

Healthcare professionals' conceptualisation of self-management for individuals living with Sickle Cell Disease: A qualitative study in a Ghanaian teaching hospital

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Abstract

Background

Self-management is a foundation of comprehensive sickle cell disease (SCD) care, yet little is known about how healthcare professionals conceptualise self-management in resource-constrained settings. Understanding these perspectives is important for informing contextually appropriate approaches to supporting individuals living with SCD. This study explored healthcare professionals' conceptualisation of self-management for individuals living with SCD at Cape Coast Teaching Hospital, Ghana.

Methods

An exploratory descriptive qualitative study, underpinned by a constructivist paradigm, was conducted among 20 purposively selected healthcare professionals involved in SCD care. Data were collected through semi-structured interviews and analysed using Braun and Clarke's six-phase reflexive thematic analysis.

Results

Three themes emerged. Self-management as active patient responsibility supported by healthcare partnership described self-management as a knowledge-driven process requiring patient responsibility, informed decision-making, and collaboration with healthcare professionals. Preventive self-care as the foundation of effective self-management highlighted the importance of recognising crisis triggers, adopting preventive lifestyle and treatment practices, and responding promptly to early warning signs. Self-management capacity is shaped by social, economic, and psychological contexts, and participants viewed financial hardship, health literacy, psychological wellbeing, family support, and sociocultural beliefs as important influences on patients' ability to manage their condition effectively.

Conclusion

Healthcare professionals conceptualised self-management as a multidimensional process that extends beyond medication adherence to encompass patient knowledge, preventive self-care, shared responsibility, and contextual influences on disease management. These findings provide a foundation for developing contextually appropriate self-management interventions and policies for individuals living with SCD in resource-limited settings.

Introduction

Sickle cell disease (SCD) is one of the most common inherited haemoglobin disorders worldwide and remains a major public health challenge, particularly in sub-Saharan Africa, where the burden of

morbidity and premature mortality is greatest [1, 2]. Ghana is among the countries with the highest disease burden, with approximately 2% of newborns affected annually [3]. Despite advances in diagnosis and treatment, individuals living with SCD continue to experience recurrent painful crises, chronic organ complications, psychosocial challenges, and frequent healthcare utilisation, placing considerable pressure on patients, families, and an already resource-constrained health system [3, 4].

Self-management has become a central component of chronic disease management because it enables individuals to take an active role in managing the medical, behavioural, and emotional demands of living with long-term conditions [5, 6]. In the context of SCD, self-management extends beyond medication adherence to include recognising and responding to disease triggers, maintaining adequate hydration and nutrition, preventing infections, monitoring symptoms, and making informed decisions regarding healthcare utilisation [7, 8]. Effective self-management has been associated with improved self-efficacy, reduced disease complications, enhanced quality of life, and fewer hospital admissions among individuals living with SCD [7, 9].

Healthcare professionals play a critical role in shaping patients' understanding and practice of self-management. Through clinical encounters, they influence how patients perceive their illness, interpret treatment recommendations, and adopt behaviours that support long-term disease management [6, 10]. Consequently, healthcare professionals' own conceptualisation of self-management may influence the way self-management is promoted and integrated into routine clinical practice. However, conceptualisations of self-management are not necessarily uniform and may vary according to professional experience, clinical context, and available healthcare resources.

Although previous studies have explored patients' experiences of living with SCD and examined self-management interventions, considerably less attention has been paid to how healthcare professionals themselves conceptualise self-management, particularly in low- and middle-income countries (LMICs) where health systems operate under significant resource constraints [3, 11]. Existing evidence from Ghana has largely focused on disease burden, clinical management, and patient experiences, with limited understanding of the perspectives of healthcare professionals responsible for supporting self-management in routine care. Understanding these perspectives is important because healthcare professionals' conceptualisations influence patient education, clinical decision-making, and the expectations placed on individuals living with SCD regarding their role in managing the condition.

This study therefore explored healthcare professionals' conceptualisation of self-management for individuals living with sickle cell disease at Cape Coast Teaching Hospital, Ghana. By examining how healthcare professionals define, understand, and describe self-management, the study provides evidence to inform the development of contextually appropriate self-management interventions and contributes to the growing literature on chronic disease management in resource-constrained settings.

Methods

Study design

This study employed an exploratory descriptive qualitative design informed by a constructivist paradigm. Constructivism assumes that knowledge is socially constructed through individuals' experiences and interactions, making it appropriate for exploring healthcare professionals' understandings of SMS within their clinical and organisational contexts [12, 13]. An exploratory descriptive approach was chosen because it allows rich, practice-based descriptions of underexplored phenomena while remaining close to participants' accounts [14, 15].

Researcher characteristics and reflexivity

All interviews were conducted by the first author (FOO), a male Registered General Nurse working in Internal Medicine at Cape Coast Teaching Hospital and a Master of Science in Nursing (MSN) candidate at the University of Cape Coast at the time of data collection. The interviewer had received training in qualitative research methods as part of postgraduate coursework and conducted two pilot interviews before data collection. The interviewer had no prior personal or professional relationship with participants, with one exception: for the one participant personally known to the interviewer, the interview was instead conducted by a co-author (AA) to minimise potential bias. Participants received a standard study information sheet describing the purpose of the study and the researcher's role, and were briefed before the interview to allow them to agree on a convenient and private location. As a nurse with clinical experience in internal medicine, the researcher held prior assumptions about resource constraints in SCD care; these were documented in reflexive memos and discussed during peer debriefing with the supervisory team to limit their influence on data collection and interpretation.

Study setting

The study was conducted at Cape Coast Teaching Hospital (CCTH), a 400-bed tertiary referral hospital located in the Central Region of Ghana. As the region's principal referral facility, the hospital provides comprehensive inpatient, outpatient, emergency, and specialist healthcare services to patients from the Central Region and neighbouring districts. Care for individuals living with SCD is delivered through a dedicated weekly SCD clinic that offers routine follow-up, hydroxyurea therapy, laboratory monitoring, genetic counselling, patient education, and multidisciplinary care involving medical officers, nurses, pharmacists, psychologists, nutritionists, physiotherapists, and laboratory scientists. The hospital's multidisciplinary approach to SCD management made it an appropriate setting for exploring healthcare professionals' perspectives on the resources required for, and barriers affecting, the delivery of self-management support.

Participants and sampling

Purposive sampling was used to recruit healthcare professionals involved in the care of individuals living with SCD, as this sampling strategy enables the selection of information-rich participants with relevant knowledge and experience of the phenomenon under investigation [16]. Eligible participants had at least six months' direct or indirect experience in SCD management, were employed at CCTH, and were able to communicate in English. Healthcare professionals working exclusively in administrative roles or without experience in SCD care were excluded. Participants represented multiple disciplines, including medicine, nursing, pharmacy, psychology, nutrition, physiotherapy, laboratory science, and public health, to ensure a broad range of perspectives. Eligible healthcare professionals were first identified in consultation with the heads of their respective clinical units, who facilitated introductions to the research team. The researcher subsequently approached each professional in person within their unit to explain the study and invite participation. Recruitment continued until data saturation was achieved, operationalised as three consecutive interviews yielding no new codes, which occurred after the fourteenth interview. Six additional interviews were conducted to confirm thematic sufficiency, resulting in a final sample of 20 participants, consistent with recommendations for ensuring adequate information power and saturation in qualitative research [17, 18]. All healthcare professionals approached agreed to participate; there were no refusals or withdrawals.

Data collection and instrument

Data were collected between June and September 2025 using a semi-structured interview guide developed by the research team specifically for this study, based on the study objectives and a review of the relevant literature (Supplementary File 1). Semi-structured interviews were selected because they provide flexibility to explore participants' experiences while ensuring consistency across interviews [19]. The guide was pretested with two healthcare professionals who met the inclusion criteria but were excluded from the main study. The pre-test interviews helped refine the wording, sequence, and clarity of the interview questions and assess the feasibility of the interview procedures. Face-to-face interviews were conducted by the principal researcher in private rooms within the hospital, lasted between 30 and 60 minutes (mean duration: 45 minutes), and were audio-recorded with participants' written informed consent. Each participant was interviewed once, no repeat interviews were conducted. No one other than the participant and the interviewer was present during data collection. Field notes and reflexive memos were maintained throughout data collection to document contextual observations, researcher reflections, and methodological decisions, thereby enhancing reflexivity and supporting interpretation of the findings [20].

Data analysis

Audio recordings were transcribed verbatim by the first author and checked against the original recordings for accuracy before analysis began. Data were analysed manually using Braun and Clarke's six-phase reflexive thematic analysis [20, 21] applied as follows. In Phase 1 (familiarisation with the data), the first author repeatedly read all 20 transcripts alongside the original audio recordings, recording

initial observations and analytic memos to capture early impressions of recurring ideas, such as the recurrent emphasis on patient knowledge, prevention, and contextual constraints.

In Phase 2 (generating initial codes), meaningful segments of text across all transcripts were systematically labelled with concise codes capturing the essence of each participant's statement. Coding was inductive, meaning codes were derived directly from participants' accounts rather than fitted to a pre-existing framework. In Phase 3 (searching for themes), related codes were collated and organised into candidate themes and subthemes based on shared conceptual meaning. For example, codes relating to hydration, infection prevention, and weather-related precautions were grouped under a candidate subtheme concerned with recognising and avoiding crisis triggers.

In Phase 4 (reviewing themes), candidate themes were checked against both the coded extracts and the full dataset to confirm internal coherence and clear distinction between themes. Themes that overlapped conceptually were merged, and themes that captured more than one distinct idea were split into separate subthemes. In Phase 5 (defining and naming themes), each theme and subtheme was refined into a clear, concise definition capturing its analytic scope, and illustrative participant quotations were selected to represent each subtheme.

In Phase 6 (producing the report), the final themes were synthesised into a coherent narrative addressing the study objective, supported throughout by verbatim participant quotations. This process generated three overarching themes and seven subthemes describing healthcare professionals' conceptualisation of self-management (Table 3). Data were coded independently by the first author, with coding decisions and emerging themes reviewed and verified by the supervisory team (AD) and a co-author (AA) at each phase to enhance coding consistency and analytic rigour. Data were managed and coded manually using Microsoft Word and Microsoft Excel, no qualitative data analysis software (NVivo) was used. Table 1 presents a representative excerpt of the coding process, illustrating the progression from raw data to final theme for one extract per subtheme (Table 1).

Table 1
Coding Tree Excerpt

Raw Data Extract	Initial Code	Subtheme	Theme
"The patient's knowledge on what to do for him or herself... understanding of the medications..." (R8)	Disease and treatment knowledge	Knowledge and Understanding as the Basis for Self-Management	1. Self-Management as Active Patient Responsibility Supported by Healthcare Partnership
"There is a shared responsibility between the patient and the healthcare professional." (R1)	Shared patient-provider responsibility	Self-Management as Patient Responsibility and Shared Partnership	1. Self-Management as Active Patient Responsibility Supported by Healthcare Partnership
"They will need a lot of hydration... to always make sure their cells don't stick to each other, leading them to crises." (R1)	Hydration as trigger prevention	Understanding and Recognising Crisis Triggers	2. Preventive Self-Care as the Foundation of Self-Management
"Lifestyle modifications... how to protect themselves from the predisposing factors of the crisis... water... diet... clothing." (R8)	Daily preventive lifestyle practices	Integrating Preventive Self-Care into Daily Life	2. Preventive Self-Care as the Foundation of Self-Management
"Patients don't have to wait for the crisis to arise before putting in the necessary remedies." (R7)	Prompt symptom response	Early Recognition and Timely Response to Impending Crises	2. Preventive Self-Care as the Foundation of Self-Management
"Economically, managing them is hard... their treatment involves a lot of money." (R1)	Financial hardship limiting adherence	Socioeconomic Conditions Influence on Self-Management	3. Self-Management Capacity as Context-Dependent
"Living with such a lifelong condition is emotionally draining." (R15)	Emotional burden of chronic illness	Psychological Readiness of Self-Management	3. Self-Management Capacity as Context-Dependent

Rigour

Trustworthiness was established using Lincoln and Guba's criteria of credibility, transferability, dependability, and confirmability [22]. Credibility was enhanced through prolonged engagement with participants, member checking of interpretations during interviews, and regular peer debriefing with the supervisory team. In addition, a subset of participants reviewed their transcripts for accuracy and clarity and were allowed to correct or elaborate on their responses. Dependability and confirmability were strengthened through the maintenance of an audit trail documenting methodological decisions, coding development, and analytical memos. Reflexive journalling was maintained throughout the study to acknowledge and critically examine the researcher's assumptions and potential influence on the

research process [20]. Rich descriptions of the study context, participants, and findings were provided to facilitate readers' assessment of the transferability of the findings [22].

Ethical considerations

Ethical approval was obtained from the University of Cape Coast Institutional Review Board (CCTHERC/EC/2024/041), followed by administrative approval from Cape Coast Teaching Hospital. The study was conducted in accordance with the ethical principles of the Declaration of Helsinki. All participants provided written informed consent before participation and were informed of their right to withdraw at any stage without consequence. Confidentiality and anonymity were maintained by removing personally identifiable information from transcripts, assigning participant codes (P1–P20), and securely storing electronic and hard-copy data in password-protected and locked facilities accessible only to the research team.

Results

Twenty healthcare professionals participated in the study. Participants represented eight professional groups involved in SCD care, including nurses, doctors, pharmacists, public health nurses, physiotherapists, laboratory scientists, psychologists, and nutritionists. Their professional experience ranged from less than one year to eight years, providing perspectives from both relatively early-career and experienced practitioners. Participants were recruited from clinical departments directly or indirectly involved in the multidisciplinary management of individuals living with SCD at Cape Coast Teaching Hospital. The diversity of professional backgrounds enabled a comprehensive exploration of healthcare professionals' perspectives on SMS (Table 2).

Table 2
Demographic Characteristics of Participants

Participant Code	Profession	Years of Experience	Department/Unit
P1	Nurse	3 years	Female Medical Ward
P2	Medical Officer	2 years	Internal Medicine
P3	Psychologist	1 year	Psychology Department
P4	Nurse	2 years	Female Medical Ward
P5	Laboratory Scientist	4 years	Haematology Laboratory
P6	Pharmacist	5 years	Pharmacy Department
P7	Public Health Nurse	7 years	Public Health Unit
P8	Medical Officer	< 1 year	Internal Medicine
P9	Nurse	4 years	Children's Ward
P10	Psychologist	1 year	Psychology Unit
P11	Pharmacist	6 years	Pharmacy
P12	Public Health Nurse	8 years	Public Health/Preventive Care
P13	Physiotherapist	7 years	Physiotherapy Department
P14	Nutritionist	3 years	Nutrition Unit
P15	Nurse	3 years	Female Medical Ward
P16	Medical Doctor	< 1 year	Internal Medicine
P17	Laboratory Scientist	2 years	Haematology
P18	Nurse	< 1 year	Internal Medicine
P19	Nurse	2 years	Female Medical Ward
P20	Physiotherapist	7 years	Physiotherapy

NB: Age and sex were not recorded as part of participant demographic data.

Themes

Analysis generated three interrelated themes and seven sub-themes describing healthcare professionals' conceptualisation of self-management among individuals living with sickle cell disease. Participants conceptualised self-management as an informed and patient-centred process characterised by personal responsibility, preventive self-care, and an awareness that successful self-management is shaped by broader contextual influences. An overview of the themes and sub-themes is presented in Table 3.

Table 3
Themes and sub-themes

Theme	Sub-themes
1. Self-Management as active patient responsibility supported by healthcare partnership	1.1 Knowledge and understanding as the basis for self-management 1.2 Self-management as patient responsibility and shared partnership
2. Preventive self-care as the foundation of effective self-management	2.1 Understanding and recognising crisis triggers 2.2 Integrating preventive self-care into daily life 2.3 Early recognition and timely response to impending crises
3. Self-Management capacity as context-dependent	3.1 Socioeconomic conditions influencing self-management capacity 3.2 Psychological readiness for self-management 3.3 Health literacy, family support, and sociocultural contexts shaping self-management

Self-Management as active patient responsibility supported by healthcare partnership

Healthcare professionals consistently described self-management as an active process in which individuals living with sickle cell disease assumed responsibility for managing their condition while receiving ongoing guidance from healthcare professionals. Participants viewed self-management as extending beyond medication adherence to include patients' active participation in care, preventive practices, and the ability to make informed decisions about their health. Three interrelated sub-themes captured this conceptualisation: (1) Knowledge and Understanding as the Basis for Self-Management (2) self-management as patient responsibility and shared partnership; (3) preventive self-care as the foundation of self-management; and (4) contextual influences on self-management capacity.

Knowledge and understanding as the basis for self-management

Participants consistently described knowledge and understanding of sickle cell disease as fundamental to effective self-management. Across professional groups, participants emphasised that patients should understand their condition, prescribed medications, and recommended lifestyle practices to enable them to manage their health independently. Self-management was therefore presented as requiring informed decision-making based on adequate knowledge of the disease and its management.

Several participants associated self-management with patients' awareness of their diagnosis and understanding of the actions required to maintain their health. One participant described self-

management as patients *"being aware of their status and taking care of themselves, adhering to their medications and then early reporting to the hospital when they are in crisis"* (R4). Similarly, another participant explained that self-management depended on *"the patient's knowledge on what to do for him or herself... understanding of the medications... lifestyle modifications"* (R8).

Participants further indicated that knowledge enabled patients to participate actively in managing their condition. One participant stated, *"If they know the medications they are supposed to take... I believe they can manage themselves"* (R3), suggesting that understanding treatment recommendations supported patients' ability to care for themselves outside the healthcare setting. Likewise, another participant described self-management as *"the patient's ability to understand their condition and actively take part in maintaining their own health"* (R13).

Participants also described disease knowledge as extending beyond medication use to include understanding factors that influence health outcomes and making appropriate decisions in everyday life. As one participant explained, self-management involved *"the steps or measures, the lifestyles, they have to put in place"* to manage the condition effectively (R5). Collectively, participants described knowledge and understanding as the foundation upon which individuals living with SCD develop the confidence and ability to engage in self-management practices.

Self-Management as patient responsibility and shared partnership

Participants consistently described self-management as the patient's responsibility for managing the condition in everyday life. Across professional groups, self-management was understood as patients actively participating in their care through adherence to treatment recommendations, understanding their condition, and making informed decisions to maintain their health.

One participant simply described self-management as *"how the person takes care or manages their condition"* (R2). Similarly, another participant explained that it involved *"the patient taking active responsibility for managing their own health"* (R17). Participants further associated self-management with patients' understanding of their condition and their ability to participate in maintaining their health. As one participant stated, *"self-management means the patient's ability to understand their condition and actively take part in maintaining their own health"* (R13).

Although participants emphasised patients' responsibility, they also described self-management as a collaborative process involving healthcare professionals. Participants explained that healthcare professionals provide education, guidance, and support while patients assume responsibility for implementing recommended care. This shared role was reflected in one participant's statement, *"There is a shared responsibility between the patient and the healthcare professional."* (R1) Similarly, another participant linked patient autonomy to involvement in healthcare decisions, stating, *"Patient autonomy... has to do with the patient being able to decide on the kind of healthcare that should be rendered to him or her."* (R1).

These accounts show that participants viewed self-management as an active partnership in which patients remained central to managing their condition while healthcare professionals provided continuous support.

Preventive as an inherent characteristic of self-management

Participants consistently conceptualised self-management as a preventive process aimed at maintaining health and reducing the occurrence of sickle cell crises. Across professional groups, self-management was described as extending beyond responding to illness episodes to include the consistent adoption of behaviours that minimise the risk of disease exacerbations. Participants emphasised that effective self-management requires individuals living with SCD to recognise factors that predispose them to crises, incorporate preventive practices into their daily routines, and respond promptly to changes in their health status. Three sub-themes were identified: understanding and recognising crisis triggers, integrating preventive self-care into daily life, and early recognition and timely response to impending crises.

Understanding and recognising crisis triggers

Participants consistently described the ability to recognise individual crisis triggers as fundamental to self-management. They conceptualised self-management as requiring patients to understand the circumstances that increase their susceptibility to vaso-occlusive crises and make informed decisions that minimise exposure to these triggers. Dehydration, infections, exposure to cold weather, psychological stress, malaria, and strenuous physical activity were frequently identified as factors requiring continuous attention.

Hydration was the preventive practice most consistently emphasised across the interviews. One participant explained that patients *"need a lot of hydration... to always make sure their cells don't stick to each other, leading them to crises"* (R1). Similarly, another participant highlighted the importance of educating patients about *"frequent triggers, dehydration, infections"* while encouraging them to *"take in adequate water"* and prevent malaria through the use of insecticide-treated nets (R6). Participants also recognised environmental and behavioural factors as important considerations in day-to-day self-management. For example, one participant observed that *"this weather is not really favourable for them"* and identified strenuous physical activity as one of the factors patients *"have to limit or control"* (R3). Likewise, another participant said that patients should understand *"what triggers their crises, such as infections, dehydration, or stress"* so they could make informed decisions to protect their health (R16).

Integrating preventive self-care into daily life

Participants consistently described preventive self-care practices as an integral component of self-management. Across professional groups, self-management was characterised by the routine incorporation of behaviours that promote health, prevent complications, and minimise the occurrence of sickle cell crises. Participants associated effective self-management with consistently adhering to

prescribed medications, maintaining adequate hydration, consuming a healthy diet, preventing infections, dressing appropriately for prevailing weather conditions, and attending scheduled clinic appointments.

Preventive lifestyle modification was repeatedly described as part of patients' day-to-day responsibility for managing their condition. One participant explained that self-management involved *"lifestyle modifications... how to protect themselves from the predisposing factors of the crisis... water... diet... clothing"* (R8). Similarly, another participant described self-management as focusing on *"medication and also other self-care management, including diet, intake of water... clothing... prevention of infections"* (R8). Medication adherence was consistently viewed as a central preventive practice, with one participant explaining that *"if they don't take their medicines as prescribed, they are likely to have frequent crises and complications"* (R12). Participants also identified regular clinic attendance, healthy nutrition, and adherence to professional advice as routine practices that form part of effective self-management. As one participant explained, self-management involved *"adherence to medical advice, attending clinic regularly, eating well, and recognising early warning signs"* (R13).

Early recognition and timely response to impending crises

Participants consistently described the ability to recognise early warning signs and respond promptly as an essential part of effective self-management. Across professional groups, self-management was conceptualised as requiring individuals living with SCD to remain attentive to changes in their health status and to take appropriate action before symptoms progressed to severe complications. Participants emphasised that timely decision-making, including seeking professional care when necessary, was fundamental to preventing disease exacerbations and maintaining health.

One participant explained that patients *"don't have to wait for the crisis to arise before putting in the necessary remedies"* (R7), highlighting the importance of early intervention. Similarly, another participant stated that patients should *"understand their triggers... avoid those triggers"* and be taught *"how to seek immediate health care when they see the early signs"* (R10). Expanding on this perspective, the same participant illustrated how patients should recognise early symptoms, such as *"I'm feeling chills... crisis is coming,"* and *"immediately seek health care"* (R10). Participants also viewed prompt healthcare-seeking as an important strategy for preventing disease progression. As one participant explained, effective self-management involved the ability to *"manage the predisposing triggers, how to avoid them... identify complications and seek prompt care"* (R9).

Taken together, participants conceptualised preventive self-care as a continuous and proactive process that extends beyond managing acute illness episodes. Effective self-management was described as requiring individuals living with SCD to recognise factors that predispose them to crises, integrate preventive practices into their daily routines, adhere to prescribed treatment, and respond promptly to early warning signs to maintain health and minimise disease complications.

Self-Management capacity as context-dependent

Participants consistently described self-management as being influenced by factors beyond patients' knowledge and willingness to manage their condition. Across professional groups, participants identified financial resources, health literacy, psychological wellbeing, family support, healthcare access, and sociocultural beliefs as factors that affected patients' ability to implement recommended self-management practices. Three sub-themes were identified: socioeconomic influences on self-management, psychological and emotional influences, and health literacy, family, and sociocultural influences.

Socioeconomic conditions influence on self-management

Participants consistently described socioeconomic circumstances as an important factor shaping patients' capacity to practise self-management. Rather than viewing self-management solely as an individual responsibility, they recognised that patients' ability to adhere to recommended practices was influenced by their financial resources and access to healthcare. The costs associated with medications, laboratory investigations, transportation, and routine clinic attendance were frequently described as influencing patients' ability to implement recommended self-management behaviours.

One participant explained that *"economically, managing them is hard"* because *"their treatment involves a lot of money"* and many patients *"face a whole lot of problems in their management"* (R1). Another participant similarly noted that *"financial constraints lead to not complying"* with recommended care (R2). Participants also observed that limited financial resources affected patients' ability to obtain medications, maintain adequate nutrition, and attend scheduled clinic appointments. As one participant explained, *"Poverty is a major factor... they can't afford healthy food, clean water"* (R16).

The influence of socioeconomic circumstances on self-management capacity was further illustrated by one participant who explained:

"Access to medications and access to health care becomes a problem. Transportation becomes a problem because some of the medications are not covered under the National Health Insurance Scheme, so they have to purchase them. If they don't have the money, then adherence becomes very difficult." (R6)

Participants also recognised that strengthening financial support mechanisms could enhance patients' capacity to engage in self-management. Suggestions included improving access to financial assistance for medications, investigations, and transportation, thereby enabling patients to implement recommended self-management practices more consistently.

Psychological readiness for self-management

Participants consistently described psychological wellbeing as an important element of patients' capacity to engage in self-management. They conceptualised self-management as requiring not only knowledge and practical skills but also emotional readiness to cope with the lifelong demands of living with sickle cell disease. Emotional distress, anxiety, stress, motivation, and acceptance of the condition

were described as influencing patients' ability to adhere to treatment recommendations and actively participate in managing their health.

Participants explained that the emotional burden of living with SCD could affect patients' engagement in self-management. One participant reflected that *"psychologically... 'Why can't I live a normal life?'... that brings distress on them"* (R1), while another observed that *"living with such a lifelong condition is emotionally draining"* (R15). Participants also recognised the relationship between psychological wellbeing and disease outcomes, with one participant noting that *"psychological stress can even trigger crises"* (R15).

Acceptance of the condition was also described as an important aspect of psychological readiness for self-management. Participants indicated that patients who struggled to accept their diagnosis were less likely to engage consistently in recommended self-management practices. As one participant explained, *"acceptance of medical conditions is one barrier... if you fail to accept your condition, adherence... will be greatly impacted"* (R10).

Participants further describe emotional and psychological support as resources that strengthen patients' readiness to manage their condition. One participant remarked that *"emotional support is very key"* (R11), while another suggested that patients *"should... be referred to see the psychology team once in a while"* (R4). These accounts reflected participants' conceptualisation of psychological wellbeing as an integral part of self-management capacity rather than as a separate aspect of clinical care.

Health literacy, family support, and sociocultural contexts shaping self-management

Participants consistently described health literacy, family support, and sociocultural contexts as important influences on patients' capacity to engage in self-management. They explained that effective self-management requires patients to understand their condition, recognise symptoms, follow treatment recommendations, and apply appropriate self-care practices. Participants further indicated that these abilities were influenced by the support patients received from their families and by the broader social and cultural environments in which they lived.

Participants frequently associated limited health literacy with reduced self-management capacity. They observed that patients with inadequate knowledge of SCD were less likely to recognise early symptoms, understand treatment recommendations, or implement appropriate preventive measures. One participant explained that *"those with lower health literacy... will not know much about what they should do"* (R8), while another remarked that *"those with low educational backgrounds often know little"* about managing the condition (R16). Participants also referred to ignorance and misconceptions about SCD as limiting patients' understanding of appropriate self-management practices.

Family support was similarly described as an important influence on self-management. Participants explained that supportive family members encouraged adherence to medications, reinforced healthy

behaviours, and facilitated access to healthcare services, whereas inadequate family support reduced patients' ability to sustain recommended self-management practices. One participant noted that *"financial constraints... caregiver neglect... lack of support"* affected patients' ability to manage their condition (R10), while another emphasised that *"emotional support is very key"* (R11), highlighting the contribution of close social relationships to ongoing disease management.

Participants also described sociocultural and religious beliefs as shaping how patients understood and managed their condition. Some explained that traditional beliefs influenced healthcare-seeking behaviours and treatment decisions. One participant observed that some patients *"think they have some sort of spiritual disease... they will use their herbs and worsen their condition"* (R6), while another noted that certain religious beliefs *"hinder their congregants from blood transfusion"* (R5). Participants further described stigma as a social influence affecting engagement with healthcare services, with one participant explaining that *"stigma also discourages some patients from attending clinics regularly"* (R17). These accounts reflected participants' view that self-management capacity is influenced not only by individual knowledge and skills but also by the social, family, and cultural contexts within which individuals live and manage their condition.

Views on self-management were broadly consistent across professional groups; no substantive contrasting perspectives were identified during analysis.

Discussion

The study explored healthcare professionals' conceptualisation of self-management among individuals living with sickle cell disease (SCD) in a Ghanaian teaching hospital. Healthcare professionals conceptualised self-management as a multidimensional process comprising active patient responsibility supported through collaborative healthcare partnerships, preventive self-care behaviours, and the broader social, economic, psychological, and sociocultural contexts within which patients manage their condition.

The finding demonstrated that healthcare professionals conceptualised self-management as an active patient responsibility supported by healthcare partnership. Participants consistently identified knowledge and understanding as the foundation upon which effective self-management is built, emphasising that patients require adequate understanding of their diagnosis, medications, lifestyle recommendations, and potential complications before they can make informed decisions about managing their condition. This conceptualisation reflects the central premise of chronic disease self-management that individuals require knowledge, confidence, and problem-solving skills to manage the medical, behavioural, and emotional consequences of chronic illness effectively.[6]. Similar findings have been reported among adults living with SCD, who described understanding their condition and recognising bodily changes as essential to making informed self-management decisions [7]. Within Ghana, qualitative studies involving both healthcare professionals and individuals living with SCD have

likewise demonstrated that disease knowledge, self-monitoring, and preventive care form the basis of self-management, indicating considerable agreement between patient and provider perspectives [23, 24].

Participants also conceptualised self-management as a responsibility primarily borne by patients but exercised within a collaborative partnership with healthcare professionals. While patients were expected to assume responsibility for their daily disease management, healthcare professionals described their own role as providing education, guidance, and ongoing clinical support. This finding shows the shift in chronic disease care from paternalistic models towards collaborative partnerships that promote patient activation, shared decision-making, and self-efficacy [5, 10, 25]. This conceptualisation is further supported by Self-Determination Theory, which proposes that sustained engagement in health behaviours depends upon satisfying the psychological needs for competence, autonomy, and relatedness [26, 27]. Participants' emphasis on disease knowledge reflects competence, their expectation that patients assume responsibility for their care reflects autonomy, and their description of healthcare professionals as ongoing partners reflects relatedness. Together, these findings suggest that healthcare professionals viewed self-management as a developmental process through which patients gradually acquire the confidence and capability to manage their condition within supportive therapeutic relationships.

Furthermore, the findings positioned preventive self-care as the practical foundation of effective self-management. Participants consistently described self-management as a proactive process centred on preventing crises rather than responding to them after they occur. Recognising and avoiding triggers, adopting preventive lifestyle and treatment practices, and responding promptly to early warning signs were viewed as essential expressions of effective self-management. Participants described dehydration, infection, malaria, exposure to cold weather, and strenuous physical activity as common precipitating factors that patients should recognise and avoid. Similar recommendations appear within international evidence-based guidelines for SCD management, which identify hydration, infection prevention, avoidance of known triggers, and early recognition of symptoms as fundamental components of comprehensive disease management [8]. Qualitative studies conducted in Ghana and other settings similarly report that both healthcare professionals and individuals living with SCD perceive trigger avoidance and proactive self-care as central to successful disease management [7, 23].

Participants further described preventive lifestyle practices, including medication adherence, adequate hydration, healthy nutrition, and appropriate clothing, as routine behaviours through which patients maintain health and reduce the likelihood of crises. They also emphasised the importance of responding promptly to early warning signs by seeking timely healthcare rather than delaying treatment until symptoms worsen. These findings are consistent with the Theory of Self-Care Management for Vulnerable Populations, which conceptualises self-management as a continuous process involving symptom recognition, preventive action, and timely responses to changes in health status [28, 29]. The findings therefore suggest that healthcare professionals viewed effective self-management as an anticipatory process aimed at maintaining stability through continuous preventive action.

The finding also demonstrated that healthcare professionals conceptualised self-management capacity as being shaped by patients' broader social, economic, and psychological circumstances. Participants consistently recognised that patients' ability to implement recommended self-management practices depended not only on knowledge and motivation but also on the contexts within which they lived. Financial hardship was frequently described as influencing access to medications, laboratory investigations, transportation, and routine healthcare, thereby affecting patients' ability to sustain recommended self-management practices. Similar findings have been reported in Nigeria, where out-of-pocket expenditure for SCD care has been shown to result in catastrophic health expenditure, particularly among socioeconomically disadvantaged households [30].

Participants also identified psychological wellbeing as an important determinant of self-management capacity. Emotional distress, difficulty accepting the diagnosis, anxiety, and reduced motivation were described as influencing patients' willingness to engage in self-management, while emotional support and psychological care were viewed as facilitating ongoing disease management. These observations are consistent with evidence demonstrating that psychological distress negatively influences adherence and self-management across chronic diseases, including SCD [7].

Health literacy, family support, and sociocultural influences were similarly conceptualised as shaping patients' capacity for self-management. Participants described limited health literacy as reducing patients' understanding of appropriate self-management practices, while supportive family relationships facilitated adherence and engagement with healthcare services. They also highlighted the influence of traditional beliefs, religious practices, and stigma on healthcare-seeking behaviours and treatment decisions. Comparable findings have been reported across Ghana and other African countries, where misconceptions about SCD, spiritual interpretations of illness, stigma, and inadequate social support continue to influence treatment adherence and healthcare utilisation [31, 32].

These contextual findings align closely with the Theory of Self-Care Management for Vulnerable Populations, which proposes that self-management capacity is shaped by interactions between individual, family, community, and healthcare system factors [28, 29]. They are also consistent with the Expanded Chronic Care Model, which emphasises that successful chronic disease management depends upon coordinated support from healthcare systems, families, and communities in addition to patient engagement (Barr et al., 2003). Collectively, these frameworks reinforce healthcare professionals' conceptualisation of self-management as a dynamic process influenced by both individual capability and the wider social and health-system environment.

Strengths and limitations

A key strength of this study was the inclusion of healthcare professionals from eight disciplines involved in SCD care, providing diverse perspectives on self-management support within a multidisciplinary context. The use of an exploratory qualitative design enabled an in-depth understanding of healthcare

professionals' experiences and perceptions. Rigour was enhanced through purposive sampling, reflexive thematic analysis, peer debriefing, and an audit trail.

The findings should, however, be interpreted considering some limitations. As the study was conducted in a single teaching hospital, the findings may not be transferable to other healthcare settings with different organisational structures and resource availability. In addition, participants' accounts were self-reported and may have been influenced by social desirability bias. These risks were minimised through confidential interviews, reflexive practice, and the inclusion of participants from diverse professional backgrounds.

Implications for research

The findings underscore the need for further research to examine how self-management is conceptualised by healthcare professionals, individuals living with sickle cell disease, and family caregivers across diverse healthcare settings. Comparative multi-centre qualitative and mixed-methods studies would provide a broader understanding of how contextual, cultural, and health system factors shape perceptions of self-management in Ghana and other low- and middle-income countries. Future research should also investigate the relationship between healthcare professionals' conceptualisations of self-management and the design, delivery, and uptake of self-management interventions. In addition, intervention studies are needed to develop and evaluate context-specific self-management programmes that are informed by the perspectives of healthcare professionals, patients, and caregivers, with particular attention to patient empowerment, preventive self-care, collaborative care, and the contextual factors that influence individuals' capacity to manage sickle cell disease.

Conclusion

Healthcare professionals conceptualised self-management for individuals living with sickle cell disease as a multidimensional and continuous process that extends beyond patients' knowledge of the disease. They viewed effective self-management as requiring active patient responsibility, supported through collaborative partnerships with healthcare professionals, sustained engagement in preventive self-care, and the capacity to respond to the social, economic, psychological, and sociocultural contexts that influence disease management. These findings demonstrate that healthcare professionals recognise self-management as a dynamic process shaped by both individual behaviours and contextual factors. Strengthening self-management interventions for individuals living with SCD should therefore adopt a holistic, context-specific approach that promotes patient empowerment, preventive self-care, and collaborative care while addressing the broader contextual factors that influence patients' capacity to effectively manage their condition.

Abbreviations

CCTH
Cape Coast Teaching Hospital

ECCM
Expanded Chronic Care Model
HCP
Healthcare Professional
LMIC
Low- and Middle-Income Country
SCD
Sickle Cell Disease
SDT
Self-Determination Theory
SMS
Self-Management Support
SCMVP
Self-Care Management for Vulnerable Populations

Declarations

Human Ethics and Consent to Participate

Not applicable.

Ethics Approval

Ethical approval was obtained from the University of Cape Coast Institutional Review Board (CCTHERC/EC/2024/041). Administrative approval was subsequently obtained from Cape Coast Teaching Hospital. The study was conducted in accordance with the ethical principles of the Declaration of Helsinki. Written informed consent was obtained from all participants before data collection, and participation was voluntary, with confidentiality and privacy maintained throughout the study.

Consent for Publication

Not applicable.

Competing Interests

The authors declare that they have no competing interests.

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Author Contribution

Frank Offei Odonkor (FOO): Conceptualisation, methodology, investigation, data curation, formal analysis, project administration, writing original draft, and writing review and editing. Amidu Alhassan (AA): Methodology, validation, writing review and editing. Irene Korkoi Aboh (IKA): Validation, writing review and editing. Amos Dzamefe (AMD): Validation, writing review and editing. Yvonne Dorothy Mintah (YDM): Writing review and editing, language editing, and manuscript refinement. Andrews Druye (AD): Supervision, methodology, validation, writing review and editing, and overall critical revision of the manuscript.

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Data Availability

The datasets generated and analysed during the current study are not publicly available because they contain information that could compromise participant confidentiality but are available from the corresponding author upon reasonable request.

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