

Exploring self-management strategies for people with degenerative spine disease: An interpretative descriptive study

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<https://doi.org/10.51867/ajernet.7.4.20>

ABSTRACT

Degenerative Spine Disease (DSD) is a progressive, chronic condition characterised by deterioration of spinal tissues. Although DSD is a wear-and-tear condition associated with ageing, it has become increasingly common among the younger population in recent years. Despite its incidence, lived experiences of people with DSD, specifically in the Zambian setting, remain uninvestigated. Research objective(s): The study aimed to explore lived experiences of people with DSD and the self-management strategies employed in order to establish evidence for both home and clinical care. Methods: The study used a qualitative Interpretative Descriptive design and included 12 participants aged between 23 and 49 years. Participant selection was through purposeful sampling. Data were collected through face-to-face semi-structured interviews and analysed using inductive thematic analysis with NVivo software version 12. Key findings included narratives on the impact of DSD on individuals and the self-management strategies developed. The study identified multifactorial symptoms across different facets of one's life. The struggles sufferers go through are not only with their clinical symptoms but also with those involving society and the work environment. Consequently, self-management involved their own unique context. These self-management strategies included using home-based pain-relief equipment, pacing activity, resting, adjusting postures, bracing, and managing diet. Conclusion: The study established the impact of DSD on individuals and reported on condition-specific self-management strategies sufferers developed over time, the knowledge that can be used in clinical practice to improve patients' symptoms and quality of life. Further, the results contribute to the body of research and form a foundation for further research on chronic conditions and patient management, particularly in developing countries like Zambia. Practical Recommendation: The knowledge gained could inform and form part of the evidence for developing a standardised self-management model for people with DSD.

Keywords: Chronic Pain, Degenerative Spine Disease, Healthcare Provider, Self-Management

I. INTRODUCTION

Degenerative Spine Disease (DSD) is defined by the wear and tear of spinal structures, including discs, vertebral bones and facet joints (Bhute et al., 2025) and may include pathologies such as disc bulges, disc herniations, osteophyte formation, loss of disc height, disc desiccation, spondylosis, and spondylolisthesis (Parenteau et al., 2021; Aoki et al., 2021). Generally, DSD is associated with advanced age; however, in recent years, it has become increasingly common among younger populations (Kirnaz et al., 2021; Kostka et al., 2023; Scarcia et al., 2022). In a study by Takatalo et al. (2009) on young Finnish adults aged 21 years, half of the participants had at least one degenerated disc, while a quarter of the participants had a bulging disc (Takatalo et al., 2009). Similarly, a meta-analysis by Berg et al. (2020) and a study by Brinjikji et al. (2015) report that spine degenerative changes on Magnetic Resonance Imaging (MRI) are common in young adults aged 50 years and below (Berg et al., 2020; Brinjikji et al., 2015). Likewise, a prospective 30-year follow-up MRI study reported that early-onset degenerative changes in lumbar discs predicted progressive degenerative changes in the respective discs (Sääksjärvi et al., 2020). This was similar to Parwani et al. (2025), who reported that disc herniation was particularly common among people aged 30 to 50 years.

Several factors contribute to the development of spine degenerative changes including: age due to the natural aging process (Chou et al., 2021), obesity places additional stress on the lower spine (Koes et al., 2007), while physical jobs that engage repetitive lifting, pulling, pushing, bending, or twisting movements significantly increase the risk of spine degeneration (Ropper & Zafonte, 2015), genetic predisposition to intervertebral disc degeneration, making them more susceptible to herniation even with minimal physical strain (Deyo et al., 2016), smoking is reported to impact on effective flow of oxygen to discs (Parwani et al. (2025), prolonged sitting leads to overload of the spine particularly the lumbar spine resulting in degeneration (Parwani et al., 2025). As documented by Sasiadek &

Jacków-Nowicka (2024), symptoms in degeneration of the spine include compression of the nerve root or spinal cord by disc herniations or osteophytes, disc herniation, Modic type 1 degenerative changes of the vertebral bodies, degenerative changes of the vertebral endplates, degenerative changes of the facet joints and ligamenta flava, degenerative spinal canal stenosis, degenerative spondylolisthesis, and Baastrup's disease (Sąsiadek & Jacków-Nowicka, 2024).

As a global burden, Ravindra et al. (2018) evidenced that 266 million persons worldwide have DSD, with the highest and lowest estimated incidences reported in Europe (5.7%) and Africa (2.4%), respectively (Ravindra et al., 2018). The authors further established that, based on population sizes, small- and middle-income countries have 4 times as many cases as high-income countries (Ravindra et al., 2018). Thirty-nine million individuals worldwide were found to have spondylolisthesis, 403 million individuals worldwide with symptomatic disc degeneration, and 103 million individuals worldwide with spinal stenosis annually (Ravindra et al., 2018). The incidence of degenerative spine disease in the population aged less than 50 years was 71% for men and 77% for women, and in the population aged more than 50 years was >90% in both genders (Ishiguro et al., 2019; Teraguchi et al., 2014). Back-spine pain is a major health issue, with prevalence between 12% and 30%, with around 10% developing into chronic pain (Ishiguro et al., 2019). It affects not only physical well-being, but also psychological well-being, well-being, well-being, as it increases stress, depression, and anxiety. The socioeconomic impact has also increased due to rising costs over the years (Mahyudin et al., 2022). Similar reports have been documented in Africa. Garba et al. (2025) reported that in clinical consultation involving spinal symptoms, 60.8% were degenerative spine disease (Garba et al., 2025). Similarly, Bash et al. (2025) reported that 92% of young patients referred for spine MRI had DSD. As such, Bash et al. (2025) recommended future studies to observe progression of degenerative changes over time in order to establish effective preventive measures in younger populations (Bash et al., 2025). In a systematic review on global, regional, and national burden of back pain between 1990–2019, the authors found that Zambia, Zimbabwe, and Canada showed the highest increase in the age-standardised prevalence of back pain during 1990–2019 and concluded that lower back spine pain remains a major public health issue globally, regionally, and nationally (Chen et al., 2022). In a study conducted between Zambia and Kenya, the authors reported that lumbar spine pain was one of the common sources of symptoms among those who consulted them and that degenerative disc disease was frequently associated with reduced movement and with features of nerve root irritation (Kuo et al., 2022). In another study conducted in Zambia on back pain, the authors reported that 90% of caregivers self-reported experiencing lower back pain (Koitsiwe et al., 2025).

Currently, there is no cure for DSD, and treatment options to manage symptoms include conservative and invasive surgical procedures (Xin et al., 2022). Some interventions aim to control symptom severity, while others aim to address the consequences of disc degeneration (Loibl et al., 2019). DSD treatment interventions include conservative and surgical procedures (Chou et al., 2017; Parwani et al., 2025). Surgery is a treatment option for people with severe neurological symptoms (Parwani et al., 2025). Future promising treatment approaches include regenerative medicine and biologic therapies aimed at repairing the disc at the cell level, which remain promising (Parwani et al., 2025). In vitro and in vivo studies show that stem cell-based treatments and tissue engineering approaches are promising; unfortunately, there is no current curative treatment approach for the spine (Xin et al., 2022). In the absence of a cure, the current study aimed to explore lived experiences of self-management among people with degenerative spine disease.

Self-management strategies have been reported to be an important component in managing chronic conditions (Panpanit, 2012). Chronic conditions are often long-term and are defined as ongoing, usually non-communicable health conditions that, in most cases, cannot be cured and yet can significantly impact a person's quality of life (Francis, 2017). DSD is a long-term health condition, currently not curable, yet symptoms can progress or worsen over time with a psychological impact on the sufferer (Francis, 2017). Self-management is recommended as important for maintaining well-being in individuals with long-term chronic conditions (Panpanit, 2012; Kannan, 2008), and it is a complex and evolving construct (Dukhu et al., 2018). It is a multidimensional construct comprising aspects such as treatment management, relationships with health care providers, and general coping strategies to improve the quality of life (Bishop et al., 2008). Self-management involves actions taken by an individual to manage their own health, and is conducted independently or in partnership with healthcare professionals (Anderson & Ozakinci, 2019). The primary objective of self-management is to improve health outcomes by supplementing medical care rather than replacing it (Walker et al., 2003), and this has been shown to reduce symptoms and enable individuals to participate in decision-making regarding clinical treatments (Kralik et al., 2004; Al Abbad, 2020). While self-management has been researched in other chronic conditions, currently, there is no research located that has investigated self-management in people with degenerative spine (disc) disease.

DSD is a public health issue with consequences on the healthcare systems and work productivity (Parwani et al., 2025). Therefore, it was important to establish the impact of the disease in a context such as Zambia and to explore how people in this patient population self-manage.

1.1 Problem Statement

Degenerative spine disease is a progressive and irreversible condition (Qian et al., 2019). Many younger people with degenerative spine disease are in full-time employment and need to cope with the challenges of their condition (Makino et al., 2017). This is also a clinical observation in Zambia of an increase in degenerative spine disease among young people. The treatments for degenerative disc disease are controversial, and failures are common (Liyew, 2020). Current available treatments aim to reduce symptoms and do not treat the underlying degenerative changes (Kirnaz et al., 2022). While some potential and extremely expensive treatments, including regenerative biological therapies, gene therapies, growth factors, cellular-based injections, and tissue-engineered constructs, have attracted significant attention considering their potential to address the degenerative process directly (Kirnaz et al., 2022), these possible therapies remain in trials (Xin et al., 2022; Soufi et al., 2023). In the absence of a cure, complementary measures such as self-management strategies are vital (Devan et al., 2018). Strong evidence supports the benefits of the self-management approach as part of comprehensive care for incurable conditions (Graham, 2014). Establishing patients' experiences with self-management strategies in degenerative spinal disease, especially in Zambia, where medical intervention is inadequate, is necessary (Ferrinho et al., 2011; Aantjes et al., 2014; Mwambazi & Mpundu, 2024; Mapulanga & Dlungwane, 2024). Hence, the current study explored self-management strategies in young adults living with DSD. The findings aimed to support overall care for patients with DSD and to inform clinical practice and healthcare policies related to people with chronic illnesses such as DSD within the Zambian context.

1.2 Study objectives

- i. To explore the impact of the degenerative spine disease condition on sufferers.
- ii. To explore self-management strategies employed by people living with degenerative spine disease.

1.3 Study Question

- i. What are the experiences of living with degenerative spine disease for sufferers?
- ii. What self-management strategies are employed by people living with degenerative spinal disease?

II. LITERATURE REVIEW

2.1 Theoretical Review

This qualitative study explores how people living with degenerative spinal disease self-manage and the meanings they attach to their self-management actions across different aspects of their lives. This area of research best fits interpretivist and constructivist frameworks. Thus, the ontology of the study was that of interpretivism; that the nature of reality may be interpreted in various ways (Van, 2013), while the epistemology, how reality is known, is constructivism (Denzin & Lincoln, 2005). Constructivism denotes that meaning is constructed with or through the knower; in this case, patients living with degenerative spine disease, thus, interpretivism is epistemologically supported by constructivism (Denzin & Lincoln, 2005; Van, 2013). This epistemology is appropriate for gaining insight into the experiences of people with degenerative spine disease, interpreting experiences of self-management (Creswell & Clark, 2017), and understanding the complexity of this constructed knowledge of self-management in the context of degenerative spine disease.

2.2 Empirical Review

2.2.1 Impact of Degenerative Spine Disease on Sufferers

The management of long-term conditions is influenced by a number of distinct yet overlapping spheres, including social context, the clinical setting, and the physical environment, that shape the feasibility of engagement in self-management practices (Morris, 2011). Rujipong et al. (2021) pointed out the significant cultural differences in self-management modalities, and use was dependent on medical support from practitioners as well as social and other support (Rujipong et al., 2021). In addition, previous literature has identified variation in self-management approaches, including cultural influences, patient adherence, and contextual support mechanisms (Rujipong et al., 2021; Adem, 2017; Zhou et al., 2022), yet these factors have not been explored in the Zambian context among individuals with DSD.

Pearson et al. (2020) researched among patients with fibromyalgia and reported positive changes, including increased activity levels, pacing, better quality sleep, improved communication with family members, and improved symptoms (Pearson et al., 2020). Equally, studies by Nott et al. (2021) and Pereira et al. (2025) focused on self-management in stroke and found that engagement in a stroke-specific self-management program can improve physical function, emotional state, health-related quality of life, client-perceived occupational performance and satisfaction. Likewise, studies that investigated self-management in osteoarthritis reported improved quality of life and self-management skills; however, they documented a lack of disease-specific self-management (Biscaro et al., 2022; Damgaard et al., 2023; Yurtkuran et al., 2007; Steinbarger, 2021).

Similarly, researchers have studied individuals with mental health conditions (Beaudin et al., 2025; Gao et al., 2025; Chambers et al., 2015). In addition to reporting improved mental health among people who engaged in self-management, the studies also reported multiple factors that influenced self-management, including disease impact, the degree of symptom control, and support (Gao et al., 2025). Other research has focused on self-management in cancer (McCorkle et al., 2011; Dadi et al., 2024; Hurtado et al., 2017). It was noted that with improved early detection and treatment of cancer, people in this patient population are living longer, and their cancer may be managed as a chronic illness with consequent need for self-management strategies (Hurtado et al., 2017; McCorkle et al., 2011; Dadi et al., 2024).

Dadi et al. (2024) and Wu et al. (2024) on self-management among people living with HIV found that the success of medical treatment for HIV is dependent on patients' self-management tools and the support of their family and health service providers. These studies also recommended condition-specific self-management strategies (Dadi et al., 2024 & Wu et al., 2024). Furthermore, Halding et al. (2018) in chronic obstructive pulmonary disease; Wang et al. (2024) in ischemic heart disease and O'Hara and Roufeil (2025) in endometriosis established that self-management plays a clinical role in the care of chronic conditions and recommended condition-specific self-management strategies. These studies also highlighted the need to understand factors such as "attribution" and "barriers and facilitators" for effective clinical guidelines (Wang et al., 2024).

Despite extensive research on self-management in chronic conditions, there remains a notable absence of condition-specific self-management research addressing degenerative spine disease (DSD). Therefore, there is a critical need to investigate the lived experiences of self-management within their contexts among people with degenerative spinal disease in Zambia.

2.2.2 Self-Management Strategies Employed by People Living with Degenerative Spine Disease

In a review of self-management approaches for people with chronic illness, Barlow et al. (2002) found that there was a growing body of evidence indicating that individuals who had been educated in self-management of their chronic illness had better health status than those who had not been educated in self-management (Barlow et al., 2002). Further, proper self-management can help reduce the burden and health costs surrounding chronic illness (Gallagher et al., 2008; Panpanit, 2012).

Rujipong et al. (2021) reported that self-management strategies among chronic back pain sufferers involved modalities, exercises, food, rest, and prayers. Likewise, studies that investigated self-management in osteoarthritis reported improved quality of life and self-management skills; however, they documented a lack of disease-specific self-management (Biscaro et al., 2022; Damgaard et al., 2023; Yurtkuran et al., 2007; Steinbarger, 2021). Similarly, self-management in diabetes included regular monitoring of their sugar, food, exercise, and adherence to medication (Coyle et al., 2013; Daramilas et al., 2025). These studies also established that self-management practices change over time and whether this impacts health outcomes is an area for future research (Coyle et al., 2013).

Other research has focused on self-management in cancer (McCorkle et al., 2011; Dadi et al., 2024; Hurtado et al., 2017). These studies found a need for a common language to discuss self-management and a common set of self-management actions for cancer care (Hurtado et al., 2017; Dadi et al., 2024; McCorkle et al., 2011 & van Dongen et al., 2020).

Dadi et al. (2024) and Wu et al. (2024) on self-management among people living with HIV found that the success of medical treatment for HIV is dependent on patients' self-management tools and the support of their family and health service providers. These studies also recommended condition-specific self-management strategies (Dadi et al., 2024 & Wu et al., 2024). Similarly, researchers have studied individuals with mental health conditions (Beaudin et al., 2025; Gao et al., 2025; Chambers et al., 2015). In addition to reporting improved mental health among people who engaged in self-management, the studies also reported multiple factors that influenced self-management, including disease impact, the degree of symptom control, and support (Gao et al., 2025).

Self-management has been researched in many conditions, including Zeng et al. (2025), who researched among the hypertension patient population and reported that self-management was even more vital when they had lower medical insurance coverage (Zeng et al., 2025), implying that self-management is cost-effective. Pearson et al. (2020) researched among patients with fibromyalgia and reported positive changes, including increased activity levels, pacing, better quality sleep, improved communication with family members, and improved symptoms (Pearson et al., 2020). Furthermore, Halding et al. (2018) in chronic obstructive pulmonary disease; Wang et al. (2024) in ischemic heart disease and O'Hara and Roufeil (2025) in endometriosis established that self-management plays a clinical role in the care of chronic conditions and recommended condition-specific self-management strategies.

Similarly, studies that have explored self-management among adolescents with systemic lupus erythematosus have reported improvement in symptoms and suggested that the self-management program improves awareness among adolescents with systemic lupus erythematosus. Abdallah Salem et al. (2024) recommended the ongoing implementation of specialised self-care training programs for adolescents with systemic lupus erythematosus to enhance their awareness. While other studies looked into the efficacy of self-management, studies such as Gordon et

al. (2016) established barriers to self-management as faced both by healthcare professionals and patients (Gordon et al., 2016). Also, Elbers et al. (2018) on generic self-management approaches reported that generic self-management interventions have a marginal benefit (Elbers et al., 2018).

In addition, previous literature has identified variation in self-management approaches, including cultural influences, patient adherence, and contextual support mechanisms (Rujipong et al., 2021; Adem, 2017; Zhou et al., 2022), yet these factors have not been explored in the Zambian context among individuals with DSD. Therefore, there is a critical need to investigate the lived experiences of self-management within their contexts among people with degenerative spinal disease in Zambia.

III. METHODOLOGY

3.1 Research Design

This study used interpretive description methodology as it aligns with a constructivist and naturalistic orientation to inquiry (Hunt, 2009). Interpretive description arose from a perceived lack of qualitative methodological options to address research questions in a clinical setting (Van, 2013). Since the late 1990s, researchers have shown interest in developing a methodology suited to research questions in a clinical setting (Thorne et al., 2014). Interpretive Descriptive (ID), advanced by Thorne and colleagues, is one such methodological development to suit the intricacies of qualitative, clinically based research (Thorne et al., 2014). Interpretivism, the study ontology, rests on naturalistic methods to reveal the multiple faces of reality while maintaining distinctions between the different realities presented (Thorne et al., 2014; Van, 2013). This ensures that contextuality, daily life, and their complexity are not lost during data collection and synthesis (Van, 2013), thus placing the clinical setting at the forefront of ID (Van, 2013). ID was suitable as a methodology grounded in the epistemological theory of knowledge construction, particularly in clinical settings (Thorne, et al., 2016; Van, 2013). The interpretivist and constructivist perspectives provide the theoretical framework for ID's methodological operations. The researcher is an interpreter, preoccupied with making meaning, which is harnessed to understand clinical phenomena, simultaneously constructing knowledge from the understanding gleaned through interpretation (Van, 2013). Knowledge is constructed within a clinical context (those with degenerative spine disease) because participants interpret their health predicament as does the researcher (Jonsdottir et al., 2004).

3.2 Pilot Study

The study was piloted on 5 volunteers who were not included in the final study.

3.3 Target Population and Sampling Technique

The study included 12 participants living with DSD who had their condition clinically diagnosed using an MRI and were 18 to 49 years of age. Purposive sampling was used to select participants (Akhtar & Shaheen, 2024) from Hallamshire Wellness Clinic, University Teaching, Levy Mwanawasa, and Italian hospitals in Lusaka, Zambia.

3.4 Data Collection

Data were collected using open-ended, semi-structured face-to-face interviews (Scanlan, 2020; Chala et al., 2022). Semi-structured in-depth interviews are a valuable tool in qualitative descriptive approaches, as they encourage depth and openness, enabling participants to express themselves freely and allowing for the collection of rich data (Bradshaw et al., 2017; Monk, 2021). A topic guide supported open discussions around the phenomena being studied (Chenitz, 1986; Van, 2013), and all interviews were audio-recorded, with field notes taken to supplement each interview.

3.5 Ethical Approval

The study received ethical approval from the HSSRE Committee at the University of Zambia, and all the ethical requirements were observed.

3.6 Methodology Integrity

ID quality assessment criteria include epistemological integrity (the consistency and coherence of the study's ontological, epistemological, and methodological choices), representational credibility (research findings reflect the perspectives and experiences of the population under study; achieved through purposive sampling, which enabled the inclusion of people with DSD), analytic logic (the transparent and coherent linkages between data, interpretations, and findings, supporting the dependability of the research process and enabling another researcher to successfully scrutinize the study data. The use of audit trails and a reflective journal allowed the researchers to track evolving interpretations, thereby illustrating the thought processes and decisions made during data analysis), and interpretive authority (achieved by the researcher's ability to ensure transparency throughout the research process) (Thorn, 2016;

Tennant, 2023). Likewise, Braun and Clarke (2019) recommend that methodological integrity in research using RTA should involve reflexivity and transparency throughout the data.

3.7 Data Analysis

This study used reflexive thematic analysis and followed the six-step analytic process outlined by Braun & Clarke (2006). Table 1 below shows participants' demographic information.

Table 1

Demographic Data

Gender	Age Range	Ethnicity	Pain Duration range	Occupation
F: 7 M: 5	23 - 49 years	African: 10 European-African 2	2 - 27 years	11 Employed 1 Self Employed

Table 2 below shows the process of developing themes based on Research Question 1: *What are the experiences of living with degenerative spine disease among sufferers?*

Table 2

Example of Development of Themes

Codes	Subthemes	Themes
Changes To Daily Routines, Interests, And Hobbies, Not Able to Care for Family	Isolation, Affected Participation in Family Life	Impact Of the Condition
Fear Of Future, Not Able to Work, Discharge from Work	Impact On Career, Performance, And Professional Identity	
Emotional Distress, Stress, Depressive, Self-Doubt	Affected Self-Esteem and Self-Concept	

Table 3 below shows the process of developing the themes based on research question 2: *What are the self-management strategies employed by people living with degenerative spine disease?*

Table 3

Example of Development of Themes

Codes	Subthemes	Themes
Exercise, Movement, Physical Activities	Planning And Pacing Activities	Self-Management
Taking Breaks, Resting	Intentional Body Positioning and Posture	
Growing Resilience, Acceptance, Positive Outlook, Spiritual Coping, Family, Healthcare Provider, Friend Support	Psychological Coping Strategies	
Food, Sugars, Diet, Weight	Diet And Supplements	

IV. FINDINGS & DISCUSSION

4.1 Introduction

This study explored self-management strategies among people living with degenerative spine disease in Zambia and deepened understanding of the condition's impact and the self-management strategies participants shared. This knowledge contributes to both clinical and practical evidence as well as future research.

4.1.1 Theme 1 Impact of the Condition

Participants described many ways the condition affected their lives personally and professionally. Isolation and affected social life were commonly mentioned, with several participants explaining that they had either gradually withdrawn from participation in social events due to their condition or stopped being invited to participate. Other participants explained that the isolation was a natural result of them not being able to do what they used to do together with their friends due to their ongoing symptoms, as described by participant 8,

“Because my pain is triggered by standing or sitting more, even just 30 minutes, it is difficult to socialise. I need to either lie down or walk about. You cannot maintain conversations like that. It is frustrating, and I prefer to stay home. It has limited my social circles” (P8, 05 November 2025).

This is consistent with research that has investigated chronic illness and social isolation. According to Freeman et al. (2020), social isolation is complex. It represents a spiral of effects, such as physical deterioration leading to limited social interaction and, in turn, affected self-identity (Freeman et al., 2020). This can lead to further

self-isolation (Freeman et al., 2020). These narratives mirrored the current study's findings. Similarly, Stensland and Sanders (2018) reported the systemic implications of chronic low back pain, including feeling socially and recreationally repressed. Current study participants reported that social exclusion was sometimes dictated by their symptoms, particularly functional limitations and difficulty with prolonged sitting or standing, as these triggered symptoms.

Similarly, Voorhees (2023) in their study, sufferers described an overall sense of loneliness and abandonment as if their pain separated them from society in general. They were no longer able to relate to or connect with others in the ways they had before, due to the physical, mental, or emotional ramifications of their ongoing pain. This caused them to feel shut off from society at large because their communication with people had changed as a whole (Voorhees, 2023). Furthermore, participants shared the stigma they experienced from co-workers, employers, and sometimes from extended family members. Participants discussed experiencing shaming and mockery because of the physical limitation caused by their symptoms, as expressed by participant 1,

"At work, I am unable to lift heavy equipment, but because I am a man, I am expected to be strong" (P1, 03 October 2025)

While participant 7 shared being mocked for,

"Wearing a spine brace or needing to sit with their back supported by a pillow" (P7, 04 October 2025).

Participants reflected that stigma and social scrutiny contributed to social isolation. This aligns with broader literature documenting stigma in health contexts (Perugino et al., 2022). Literature reports that stigma experienced by individuals with chronic pain affects their entire life and that there is an inadequate education of health care professionals regarding pain assessment and their insecurity to manage patients with chronic pain and the consequent need to promote pain education and to expand knowledge and assessment of chronic pain (Perugino et al., 2022). Current study participants echoed similar experiences not only of stigma but also of a lack of patient education on chronic conditions and, for the current study, degenerative spine disease. While current study participants expressed more of external stigma, however, O'Donnell and Habenicht, (2022) indicated that there is a relationship between experienced, anticipated, internalized stigma and illness self-concept suggesting that stigma is associated with increased preoccupation and perceived impact of one's illness on the self especially in those with concealable chronic illnesses (O'Donnell, & Habenicht, 2022) thus, the need for different methods of coping (O'Donnell, & Habenicht, 2022). Another impact on their personal, daily life was affected participation in family life, with several participants specifically raising concerns; participant 2 emphasized the limitations on interacting with children:

"I have small kids who like to play around, to run around. Oh, you lift them, you do this but I cannot play with my kids. Due to pain. I have to think about what I am doing and how I am doing it" (P2, 04 October 2025).

Similarly, participant 6 shared that,

"I can no longer do the activities that I enjoyed, and that is a huge change and a sad experience" (P6, 14 October 2025).

While participant 12 described reliance on family for assistance during severe pain, sharing that,

"When I am in severe pain, and I cannot move out of bed alone, my wife helped me out of bed, and my wife does step in and work on my behalf at my workplaces as a gardener. Other times when I am in severe pain, my brother helps me, and we split the salary" (P12, 06 December 2025).

While participants described relying on family for assistance during severe symptoms, they also discussed the resulting limitations in their daily lives. Participants further discussed the helplessness of having to change roles or ask for help; particularly, male participants discussed their pain in vulnerability of not being a strong, muscular figure. In contrast, others allowed help from their partners. All participants reflected on how pain had changed them over time. Like the current study findings, Holloway et al. (2000) reported that ongoing pain forced participants and their relational partners to acknowledge new limitations, worries, and fears; subsequently, relational roles sometimes changed, with participants going from caregiver to care receiver or from dependable confidant to unreliable individual with less time for others (Holloway et al., 2000). Current study participants reported altered self-concept and self-esteem. In many cases, this inability to perform the parent role they feel is expected of them contributes to affected self-esteem and self-concept. Participant 3 echoed,

"I've known myself to be a very strong person," but at the moment "that's far from my current reality" (P3, 10 October 2025).

Participant 8 shared that

"The condition has changed me a lot." I am no longer the same person I used to be" (P8, 05 November 2025).

Their current self-perceptions conflict with who they believe they should be or traditionally were, which can be a devastating realisation. This may relate to family life or to any other activities. Participant 7 described that,

"I can no longer do the activities that I enjoyed and that is a huge change and sad experience" (P7, 04 October 2025).

These experiences align with the wider literature. A study on self-concept among youth with a chronic illness reported that self-concept is compromised in youth with a chronic illness (Ferro & Boyle, 2013). Likewise, a study on physical-mental comorbidity found that it was associated with lower self-concept, and the authors concluded that clinical guidelines to support positive self-perceptions were warranted (Ferro et al., 2023). Participants shared how their degenerative spine disease affected professional identity and self-worth. Several participants described how their performance at work has been affected, which, in addition to the previously mentioned self-doubt and psychological impact, sometimes resulted in transfers to less favourable roles or workplaces, a lack of trust at work, or an inability to work as much as they can. This led to loss of professional identity. Meanwhile, for some participants, the symptoms had significantly affected their career progress as shared by participant 11 explained,

"It's also psychological because you start to think how long can I be useful in my employment before they discharge me because of reduced work performance due to pain" (P11, 04 December 2025).

Slightly different but on the same topic, participant 11 further emphasised financial strain and family responsibilities;

"I also have kids to take to school; it is straining for the average Zambian; they won't afford it. If they do, they would need to get loans and loans, and eventually it becomes a cycle that technically is not sustainable" (P11, 04 December 2025).

While participant 9 on the impact pain has on their professional identity;

"Because my job entails travelling a lot and moving around, being quite mobile. So, there are times, especially on my bad days, when I'm in extreme pain. It becomes a bit difficult to manage work" (P9, 26 October 2025).

In contrast, participant 10 reflected on the consequences for and loss of a leadership role as a result:

"The condition caused me to lose my position as acting head of department at my former school. Apparently, management asked me to declare my position because I was not actively involved in the running of the affairs of the school" (P10, 05 October 2025).

Holloway et al. (2000) in their study reported that chronic pain sufferers go through a status transition from a well persons to becoming "pain afflicted" resulting in a change in perceived identity and consequent grieve over the loss of former selves, future, social relationships, and occupational careers (Holloway et al., 2000). Furthermore, Holloway et al. (2000) reported in their study before the onset of chronic pain, participants had goals and expectations for how they would enact their identity, across their family life, social and career ambitions, however, chronic pain changed how they were able to perform their sense of self; meaning the way one moves one's body, the ways one spends one's free time and the type of career or family one chooses all demonstrate and influence one's identity (Holloway et al., 2000). Correspondingly, in their study, Strub et al. (2022) reported that chronic conditions can change a sufferer's occupational identity. Likewise, participants in the current study echoed these reflections, describing sadness and loneliness even when surrounded by loved ones.

Not surprisingly, emotional distress, stress, and depressive episodes were also reported as one of the impacts of living with degenerative spine disease. As expressed in the quotes from participants, they found these realisations, as well as their general experiences of living with this condition, were "*depressing*" and "*stressful*". Like a double-edged sword, participants reflected on how stress and pain symptoms exacerbate each other and felt trapped in the cycle of symptoms as described by participant 4:

"It is emotionally draining. And I think it was also making the situation worse, because I realised whenever I stress, my back pain is worse, my muscles get more compact" (P4, 11 October 2025).

Participants further discussed the anxiety that they may be paralysed and lose all function, while others fear losing their marriage and relationships. Participant 2 described this as "mental pain" (04 October 2025). Participants furthermore expressed the stress they suffered to even ask for permission regularly for their hospital visits due to the mockery and stigma they experienced. Participant 6 expressed,

"it's the hidden symptoms; people may not visibly see numbness or tingling sensation because my nerve is trapped in the spine"; therefore, people are quick to judge and suggest that I am faking the illness" (P6, 14 October 2025).

These narratives further raised the impact of not only DSD but also those of non-communicable diseases, which are often invisible.

The impact of suffering from DSD on career, performance, and professional identity often overlaps with uncertainty about the condition and future, part of which is the previously mentioned doubts about the future in terms of professional career. Concerns about the ability to sustain their family and earn enough money were common:

"Worried that I would not work long enough to earn a living for myself and for my family" (P1, 03 October 2025).

Participants' reflections in the current study show that managing a chronic condition can be expensive and can cause fears not only about medical bills but also about the finances needed to sustain oneself and one's family. As one participant elaborated, these anxieties become severe when their carer is impacted.

"I am a mom raising a young family, fear that one day I would be stopped working, so that's just been the worry, it gives that anxiety, and sometimes, it's depressing as well" (P5, 05 October 2025).

As found in the current study, Clarke et al. (2022) also found that uncertainties were related to disease causative factors, treatments, prognosis, and uncertainty about the future. Participants in the current study reflected at length on fears about the future, especially anxieties about disease progression and symptom recurrence in the absence of a cure. Furthermore, current study findings are mirrored in related research. Participants in a study on *"how chronic pain changes multiple frames of identity"* shared the anxiety related not only to the physical and financial limitations of chronic pain but also to the uncertainty of their symptoms and long-term prognoses (Voorhees, 2023). Sufferers often report having to retrain their minds to adapt (Brown et al., 2020). Participants in the current study discussed how they needed to brace themselves mentally, realising that they are trapped in a new body with a chronic condition:

"So over the 20 years it has been a journey of restraint. It's showing strength by a restraint" (P2, 04 October 2025).

Participants discussed mental strength and how that became their conscious decision to cope and rise above their fears, especially of the unknown future.

4.1.2 Theme 2 Self-management

Following discussions on the condition's impact on individual lives, the study explored the self-management strategies participants had developed. Participants discussed scheduling movement, avoiding triggers, and pacing activities as self-management strategies. Participants also discussed that planning and pacing activities helped reduce symptoms, as articulated by participant 10:

"I have learned now to adequately plan my work well in advance because I walk slow and I cannot do things at a faster rate anymore due to pain" (P10, 05 October 2025).

Participants also discussed that, over time, they learned to schedule their activities accordingly:

"Knowing what activities to avoid completely and which ones to minimise helps to reduce pain" (P3, 10 October 2025).

Most participants reported that scheduling their workload at work, at home, or during social activities helped manage their symptoms. Participants specifically, discussed that working straight through for hours would trigger symptoms, therefore, found that breaking their workload in intervals of 30 minutes with breaks in between helped, participant 4 discoursed that

"I am not able to work for longer than 30 minutes at a time, otherwise, my back and neck become painful, so I have a reminder on my watch to stand or work from standing every 30 minutes and I do some stretching exercises during my work break time" (P2, 04 October 2025).

While other participants shared that scheduling their work by alternating between heavy and light workloads, with corresponding changes in standing and sitting postures, along with adequate rest or short walks in between, reduced spinal strain helped reduce their symptoms. Participant 12 further explained that gentle physical activity was effective,

"I also find that when I take short walks, my muscles ease and the pain reduce" (P12, 06 December 2025).

Across participants' reflections, slow-paced movements or actions were highly discussed:

"I have also adjusted the way I move; I don't walk as fast as I used to knowing that the pain comes from my spine, I make sure that I walk carefully, and to make sure that I balance this step" (P8, 05 November 2025).

Participants reported that quick movements or actions triggered their symptoms, while slow, deliberate movement did not; therefore, many had learned to walk slowly and carefully, turning or reaching carefully. Because of this, participants reported starting an activity or job assignment hours beforehand to keep up with everyone's pace for employment duties. Participants reported the resilience they had developed to keep working and earn a living through these self-management approaches. This is reflected in literature, Barakou et al. (2025) explored activity pacing among adults with chronic fatigue syndrome and found that overactivity, mental health issues, and workplace challenges hindered self-management, however, highlighted rest, restful activities, and supportive social environment as facilitators of effective fatigue management, along with the importance of activity pacing was identified as a promising solution (Barakou et al., 2025). Like the current study, the challenge for sufferers remains that the work environment has not yet taken up or adopted work models that allow people with chronic conditions to work differently while achieving the task at hand. This type of pacing-based work model needs further research.

Participants further elaborated on why they found resting helpful, noting that it was because of intentional body positioning and posture. Participant 2 described that,

"I have been studying mostly either standing, or I'm lying on my tummy, in order to reduce lumbar spine pain and during work meetings, I do attend by standing at the back of the room, most of my colleagues

know about the challenge that I have with the spine, so, they understand occasionally, I need to stand up” (P2, 04 October 2025).

In this study, evidence showed that prolonged seated posture caused more pain for people with lumbar spine injury. Participants with cervical (neck) spine degeneration found prolonged seated posture equally triggered their pain and reported that lying down with the neck adequately supported either by a cervical pillow or cervical collar helped ease the symptoms. Participants further discussed that these supportive devices, a lumbar belt and cervical collar, did not always help; relief depended on symptom severity at a given time. Mild symptoms responded well with device support, while excruciating pain did not respond well; instead, it got worse. This illustrates the challenges this patient population experiences, as they cited self-management as an ongoing experience that changes daily and depends on symptom patterns. Participants shared that a self-management technique that works one day or at one time may not provide the same symptom relief another day or at another time; these techniques change frequently. This highlights how self-management is specific to each condition and may not generalise to all people with chronic conditions; thus, this study contributes vital information for people with DSD.

Participants discussed how they have to deliberately position their bodies until they can find a position that feels comfortable, as explored by participant 3, who shared a posture related to sleeping position as part of their self-pain management strategy:

“I have a sleeping strategy. I put a pillow between my knees or my legs; it helps to ease the pain in the back and leg” (P3, 10 October 2025).

Overall, participants reported that intentional positions such as side sleeping with a pillow between the knees, sleeping on their back with a pillow behind their knees, sitting with back support such as a cushion, or using a cervical or lumbar belt on a worse day helped. Thus, self-management in this population is ongoing with constant adaptation based on symptom signals. Most of the participants described this experience as listening to their body and responding accordingly,

“If you don’t change the position quickly, it would trigger pain that lasts the entire week and sleepless nights. It’s now comfort over fashion” (P9, 26 October 2025).

Intentional positioning was further discussed in work environments, where participants shared that when working at a desk/computer, for example, they had to adjust their workstation accordingly to prevent triggering or minimise symptoms. Research shows that prolonged static postures can affect the body's wellbeing (Lis et al., 2007). The current study found that people with DSD find especially prolonged sitting and prolonged standing to cause more symptoms, and others discussed that at the worst of symptoms, sleeping positions were difficult too. Current study participants therefore found that scheduling activities around postural positions helped alleviate spine pain. Participants also discussed that maintaining good posture in different body positions is vital to reducing symptoms or preventing symptom aggravation. Many participants therefore discussed using supportive devices to help align the spine and overall posture.

Psychological coping strategies included different mindsets and realisations, many of which developed gradually over time. These themes described the different realisations that the participants experienced, which usually involved acceptance and a mindset of *“trying” to be more positive* and *“taking” every day at the time*, as well as increased gratefulness and trying not to take things for granted. Several participants expressed similar views and noted that

“The only solution I had was to adjust and accept the new normal and change of lifestyle” as described (P3, 10 October 2025).

When asked about learning and changing over time, some explained how their resilience improved and how, unsurprisingly, they also learned to better understand and address their condition. A more commonly reported change, however, involved a growing sense of gratitude and positive reorientation. Several participants described becoming thankful for small, everyday abilities, such as

“Waking up and stepping just a foot on the floor. It is a blessing,” as highlighted by P3, 10 October 2025.

The participant discussed the developed mental strength from the many years of suffering.

“So, over the 20 years, it has been a journey of restraint. It’s showing strength by a restraint” (P2, 04 October 2025).

Here, participants discussed how they realised that they could not escape their own bodies and needed to learn to live with their conditions and the mental pain experiences alongside the frustrations and setbacks due to pain. Faith was also a strong theme for most participants. They reported finding solace in believing in powers above, such as God, and this came with acceptance of their condition.

Ghafari et al. (2015) found that, to improve mental well-being, affected persons need to remain as active as possible and shift their mindset to embrace these changes. Ghafari et al. (2015) further reported that individuals who can access these strategies have the best chance of successfully adjusting to the challenge posed by a chronic illness (Ghafari et al., 2015). In summary, self-management in chronic conditions such as DSD entails people tapping into different aspects of their lives, including their faith, to manage their conditions. Sources of self-management strategies

include not only physical techniques but also spiritual practices that help with the psychological symptoms brought on by the chronic condition.

Participants also explored external support, including healthcare services, family, and friends. The most reported healthcare provider support came from physiotherapists, and most participants reported that, as a result, they attended “regular physiotherapy” (P11, 04 December 2025); some also used other services such as “counselling” (P11, 04 December 2025). Family support was also important, with several participants explaining that family support was the main factor that kept them going and thus, a coping strategy. Participants reported leaning on their family, especially when symptoms worsened, and appreciated both the practical help and emotional support, “talking about pain with family could act as psychological therapy in its own” (P7, 04 October 2025). Other participants said children were often a key source of reassurance and motivation to carry on or push through their symptoms. These findings align with wider research. This is consistent with Kongsted et al. (2021), who found that successful self-management of chronic pain is not mainly about clinicians diagnosing and curing patients, but about a partnership in which clinicians help individuals live good lives despite their chronic condition.

While the current study found that participants reported receiving minimal positive support outside the family, they noted that support from friends and the workplace was still an important part of their coping. Unfortunately, this low number of such accounts regarding positive workplace support arguably confirms the previously discussed finding about the overall low awareness of chronic conditions among the public, which generally leads to a lack of support as well as many unpleasant experiences. These findings resonate with other research, which reported that work-health conflict, anticipated stigma, and job insecurity all contribute to an unhealthy work environment for people with chronic conditions (McGonagle et al., 2024).

Participants also discussed modifying diet as a self-management strategy. Participants shared that they had to change their eating habits; thus, diet and supplements involve eating anti-inflammatory foods and generally being mindful of when and what to eat. While some participants shared discovering certain foods that trigger their symptoms through symptom monitoring, others said their healthcare providers guided them on which foods to add to their diet. One in particular shared that they realised that when they had a lot of starch foods, they were in more pain, thus they reduced and sometime, went for a period of time without taking starchy foods and felt that pain reduced significantly,

“When I reduce sugar intake and start to eat brown rice or brown bread instead, over time, I feel less pain” as shared by participant (P2, 04 October 2025).

Similarly, participant 6 echoed a comparable self-management strategy explaining that, “

I follow an anti-inflammatory diet where I have reduced starch and sugars, and take turmeric as my herbal medicine. It helps to manage pain” (P6, 14 October 2025).

Furthermore, participant 10 discussed that:

“First and foremost, my diet has drastically changed. I have introduced the anti-inflammatory foods: spinach, millet meal, ginger, cinnamon” (P10, 05 October 2025).

While Participant 8 shared a similar coping strategy,

“I now drink turmeric, add it to my food because I read that it helps to reduce pain such as my pain”. Uniformly, participant 6 shared that they had removed “sugar foods” (P6, 14 October 2025) from their diet, while Participant 3 shared that they “drink ginger and cinnamon” (P3, 10 October 2025).

Correspondingly, participant 10 also discussed taking “vitamins” and reported a diet mainly consisting of “white meat and vegetables and anti-inflammatory foods such as spinach, millet meal, ginger, cinnamon” (P10, 05 October 2025). The literature supports diet and supplements as a valid solution because many components have antioxidant and anti-inflammatory qualities that can influence chronic pain and improve quality of life (Dragan et al., 2020). Further research suggests complementary treatment models for chronic pain management are more beneficial than traditional pharmaceutical approaches on their own (Philpot & Johnson, 2019). This evidence on complementary pain management is reflected in previous studies, such as Johnson et al. (2014).

CCXXXVIII. CONCLUSION & RECOMMENDATIONS

5.1 Conclusion

The current study has evidenced lived experiences and self-management in people with DSD. The study identified multifactorial symptoms across different facets of one’s life. The struggles sufferers go through are not only with their clinical symptoms but also with those involving society and the work environment. The study further reported on condition-specific self-management strategies sufferers developed over time. These findings contribute to both clinical practice and the body of research and form a foundation for further research on chronic conditions and patient management, particularly in developing countries like Zambia.

5.2 Recommendations

Participants discussed at length the challenges faced by living with a chronic condition, but also self-management strategies that they have developed over time. This is vital clinical information that can inform care for people with degenerative spine/disc disease and could form part of developing a standardised self-management model for people with DSD.

Declaration of Interest

The authors declare that they do not have any known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Funding Declaration

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Ethics Statement

We declare that we observed research ethics and citation criteria throughout the study; there was no conflict of interest, and the study was not funded.

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