see in interaction at a given time, as we cannot demonstrate that they necessarily share this in different contexts [39]. In this sense, identities are locally occasioned in talk-in-interaction, constructed and produced to serve a certain function, and consequential for the interaction at hand. Invisible disability identity, therefore, is not considered a fixed entity but something that is negotiated through everyday practices [40].

All data collection was audio-recorded and transcribed verbatim. All participants’ identities were kept anonymous by using pseudonyms and removing any identifying features from the transcripts. Data were available only to the named authors and were securely kept on password-protected devices and accounts. The specific research questions the analysis aimed to investigate, therefore, were:

- (1) What is the lived experience of invisible disabilities in social life?
- (2) What is the lived experience of invisible disabilities in the workplace?

## 2.2. Data Collection

Data collection took place across two studies, following ethical approval from the (same) home institution. Originally, the studies were conceived as separate projects, and data collection took place by two different researchers across the course of two years. It was identified, however, that given the same focus on invisible disabilities, the findings could be considered together for the purpose of the current paper. Inclusion criteria for both studies was kept fairly broad in order to encourage participation from a wide range of individuals. As such, the only inclusion criteria were that participants had to identify as having an invisible disability. In both studies, participants were not asked to disclose what type of invisible disability they had, given that we were interested in experiences from persons with invisible disability in general. However, participants were given a definition of invisible disability in order to ensure they were clear with how the research team conceptualised the term. In both studies, all participants resided in Scotland, and we did not collect race, ethnicity, or age information as the project was simply not focused on any of these factors. This also helped us to ensure that we maintained participant confidentiality as securely as possible, so it was decided that the less personal information we collected, the better.

### 2.2.1. Study 1

In Study 1, 18 participants (9 males and 9 females; Participants 1–18) with an invisible disability were recruited between October and December 2016 from the support centres of two charitable organisations in Scotland to discuss the impact their disability had on their social lives. Three focus groups were conducted within the aforementioned support centres, with participation being voluntary. Participants signed consent forms to take part in the study, acknowledging that they could withdraw at any time without jeopardizing the ongoing support they received from the charity. Each group was facilitated by two researchers who were experienced in this method of data collection, and all participants were presented with the opportunity to respond to each question, with discussion being encouraged and supported. Example focus group questions were as follows (please note that the schedule was semi-structured to allow flexibility in conversation):

- (i) In what ways does your disability affect your life?
- (ii) Do you feel there are differences in how people treat those with non-visible disabilities compared with visible disabilities? If so, what are they?
- (iii) What are the main challenges that you face as a person with a non-visible disability?

In a focus group setting, people with something in common or who believe they are like the others in the group may be more likely to share attitudes, beliefs, and experiences. As such, focus groups can allow individuals not to feel so alone when talking about their experiences [41]. Contrastingly, individuals' contributions can be challenged, extended, developed, undermined, or qualified in ways that generate rich data for the researcher. Thus, focus groups are a means of data collection that have higher ecological validity than, for instance, one-to-one interviews [42], and hence were selected as a suitable data collection method for the study.

### 2.2.2. Study 2

In Study 2, seven semi-structured, one-to-one interviews were conducted to explore the experience of having an invisible disability in the workplace. All 7 participants were female (Participants 19–25; participation was voluntary with only the aforementioned inclusion criteria of identifying as having an invisible disability, which meant we could not specifically recruit any male participants) and had invisible disabilities; they were recruited between October and December 2018 from a Scottish 'Disability Confident' employer, which is a company that encourages applications from people with disabilities [43]. The Scottish

Government introduced the Disability Confident Scheme to support employers to think differently about disability and take action to improve how they recruit, retain and develop disabled people. Employers who sign up are given free access to disability guidance, self-assessments and resources. Interviews were conducted either in participants' places of work or within the home institution, and lasted between 8 and 41 min (averaging 23 min). Participants, again, completed all usual ethics procedures with regard to understanding what was involved in the study and providing consent, before being requested to respond to interview questions. Participants were asked the likes of the following questions to further understand their experience of having an invisible disability in the workplace, specifically:

- (i) Can you tell me about the extent to which you feel your invisible disability inhibits your performance at work (if at all)?
- (ii) In general, what is your perception of employers' understanding and awareness of invisible disabilities?
- (iii) Can you tell me about your previous employment experiences specifically in relation to your invisible disability?

Despite the benefits of data collection via focus groups as detailed earlier, interviews allow the researcher to examine complicated topics and gain understanding of each individual's experience on an individual basis [42]. They allow participants to express their thoughts and feelings on a topic without being influenced by, or feeling intimidated by, other people's (potentially different) perspectives. Semi-structured interviews in particular allow for a degree of flexibility in discussions, but with structure to ensure that research questions are addressed. Silverman [44] provides an insightful discussion around the use of interviewing as a research method, highlighting the importance of their collaborative nature and the impact the interviewer can have on participants' ability to be forthcoming with their input. As such, this was selected as an appropriate data collection method for this second study. Collecting data via both focus groups and interviews allowed for the research team to embrace the benefits of both approaches.

### 2.3. Data Analysis

Data collection and analysis were concurrent and data saturation for both data sets (focused on social life and working life) was achieved. Subsequent transcripts were independently examined by the authors using Braun and Clarke's [45] reflexive thematic analysis. This method is suitable for analysing large data sets and allows researchers to identify and examine nuances in the data that mimic real life discussions [46,47]. Thematic analysis has been identified as being particularly compatible with phenomenology [48,49] and even as a phenomenological method [50]. Although typically a phenomenological study such as this may be analysed via interpretative phenomenological analysis, (e.g., [51–53]), some work has questioned the appropriateness of this, given the difficulties of extrapolating individual voices in the likes of focus groups and the added complexity of multiple hermeneutics occurring [54]. However, given that a number of studies have applied thematic analysis to focus group and interview data on the same topic [55,56], it was decided by the research team that thematic analysis would be most appropriate analytical method to adopt to the current data set.

The approach involves identifying and reporting patterns within data and allows the researcher to systematically find common meaning in language, and how this contributes to the overall understanding of the phenomena under investigation. The first step of this approach is to become familiar with the data through a process of reading and re-reading the transcript. Next, initial codes are generated, which are used to search for themes. Identified themes are then reviewed, defined, and named. At this point, the analysis can be written. The coding of the two data sets resulted in the identification of 94 codes; 55 in relation to social life, and 39 in relation to workplace. From these codes, the themes shown in Table 1 were established:



**Table 1.** Themes identified for each research question.

| Research Question                                                        | Themes                                                                                                                                                                              |
|--------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                          | - Incongruity between looking and feeling                                                                                                                                           |
|                                                                          | - Restrictions                                                                                                                                                                      |
| What is the lived experience of invisible disabilities in social life?   | - Identity<br>- The impact of others<br>- Support/understanding/acceptance<br>- Negatives<br>- Adaptation<br>- Miscellaneous                                                        |
|                                                                          | - Discrimination/legislation                                                                                                                                                        |
| What is the lived experience of invisible disabilities in the workplace? | - Physical impact of working<br>- (Un)supported and (un)accepted<br>- Mental impact<br>Impact on/for/of others<br>- Talking about disability<br>- Being “normal”<br>- Miscellaneous |

For the sake of brevity, only three themes for each question will be discussed below, chosen for their specific and realistic addition to our understanding of the topic of invisible disabilities in society and in the workplace.

#### 2.4. Reflexivity Statement

Qualitative research, by its nature, has an element of subjectivity, as we simply cannot remove our own identities when designing questions, talking to people, and doing analysis. As detailed by Gough and Madill [57], scientific psychology continues to assume that objectivity is desirable and that subjectivity should be eliminated as much as possible. However, this neglects the clear benefits of analyzing and extrapolating people’s opinions and experiences. Instead of trying to not be subjective, we focus on what we can do to ensure that our research is as transparent as possible, such as multiple coding of the data, triangulation, and providing a paper trail as we did here, as recommended by Yardley [58], to ensure validity and rigor in the research process. In addition, Braun and Clarke [45] note the importance of reflexivity: none of the authors, by their own admission, have experience of invisible disability, so we are not able to fully understand the impact it has on one’s lived experiences. However, this arguably makes the analysis more robust in that we are unable to report our own experience of the phenomenon under investigation. Despite the fact that we do not have invisible disabilities ourselves, we still recognise the importance of conducting and disseminating research, despite these limitations, on what is an important topic.

### 3. Results

#### 3.1. Social Life Findings

Three themes were identified which addressed the first research question “What is the lived experience of invisible disabilities in social life?”. These were: (1) Incongruity between looking and feeling, (2) The impact of others and (3) Adaptation.

### 3.1.1. Theme 1: Incongruity between Looking and Feeling

Participants shared that there is incongruity between how a person with an invisible disability looks and feels:

*“If you can walk, there’s not anything wrong with you.”* (Participant 15)

*“You can’t see it; you look fine if you’ve got your makeup on.”* (Participant 20)

*“People outside don’t realise in looking at me . . . I say, ‘I might look alright but I’m not alright.’”* (Participant 12)

For many of the participants, the visibility of their disability appears to be a factor in how seriously their disability is considered. Because the disability cannot be seen, assumptions are made about how well or otherwise the individual is feeling, though research has highlighted that to be told they “look well” is one of the most frustrating things that a person with an invisible disability can hear [6,59]. As such, participants spoke about the contrast between the visible and the invisible, and, in particular, that there is a perceived benefit of having a visible disability as compared to an invisible one:

*“I think people treat those with visible disabilities with more respect than people with hidden.”* (Participant 17)

Therefore, the lack of visibility and, thus, the inability to “pass” as a person with a disability impacts the legitimacy of the disability.

For some participants, therefore, deciding to disclose their disability was perceived as a way to inform others’ perceptions, as a way to demonstrate their claim to the identity “disabled”:

*“That’s one reason I use a stick, because I don’t really need it. I use this as a ‘I’m disabled thing’ so when I’m out, on the bus or whatever and I have problems, if it wasn’t for this then I would just get completely ignored or stared at and so I find it makes a big difference in how I can cope”* (Participant 10)

*“I tell everyone, more so to make them think that I’m not drunk and I’m not on drugs. So I tell a lot of people just what’s happened to me and that I’m a bit slow at things and all that.”* (Participant 8)

The participants here detail the importance of making their invisible disabilities visible by justifying themselves either with a physical aid or through speech in order to prevent being misjudged [60], as research has shown that there may be more stigma attached to those who are different when there is no apparent cause [5]. Demonstrating and disclosing their disabilities, therefore, allows them to be treated as disabled, thus addressing one of the main challenges faced by persons with invisible disabilities: the disparity between how they look and how they feel. Another challenge faced by persons with invisible disabilities relates to their treatment by others.

### 3.1.2. Theme 2: The Impact of Others

Whilst there is a plethora of literature pertaining to the experience of receiving a diagnosis of an illness or disability for the individual themselves (e.g. [61–64]), there is less work on the impact that other, non-disabled, people can have on the individual. Participants shared experiences of losing relationships because of their disability:

*“I’ve lost my whole family, nobody’s came near, ‘cause I couldn’t walk or talk, no(t) seen them in three years . . . I lost all my friends as well, was in my job 23 years full time and not one of them came to the hospital.”* (Participant 11)

Here, Participant 11 discusses the loss experienced following the onset of their invisible disability; echoed by the likes of Reeve’s work that demonstrates that persons with a disability often report feeling a sense of isolation by family and friends in the aftermath of the onset [65]. Of interest is the way in which Participant 11 (and others) position themselves as being at least partly responsible for this loss; that not being able to engage physically or verbally has resulted in the deterioration of relationships. One reason given for this is as follows:

*“People don’t have the knowledge to . . . talk to people who are different, who have a disability.”(Participant 17)*

Evidence suggests that negative reactions from those close to the individual may be a result of not knowing how to cope with the disability [66], or not having any knowledge of it [67], and which may be perpetuated due to its invisible nature, linking back to the previous theme regarding the disparity between looking and feeling. This results in frustrations and subsequent disengagement. For example:

*“I get fed up with it (explaining), I just stay in the house now so I don’t need to (explain).”(Participant 16)*

To avoid having to repeatedly explain their disability to others, Participant 16 would rather be isolated, emphasizing the effect it has on them. Such a desire to avoid others directly impacts upon the integration of persons with a disability in the community which we know is problematic [23,24], unless, that it, there is support available from and for individuals facing similar situations, as detailed by Participant 15:

*“It definitely affects me socially, apart from coming here (to the support group) because I know people here, I’m comfortable here.”(Participant 15)*

Participant 15 highlights the social impact of having an invisible disability by detailing situations where they are comfortable and where they are not. By positioning coming to the support group as the only exemption to being “affected socially” by their disability, we can see the importance of such a service to them in terms of being around people who understand. People often exclude themselves from situations in which they do not feel comfortable. Stone, for instance, argued that self-exclusion and isolation is often a result of an individual being unwilling to put themselves in situations where they know they would face difficulties [14]. These findings highlight the need for society to be more comfortable with talking about disability, even if they cannot see it, bringing to light the focus of the next theme: adaptation.

### 3.1.3. Theme 3: Adaptation

The third theme focuses on the adaptations participants have made to their lives since the onset of their disability, and the impact this has had. Research has shown that people with invisible disabilities “travel between two worlds” [16] as they adjust to the new situation in which they find themselves. They emphasize or de-emphasize aspects of their identity, highlighting whatever they think does not “fit” into any one category at any one time due to the invisibility of their disability. As such, adaptability relates to the changes in participants’ routines and aspects of life that are no longer viable to continue with, as demonstrated below:

*“When I became ill, I had to learn to say no even though I might want to go (out) but you know if you go you’re going to make yourself worse.”(Participant 11)*

Here, Participant 11 discusses contending with continuing with the life they want to lead and what is now realistic for them. They frame this as a learning process: that even though they may want to go out, they have learned that doing so would have a negative effect on their health. It highlights that, when they first became ill, they did not suddenly adapt their behaviour and stop doing the things they had done previously; this happened with experience. Participant 9 below provides another example of having to adapt:

*“It’s not being able to do things you used to be able to do and getting pleased with yourself if you do manage something . . . and then you think ‘well done, you put the bin out’ but then think ‘that’s something you used to do all of the time’. It’s a struggle sometimes, a real struggle.”(Participant 9)*

Detailing the achievement of something they used to do routinely highlights a sense of loss of their former capabilities, even if it momentarily pleases them to have managed it. Both



Participant 9 and Participant 13 use the mundane example of taking the bins out to highlight the importance of such feats, and the impact they can have on their sense of independence:

*“I’ve got five sons right, since my accident, if I go to take out the bin or whatever, they go (to) do it, and I’m like ‘leave it, I want to do it.’”*(Participant 13)

Research has shown a link between adaptation and frustration [68] which is demonstrated here in terms of Participant 13 having to adapt to people doing things for them. This reiterates the idea that such changes happen over time, as discussed below:

*“It’s taken me probably 20 years to . . . create all of the strategies for coping, all the mechanisms to try minimise the effect on my life.”*(Participant 10)

The length of time it has taken Participant 10 to learn how to deal with the changes that have occurred emphasises the extent of the impact it has had on their life. Their reference to “coping” and attempts at “minimis(ing) the effect” on their life further highlight the challenges they have faced and the necessity of adapting to their new way of living.

So far, the analysis has considered how an invisible disability may impact upon social life in terms of the incongruity between how an individual looks on the outside and feels on the inside. Some participants attempt to make the invisible visible in order to account for their disability status and justify it to other people who may find it difficult to engage with disability, which in turn has the potential to isolate individuals even more. In addition to managing faltering social relationships due to other people not understanding disability, participants have had to learn to adapt to their new lives. This takes time and patience, demonstrating that it is not something that happens easily. Together, these findings paradoxically highlight the invisibility of an invisible condition; that not being able to see the disability renders it more difficult to justify, address and adapt to.

### 3.2. Workplace Findings

Three themes were identified which addressed the second research question, “What is the lived experience of invisible disabilities in the workplace?”. These were: (4) Talking about disability, (5) (Un)supported and (un)accepted, and (6) Discrimination/legislation.

#### 3.2.1. Theme 4: Talking about Disability

It is generally considered advantageous to talk about and raise awareness of disability in order to address stigma and common misconceptions regarding what people with disabilities can and cannot do. This is of pertinence in the workplace where individuals have certain responsibilities [e.g., 25–27], and of particular pertinence when such disabilities are not visible. Past work has highlighted the negative treatment that can accompany disclosure of disability in such professional environments (e.g. [28]), leading to potentially undermining the professional role in that a disparity arises in terms of being treated as part of the team like everyone else, though with adjustments in place. Some participants in the current study detailed that they had informed their workplaces of their invisible disabilities, and some detailed that they had not:

*“I have disclosed things but that does carry prejudices.”*(Participant 19)

*“I didn’t really tell anybody at my work.”*(Participant 20)

*“I feel like I can’t really talk to anyone honestly about my illness in work . . . It can be an isolating experience.”*(Participant 23)

Not talking about their disabilities has the potential to lead to inadequate support and a lack of understanding from colleagues. Participant 23 above notes the isolation felt from not being able to talk “honestly”, suggesting that something is holding them back from doing so. If the disability is not disclosed, then individuals are treated like anyone else, which, in some cases, is beneficial and appreciated. Yet, it also means that they are held accountable to the same extent as people without such impairments, demonstrating the complex relationship between professional identity and invisible disability; i.e., the

contention between retaining privacy and being treated differently [69]. In the workplace, this is of particular significance.

Participants recognised, too, that the reluctance to talk about disability does not just come from the individual, but from the workplace:

*“Where companies and management and people are missing out is there’s still an element of nervousness around talking about disability and talking about illness.”*(Participant 21)

Participant 21 highlights the issue of workplaces avoiding discussing with their employees how their disabilities may impact their work ability, potentially for fear of saying the wrong thing. This is framed as a “missed opportunity”: if employers do not consider the disability, they are not acknowledging the full essence of what that person can bring to the position; again highlighting the complicated relationship between professional identity and invisible disability.

In addition, a reluctance to disclose a disability to potential employers was noted, even before they had applied for a job:

*“A lot of employers will take it as a disadvantage if you put on a form you have disabilities.”*(Participant 3)

*“Companies are reluctant to be hiring people if they’re going to cause them any hassles or money in sick days.”*(Participant 24)

*“It has sort of been a barrier already because I’ve managed to get to two interviews face to face for jobs and when I sort of spoke truly and honestly and told them that [condition] could have an impact . . . you could see on their facial expressions that they were already going from ‘we like this candidate’ to ‘no you’re not for us.’”*(Participant 25)

This perception that disabled candidates are less desirable than their non-disabled counterparts is well documented in the literature (e.g. [70]). People with disabilities feel overlooked for positions they are capable of, and even filling out an application form is challenging due to the disclosure decision. Facing such stigma can have major implications for psychological wellbeing [71] and some research has even suggested that invisible disabilities should not be disclosed, due to the negative treatment that could occur [29]. Like in the previous section, there appears to be a need to open up new avenues of communication in the workplace regarding invisible disabilities to ensure that workers are not being discriminated against. Of particular importance is workplace support and acceptance, as detailed in the next theme.

### 3.2.2. Theme 5: (Un)supported and (Un)accepted

The majority of participants in the current study chose not to openly discuss their disabilities in the workplace—even if they had officially disclosed them—but for those who did, there was a general consensus that they were not supported adequately:

*“I didn’t feel like across the management in there that I had the same level of support.”*(Participant 20)

*“They’re honestly not as supportive as I feel I need them to be.”*(Participant 23)

Such support is vital in the workplace. Wright demonstrated a link between a lack of support and increased loneliness [72], while Villotti and colleagues showed that high levels of support can improve self-esteem [73]. Given that these participants detailed that such support was not happening, we can infer the negative impact this can have. Participants noted, too, the struggle between getting adequate support in order to cope in the workplace while simultaneously trying not to be singled out as being different:

*“In some senses, it’s good that they didn’t treat me differently because I really don’t want to stand out and be a problem to people. But on the other hand, I’m not like everyone else; so why haven’t I been given extra support?”*(Participant 22)

Research has shown that an unsupportive work environment can lead to those with disabilities feeling that they need to disguise it in order to feel better socially adjusted in

the workplace [74]. As Participant 22 notes above, they do not want to be a “problem,” but they equally identify that they need extra support to be able to carry out their work, and if such support is not being offered, not only are they not able to do so, it suggests that individuals are not being accepted for who they are: again highlighting the relationship between professional identity and invisible disability.

Participants raised a subsequent point about “fitting in”:

*“I was worried that I wouldn’t find an accepting workplace.”*(Participant 24)

*“They (employers) see you as a drain on their resources . . . they don’t seem to understand.”*(Participant 19)

We can see from Participant 24 that before they had even found a job, they were worried about what the work environment would be like. Crucially, they do not express concerns about what the job will entail, but rather that the workplace would be accepting of them. Participant 19 highlights employers’ lack of understanding, which suggests a lack of acceptance. Feeling like a “drain on resources” will inevitably negatively impact self-esteem and, similar to support, acceptance in the workplace is crucial for positive mental and physical wellbeing in the workplace [75].

Participants noted too the specific impact of management in terms of support and acceptance in particular:

*“It’s as if they don’t have time for that; you’ve just got to get your work done and not be a problem.”*(Participant 22)

*“Provided you can get what you need from management in terms of support then that’s more than half the battle.”*(Participant 24)

Although collegiate relationships can enhance the working environment, the longevity of employment is dependent on management. Management, too, are ultimately responsible for the support employees receive, and so they play a big role in the job satisfaction of workers with a disability, as detailed above by Participants 22 and 24. The findings suggest the importance of persons with invisible disabilities being supported and accepted in the workplace, though this is routinely not happening. As such, there must be more adherence to legislation in place to protect workers with a disability and the discrimination that they face. Like with support and acceptance, however, this is not necessarily happening; as detailed in the final theme.

### 3.2.3. Theme 6: Discrimination/Legislation

Participants spoke about the discrimination they felt they had faced in the workplace. Workplace discrimination of any kind towards persons with disabilities is illegal under current UK law due to the Equality Act 2010 and the United Nations Convention on the Rights of Persons with Disabilities 2007. However, the current findings evidenced that employers do and are discriminating—knowingly or unknowingly—against those with disabilities:

*(On losing their job) “I had made a real effort to be in in terms of when I wasn’t really well enough to go in and there was no discussion about the fact that this was disability discrimination.”*(Participant 21)

*“The best thing you can do legally is disclose things because it means that if they (employers) don’t put things in place they’re breaking the law.”*(Participant 19)

Participants themselves are knowledgeable about anti-discrimination laws and, consequently, are able to identify discrimination when it happens. Conversely, it was highlighted that many managers participants currently or previously had in the workplace were unfamiliar with these laws and thus were perhaps not appropriately informed about the support that should be offered for employees with disabilities. Again, this highlights the lack of visibility of disability: if a worker had, for instance, broken their leg, they would not

be expected to stand for hours in the workplace, but because invisible disabilities cannot be seen, there appears to be less acceptance of the impact they can have.

However, participants did not necessarily feel like they could request extra support and, if they did, questioned whether it would be provided:

(When asked if she'd feel comfortable asking for reasonable adjustments) *"Not really, no. I mean if I needed it I would do it but I'd be hard pushed to ask to be honest, I don't know if they'd be understanding."* (Participant 22)

*"We just see so much about equality and visibility and diversity and all the rest of it these days but I'd say to be honest . . . that doesn't really exist yet despite what some companies would have you believe."* (Participant 23)

Participant 22 above expresses reluctance at requesting reasonable adjustments even though these should be provided by law, and Participant 23 suggests that workplace inclusivity may be more idealised than reality: it is disappointing that individuals need to even consider whether they feel comfortable asking for support, when this is something that should be available to discuss.

In addition, like management being key for facilitating a supportive and accepting working environment, they are also key for ensuring employee rights:

*"If employers know their employees' rights and they know their stuff and they realise that the best way to get a motivated workforce and employees who feel supported is to be there and listen to them."* (Participant 20)

*"When you get to the stage where you're a manager . . . you should be at the stage where you're aware of what the rights and responsibilities and what the laws are, what you need to provide, what reasonable adjustments you should be providing and what leeway you should be prepared to give."* (Participant 21)

Managers' poor knowledge of anti-discrimination legislation has been highlighted in other work [76], and it is clear from the above quotes that participants expect managers/employers to know what they have to do. As highlighted by Participant 20, this would be beneficial for all: staff with a disability would feel supported and, in turn, would be likely to be more motivated at work. A lack of engaging with legislation (such as not providing reasonable adjustments or even not knowing what they are) demonstrates discrimination, and there is an established link between discrimination and stigma [71]. As such, it is crucial that employers are knowledgeable about their employees' rights.

In summary, the above analysis detailed some of the challenges of having an invisible disability on working life. There was much discussion around disclosure and talking about disability. Although the majority of participants had officially informed their employers of their disability and access needs, they were reluctant to talk about it in day-to-day interactions with peers, potentially due to fear of stigma, which has been identified as a huge concern in previous literature. Participants noted that this reluctance was two-sided: employers were reluctant to talk to them about their disability or illness, which sometimes resulted in the violation of anti-discrimination laws through neglect of reasonable adjustments being put in place. Participants highlighted the importance of support and acceptance in the workplace, as well as the particular pertinence management support has on creating a more inclusive work environment. There is clear evidence of disability stigma in the workplace, and this needs to be addressed in order to ensure that persons with invisible disabilities are being offered the same opportunities in working life as those without disabilities.

#### 4. Discussion

The current study explores the lived experiences of invisible disability in social and employment contexts and has highlighted challenges in terms of both social and working life. Six themes were discussed: Incongruity between looking and feeling; The impact of

others; Adaptation; Talking about disability; (Un)supported and (un)accepted Discrimination/legislation.

Previous research has suggested that those with disabilities are more likely to report feelings of social isolation and loneliness than persons without disabilities [77–79]. Persons with invisible disabilities tend to live in distinct social spaces [80] with small social networks that are often restricted to service providers, family, and others with disabilities [81,82]. Our findings support this literature, showing that participants felt their lives were negatively impacted as a result of their disability and reported a sense of isolation from others. Primarily, participants' social constructions of their lives, both social and working, were negative, supporting previous work that suggests persons with invisible disabilities are "not disabled enough", questioning the legitimacy of their medical conditions [83].

The current study extends previous work by identifying perceptions of interpersonal and intrapersonal factors driving this exclusion. For example, our findings highlighted the impact of incongruity between how an individual looks on the outside and feels on the inside. Some participants attempted to make their disability visible in order to increase acceptance from others, as they did not feel others would understand their disability without physical symptoms. The behaviour of others causes the individual to withdraw and further isolate themselves. Thus, participants believed their social lives were impacted by others' beliefs and actions [2,6,10,15–17,19,20,22]. Such a finding supports research that has shown that persons with disabilities experience stigmatization from others [10–12]. It also extends this literature by showing that this stigmatization may be worse for those with invisible disabilities. In addition, the process of adapting to their disability had an impact on participants' social lives; participants learned to acknowledge that social events may worsen their symptoms and recognised that others had difficulties dealing with their disability [65–67]. Perceived attributes internal to the participants may stop the individual from engaging socially and may "self-alienate" due to negative self-perceptions of their physical characteristics [5,14,25,29,62,67,84,85]. Our findings suggest a similar process may aid social exclusion in those with invisible disabilities. In terms of social life, then, participants constructed themselves as being negatively impacted by society: that because there exists a culture of how society should "look" or "act", this is the goal that persons with invisible disabilities should aim for even though this has been identified as, at best, unhelpful, and, at worst, damaging.

Our study also detailed the lived experience of having an invisible disability on working life. It was clear that participants perceived a reluctance to talk about disability at their workplaces, as identified in past work [28,70]. Participants did not want to discuss their disability with employers or peers and believed employers were also reluctant to do so. It was suggested that this lack of communication results in feelings of isolation and being unsupported at work, which has an impact on psychological wellbeing [72–75,77,78]. Further, there was consensus that employers had poor knowledge of discrimination laws and may neglect adjustments that should be made for the participants [75]. Such a finding is important given the limited research examining experiences of work from the perspective of those with a disability [18]. Lack of knowledge about disability may come from not being open to discuss it. Persons without a disability may choose not to discuss disability in fear that they use the wrong language and cause offence. The avoidance of such discussions and lack of being open to learn about disability drives exclusion [79], particularly given that research has shown different understandings of disclosure between people with invisible disabilities and employers [69].

Overall, the findings suggest that the treatment and acceptance of those with an invisible disability both socially and in the workplace are predominantly determined by other people. In relation to social life, although the decision to socialise may be impacted by internal attributions about the consequences of socialising on their symptoms, participants spoke more of their experiences of others not understanding their disability. Persons without disabilities tended to downplay the invisible disability, as they could not see physical symptoms. Such interactions led participants to feel even worse and more isolated.



This, in turn, made it easier for the participant to withdraw from social events. In addition, in the workplace, the reluctance of others to engage in discourse about disability for fear of using the wrong language further isolated the individual, meaning their needs were often unmet. However, interestingly, there is a contrast here in terms of persons with invisible disabilities being keen to discuss their disabilities in their social lives but not in their work lives, perhaps due to the extent to which their conditions impact their identities: in everyday life the disability cannot be avoided, but in the workplace, they are adopting a professional identity that supersedes the disability [86,87]. This is a topic that is under-researched and so further work would be useful. Ultimately, there is clear evidence of disability stigma in social life and workplace. This needs to be addressed in order to ensure that persons with invisible disabilities are being offered the same opportunities as those without a disability.

#### *4.1. Implications*

The findings have practical implications important to the inclusion of those with invisible disabilities in society and thus a sustainable future. In order to encourage inclusion both in social and working life, the onus is on individuals with no disability to change their behaviour. For example, it is important not to tell those with invisible disabilities that “they look good”, even if intended as a compliment, as it is not possible to understand a disability simply by visibility. In doing so, our findings suggest that this heightens negative feelings related to the disability. Further, attitudes relating to the need to treat those with invisible disabilities differently should change. It is important to consider individuals’ abilities rather than focusing only on limitations. One way to do this is to be open to discuss the disability; the importance of willingness to talk and learn about disability, rather than avoiding such conversations out of fear of using incorrect language and causing offence have been highlighted as a practical way to address the barriers highlighted by participants. More resources and education need to be available in order to teach society how to talk about invisible disability and the appropriate use of language, which can be fed into policy in the likes of schools, workplaces, and at government level, to encourage inclusion. Such resources should be co-created with those with an invisible disability in order to capture lived experience as far as possible. Future work is needed to develop such training and resources.

#### *4.2. Limitations*

With regard to participation, as both studies were voluntary, more females than males chose to take part. This is important given research which suggests gender differences may exist in the experience of disability [11,88]. As such, the findings may be more generalisable to females with invisible disabilities. It should also be noted that we did not collect information relating to participants’ race or ethnicity. Although some research has shown no impact of ethnicity on experience of disability in the workplace [84], others have refuted this [89]. There were also no specific inclusion criteria to the study based on disability. Invisible disabilities are distinct to visible disabilities, but within that umbrella term cover a number of types (e.g., sensory disabilities, mental health conditions, chronic illnesses/diseases). An individual with, for instance, hearing loss, is undoubtedly going to experience different challenges to an individual with diabetes. This also raises the question of how invisible disabilities are essentially defined. Taking the above reference to hearing loss, if an individual wears a hearing aid or cochlear implant, does that then make their disability become visible? It would be worthwhile to extend this research to consider specific disabilities individually to more coherently understand how individuals can best be supported.

Methodologically, focus group and interview data do not necessarily align with social constructionism given that discussions in both focus groups and interviews are guided by questions rather than naturally occurring interaction, described as a “halfway house” (p. 5) to obtain views, opinions and attitudes, and the exploration of “real life talk” [90]. Additionally, it appears somewhat reductionist to truncate participants’ experiences to themes, as doing so removes the richness of their insight and brings into question the

validity of researchers (without invisible disabilities) projecting findings on a topic of which they have no personal experience. To address both of these concerns, future work thus may wish to consider more naturalistic approaches to data collection in order to explore having an invisible disability in situ: exploring life as it happens.

Finally, given that our research highlighted the impact of other people on the lived experience of invisible disability, it would have been useful to incorporate data from those without disabilities to further explore the reasonings behind, for instance, telling someone that they “look well” despite their disability, or why there is a reluctance to talk about disability.

#### 4.3. Future Research

As already highlighted, future research should focus on training and production of resources to remove the stigma around talking about invisible disabilities, expand the demographics of such work to include more experiences from a wider sample of the population; for instance, to incorporate the views of more males and across races, and potentially to further investigate the challenges faced by persons with disability. In addition, given that this paper has demonstrated the fundamental impact of other people affecting how persons with invisible disabilities deal with, treat and feel about themselves, future research should explore the attitudes of people without a disability towards those with invisible disabilities. Research has previously shown that people with no disabilities treat those with a disability in stigmatizing ways [91,92], but there has been little work that looks specifically at perceptions of invisible disabilities. The findings reported in this paper identified a clear discomfort from persons without a disability in talking about invisible disability, so if this can be addressed in future work, then it may go some way to help break down the stigma and, as such, lead to a more positive self-perception for people with invisible disabilities.

### 5. Conclusions

The study examined persons’ experiences of having an invisible disability in relation to both social and working life. Three themes were identified as important to social life: (1) Incongruity between looking and feeling, (2) The impact of others, (3) Adaptation; and three themes were identified as important to working life: (1) Talking about disability, (2) (Un)supported and (un)accepted, (3) Discrimination/legislation. Together, these themes highlighted that the language, attitudes and behaviours of others (individuals without disabilities) can have a real impact and are important to support inclusion in the social and working lives of those with invisible disabilities. There is a need for a more open and honest dialogue about disability, in addition to the production of further resources, training, and education in order to promote awareness of invisible disabilities among employers and the general public. This may increase the willingness to not only engage in discussions about disability and what language is appropriate, but may heighten feelings of inclusion among those with invisible disabilities. Although having an invisible disability may be a personal experience, the impact of it is mediated by society.

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