


# Invisibility, stigma and workplace support: Experiences of individuals with chronic disorders

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**Orientation:** Individuals with chronic disorders such as systemic lupus erythematosus (SLE) face challenges in disclosing their condition at work due to symptom invisibility and stigma. Managers play a crucial role in managing employees as stakeholders and shaping workplace culture and inclusivity.

**Research purpose:** This study explores how workplace culture and support systems influence disclosure decisions among individuals with SLE, focusing on the role of managers in shaping these experiences.

**Motivation for the study:** Limited research exists on the disclosure of invisible illnesses like SLE in professional settings. This study seeks to understand how stigma and inadequate support lead employees to conceal their condition.

**Research approach/design and method:** Using document analysis and semi-structured interviews with participants from various industries in South Africa, the research explores the interplay between workplace culture, support systems and disclosure decisions.

**Main findings:** Findings show that the invisibility and stigma of SLE, challenges in recognising it as a disability, and insufficient workplace support contribute to concealment. Managers often perpetuate unsafe spaces for disclosure.

**Practical/managerial implications:** Organisations must address the systemic exclusion and stigma faced by employees with chronic illnesses. Enhancing training and support for managers is critical to fostering inclusive workplaces and safe disclosure environments.

**Contribution/value-add:** By exploring the strategies individuals with SLE use to navigate workplace challenges, the study provides insights into the relationship between chronic illness, stigma and workplace inclusivity, enriching the broader discourse on disability in professional contexts.

**Keywords:** systemic lupus erythematosus; workplace disclosure; chronic illness; organisational culture; stigma; stakeholder management.

## Introduction

Systemic lupus erythematosus (SLE) is a chronic autoimmune disorder that can significantly impact an individual's ability to participate in the workforce. The unpredictable nature of SLE, characterised by episodic flares and remissions, poses unique challenges for affected individuals, particularly in professional environments. These challenges are exacerbated by the invisibility of symptoms and the stigma associated with chronic illnesses, making the decision to disclose one's condition at work extremely complex.

Despite extensive research on workplace disclosure of chronic illnesses (Camacho et al., 2020; Charmaz, 2002; Gignac et al., 2021a; Kulkarni, 2022), there is a notable gap in understanding the specific experiences of individuals with SLE. Most existing studies focus on broader categories of chronic illnesses or disabilities, overlooking the nuanced challenges posed by SLE's variable nature. This study addresses this gap by exploring the factors that impede or discourage disclosure decisions among individuals with SLE and explores the impact of workplace culture and support systems on their ability to manage their condition.

The goal of this research is to provide insights that can inform the development of more inclusive and supportive workplace policies and practices by managers. By focussing on the intersection of organisational culture (Bam & Ronnie, 2021), stigma and chronic illness (Jurcevic et al., 2021) and stakeholder management (Freeman, 2010), this study seeks to advance the discourse on disability

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in the workplace, emphasising the need for targeted interventions that empower employees to disclose their conditions without fear of discrimination.

### Disclosure and creating safe workspaces

The decision to disclose a health condition in the workplace is complex and highly personal. For employees with episodic or invisible disabilities, this decision is often imposed when requesting workplace support resulting in a diverse range of disclosure experiences and outcomes (Gignac et al., 2021a, 2021b). Moreover, this decision is influenced among others by factors such as perceived stigma (Camacho et al., 2020; Jurcevic et al., 2021; Thomson & Grandy, 2018), anticipated negative reactions of colleagues and supervisors (Mik-Meyer, 2016) and the potential negative impact on career prospects (Dispenza et al., 2019; Lindsay et al., 2021). For Charmaz (2010), these factors generally cause people to resist disclosure to maintain their professional identity as revealing a health condition may lead to being perceived through the lens of their illness rather than their capabilities, thereby undermining their competence, credibility and status in the workplace. Significantly, Norstedt (2019) has shown that the fear of being perceived as unreliable despite the potential benefits of doing so deters disclosure. Here, the internalisation of an illness plays a major role when employees feel reduced to their condition rather than assessed on their abilities (Abu Bakar et al., 2020; Allen & Carlson, 2003; Butler & Modaff, 2016; Charmaz, 2008).

The extent to which an individual feels safe and supported has a direct impact on their disclosure decision (McGonagle & Barnes-Farrell, 2014). Safe workplace spaces are predicated on being free of retribution and discrimination (Santuzzi et al., 2019), actively promoting accommodations and having well-resourced physical and social support systems (Dobusch, 2017; Kirk-Brown & Van Dijk, 2011; Rodgers, 2007; Vornholt et al., 2018). The unpredictable nature of episodic disabilities, however, can result in atypical workplace experiences requiring flexibility (Morand et al., 2023; Syma, 2019). Understanding these dynamics is important in the development of interventions that empower employees to share their experiences where disclosure is met with empathy and support (Von Schrader et al., 2014). Organisations must therefore create environments where employees can be their whole selves at work (Ragins & Cornwell, 2001), reducing the need to hide health conditions and normalise conversations about health and disability in the workplace (Jammaers et al., 2016; Kwon, 2021; Ménard & Brunet, 2011; Reis et al., 2017; Woodward & Day, 2006).

Managers play a pivotal role in shaping organisational culture, policies and practices and their commitment to inclusivity influences how safe employees feel in disclosing chronic health conditions (Barnard et al., 2023). By fostering environments where inclusivity is actively practised, guided and employee well-being prioritised, leaders can create spaces where employees seek accommodations without fear of judgement

or penalty (Foss et al., 2018; Gould et al., 2022; Haque et al., 2019; Luu, 2019; Traphagan, 2017). Moreover, when managers demonstrate an active commitment to inclusion, it permeates through organisational structures, making employees with invisible disabilities feel supported (Bruyère, 2000; Moloney et al., 2019; Stone & Colella, 1996; Vornholt et al., 2018). This leadership-driven approach can reduce the stigma associated with chronic conditions and promote a culture of understanding and empathy that is visible through daily interactions and the general commitment to supporting its employees (Abney et al., 2022; Eriksson, 2019; Kensbock & Boehm, 2016; Kulkarni, 2016; Kulkarni & Kote, 2014; Mitra & Kruse, 2016; Schur et al., 2005; Warrick, 2017).

### Stakeholder theory and a Fanonian perspective for human resource managers

The stakeholder approach as conceptualised by Freeman (1984) emphasises the need to recognise and manage the interests of all stakeholders. To fully actualise the obligations implicit in a stakeholder approach, organisations and their managers must transcend conventional practices of inclusion when focussed on employees (Foster, 2018; Philips et al., 2005; Stieb, 2009). While not implying superiority over other employees, it is crucial to balance the interests and participation of employees with disabilities (Bridoux & Vishwanathan, 2020; Moriarty, 2014). Freeman's (2010) view that not all stakeholders' interests can be met is particularly relevant to employees with disabilities who tend to be on the margins. Moreover, acknowledging the interrelatedness of their specific needs within employee stakeholder groups is critical in advancing inclusionary efforts in the workplace. With this difficulty, Migliaccio (2019, pp. 1666–1667) points out that progress is best made where managers display a 'willingness to listen'. As safe workspaces have a significant influence on participation and the willingness to disclose, managers must evolve their application of any stakeholder approach to foster such spaces (Dunham et al., 2006; Kaler, 2003, 2006).

Frantz Fanon's concept of 'leaning over', as articulated in his work *Black Skin, White Masks* (Fanon, 1986), can provide this critical lens for managers as a means to improve their stakeholder management. The examination of the internalisation of oppression (Spanakos, 1998) and the psychological effects of colonialism (Kebede, 2001) offer a unique backdrop for developing a deep empathetic understanding of marginalised employees (Black, 2007). In situations where disclosure of chronic illnesses is concerned, the 'leaning over' and reshaping organisational practices presents a paradigm shift aimed at delivering more equitable and just workplaces (Arunprasad, 2017; Hosmer & Kiewitz, 2005; Im et al., 2023; Konow et al., 2020). Significantly, leaning over would require managers to evaluate their potential role in creating oppressive experiences through workplace practices that lead to the hesitancy to disclose (Abberley, 1987; McDonald et al., 2007). The exploration of the importance of embracing disability identity provides further insights into how managers can undermine the identity and culture of disabled individuals (Andrews et al., 2019). With respect to Fanon's analysis of

oppression, and how colonised people are dehumanised and identities erased or suppressed, managers are called to work towards creating opportunities for people with disabilities (PWD) to claim their identity and assert their cultural autonomy in the workplace (Finkelstein, 1980; Santuzzi et al., 2014). Fanon's concept of internalised oppression also rings true here, as the avoidance of disability in the workplace may reflect a societal discomfort with difference, pushing disabled people to downplay or mask their identities (Jurcevic et al., 2021). In both cases, the erasure of identity, whether colonial or disability related, serves to maintain power structures that marginalise these groups and limit their access to social justice.

When applied to stakeholder theory, these insights underscore the necessity for managers to recognise disabled employees as critical stakeholders whose identities must be fully acknowledged and respected (Bridoux & Vishwanathan, 2020; Crane & Ruebottom, 2011; Mitchell et al., 2015). Integrating these ideas within a business context means that managers should promote a culture where disability is seen as a valued aspect of diversity, rather than something to be hidden or minimised (Goggin et al., 2017; Schur et al., 2009). By encouraging open disclosure and providing a safe space for disabled employees to express their needs, managers are actively working against internalised oppression where individuals feel compelled to conceal their true identities because of societal pressures (Camacho et al., 2020). This approach aligns with the broader goals of stakeholder theory (Freeman et al., 2018; Kaler, 2006), which promotes balance and fairness in the treatment of all stakeholders, ensuring that traditionally marginalised groups have equal access to opportunities and resources. In this way, the workplace becomes a platform for resistance against erasure and marginalisation, echoing Fanon's broader call for the reclamation of identity as a form of liberation. Transformation like this requires a commitment to ongoing dialogue, education and reflection, and the development of more nuanced and individualised support mechanisms that recognise the complex intersectionality of these employees' identities and experiences (Wyatt et al., 2022).

## Methods

This study employed a multiple case study design to gain an in-depth understanding of the experiences of individuals living with SLE in the South African context. The selection of this approach allowed for an exploration of how participants managed their condition, navigated their work environments and addressed challenges in both their professional and personal lives in a variety of contexts. This approach enhanced the reliability and robustness of the findings by facilitating the comparison of similarities and differences across cases (Baxter & Jack, 2015). Each case was contextualised within the participant's employment setting, considering factors such as job characteristics, workplace health policies and the broader social environment (Eisenhardt, 1989). The study's geographical focus on South Africa also provided insight into the influence of local healthcare systems, labour laws and societal attitudes towards disability on the participants' experiences.

## Participants

Purposive sampling was employed, and the primary unit of analysis was people living with SLE between the ages of 18 years and 65 years who were either seeking employment, transitioning between jobs or currently employed (Devers & Frankel, 2000). A pilot case was initially conducted testing the recruitment information and interview guide with a participant within the researchers' network. On completion of the initial case and feedback from the participant, further refinements were made to the recruitment material, which were shared electronically with associations and professionals focussed on SLE for distribution into their networks.

As the pilot case delivered a rich and nuanced perspective of the experiences of SLE, the case was maintained as part of the study. In addition, snowballing was employed to recruit other knowledgeable participants. In line with the literature, six cases were selected for inclusion based on the suitability of multiple case studies that strengthen the opportunities for replication (Eisenhardt, 1991) and rigour associated with the number of cases. Because of the nature of SLE and the unique insights provided by each case, the decision to focus on these six cases is supported by Yin's (2009) argument that six to eight cases are ideal for theoretical replications. Additionally, Schoch (2020) suggests that even three to four cases can be ideal for replication, while Baxter and Jack (2015) assert that multiple case study findings can be robust with smaller sample sizes. Additionally, the episodic nature of SLE required careful attention to the individual experiences of each participant's condition and their workplace experiences. This study prioritised depth in the case over breadth in the number of cases, allowing the voices of participants to be heard and their complex experiences of disclosure, stigma and workplace support to be thoroughly examined (Devers & Frankel, 2000).

## Case profiles

Participant 1 (Consulting) was a 53-year-old re-married female, diagnosed with SLE at the age of 28 and actively living with SLE for 25 years. She holds a diploma-level qualification and works as an environmental consultant. At the time of her participation, her employment had been terminated by mutual agreement and converted to a consulting arrangement. Participant 2 (Health Education) was a 35-year-old single female, diagnosed at 21 and actively living with SLE for 14 years. She had a degree and was employed in the health sector in an educator capacity. Participant 3 (Telecommunications) was a 41-year-old divorced male, diagnosed at 28 and actively living with SLE for 13 years. He holds a master's degree and works in telecommunications. He was undergoing performance management discussions with management that he contends was related to his illness, which had not been disclosed. Participant 4 (Law) was a 43-year-old widowed female, diagnosed at 36 and actively living with SLE for 7 years. She holds a degree and works in the legal sector. Her employment was terminated because of her performance but subsequently offered a part-time contract at the same firm.

Participant 5 (Pharmaceutical) was a 57-year-old separated female, diagnosed at 37 and actively living with SLE for 20 years. She holds an honours degree and works in the pharmaceutical industry. Lastly, Participant 6 (Education) was a 38-year-old single female, diagnosed at 23 and actively living with SLE for 15 years. She has a degree and works in the education sector.

## Data collection

Each participant engaged in two semi-structured interviews, lasting between 1 h and 2 h. The interviews were held 1 week apart where possible, considering participants' work commitments and the impact of the SLE on their health. Where interviews were postponed because of health complications, they were rescheduled. The longest time between interviews was 3 weeks. All participants were informed they could schedule multiple shorter interview sessions if required. Data collected using semi-structured interviews followed a structured guide while also probing deeper into areas of interest that emerged during the conversations (Rabionet, 2011). Interviews were audio recorded and transcribed verbatim to ensure accuracy. Field notes were taken to capture non-verbal cues and contextual information that might not be apparent in the transcripts, thereby enriching the data set (Oliver et al., 2005). The use of semi-structured interviews was instrumental in eliciting personal narratives, drawing on Spradley's (1979) 12 elements approach to interviewing, addressing descriptive, structural and contrast questions. The questions in the interview guide were informed by literature and focussed on participants describing the impact of SLE on their daily living and workplace experiences, their experiences of disclosure, co-workers' responses and challenges related to SLE management.

Furthermore, the data corpus included the participant's organisation's policies on inclusion as well as other statutory allowances such as sick leave benefits for full-time or part-time employees. Those on consulting agreements also provided the contractor's policies. The researcher actively took notes observing the participants during interviews and noting their expressions and comments that were shared. In addition, the researcher reviewed the websites of all employers and contractors specifically looking at any statements promoting inclusion in the workplace.

## Data analysis

Thematic analysis was used following the systematic six-step method outlined by Braun and Clarke (2006) to identify patterns within the data. The analysis began with familiarisation where each transcript and available policy document was read a minimum of two times. This was followed by the coding to identify significant features across the data corpus. These codes were then collated into potential themes, which were reviewed along with a colleague and refined to ensure they accurately represented the data. The themes were cross-checked against the entire data set to ensure coherence and consistency and discussed with the pilot case as

another form of member checking. Additionally, cross-case synthesis was used to compare themes across different cases, providing a richer, more comprehensive understanding of the data (Yin, 2013). ATLAS.ti software was utilised to manage and organise the data, ensuring a systematic approach to the development of themes and cross-case analysis.

## Findings

The findings reveal the multifaceted challenges faced by individuals living with SLE. Participants described navigating complex emotional and practical experiences shaped by the invisibility of their symptoms, societal stigma and the fear of discrimination. The findings identify two core themes: *the invisibility, stigma and identity of Lupus and concealment and lack of workplace support*. These themes highlight the difficulties in balancing transparency and self-preservation in both professional and social settings.

Figure 1 depicts the first theme, focussing on invisibility, stigma and identity, while Figure 2 illustrates the second theme, conscious concealment.

### Invisibility, stigma and identity

Participants encountered numerous difficulties in the workplace because of the imperceptible nature of Lupus. The invisibility of symptoms eluded external observation causing misunderstandings and impeding managers' and co-workers' ability to grasp the true severity of the illness. (Participant 2, Health Education, Female) shared the views of co-workers when becoming aware of the illness who thought 'It's not that bad. You can't die of it'. Similarly, Participant 1, Consulting, Female expressed 'I think the problem in the workplace is that [when] you look you can't really see the person is ill' while Participant 6, Education, Female shared how her co-workers were surprised that she was 'coping fine just the day' and then 'you're admitted to hospital'. The severity for participants was understood differently, questioning co-workers' ability to empathise as they faced issues of their mortality:

'I lost a lot of people from it, I was so close and on a ventilator myself. Your eyes are showing the sadness you've been in and out hospital and I said to him, "Do people actually not see people's sadness in their eyes anymore?" When I look into the mirror I can see that ... are we really looking or are we just saying, "Hi, how are you doing - ooh, you're looking good."' (Participant 2, Health Education, Female)

Participant 1, Consulting, Female evocative description of Lupus as a 'wolf lurking in the shadows' reinforced the ever-present nature of the disease waiting to cause harm. The invisibility of the illness also contributed to the constant and common experience of being 'accused of being lazy' while being helpless to address this as the Lupus 'creeps up' unexpectedly. These experiences caused participants to grapple with feelings of isolation and disclosing the extent of their illness to colleagues. Participant 2, Health Education, Female explained that managers could do more to understand

their condition to promote disclosure. Her views that ‘it’s only the people in your house that really know the effect of it’ resonated with Participants 3, Telecommunication, Male who felt that ‘nobody really knows much about it’. This was also evidenced through his workplace policies that did not take into account the invisible nature of his condition.

Another significant contributing factor to withholding disclosure was related to the uncertainty surrounding the diagnosis of Lupus and the manner in which participants became aware of being ill. Participants 3, Telecommunication, Male described it as a ‘guessing game’ where ‘you got to deal with this thing of like holy shit I’m sick. I’ve got a disease that is not curable’. Significantly, he captured the common sentiment and understanding that all participants shared influencing to whom and how they disclosed as well:

‘You know, there’s nothing I can do for this thing. There’s no cure for it. The best you can do is manage it.’ (Participants 3, Telecommunication, Male)

Another significant influence on the timing of disclosure was co-workers’ and managers’ responses to their pain. Many co-workers were described as being sceptical and believing it was fictitious. (Participant 6, Education, Female) explained ‘you need to almost find a balance where they are aware that you are suffering’. Experiencing immobilising pain had an adverse consequence for participants as it inadvertently revealed their illness when becoming incapacitated or affecting their work productivity. Participant 4, Law, Female indicated her experience resulted in confronting a reality of incapacity which co-workers need to understand. For (Participant 4, Law, Female) it was vexing, as she described advising clients of their rights in the workplace and acknowledging her workplace policies did not shield her from a ‘amicable’ resignation from her employers:

‘You need to be very honest. It’s actually very difficult to say, “Listen I have pain” because if they can’t see it, they can’t see. I literally had to pick up the phone and say, “Please just come and

help me because I literally can’t get out of the door.”’ (Participant 4, Law, Female)

Lupus was complex and reported as a significant part of all participants’ identities. This was accompanied by a strong internal resistance to accepting the label of being disabled. Resisting the disability label was nuanced as participants ascribed this resistance to issues of self-perception, societal expectations, internalised stigma and the desire to maintain a sense of autonomy and normalcy:

‘I don’t describe myself from a disabled or autoimmune perspective. I have – not at all. Call it denial, call it whatever ... ’ (Participants 3, Telecommunication, Male)

While acceptance of Lupus as a disability was varied, it was described to occur on a time-based continuum and informed by the views of others. Participant 1, Consulting, Female thought that ‘it is a disability, you can’t get away from that’ captured the sense of inevitability expressed by participants. For her and most participants, it took, ‘years ... to get to that point’. Not unique to her experience, she felt conflicted receiving confirmation from ‘my rheumatologist I’m disabled’ while at the same time resisting ‘in my head’. She captured the common sentiment that these struggles to overcome the label of disabled were necessary ‘to educate people especially in business’.

While participants wanted to control the manner in which disclosure occurred, it was not always possible, especially in circumstances of indirect disclosure that occurred during pre-screening or reference checks by employers. Telecom thought that it was not obligatory to do so and compared his experience to ‘disclosing you’ve got HIV or you’re pregnant, you don’t have to disclose’. In Participant 6, Education, Female’s case, she explained the consequences of indirect disclosure ‘when they phone my references, they bring up the Lupus ... and suddenly they withdraw’. Similarly, Participant 4 explained that during her recruitment phase, the biases that occurred when she:

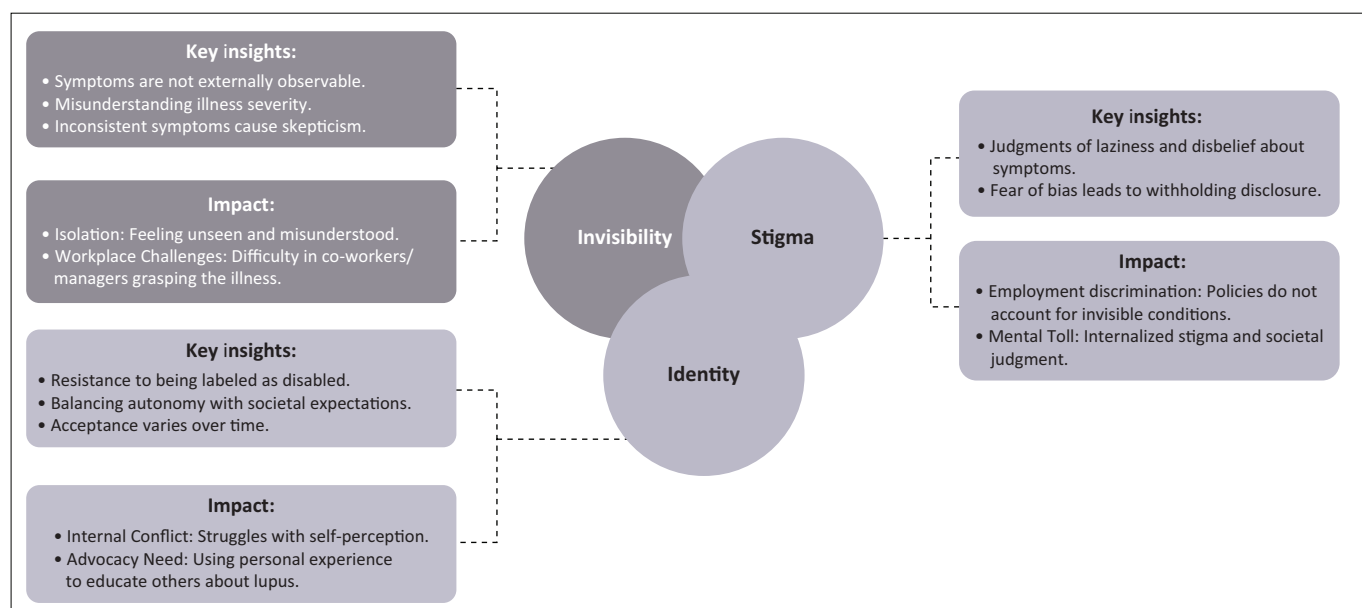


FIGURE 1: Invisibility, stigma and identity.

'[F]illed in forms and wrote Lupus because the questionnaire asked specific questions ... You shouldn't be asking do you have any illnesses or your medical history. You can't. It's a basis for discrimination.' (Participant 4, Law, Female)

## Conscious concealment

The decision to conceal symptoms and the illness prior to and during employment was a common strategy among participants, driven by the fear of being perceived as a risk or a complainer. Participant 6 confided:

'She did not mention I have Lupus in the interview. I don't think it was a question ever asked in the interview. I didn't in my CV [*curriculum vitae*], it still says my health is very good.' (Participant 6, Education, Female)

The reluctance to disclose was also influenced by the potential negative repercussions 'and I tend to not say because I don't want to let them think that I'm always complaining' (Participant 5, Pharmaceutical, Female).

Concealing medical treatments and procedures from co-workers presented additional challenges in workplace interactions. The ability to maintain a facade of normalcy was attributed to a developed resilience, yet this normalcy and concealment often perpetuated misconceptions about the severity of their condition:

'I don't tell all the staff. Some of the employees know. It's difficult when somebody says to you, "Oh, today you look so good." And then you think thank heavens it doesn't show, and my makeup skills are good because the day before I would have had chemo. I went for a fistula and kept it very quiet because the doctors are preparing for dialysis. I went into the theatre and in High Care that night and out the next day and that afternoon some of the contractors would phone and I would answer the question as if nothing happened yesterday.' (Participant 2, Health Education, Female)

Participants also concealed flares and medication management to avoid burdening others or eliciting negative perceptions and stereotypical responses of pity:

'And with that I put up with a lot of my flares and my meds in my personal capacity, I didn't feel comfortable to share that I'm sick. I shared when I needed to, but most times I didn't.' (Participants 3, Telecommunication, Male)

Pharma's views that 'from a business owner's view, I want the employee to be honest' was immediately accompanied by an acknowledgement 'that it's not a guarantee' as participants kept their conditions hidden as long as possible. Similarly, her insight that 'a business has to unfortunately think of the financial' was contrasted with the reality that employers would 'terminate your services because you're so sick you can't perform your duties'. Moreover, participants weighed up the consequences of their disclosure and the potential incentives to do so:

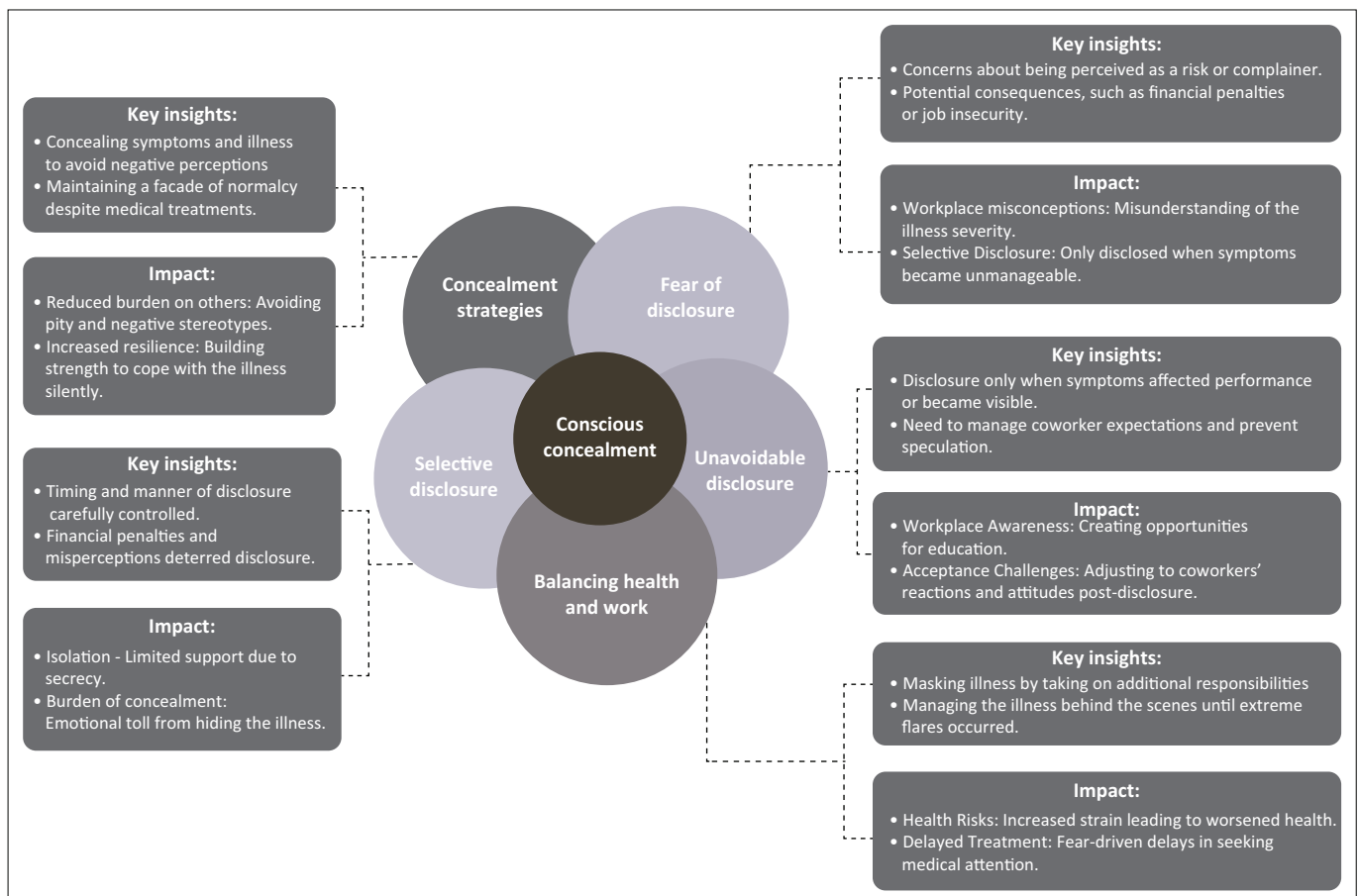


FIGURE 2: Conscious concealment.

'I doubt government will "reward" a business for employing somebody with Lupus, we're not technically disabled ... just gravely ill. People have cancer, say they undergo treatment, which makes them go off work for long periods or they're so ill from the side effects, they should also be considered, so that will be difficult.' (Participant 5, Pharmaceutical, Female)

Participants carefully controlled the timing, manner and extent of disclosure. Edu explained her reasons for concealing as she 'did not have a problem disclosing but the moment people find out they think that I don't have the ability to do the work'. She explained that she was selective in choosing work where if she knows 'it has triggers for my depression or Post Traumatic Stress Disorder (PTSD) I avoid applying'. Whereas when she was upfront with disclosure, it often came at a financial cost based on others' misperceptions and contrary to the educational institution's policies on accommodations:

'I disclosed it in a interview but the manager, we worked together at a previous company. They know the type of effort I put in when healthy, but would tell me in January you will not get a bonus in December because of the Lupus and sick leave.' (Participant 6, Education, Female)

Some participants managed to conceal their illness well enough not to be questioned during periods of illness, masking the impact of the Lupus by maintaining the appearance of good health strategically through taking on additional work responsibilities. This approach invariably placed participants at increased health risk:

'I never had to account for when I wasn't at work in that seven and a half years at [Employer Y] ... I was sick for six months if not a bit more. Now contrast to [Employer Y], I didn't spend a lot of time off at X. I managed the disease in the back end. I caught the symptoms well ahead so I wasn't walking with Lupus for a month or two [then] had a massive flare. Over time I've managed it behind the scenes ... And you do that out of fear. You normally wait until the disease is extreme before you go to hospital.' (Participants 3, Telecommunication, Male)

In some cases, disclosure occurred only when symptoms became too significant to hide, affecting job performance and making it impossible to maintain privacy. Participants described the difficulty of managing coworker expectations and the need to provide context for their condition to prevent speculation and misunderstanding:

'I would try not show that I'm feeling ill. However, they would see that I am spending more time in my office and knock and say, "Are you okay?." Then one day I just decided—enough. I'm going to sit them down at a management meeting and I went, right. "So, I have Lupus".' (Participant 1, Consulting, Female)

'In the beginning I didn't disclose then it became worse. I had to tell the work and it was where I was on top in my career managing over 7000 employees. I felt I'm sinking, and I needed to tell them. Unfortunately, then I had to disclose, "Okay, I have Lupus, and this is what's going on and this is how it's making me feel."' (Participant 2, Health Education, Female)

In conclusion, the disclosure of SLE presents a significant challenge, marked by the interplay between invisibility, stigma, identity and the need for acceptance and support.

Participants' experiences highlight the critical need for increased awareness and understanding of Lupus in workplaces and broader societal contexts.

## Discussion

This study offers a nuanced exploration of the complexities surrounding workplace disclosure for individuals with SLE. The findings emphasise how the invisibility of SLE symptoms often results in misunderstandings, trivialisation and stigma in professional environments. Participants likening the illness to a wolf provides a powerful metaphor that captures the hidden yet persistent nature of the disease. The findings align with Goffman's (1959) concept of impression management, wherein individuals manage how others perceive them in light of their health condition. Employees with episodic disabilities like SLE must carefully weigh their professional identity against the fear of being stigmatised. The results of this study show that disclosure often hinges on the perceived supportiveness of the workplace environment and the cultural understanding of chronic illnesses as participants confront when and how to disclose an illness that others may not fully understand or even recognise.

These findings have broader implications for Human Resource Management (HRM). One of the key contributions of this study is its extension of Stakeholder Theory to address the oppressive experiences of disability and managers have the responsibility to develop policies and practices that provide safe spaces for employees to disclose their health conditions without fear of stigma or professional consequences (Freeman, 1984; Gignac et al., 2021a). The role of organisational culture in shaping disclosure decisions is significant. Participants in this study who worked in more inclusive environments, where managers demonstrated a commitment to diversity and inclusivity, felt more comfortable disclosing their condition. Conversely, those in less supportive environments chose to conceal their illness because of the fear of being perceived as unreliable or weak. These findings emphasise the need for managers to foster environments where disclosure is met with empathy, understanding and appropriate accommodations. Effective HRM policies must normalise discussions of chronic illness, ensuring that employees are not penalised for their health status but are supported in maintaining their professional roles (Bruyère, 2000; Kochan et al., 2003).

Moreover, the application of Fanon's concept of 'leaning over' enriches the understanding of disclosure dynamics in the workplace. Fanon's framework of internalised oppression helps explain how employees with SLE struggle with the decision to disclose, as they navigate a professional landscape often shaped by ableist assumptions. Human Resource Management practices must actively address these systemic barriers, moving beyond traditional compliance-based approaches to foster genuine workplace inclusivity. This

requires creating organisational cultures that prioritise the dignity and agency of employees with chronic conditions (Black, 2007; Fanon, 1986).

The invisibility of SLE and its episodic nature necessitate flexibility in workplace policies. As Charmaz (2010) notes, individuals with chronic illnesses often experience stigma because their symptoms are not outwardly visible, making it difficult for others to grasp the severity of their condition. This study extends the existing literature by showing that organisations must develop more nuanced policies that address not only visible disabilities but also the unpredictable and often hidden nature of episodic conditions like SLE.

## Conclusion

This study offers contributions to the literature by deepening our understanding of the challenges associated with workplace disclosure for individuals living with a chronic disorder such as SLE. The findings underscore the need for managers and organisational leaders to go beyond superficial diversity initiatives and work towards fostering inclusive environments that provide adequate support for employees with episodic and invisible disabilities. Future research should build on these findings by examining the disclosure experiences of individuals with other chronic illnesses and exploring how cultural contexts influence the dynamics of disclosure and workplace support. Longitudinal studies could offer further insights into how disclosure decisions evolve over time, and how organisations can implement long-term strategies to support employees in balancing their health with their professional responsibilities.

From a theoretical perspective, this study makes two contributions. Firstly, it extends Stakeholder Theory by reinforcing the responsibility of organisations to prioritise the well-being of employees with chronic illnesses, particularly in the context of disclosure decisions. Secondly, it incorporates Fanon's concept of 'leaning over' to challenge traditional management practices and encourage a rethinking of workplace inclusivity. By addressing the systemic barriers that hinder the full participation of employees with disabilities, the study highlights the need for a more empathetic and structurally inclusive approach in HR management.

Practically, the study emphasises the importance of organisational culture in shaping disclosure decisions. Human resource managers should develop training programmes to ensure that both supervisors and colleagues are sensitive to the challenges faced by individuals with chronic illnesses, thus fostering an environment of support and understanding. By creating a safe space for disclosure, organisations can not only enhance employee engagement but also drive innovation by leveraging the diverse experiences of all employees.

## Acknowledgements

### Competing interests

The author declares that he has no financial or personal relationships that may have inappropriately influenced him or her in writing this article.

### Author's contributions

A.B. conceptualised the article, wrote the original draft and conducted the analysis, presentation of findings, discussion and conclusion.

### Ethical considerations

An application for full ethical approval was submitted to the Stellenbosch University Social, Behavioural and Education Research Ethics Committee and ethics consent was granted with reference number 24082. The study was conducted in accordance with established ethical guidelines. Informed consent was obtained from all participants prior to data collection, and details of a counsellor were provided for those who felt they required these services. In compliance with the *Protection of Personal Information Act (POPIA)*, all data were deidentified to protect participant confidentiality. Personal identifiers were removed or replaced with pseudonyms, and deidentified data were securely stored in encrypted, password-protected files. Consent forms were stored separately from the research data to prevent linkage to individual participants.

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### Data availability

The data that support the findings of this study are not openly available because of data containing potentially identifying or sensitive participant information and are available from the corresponding author, A.B. upon reasonable request. Data are stored in a controlled access repository. Additionally, data enquiries can also be directed to the Stellenbosch Business School Departmental Ethics Committee where requests are subject to review and approval.

### Disclaimer

The views and opinions expressed in this article are those of the author and are the product of professional research. It does not necessarily reflect the official policy or position of any affiliated institution, funder, agency or that of the publisher. The author is responsible for this article's results, findings and content.

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