Unknown social aspects of disability – on the example of patients with MS

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■ **Abstract**
Introduction and Objective. In the context of disability, much is said about the problem of disability and social exclusion. One such group of disabled people are those suffering from MS who experience a completely different form of social exclusion.The aim of the article is to show what form it takes and why this form of exclusion is so painful for the sufferers.
Materials and Method. A qualitative method was used to conduct the study, specifically a free-form interview, or a narrative interview. Seven interviews were conducted with MS patients who had been ill for at least seven years.
Results. MS and the resulting disability present not only a medical issue for those affected, but also impacts their ability to function in society. Respondents indicate the difficulties they face, including social rejection and exclusion, which they describe as different and more distressing than that experienced by individuals with disabilities other than MS. People with MS often report that they are not perceived as having a disability because their disability is frequently invisible, and are sometimes accused of faking it. They are forced to constantly explain and justify their symptoms. To avoid unpleasant situations, they often feel compelled to deny that they have a disability, even though tit exists.
Conclusions. The conclusion is that the hidden disability of discredited people in this case causes social distaste. This is because, in the social context, these people are not seen as 'disabled' but as 'strange'. As a result, this leads to the phenomenon of hiding an (already) 'hidden'/invisible disability. The problem for these people, then, is not being disabled, but precisely the lack of social perception of them as disabled – the lack of social recognition of them as disabled.

■ **Key words**
quality of life, disability, multiple sclerosis, social stigma, hidden disability

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INTRODUCTION

In the context of disability, the problem of disability and social exclusion is widely discussed. The group of people with disabilities also includes those suffering from multiple sclerosis (MS), but these people experience a completely different form of social exclusion. The primary aim of the article is to show the character of MS and why this form of exclusion is so painful for the sufferers, as well as to answer the question about new forms of social exclusion, using the example of the group of people with MS who are particularly vulnerable to this type of exclusion. People with MS also often suffer from other hidden disabilities. Over the last few years, the incidence of MS has increased and in 2020 the number of people with MS worldwide was estimated to 2.8 million, and revised diagnostic criteria of MS aim to expedite diagnosis and thereby enable more rapid treatment [].

MS is an autoimmune disease of the central nervous system (CNS) and represents the most common cause of non-traumatic disability in young adults [2] aged between 20 and 40 years, more frequently affecting females than males (3:1). The physical and mental signs of the disease, (including fatigue) are caused by demyelinating plaques in the brain and the spinal cord. Although disease-modifying-treatment has changed the course of the disease and prolonged the

development of disability, patients with MS have to overcome the problems of daily living due to neurological signs. The common symptoms of MS include problems with vision (impaired visual acuity, deficits of visual field), parenthesis, paresis, ataxia – incoordination, balance problems, mood disorders, disturbances of sphincters and cognitive disorders – memory problems [5]. Depending on clinical course of the disease, various signs dominate. For the relapsing-remitting type, visual and sensitive signs are typical, in progressive types (secondary progressive and primary progressive) – pyramidal and cerebellar syndromes, sphincter and cognitive disorders are more common. Neurologists assess the disability of MS patients with the Expanded Disability Status Scale (EDSS), in eight Functional Systems. The score ranges from 0 points (no neurological signs) to 10 (death due to MS). The scale indicates either neurological impairment (up to 4 points) or disability and problems with ambulation (4.0 – 7.0), or activities of daily living (7.5 – 9.5). EDSS does not fully reflect the neurological complaints of patients, especially problems with fatigue or cognition. The other scales used in clinical trials (e.g. MSIS-29, MuSIQoL, SF-36, SDMT) are not yet in use in clinical practice [6]. Although MS is recognised worldwide, there are still many new dilemmas and problems concerning the disease. Its diagnosis, since the consequences of MS affect the lives of individuals in almost every area of their lives, leads to many questions not only of a psychological, but also of a sociological nature.

Using the example of people with MS, the presented article, analyses the problem of so-called 'hidden disabilities', a

Annals of Agricultural and Environmental Medicine 2025, Vol 32, No 2
249

Edyta Barańska, Anna Jamroz-Wiśniewska, Konrad Rejdak. Unknown social aspects of disability – on the example of patients with MS

phenomenon that is drawing increasing attention to its existence in society, and to the problems it entails – the social phenomenon of social perception, acceptance and recognition of the disability. The problems faced by people with MS concern the quality of life, access to medication and specialists, effectiveness of treatment, material conditions, the possibility of starting a family, or being able to work [7]. There is a lot of research about the problems arising from the disability, less about problems in the perception of the disability [8].

The group of people with MS was chosen for a specific reason, because a significant portion suffer from so-called 'hidden disabilities', a concept closely linked to the broader understanding of disability, specifically in terms of whom society recognizes as a person with a disability and whom it does not. Consistent with the contemporary understanding of disability, it is assumed that disability is a social phenomenon rather than a physical condition, meaning it is understood as a social construct rather than a physical trait [9]. The social dimension of disability is expressed through the concept of stigmatization, one of the ways society reacts to disability and relates to the social functioning of the concept of disability. In the case of people with MS, stigma and stigmatization are concepts that represent and express the social aspect of the functioning of individuals with 'hidden disabilities'. The article demonstrates how this phenomenon occurs and what the process of stigmatization entails.

Since the concept of disability is a social construct rather than a matter of so-called 'empirical data', this concept is constantly being reconstructed (Guy Standing) [10]. The social definition of disability is related to the presence or absence of visible signs of a disability. Today, the concept of disability is becoming increasingly problematic because more and more new conditions are emerging that cause invisible forms of disability. In fact, a rise is being observed in the proportion of people with hidden disabilities [11]; therefore, today, understanding the perception of what constitutes disability is becoming increasingly problematic socially [12, 13].

In the paradigm of positivist criteria of 'empirical medicine' and empirical criteria of scientism, the issue of disability was obvious, mainly through the feature of its 'visibility, and the lack of this feature leads to new problems in defining what disability is. The problem mainly concerns the unknown social aspects of 'hidden' disability [11]. A disability is understood here as more of a social construct than as a psychological or a physical problem [14]; disability, therefore, is a socially constructed concept. What is understood by the term 'disability' is a matter of social recognition – that which is acknowledged under this label and what is not. The social recognition and construction of what is defined as disability, and the separation of what is excluded from this category, becomes evident in the process of social stigmatization. This is the reason for a specific interpretative framework being used in the article, which is the social theory of Erving Goffman, specifically, his concept of stigma. The article is not about an individual's feeling of rejection or being stigmatized, but rather about the social dimension of stigma. Therefore, it is considered in the context of:

1) **the social theatre theory and phenomenality of everyday life** – associated mainly with Ervin Goffman's theory, as well as Alfred Schutz's phenomenology of everyday life or Kenneth Burke's rhetoric of life [15];

2) **the social scene** – society as the stage at which human problems appear and take definite shape. This is why Goffman speaks of a strategy of action; he argues that people – more or less consciously – attempt to control the impression they make on others by controlling the way they behave [16];

3) **stigmatization** – human behaviour is social, by the simple fact of its visibility. Goffman uses here the notion of stigma which relates to the issue of hidden disability. In analysing the problem of disability, he places it in the context of social stigmatization, as a phenomenon of apparent social identity. This happens when there is a mismatch between apparent and actual social identity. Stigma, then, is a certain attribute resulting from the incompatibility between our stereotypical beliefs about who a person is, and their actual identity. This is an attribute that discredits a person in social interaction relationships. There are three types of stigma: physical ugliness, character defects relating to weak will, and group stigma: race, nationality and religion [16].

Goffman, in referring to discredited people, including those with hidden disabilities, and, among others, people with MS, mainly raises the issue of the dilemma of 'to reveal' or 'not to reveal' a disability. This is the management of information about their stigma, the control of which further intensifies the already strong anxiety about the stigma. Such people have to constantly calculate which is more 'worthwhile' for them – to tell, to reveal themselves, or to keep the information hidden. In the case of discreditable people, the need to control the information about an (invisible) disability introduces additional undermines and disrupts the sense of identity of the individual [14, 17]. People with visible disabilities are able more easily to bear the consequences of being 'stigmatised', and are able to admit it, to acknowledge their 'shortcomings'. Everyone around them can obviously see the disability and can state: 'You are disabled", 'You may not be able to do something, you may be tired', etc, and add: 'You have our support' [11].

MATERIALS AND METHOD

The qualitative method used in this study was the open-ended interview, seven of which were conducted, made it possible to formulate general conclusions: the statements by the respondents, while seeming singular, in fact, show how specific phenomena function in society. This assumption about the possibility of formulating general theorems is the starting point for qualitative researchers.

The qualitative method is an independent, interdisciplinary research field, crossing many disciplines, fields and problems. Denzin and Lincoln define them as:

A situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings and memos to the self.

At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings,

250

Annals of Agricultural and Environmental Medicine 2025, Vol 32, No 2

Edyta Barańska, Anna Jamroz-Wiśniewska, Konrad Rejdak. Unknown social aspects of disability – on the example of patients with MS

attempting to make sense of or interpret, phenomena in terms of the meanings people bring to them [18].

Ethnographers state that the choice of research practices depends upon the questions asked, and the questions depend on the context, and it is the so-called context that determines how the research is conducted. It has tools at its disposal that other research methods do not. This is because qualitative researchers pay more attention to the socially constructed nature of reality, the context, the situation that influences the research, the way problems are constructed, and the way they are described [18].

The field in which qualitative research has developed today a model that meets scientific standards, a model which, broadly speaking, describes the skills, assumptions, implementation and techniques of analysis. This is called collective case study and is known as the processual approach [19].

A qualitative method was used to carry out the current study, specifically, a free-form interview or a narrative interview. Seven interviews were conducted with MS patients who had been ill for seven to fifteen years (Tab. 1).

The study was conducted from November 2021 – March 2022 and the study material consisted of recordings from the interviews conducted. A free, open-ended interview method was used, incorporating auxiliary and narrative questions. Initiating questions were prepared:
– How did you feel when the doctor gave you the diagnosis of MS?
– What is your illness? Please tell me about your illness.
– How does your day look? What activities do you do throughout the day?
– What do you expect from others?
– What do you understand by the term 'support'?
– How would you describe a person with a disability?

Additional questions were formulated based on the course of the conversation and the responses received.

The interviews were conducted with individuals suffering from MS. Participation in the study was contingent upon meeting certain criteria: the MS had to present in a similar form across participants. An important criterion was the nature of the disability – while all participants were individuals with disabilities – in this case, the disability was largely invisible. The individuals studied are those who, despite having various disabilities, did not show visible signs of them. The lack of visible signs of a particular disability did not inform others of its existence, despite its presence. This was reflected in the type of assistive devices the respondents used – for instance, none of them, used a wheelchair, the obvious social sign of individuals with visible disabilities. Some of the individuals had worked but had to give up their jobs due to the disease, while others continued to work, and most of them had managed to start families. It is worth noting that the interviews also covered memories and experiences from the past when their disability was even less visible. Currently, these individuals speak about experiencing a hidden disability that made it difficult for them to function, despite it not being visible, such as pain or fatigue.

Although the majority of respondents were women, in the context of the responses provided, gender did not significantly influence the course of the study or its outcome. Both men and women play certain social roles, and in the case of individuals with MS, there is some disruption in fulfilling these roles. The interviews were conducted in each respondent's home, in conditions that were comfortable for them. The interviews lasted from three to four hours, depending on the respondent. Family members at home but were not directly present during the interview. The interviews were conducted by a researcher – a sociologist. The material was transcribed and subjected to transcription and interpretation in accordance with the methodological requirements of qualitative methods. During the interview, the researcher did not control the pattern of responses, their directness, or the manner in which they were given, in accordance with guidelines by R. E. Stake's, which state that the cases studied should tell their own story, and the researcher should interpret the data in the context of the phenomenon under study [18]. Qualitative research analyses respondents' accounts and narratives of social actors as an

Table 1. Characteristics of the study group

Subject	Gender	Age (years)	Disease onset (year)	Type of MS	Past treatment	Present treatment	Neurological signs	EDSS	Mood disorders (depression)
1	Female	48	2010	secondary progressive	interferon beta 1-b, fingolimod	ocrelizumab	spastic paresis of lower limbs, mild paresis of right upper limb, intention tremor of upper limbs, central facial palsy on the left, neurogenic bladder	6.0	present
2	Female	57	2008	secondary progressive	interferon beta-1b, interferon beta-1a	dimethyl fumarate	spastic paresis of lower limbs, neurogenic bladder	6.5	present
3	Female	57	2014	secondary progressive	pegylated interferon, dimethyl fumarate	ocrelizumab	spastic paresis of lower limbs, neurogenic bladder	6.0	present
4	Male	59	2012	primary progressive	mitoxantone	ocrelizumab	spastic paresis of lower limbs, impaired sensation, paraesthesia and burning sensation in lower limbs	6.5	present
5	Female	54	2004	secondary progressive	no treatment	no treatment	spastic paresis of lower limbs, neurogenic bladder	6.0	present
6	Female	56	2000	secondary progressive	interferon beta-1b	no treatment	spastic paresis of lower limbs, neurogenic bladder	7.0	present
7	Female	43	2015	secondary progressive	interferon beta-1a, dimethyl fumarate, autologous stem cell transplant	siponimod	ataxia of left limbs, mild paresis of lower limbs, position tremor of upper and lower limbs, EDSS=6,0	6.0	absent

EDSS – Expanded Disability Status Scale

expression of a broader social context, rather than as a result of psychological states. Respondents are viewed as social actors, and during the study, were interpreted in terms of the social roles they fulfilled [11].

RESULTS

The starting point in the analysis of 'hidden disability' is the issue of the so-called 'visibility' of the stigmatizing element. As is known, in the case of people who discredit us, we are dealing with the lack of such a feature of disability. The statements quoted below illustrate the problems of discrediting people from the so-called an 'invisible disability'. The problem indicated by the surveyed people is – generally speaking – the lack of legitimization of the disease, loneliness and social isolation [16]. In the case of discreditable people, the absence of a visible disability often leads to accusations of 'faking' illness'. Here are some example statements:

1) I actually think that, particularly my son and the girls at work, I think they must think I am odd. I honestly think that they think that I am just telling a story. I don't know, I just don't believe that some of them believe I have MS.
2) I suppose I could get away really at a pinch with parking half a mile away. I could, compared to people who are really disabled, you know, in wheelchairs or with walking frames or that. […] I really, at a pinch, could get away with it or even if I got tired, I could stand there or find somewhere to sit down or something to recuperate. (Amy, MS study).
3) When I see these other two ladies reaching and walking really painfully, like they should be in a wheelchair, well, you know, you think: 'You're not so badly off. […] Like you're a bit of a fraud […] these people have so much more disability (MS).
4) If you are getting around with a walking stick or really wobbly or in a chair, people react really different. [But if your disability is hidden] people don't treat you any different. People treat you like nothing is wrong. (Jane, MS study).
5) I mean, I get out there and help and I do the whole lot, if and when I am able. Anything. I have done it all. Let me tell you. But I will do it to a point where I know I shouldn't be, you know, lifting and carrying or pushing or things I know I shouldn't really be doing. But I want to still be involved. (MS) [20].

The above are examples of statements illustrating the social problem related to the functioning of people with disabilities in society. As we indicated in the introduction, disability is a matter of social interpretation, the result of social meaning given to the concept of disability. People with hidden disabilities are somehow outside (to use Goffman's stigma category) – outside this model of meaning-making: they are not people with disabilities, nor are they considered people without disabilities. More precisely, they are not 'considered' to be people with disabilities, although – de facto – they are [21]. The current study confirms the assumptions.

Respondents commented about their disease that it is a disease that affects the whole person, not only physically, but also mentally. The physical aspects concern constant pain, fatigue, problems with balance, sensitivity to the environment, noise, intolerance to excessive external stimuli, lack of strength in leg and arm muscles, and problems with eyesight, incontinence, etc.

The very nature of MS makes it a highly complex disease. Sufferers may feel better or worse. Sometimes the disease may be more 'visible', and sometimes not at all. It may also be the case that the disability is permanently hidden, but the affected person suffers nevertheless, suffering from ailments, has difficulties in functioning, more or less, which – at first glance – which are not apparent, and often it is not even visible after a longer observation. [22]. One respondent recounted how she would meticulously and in passing hold on to a wall, or other things when out walking, pretending she was doing so casually, in order to hide her disability. However, she did not do this to hide her *mobility* problems because she was afraid, for example, of being labelled disabled, but precisely of being denied by others of her disability, of discussing this stigmatisation. If she looked 'normal', there could not be anything wrong with her. As a result, the problem of the visibility of the disease – MS – becomes even more problematic and vexing. One interviewee describes her experience of the disease as follows:

I have a problem with falling over. I always have. It happens to me a lot. Relatives have moved away from me. I have a problem communicating with them. I like to stay at home, I'm afraid of taking some new treatment, that after that, I'll get worse. I have learnt to hide things, not to say what is wrong with me. I feel as if they (relatives at home) think I am faking it.

Almost all respondents expressed such fears of being accused of pretending, exaggerating, or making things up:

We have extra weight in our disability, because we can't see it. In a wheelchair – paradoxically – it is safer, because it is known that the person is not walking, there is something wrong with them, they are ill, disabled. As far as we are concerned, you often can't see anything. And it is bad.

This disease is very specific, it attacks the whole person, says one of the interviewees later in the interview:

I call it an 'affliction' because it's an affliction and more. It is difficult to call it a disability. It's not one specific organ that gets sick here, but the whole body. I stopped explaining and explaining to people what ails me a long time ago. I have now realised that this is impossible. As MS sufferers, we are in the minority, and we have to accept that. We simply have no choice. I have done it. I have changed my attitude towards myself. It seems to me that this is – in our case – the only possible move. We have to stop expecting people to understand. To be selfish. I, for example, say in a shop: 'Give me such and such a product from the shelf', and I don't go into details, and someone gives it to me. That's it. Everything around us is happening fast. That's how we feel about the disease, and I simply stopped paying attention. Explaining to people what and how, why, etc. I miss work, I miss contact with people. The most important thing is to feel needed. I feel that way. I have made the assumption that I am the one who has to adapt to my surroundings. It's not up to me. It is an unbridgeable chasm. I am frustrated by dependency and the lack of a good cure for this disease of mine. It is a known fact that no one wants to be dependent.

252   Annals of Agricultural and Environmental Medicine 2025, Vol 32, No 2

Edyta Barańska, Anna Jamroz-Wiśniewska, Konrad Rejdak. Unknown social aspects of disability – on the example of patients with MS

You have to talk about it, but in such a way that someone can understand, e.g., 'Please help me unscrew the bottle', but it's impossible to explain why, and that, e.g. 'I'm tired', because it's not tired after all. But again, there is no other word. It is impossible to explain to others what I am feeling. I guess – in my opinion – every MS sufferer has to self-judge. It's the basis of how we function in society. I am a rotten apple. That's how I think of myself. And that apple is going to get more and more rotten. And there's nothing I can do about it. But I have stopped looking for understanding. I also know that this illness cannot be described to others. To understand it, you have to be sick.

All respondents felt anxieties typical of Goffman's category of discredited people. For they are aware of their incompatibility with society, of the fact that – because of their illness – they are forced to function differently from the people around them.
Another person with MS wrote:

My friends abandoned me pretty quickly. I was unable to keep up with the way they functioned. Socialising was very disruptive for me. I looked normal, but was unable to attend them. Explaining that they should somehow take me into account when organising this time was completely pointless. It didn't do anything. So, I stopped seeing them. I felt like I was in the way and felt uncomfortable. My children are now grown up, but I remember it was one of the worst experiences: being sick and having young children. I mostly sit at home now and read. But I miss going out and meeting people. The worst thing is also the sense of dependency. I've always valued mobility, and mobility is something I've lost. I don't really know what to do with my life now. I am rooting for the children. I let them do everything. I guess it's supposed to be a kind of compensation, for these shortcomings of mine, and that I can't. I have a victim mentality. A lot of things don't work out for me. I also find people rather uninteresting and mostly just plain mean, because they don't appreciate what they have, they don't even know what they have. I already agree to just about anything. I withdraw. I don't fight for anything. I don't care about anything. A job would probably change a lot. But I don't have one. Now I'm just vegetating. I think people with MS have to fight to avoid vegetating. And the worst thing is this dependency.

But at the same time, they feel the discomfort of not belonging explicitly to the discredited. Because of this, however, as more discreditable, they face a new experience – the loneliness of illness. They cannot feel rejection because of their (obvious) disability, because they often do not look disabled.

I feel disabled, but I look normal, and people are unable to understand what my ailment is about. I have difficulty explaining it to them myself. I don't know how to communicate it. It's not possible. I walk with a cane, but that's only one of my disabilities. The others can't be seen, although they are there.

Another respondent had had MS for nine years. In her case, the disease, as in other cases, had already taken a secondary form. She wrote:

I have support. It is difficult to tell someone what it is and why I am disabled. I can't manage to communicate my ailments to others. Someone once told me: 'You don't need anything anymore'. And it's true. Because when you are sick with MS, you already know you don't have to do anything. That was supposed to be such a consolation. In this disease you can't do anything by force. If I want to tell someone what's wrong with me, it won't come out. Once someone asked me: 'Well, what's wrong with you actually, what's wrong with you?' Well I thought 'probably nothing', because I didn't know what to answer. You can answer something specific, that it's leg pain or back pain, but that doesn't do it justice. It is difficult to explain. You definitely need to change your attitude towards yourself. I still drive a car. It saves my life. I do – as far as possible – housework. I help my husband at work. But I do everything at my own pace. I have a family that, ever since I became ill, has been completely unable to understand what ails me. They think I'm not doing anything, that I'm slacking off, bored at home. And they've been thinking that for a few years now.
Once – this is another story – a family member suggested we do Christmas together, but at my house, at our house. And over the phone I heard: 'Don't worry, you don't have to do anything, bake, cook, etc., we'll do everything and bring it.' To this day, I can't understand how this person could even think that I could want to prepare anything. I still can't fathom it. It proves that all these people around me, they really have absolutely no awareness of what is wrong with me, how I feel, and what MS is. I felt sorry for them. It shows that people think that I'm actually functioning normally, and that I don't know […]? Maybe the fact that sometimes I'm tired. Something like that.

The quoted statements from people with MS show only a small part of the scale of the problem of the disability phenomenon. In their case, because it often takes on an invisible form, this disability is not only about the issue of acceptability, by society, of 'disorders' in functioning, of 'otherness' in appearance or behaviour. This is only one side of the coin. Patients with MS, even if they move around in a wheelchair or with the help of a cane, this is only one of their many 'ailments' that can be seen. But the area of these MS-related ailments, the things that MS patients have to get used to, so to speak, in order to be able to function at all in everyday life, is so great that it cannot be described to 'normal' people. This is what the patients themselves say. Most of those interviewed spoke of how, in order to get through the day, they have to get used to the pain, the fatigue, the mobility problems, and their sort of clumsiness. All this has to become an unnoticeable daily routine. There is no other way and no other way out, as explained by a respondent:

I like to do things at night, because then I am alone and I know that no one is looking at me. Then I can do all these things my own way. I don't worry that someone will see me and think I can't do it and want to help me. And that stresses me out. It bothers me that someone cares about me. It bothers me that someone looks at me and can see that even though I look 'normal', I am still behaving strangely. So, I try to hide it. I don't want to make problems for someone, so I pretend everything is fine, even though it's not. But I don't want anyone to care about me. I know anyway that no one will understand how I feel. I once saw

Annals of Agricultural and Environmental Medicine 2025, Vol 32, No 2

253

Edyta Barańska, Anna Jamroz-Wiśniewska, Konrad Rejdak. Unknown social aspects of disability – on the example of patients with MS

a person with a hand in a plaster cast ask for help and she didn't have any resistance to do it. And someone helped her straight away. I feel I have to ask for help, and I feel terribly stupid. Because I don't have my arm in a plaster cast. You can't see that there is something wrong with me, and yet I ask for help. I feel stupid because I don't think I have the right to ask for help, to say that I am disabled.

People with MS say that they are often perceived as 'weird', as if something is wrong with them. According to a respondent:

I know that no one will understand what I'm going through. I've stopped expecting understanding. With MS, you just have to stop expecting anything from others. And then life gets better. Each person with the illness has to come to terms with this eventually. Only then do people stop looking at us, the sick, as oddities. When we stop constantly explaining and justifying ourselves. I don't say anything anymore. Maybe just that everything's is fine.

Hidden disabilities in people with MS often lead to them being perceived as 'faking' or 'lazy'. One respondent has stated: 'I know that they (my family) think I'm pretending to avoid doing things. At first, I denied it and explained myself. I've stopped now.' But it's a painful feeling". Another respondent also explained that he performed his tasks at night, in the way he know how and wanted to do them.

I don't have to explain myself then. I care about what others think of me. And when I do things during the day, around them, they think I'm 'clumsy' or 'weird'. I care about that. So I've learned to do things when I know no one is watching me, mostly at night. Then I feel normal, ordinary. Constantly explaining and justifying my 'strange' behaviours to others, not expecting understanding – quite the opposite, in fact – is very exhausting. So I do things at night. That way, I can do them my way."

Another respondent talks about being perceived as 'clumsy':

When I'm at the store, packing my groceries at the checkout, the people behind me in line roll their eyes and sigh loudly. Packing my groceries is a challenge for me, but I manage – just a bit slower. I don't shop often, partly to avoid these situations. And I only buy a few items. But I still try to avoid it because people look at me like I'm clumsy. I'm middle-aged. I look good. I take care of myself, just like anyone else. I try to function in society for as long as possible. But that doesn't help. Once on a bus, I had to give up my seat to someone else, even though I really needed to sit down. But someone pointed out, with irritation, that I should give up my seat to an older person nearby. I didn't know what to say because that person seemed just fine – just older. She spent the entire ride talking and laughing with the person next to her, while I was trying not to fall. Now, when I take the bus, I don't sit down, or I do so rarely. Because if I 'admit' to my 'ailments' I'm either seen as clumsy or as 'rude'. And if I look well-groomed, that's also a problem because I shouldn't be, since I'm supposed to be sick. It feels like people expect me to be lying in bed or sitting on a couch at home, watching TV – and nothing more. When I talk to others with MS, they say the most important thing

is not to let it bring you down. There's truth in that. I feel like other people want to bring us down. MS is a terrible disease. It condemns you to awful loneliness. I'd rather have cancer, honestly.

DISCUSSION

People with MS are stigmatized through various social mechanisms, such as: ignoring a 'hidden' disability or over-protective and excessive kindness of family and friends. In an effort to cope with their difficult situation, and out of fear of stigmatization, losing their job, or losing their family, people with MS often choose solitude, resignation, and acceptance of the lack of understanding. Ultimately, the process of stigmatization leads to loneliness [23]. Fitzgerald and Paterson [20]. talk about 'hiding a hidden disability'. People with MS choose it as a way out of this impasse. MS is a disease where you are alone [20]. People with MS, with invisible disabilities, avoid support groups. They often do not identify themselves with disability [11]. This is the essence of the stigmatisation of people with a hidden disability. Grytten and Maseide [21] write about the lack of social recognition. People with MS who have hidden disabilities do not receive this recognition. They struggle with many problems and difficulties in their daily lives due to their disabilities, but they cannot rely on them or expect social understanding and recognition. In this case, these individuals are denied the right to function as persons with disabilities, even though they are. Racław and Szawarska also use Goffman's social concept of stigma here [11]. This stigmatization is a particular form of stigmatization. To avoid being accused of faking, they have to pretend that they are not people with disabilities and that they feel fine – that is the essence of their social stigma.

'They call me a fraud', says Marta Rybarczyk-Marciniak, who suffers from MS:

People tell me that 'people like me' don't deserve help because I look nice and well-groomed. People like me shouldn't smile because the sick don't smile. MS involves symptoms that are invisible, and that's why people don't grant us, the sick, the right to disability. But we experience a lot of pain and suffering, along with the shame because our daily life is a constant battle to have our illness and disability recognized. I am often attacked, for example, for parking in a disabled spot [22].

Malina Wieczorek, president of the MS Foundation, who also has MS, states that:

People with MS often don't look disabled, even though they are and intensely feel it. Our illness isn't visible. The public perception is hurtful. They expect us, people with MS, to look sick. People have an image of someone with MS sitting in a wheelchair. However, our disease takes on a different form. Nowadays, there are more and more medications that slow the progression of the disease, and people with MS end up in a wheelchair later, but that doesn't mean they are healthy. They experience disability and a lot of pain. It's just not visible [22].

254

Annals of Agricultural and Environmental Medicine 2025, Vol 32, No 2

Edyta Barańska, Anna Jamroz-Wiśniewska, Konrad Rejdak. Unknown social aspects of disability – on the example of patients with MS

Some researchers blame the media because, they claim, media does not explain what the disease is. They give people the wrong picture about this disease. They misinform people. Therefore, the media should properly communicate information about MS [23]. A social support system also needs to be built. Since self-acceptance is more difficult in the case of hidden disabilities, it is necessary to create appropriate social support programmes and social policies [24].

Today, the focus is on the 'functioning' of people with MS in society, rather than just their illness or 'vegetation'. This changes the perspective. Therefore, institutional, social support is not only needed but is crucial in order to change the way these individuals are perceived by society [22].

CONCLUSIONS

The study comes to three conclusions. The first is that the process of social identification of a person with a disability, in this case a person with multiple sclerosis, is somehow disturbed. These people, who – in Goffman's theory – are called 'discredited', their behaviour can only be seen in the eyes of those around them as 'bizarre' and 'clumsy'. Socially, these people are seen as 'weird', 'pretending' and, 'lazy', and their presence and behaviour cause embarrassment. They have no right to be people with disabilities, even if they are disabled. The disability status gives those who have it the 'recognition' of disability. Obtaining such 'recognition' turns out to be crucial – socially important – because it gives people with disabilities, as it were, the right to be people with disabilities. People with hidden disabilities find themselves in a situation of double burden: not only struggling with a real (though invisible) 'disability', but, above all, with the lack of social 'recognition' of their disability.

The second conclusion is that the hidden disability of discredited people in this case causes social distaste because, in the social context, these people are not seen as 'disabled' but as 'strange'. As a result, this leads to the phenomenon of hiding an (already) 'hidden'/invisible disability.

The third conclusion is that people with MS and hidden disabilities experience a particular type of social stigmatization. Since their disabilities are not visible – because, for example, they do not use a wheelchair, and also do not function like those without disabilities – to avoid accusations of 'faking' their illness or pretending to have a disability (as socially recognized disabilities are typically visible), people with MS are compelled to pretend to be without disabilities, even though their situation is quite different. Paradoxically, by concealing their disability, they can avoid social stigmatization. The problem of people with MS is not their disability, but the lack of social perception of them as people with disabilities – the lack of social recognition of them as people with disabilities.

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