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The Rehabilitation Care Gap: Coping Strategies and Unmet Needs Among Zambian Stroke Survivors Following COVID-19 Service Disruptions

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Abstract

Background: The COVID-19 pandemic triggered unprecedented disruptions in healthcare delivery worldwide, with particularly severe consequences for chronic disease management in low-resource settings. For stroke survivors whose functional recovery depends on consistent, supervised rehabilitation, these disruptions created critical challenges in maintaining therapeutic continuity and preventing functional decline.

Objective: This study aimed to characterize the coping strategies adopted by stroke survivors in Lusaka, Zambia, following disruptions to routine physiotherapy services during the COVID-19 pandemic, and to systematically analyze the resultant “care gap” and unmet clinical needs that emerged from this health system shock.

Methods: A cross-sectional mixed-methods study was conducted with 26 chronic stroke survivors purposively recruited from six referral hospitals in Lusaka. Data were collected via structured, researcher-administered questionnaires capturing detailed service attendance patterns, self-initiated management strategies, resource utilization, and access to alternative support systems. Descriptive and inferential statistics were computed, and qualitative content analysis using a framework approach was applied to open-ended responses to characterize adaptive behaviors, limitations, and health system failure points.

Results: A substantial multidimensional care gap was identified. Quantitatively, pre-pandemic attendance of 2-3 sessions weekly (76.9%, n=20) collapsed to 15.4% (n=4) during the pandemic, with most patients (61.5%, n=16) reduced to once-weekly sessions. Qualitatively, the primary coping strategy was a self-directed shift to unsupervised home exercises (76.9%, n=20), but only 15.4% (n=4) received specific, updated home-exercise instructions from their physiotherapist during this transition period. Systemic support was notably absent, with 73.1% (n=19) reporting no remote follow-up from healthcare providers. Thematic analysis revealed three core domains of unmet needs: (1) Technical deficits (absent hands-on correction, limited equipment access), (2) Knowledge gaps (uncertainty about exercise progression and safety), and (3) Psychosocial vulnerabilities (diminished motivation, therapeutic isolation).

Conclusion: Stroke survivors responded to service disruptions through predominantly unsupported, self-managed adaptations that exposed significant limitations in health system crisis responsiveness. The care gap that emerged was characterized not merely by reduced service volume but by a fundamental breakdown in the therapeutic alliance and continuity of care. Thus, the urgent necessity for healthcare systems in resource-limited settings is needed to develop proactive, structured self-management protocols, integrate low-tech remote support mechanisms, and formalize rehabilitation continuity plans that can maintain therapeutic engagement during public health crises.

Keywords: Stroke Rehabilitation, COVID-19, Healthcare Disruptions, Coping Strategies, Health Systems Resilience

1. Introduction

The COVID-19 pandemic constituted an unprecedented global stress test for health systems, exposing profound vulnerabilities in the management of chronic conditions across all economic contexts [1]. In low- and middle-income countries (LMICs), where health infrastructure was already strained, the pandemic's secondary effects on non-communicable disease management have been particularly devastating [2]. For stroke survivors whose functional recovery, independence, and long-term quality of life depend critically on consistent, supervised rehabilitation—the interruption of services posed a direct and severe threat to health outcomes [3, 4].

In Zambia, stroke represents a growing public health challenge, with prevalence estimates indicating it accounts for approximately 43% of neurological admissions at the University Teaching Hospital in Lusaka [5]. The country's rehabilitation infrastructure, like many in sub-Saharan Africa, is characterized by limited specialist personnel, centralized service delivery, and resource constraints that predated the pandemic [6]. When COVID-19 emerged, public health mandates, infection control measures, and population fears converged to disrupt this fragile system, leading to documented reductions in physiotherapy attendance, session frequency, and therapeutic intensity [7]

While prior research has outlined barriers to access and quantified changes in service utilization patterns during the pandemic [7, 8], a crucial dimension remains insufficiently examined, which are the adaptive behaviors and coping mechanisms that emerge when formal care structures collapse. How do stroke survivors and their support networks respond when scheduled rehabilitation disappears? What strategies do they employ to maintain function? More critically, to what extent does the healthcare system anticipate, facilitate, or support these adaptations? The pandemic rendered bluntly visible, what health systems researchers term the "care gap", the measurable disparity between evidence-based standards of care and the care actually received during crisis conditions [9].

For neurorehabilitation, this gap encompasses not merely reduced service quantity but potentially compromised quality, safety, progression, and therapeutic efficacy. Unsupervised practice risks reinforcing maladaptive movement patterns, while discontinued therapy may lead to preventable functional decline, contractures, and secondary complications [10]. Understanding the nature, dimensions, and consequences of this gap is therefore essential for building more resilient, responsive, and patient-centered rehabilitation systems capable of withstanding future health shocks.

This study, building upon foundational research documenting attendance disruptions [7], moves deliberately from problem documentation to adaptation analysis. By examining the coping strategies, resource utilization patterns, and unmet needs of a cohort of chronic stroke survivors in Lusaka, Zambia, we aim to characterize the rehabilitation care gap that emerged during the pandemic's acute phases. Our analysis seeks to answer three interconnected questions: (1) How did patients adapt their rehabilitation practices when formal services were disrupted? (2) What supports (if any) did the health system provide for these adaptations? (3) What were the perceived limitations and unmet needs resulting from this crisis-driven care model transition? Answers to these questions will provide an evidence base for designing crisis-responsive continuity-of-care protocols and reimagining rehabilitation systems that maintain therapeutic integrity even when face-to-face services are compromised.

2. Methods

2.1. Study Design and Setting

A cross-sectional convergent mixed-methods study was conducted between September and October 2024 in Lusaka, Zambia's capital and largest urban center. The study was implemented across the physiotherapy departments of six strategically selected referral hospitals serving diverse socioeconomic populations. These included Chawama, Mtendere, Kanyama, Bauleni, Chilenje, and George Urban Health Centers. These facilities represent the primary public-sector rehabilitation providers for Lusaka's population of approximately 3 million people, offering insights into both secondary and tertiary care levels within Zambia's decentralized health system.

2.2. Study Population and Sampling Strategy

The study population comprised chronic stroke survivors engaged in long-term rehabilitation. Participants were recruited through purposive sampling to ensure representation of varied durations post-stroke and demographic characteristics. Inclusion criteria were: (1) clinically confirmed diagnosis of stroke (ischemic or hemorrhagic) through imaging or clinical assessment; (2) a history of stroke and continuous physiotherapy engagement for four years or more, establishing them as experienced rehabilitation recipients familiar with standard care protocols; (3) documented attendance at one of the study sites both before (2019) and during (2020-2024) the COVID-19 pandemic; and (4) sufficient cognitive and communicative ability to provide informed consent and participate in interviews, as determined by a standardized mental status screening.

Exclusion criteria included: (1) stroke less than 4 years, as these patients would have different care pathways; (2) severe aphasia or cognitive impairment preventing reliable participation; and (3) participants not accessing rehabilitation services at the study sites. The final sample comprised 26 participants, which, while modest, represents a substantial proportion of the eligible long-term stroke survivor population regularly accessing these facilities and provided sufficient data saturation for the qualitative components of the analysis.

2.3. Data Collection Instrument and Procedures

Data were collected using a structured, researcher-administered questionnaire developed through a rigorous process of literature review, expert consultation, and pilot testing. The instrument consisted of four integrated sections:

Section A: Socio-demographic and clinical characteristics captured age, gender, educational attainment, employment status, residential location, stroke type and chronicity, comorbidities, and functional status indicators.

Section B: Service utilization metrics employed retrospective recall with temporal anchoring to major pandemic events to document pre-pandemic and pandemic-period physiotherapy attendance frequency, session duration, transportation and hands of physiotherapy access. Recall validation techniques, including cross-referencing with major life events and hospital policy changes, were employed to enhance accuracy.

Section C: Coping strategies and alternative care arrangements used both closed and open-ended items to capture:

1. primary adaptive actions taken when regular services were disrupted (e.g., complete cessation, transition to home exercises, seeking private care, relying on family assistance);
2. sources of guidance for these adaptations (self-initiated, therapist-directed, family-suggested, community-based);
3. access to and utilization of remote support mechanisms (telephone check-ins, SMS reminders, telehealth platforms); and
4. modifications to home environments to facilitate continued rehabilitation.

Section D: Unmet Needs and Perceived Limitations employed open-ended questions to explore:

1. challenges encountered with adapted routines;
2. safety concerns;
3. equipment and resource limitations;
4. psychological and motivational barriers; and
5. specific areas where professional input was missed.

Data collection was conducted by trained research assistants fluent in English and local languages (Nyanja and Bemba)

2.4. Data Analysis Framework

Quantitative data were analyzed using IBM SPSS Statistics (Version 27.0). Qualitative data from open-ended responses were analyzed using a framework approach with both deductive and inductive elements [11]. Analysis proceeded through five stages:

1. Familiarization with the data through repeated reading of transcripts;
2. Identifying a thematic framework based on both research questions and emergent concepts;
3. Indexing all data according to the framework;
4. Charting the indexed data into a matrix of themes by cases;
5. Mapping and interpretation to develop explanations and associations. Triangulation between quantitative and qualitative findings occurred at the interpretation stage to develop a comprehensive understanding of the care gap phenomenon.

2.5. Ethical Considerations and Rigor

Ethical approval was obtained from the ERES Converge Institutional Review Board (Protocol number 2023-Sep-008) and the Zambia National Health Research Authority (Approval number NHRA001/13/07/2023). Written informed consent was obtained from all participants, with thumbprints accepted for those with physical limitations affecting signature.

3. Results

3.1. Participant Characteristics

The study included 26 chronic stroke survivors with a mean age of 54.42 years (SD±10.14, range 37-74). There was a female predominance (57.7%, n=15), reflecting gender patterns in healthcare utilization observed in similar Zambian studies [12]. Educational attainment varied, with a few participants (11.5%, n=3) having completed secondary education, 46.2% (n=12) primary education, 30.8% (n=8) tertiary education, and 11.5% (n=3) received no formal education. Most participants (53.8%, n=14) resided in low-density residential areas, with smaller proportions in medium-density (34.6%, n=9) and high-density (11.5%, n=3) neighborhoods. Stroke chronicity averaged 4.2 years (SD±1.8), with all participants having engaged in physiotherapy for at least four years prior to the pandemic, establishing them as experienced consumers of rehabilitation services.

Table 1: Demographic and Clinical Characteristics of Participants (N=26)

Variable	Frequency	Percentage
Gender		
Male	11	42.3
Female	15	57.7
Age group (years)*		
31 - 45	4	15.4
46 -59	15	57.7
60 - 74	7	26.9
Education level		
Primary	12	46.2
Secondary	3	11.5
Tertiary	8	30.8
None	3	11.5
Employment status		
Formal employment	6	23.1
Informal employment	6	23.1
None	14	53.8
Years with stroke		
4 to 5 years	17	65.4
More than 5 years	8	30.8
Home environment		
Low density	14	53.8
Medium density	9	34.6
High density	3	11.5
Duration on physiotherapy		
4 to 5 years	22	84.6
5 years or more	4	15.4

3.2. The Rehabilitation Care Gap:

The disparity between the recommended standard of rehabilitation care and the care actually received by stroke survivors during the COVID-19 disruption was not merely a reduction in services, but a fundamental breakdown in the quality, safety, and therapeutic integrity of care.

This gap manifested in three interconnected dimensions:

The Guidance Gap: When service preference shifted from clinic to home, patients were left without professional support. Only 15.4% received tailored instructions. This moved rehabilitation from a therapist-guided process to an unsupervised, patient-led activity, risking ineffective or harmful practice.

The Monitoring Gap: The therapeutic relationship was severed. Majority of patients had no remote follow-up, no calls, check-ins, or safety checks. This created a dangerous void in accountability, progression, and correction, abandoning patients when they were most vulnerable.

The Structural Gap: The health system had no contingency plan. There was no protocol for transitioning care, no low-tech remote support system, and no way to maintain continuity. The system's response was rather passive, while the burden of adaptation fell entirely on patients and families.

In essence, the care gap was the space between what the system was designed to provide (structured, supervised, progressive therapy) and what it actually delivered (unstructured, unsupervised, isolated activity). It represents a failure to maintain the therapeutic alliance and continuity of care during a crisis, exposing patients to potential regression, screaming the need for resilient, adaptable rehabilitation models.

3.3. Coping Strategies: Patient-Led Adaptations

Faced with these disruptions, participants employed varied coping strategies, with the predominant approach being a shift from institution-based to home-based rehabilitation (76.9%, n=20). However, the quality and support for this transition revealed critical system failures. With only 15.4% (n=4) of those transitioning home reported receiving structured home program from their physiotherapist tailored to pandemic constraints. For the majority (84.6%, n=16 of the 20), the move represented a self-initiated adaptation based on recall of previous exercises, often without professional reassessment or guidance regarding progression, modification, or safety precautions.

Alternative strategies included complete cessation of formal rehabilitation activities (11.5%, n=3), typically among those with fewer family supports or greater mobility challenges. Three participants (11.5%) reported increased reliance on religious or traditional healing practices as supplements to diminished physiotherapy.

3.4. Systemic Support Deficits

The healthcare system's engagement during the disruption period was minimal and inconsistent. Most participants (73.1%, n=19) reported receiving no remote follow-up of any kind from their healthcare providers during the periods of most severe service restriction. No participants accessed or were offered formal telerehabilitation platforms, citing both limited availability and digital illiteracy.

Notably, communication regarding service changes about adjusted schedules, safety protocols, or alternative service arrangements from their treatment facilities was largely absent. This communication vacuum contributed to confusion and uncertainty, with many participants unsure whether services were temporarily suspended or permanently discontinued.

3.5. Thematic Analysis of Unmet Needs and Limitations

Participants consistently expressed concerns about the technical quality and safety of their self-managed rehabilitation. The absence of hands-on correction emerged as the most frequently cited limitation with participants describing uncertainty about whether they were doing the movements correctly or possibly causing harm. Limited access to therapeutic equipment previously available in clinical settings was mentioned as constraining exercise variety and intensity.

In addition, beyond immediate technique concerns, participants described uncertainty about exercise progression, modification for fatigue or pain. Also, the therapeutic relationship's psychosocial dimensions emerged as profoundly missed elements. Participants described diminished motivation without someone to encourage them. The accountability provided by scheduled appointments was also missed, with several participants acknowledging they exercised less consistently without this structure.

4. Discussion

This study reveals that the disruption of stroke rehabilitation during the COVID-19 pandemic in Lusaka Zambia created not merely a quantitative reduction in services, but a profound qualitative transformation in the care paradigm, from supervised, progressive, relationship-based therapy to unsupported, static, and isolated self-management. The care gap that emerged was multidimensional, encompassing technical, educational, and psychosocial domains, with significant implications for both immediate functional outcomes and long-term health system resilience.

Our findings paint a concerning picture of health system passivity in crisis response. While patients actively sought to maintain rehabilitation practices through home-based adaptations, the system provided minimal guidance, structure, or support for these efforts. The stark disparity between the 76.9% transitioning to home exercises and the mere 15.4% receiving home-based rehabilitation represents a critical failure in therapeutic continuity. This disconnect suggests that rehabilitation services were conceptualized as facility-bound events rather than continuous processes that could extend beyond clinical walls, a conceptual limitation with practical consequences.

This unsupported shift carries significant clinical risks. Neurorehabilitation literature consistently demonstrates that unsupervised practice of incorrect movement patterns can reinforce maladaptive compensations, potentially leading to inefficient movement strategies, joint stress, and preventable secondary complications [10]. In the absence of professional oversight, well-intentioned self-management may inadvertently undermine therapeutic goals, an irony that highlights the necessity of supported transitions.

This finding has particular resonance for Lower to Middle Income Countries (LMIC) contexts where high-tech telehealth solutions face substantial infrastructure, literacy, and cost barriers [13]. Our study reinforces emerging evidence that low-tech tele-rehabilitation using basic mobile phones for check-ins, SMS for reminders, and paper-based pictorial guides, may represent a more immediately feasible and equitable approach in resource-constrained settings [14]. That none of these were systematically implemented points to a need for both practical protocols and philosophical shift, viewing remote support not as a technological luxury but as a fundamental component of crisis-responsive care.

Furthermore, participants articulated the loss of encouragement, accountability, and hope, all of which are elements central to rehabilitation’s therapeutic effect but often undervalued in biomedical models of care. This psychosocial dimension of the care gap warrants particular attention because it may have disproportionate impacts on adherence and outcomes [15].

The pandemic has revealed that our current rehabilitation models are brittle, they fracture when facilities become inaccessible. Building resilience requires reconceptualizing rehabilitation as a continuum that persists across different environments and circumstances. Several specific implications emerge from our findings which include how that every chronic rehabilitation patient should have a ‘crisis plan’. This is a simple, individualized home program developed during stable periods, complete with pictorial guides, safety precautions, and progression criteria. This would ensure that when disruptions occur, patients have a structured, therapist-endorsed pathway rather than relying on memory and guesswork.

Moreover, health facilities should develop stratified remote support protocols matching resource availability to patient need. At minimum, this could involve: (1) SMS reminders for all patients; (2) Scheduled phone check-ins for higher-risk individuals; (3) Community health worker visits for those with limited phone access; and (4) Paper-based progress trackers that patients can complete and bring to eventual follow-up visits. Such approaches recognize resource constraints while ensuring no patient is completely abandoned.

Integrating the education sector, rehabilitation curricula should explicitly address crisis management, including remote assessment techniques, low-tech intervention strategies, and ethical considerations in resource-constrained emergencies. Building this competency at the training level ensures future professionals enter practice with a resilience mindset.

This study has several limitations that suggest directions for future investigation. The cross-sectional design relies on retrospective recall, though temporal anchoring techniques were employed to enhance accuracy. The sample, while providing rich qualitative insights, is modest in size and limited to urban Lusaka. Rural experiences may differ substantially. The focus on chronic stroke survivors (4+ years post-stroke) means findings may not generalize to acute or subacute populations with different needs and resources.

Future research should employ longitudinal designs to track long-term functional consequences of care disruptions. Comparative studies across different LMIC contexts could identify transferrable resilience strategies. Intervention studies testing specific crisis-response protocols (e.g., structured home programs with remote check-ins) are urgently needed to build the evidence base for effective alternatives. Finally, health economic analyses quantifying the cost-effectiveness of various continuity strategies would strengthen policy advocacy for resource allocation.

In conclusion, the COVID-19 pandemic exposed a critical fragility in Zambia's stroke rehabilitation system. The absence of structured pathways to maintain therapeutic continuity when face-to-face services are disrupted. The care gap that emerged was characterized not merely by reduced service volume but by a fundamental breakdown in the therapeutic relationship and support structures essential for safe, effective rehabilitation. Patients responded with commendable resourcefulness, but their unsupported adaptations exposed them to potential harm and almost certainly suboptimal outcomes.

Our findings illuminate a paradox, in seeking to protect patients from infection by closing facilities, the health system may have inadvertently exposed them to different risks of incorrect practice, lost progression, therapeutic abandonment, and preventable decline. This paradox shows that infection control and rehabilitation continuity are not competing priorities but complementary necessities that must be balanced through creative, patient-centered solutions.

Moving forward, the goal must be to transform ad-hoc patient adaptations into therapist-guided, supported, and monitored strategies. This requires both practical innovations, structured home programs, tiered remote support, community-based options, and philosophical shifts in how we conceptualize rehabilitation, not as a series of appointments but as a continuous process supported by various means across different circumstances.

Building health system resilience is ultimately about maintaining therapeutic relationships and care continuity even amidst disruption. For stroke survivors in Lusaka Zambia and similar contexts, such resilience is not a theoretical concern but a determinant of whether they maintain independence, dignity, and quality of life through present and future crises. The pandemic has revealed the gap, our collective task is now to build the bridge.

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Data Availability: De-identified data supporting the findings are available from the corresponding author upon reasonable request, subject to approval from the ERES Converge Ethics Committee and the Zambia National Health Research Authority.

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