Original Article

A mobile application-based post-stroke care strategy for survivors and their caregivers for prevention and management of post-stroke complications – "Stroke Home Care:" Development and feasibility

Ashok Kumar[1], Dheeraj Khurana[2], Smita Pattanaik[3], Mukesh Kumar[4] , Sukhpal Kaur[1], Narayanan Chatapuram Krishnan[5], Sandhya Ghai[1], Manish Modi[2] , Manisha Nagi[1], Rajan Chellappa[6], Jitender Gairolla[7] , Divesh Kumar Munjal[2], Pramod Kumar[8]

[1]National Institute of Nursing Education, Post Graduate Institute of Medical Education and Research, Departments of [2]Neurology and [3]Pharmacology, Post Graduate Institute of Medical Education and Research, Chandigarh, India, [4]Department of Industrial Engineering, Dalhousie University, Halifax, Nova Scotia, Canada, [5]Department of Computer Science and Engineering, Indian Institute of Technology, Ropar, Punjab, [6]Department of Physical Medicine and Rehabilitation, Post Graduate Institute of Medical Education and Research, Chandigarh, [7]Department of Microbiology, AIIMS, Rishikesh, Uttarakhand, [8]Department of Nursing, Post Graduate Institute of Medical Education and Research, Chandigarh, India.

ABSTRACT

Objectives: In developing nations such as India, a disparity exists between the available resources for stroke rehabilitation and the substantial burden of stroke cases. Consequently, the provision of cost-effective and multidisciplinary post-stroke rehabilitation care to stroke survivors becomes of paramount importance. The utilization of mobile applications (apps) for stroke care has been on the rise, offering a personalized and pragmatic solution with the potential for wider reach in settings constrained by limited resources. To address the unmet needs in the prevention and management of post-stroke complications, we conceptualized a strategy known as a mobile application-based post-stroke care strategy for both survivors and their caregivers.

Materials and Methods: The scope of the app's focus was determined based on the incidence of post-stroke complications within a prospective cohort of stroke patients, in conjunction with existing literature. An initial "web-based mobile app" prototype was crafted to align with the identified focus area. Before the development of the final app version, a feasibility study was conducted involving 30 participant dyads (comprising a patient and a caregiver). Content validity was evaluated by a panel of 20 stroke experts encompassing neurologists, nurses, physiotherapists, and psychologists.

Results: The "Stroke Home Care" (SHC) mobile app was conceived as a web-based educational tool aimed at preventing and managing post-stroke complications. It seeks to train caregivers of immobile stroke patients in the administration of preventive and therapeutic care procedures, thereby potentially enhancing survivors' quality of life and alleviating caregivers' burden. The feasibility and validity studies indicated "high satisfaction" levels among most caregivers and experts (>75%), with the remainder expressing "satisfaction" and no "dissatisfaction" regarding app utilities. Stroke experts unanimously deemed the app "appropriate", with consensus on contents, video quality, video length, and voice clarity. Caregivers reported "satisfactory" user experiences, encountering no issues during app installation or operation. Suggestions from both caregivers and experts were integrated into the final app version.

Conclusion: The "SHC" app represents a feasible and well-received innovation tailored for the use by caregivers of stroke survivors. Consequently, the initial feasibility of the developed app serves as a precursor to a randomized controlled clinical trial aimed at substantiating its effectiveness within the post-stroke survivor and caregiver population. Notably, within resource-constrained contexts, this app has the potential to be a pivotal tool for post-stroke care.

Keywords: Mobile application, Development and feasibility, Stroke survivors, Caregivers, Post-stroke rehabilitation

INTRODUCTION

Stroke stands as a significant contributor to global disability and mortality, targeting the physical, intellectual, and psychosocial dimensions of survivors.[1-4] Annually, 5.5 million succumb and 116.4 million disability-adjusted life years result from strokes.[5] This burden disproportionately affects low and middle-income countries (LMICs) like India, where structured multi-disciplinary stroke rehabilitation remains scarce.[5-8] Further, primary and secondary prevention take precedence, resulting in inadequate post-stroke rehabilitation in LMICs, India included in the study.[7,9-13] Moreover, patient-centered multi-disciplinary rehabilitation is pivotal for

recovery.[4] However, India's government rehabilitation centers often operate inadequately, and private options are financially inaccessible to marginalized groups. This situation requires implementing alternative cost-effective, multidisciplinary post-stroke rehabilitation to address unmet needs and mitigate the rising burden of post-stroke disability.[7]

As of 2020, global smartphone users exceeded 3 billion, with an anticipated 760 million in India by the end of 2021, projected to reach over 950 million by 2025.[14] Smartphone-based healthcare apps aid patient education, self-management, and home care, garnering substantial attention in healthcare.

The utilization of smartphones among the general public and health-care practitioners has experienced tremendous growth over the past few years. Numerous studies[5,15-39] have highlighted the promising potential of mobile apps in post-stroke rehabilitation, with a primary focus on addressing physical disabilities, speech impediments, cognitive dysfunction, and the management of stroke risk factors. However, the app-based rehabilitation approach has yet to be explored within the context of home care for post-stroke complications, particularly as provided by caregivers. Furthermore, the effectiveness of app-based post-stroke rehabilitation is thought to encompass cost savings, quality of life improvement, and a reduction in caregiver burden.[21,22] These recent evidence supports the utilization of smartphone apps for stroke rehabilitation due to their continuous and effective provision of stroke education. This potential can provide advantages for both stroke survivors and their caregivers in efficiently handling post-stroke complications.

We developed a web-based mobile application with the purpose of delivering educational intervention to caregivers responsible for the care of immobilized stroke survivors at home. The objective is to offer guidance in preventing post-stroke complications including bedsores, urinary tract infections (UTI), aspiration, deep vein thrombosis (DVT), and contractures. This article endeavors to comprehensively elucidate the planned mobile app-centered intervention and outline the associated developmental procedures.

MATERIALS AND METHODS

Development and assessment of the feasibility and validity of the stroke home care (SHC) app was completed in two phases, the preliminary phase and pilot phase.

Development of content for intervention

An in-depth evidence search was carried out for the interventions using smartphone apps in healthcare, including stroke rehabilitations, which warranted the participation of the patients and caregivers.

The developed content of this intervention was primarily based on the unmet needs of the stroke survivors and their caregivers collected through a preliminary rehabilitation needs assessment study which was carried out exclusively to develop this intervention. Informed written consent to participate in the study was obtained from each caregiver.

Preliminary study

i. A total of 170 stroke survivors and their caregiver dyad were screened and enrolled to explore the various post-stroke rehabilitation needs experienced by them. Follow-up was done at 3 and 6 months to assess the prevalence of various post-stroke complications. Data were collected to determine smartphone usage among the caregivers of stroke patients as part of the feasibility study. Results showed that at 3 and 6 months follow-up, bedsores, aspiration pneumonia, UTI, frozen shoulder, and DVT were seen in 20.75% and 27.66%, 6.72% and 9.0%, 8.0% and 11%, 8.5% and 24.4%, and 2.0% and 2.66%, respectively. Moreover, more than 80% were using smartphone, and almost all were agreed that there should be a mobile application which is focused to train caregivers of stroke survivors' care at home.

ii. Based on the findings, intervention content was finalized by stroke experts such as neurologists, nurses, psychologists, and physiotherapists. A preliminary application, SHC, was designed and developed.

iii. Assessment of feasibility was done among 30 stroke survivors and their respective caregivers in a one ratio one fashion.

iv. A short 1-week follow-up was done to assess difficulties faced with app usage, content relevancy, voice and video clarity, and time spent exploring the content.

v. Design and content validation of the app was carried out among 20 stroke experts. Their satisfaction level regarding usage of the app was assessed and they were also asked to provide suggestions to improve the app further.

Content development for "SHC" app

Based on the feasibility and validation study, content development for SHC was carried out emphasizing patient-centric intervention to prevent and manage post-stroke complications. We have also included the suggestions of five stroke survivors and their primary caregivers for the content development.

Highlights of the SHC app

1. Bilingual: App content, including audio and visuals, is in both English and Hindi languages. Furthermore, the study has expanded into a national multicenter trial, with ongoing efforts to meet multilingual needs at regional centers.

2. The app included a step-by-step depiction of protocols for the care of stroke patients with significant residual disability (Modified Rankin Scale [mRS] 4 and 5).
3. Include protocols were as follows: Stroke education, prevention of bedsores, positioning the bedridden patients, back care, bedsore dressing, Ryle's tube feeding, oral care, active and passive range of motion exercises, urinary catheter care, psychological support to the patients, proper hand washing, and do's and don'ts for medication.
4. Visual contents were incorporated into the app through links to a YouTube channel, which may be explored by a user securely and privately using an Android smartphone.
5. A sharable link for the app was created to install it on the smartphones of participants.

SHC design and content

The app's logo represents a stroke survivor lying on the bed in Semi-Fowler's position and a hand representing the caregiver in the home environment [Figure 1]. In addition, the web-based application uses a website as an interface,

Figure 1: Logo of the application.
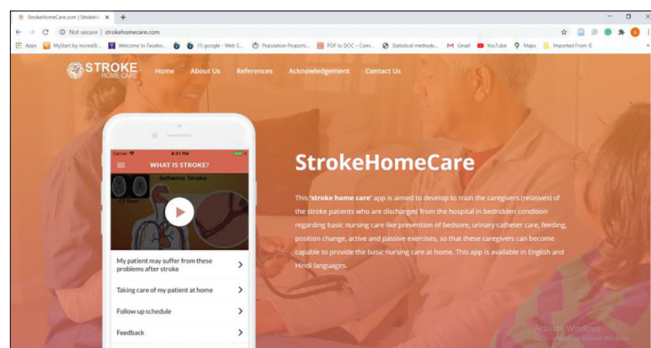
Figure 2: The introductory web page of the "Stroke Home Care" application.

www.strokehomecare.com. A brief description of the SHC app is provided on the home page of the website, and various navigation icons such as home, about us, references, acknowledgment, and contact us are also provided [Figure 2].

The app's user interface facilitates a user (stroke survivor/primary caregiver) to interact with a system (a smartphone) to execute the tasks. For example, the user can watch the videos by navigating through user-friendly interfaces in the form of icons. In addition, the app includes bilingual and audio-visual content, and above 90% of the content is in the form of videos. The summary of the content available in the SHC app is presented in the Tables 1 and 2.

Technical description of the application

Initially, this app was built for Android devices only in Ionic-Framework (Cross Platform Development) developed in AngularJS, TypeScript Language. iOS version (iPhone/iPad) has also been developed.

The backend is built on top LAMP (Linux, Apache, MySQL, PHP) Stack. In addition, the backend uses Slim Framework (API MicroFramework) to create API services that are used to send/receive data from SHC app to the database, which facilitates easy user interaction with the database (MySQL) for viewing the requested information without experiencing any difficulty.

App has multilingual functionality to facilitate the language choices of the users. The text content of the app can be translated into multiple languages, which have been linked with related. json files in the assets folder (for example, the English language is available in en.json and the Hindi language in a hi.json file). An ngx-translate command may call these files, and language text will be rendered by a simple and easy method. The app uses Cloud Flare content delivery network to counter video streaming issues in poor internet connectivity conditions to enhance the quality and speed of the video streaming. All videos are hosted privately on YouTube, and only the users who have the link or use the app can access the videos. The administrator can monitor the activities of the logged-in users through the administration

Table 1: Content of 'What is stroke?' section.		
Content of the "Stroke Home Care" application		
Main sections	**Subsections**	**Videos (Duration 6.38 minutes: English and 8.19 minutes: Hindi)**
Information about stroke	What is stroke?	A video (in Hindi and English) explaining about stroke, its types, risk factors, warning signs (FAST), code stroke activation, adverse effects of stroke, diagnostic evaluation, available treatments, and recovery after stroke.

Table 2: Content of 'Taking care of my patient at home' section.

Content of the "Stroke Home Care" application		
Main sections	**Subsections**	**Videos**
Taking care of my patient at home	What is bedsore? How to prevent bedsore?	• What is bedsore? How to prevent bedsore? • How to provide back care to my patient? • How to provide 30degree oblique position to my patient? • How to do bedsore dressing? • How to sterile articles for bedsore dressing?
	How do I feed my patient? How do I care of mouth of my patient? How do I care urinary catheter of my patient? How do I do limb exercises of my patient?	• How do I feed my patient? • How do I care of mouth of my patient? • How do I care urinary catheter of my patient? • Passive range of motion exercises (further subsections of Upper limb and lower limb exercises) • Active range of motion exercises (further subsections of Upper limb and lower limb exercises)
	How to provide psychological support to my patient? How to clean my hands properly?	• How to provide psychological support to my patient? • Hand washing with soap and water • Hand washing with hand rub
	Important do's and don'ts for medications	Important do's and don'ts for medications: only written information.

panel of the app. This panel can display and export various reports related to the user interaction with the app.

Some of the vital information that could be monitored through this app are as follows:

1. View all the recently added patients on the dashboard and recent upcoming follow-up for each patient
2. List of all users who have downloaded the app
3. User's registration and logged-in time
4. The app language being used by any user, IP from where they are using the application, session tokens, and device ID to send push notifications to them
5. Manage the content of the website pages through the admin panel itself
6. List of patients registered and caregivers attached to each patient.
7. Detailed information about a patient with complete contact and address details along with medical history such as date of stroke, bedsore time, and shoulder pain
8. To view the list of the follow-up schedule for each patient
9. List of the videos posted by patients in the feedback section.

Steps for operating "SHC" application

Sign-in page and registration

First-time users (patients/caregivers) register using their mobile number and provide the one-time password to authenticate the process. After confirmation and verification, user details are added as part of a mandatory registration process. Required details for the registration process are as follows; time of stroke, date of stroke, relation with patient, mobile number, address, education, occupation, health

insurance, if any, and previous training regarding caregiving [Figure 3a-f].

Main page/homepage

The app's homepage contains a menu option on the upper left side which contains the main page, patient details, caregivers details, acknowledgment, references, settings, and emergency helpline number [Figure 3d]. Users can select their preferred language (English or Hindi). The homepage has five sections that comprise the contents of the "SHC" intervention. Users may explore the information provided under these sections by selecting any. Details about the sections are as follows:

"What is stroke?": It contains an educational animated video about stroke, its types, risk factors, treatment, and rehabilitation [Figure 4a and b].

"My patient may suffer from these problems after a stroke": It contains the list of the post-stroke complications such as bedsore, halitosis (bad smell from the mouth), shoulder pain, limb weakness, limb spasticity/contractures, difficulty in speech, and any other health problems [Figure 4c and d]. This section comprises detailed pictorial descriptions of the post-stroke complications and helps the users understand them. After getting appraised of these complications, the user may proceed ahead to select their patient's specific complication. For example, if the patient has a feeding tube, urinary catheter, and/or contracture, the user can select a specific complication provided in the app menu. Once selected, the links to the care protocol videos associated with those specific complications get activated in the "Taking care of my patient at home" section. This feature ensures to remove the hassle of going through the entire compendium of videos, and the user only gets trained to handle the complications
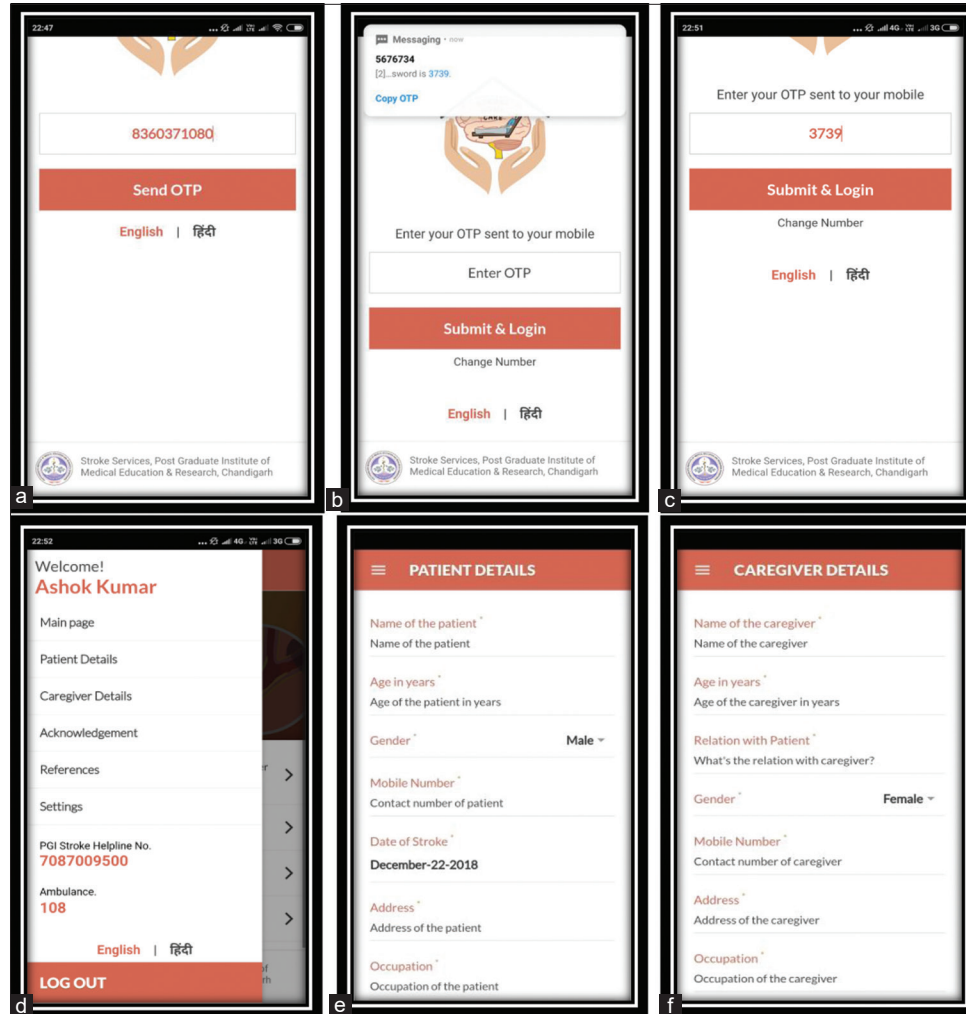
Figure 3: (a-f) Sign-in and registration pages.

being faced by him. The data of user selections are captured at the backend through a secured server for the analyses.

"Taking care of my patient at home": This section on the homepage redirects the user to a page that contains the activated links of the care protocol videos for the reference of the caregiver. The caregivers can then watch and understand the care protocols to provide home-based care to the stroke patient to prevent post-stroke complications. The intervention protocol videos are also available in both the Hindi and English languages [Figure 4e and f].

"Follow-up schedule": This section lets the user choose a preferred date for follow-up in the outpatient department. The user can choose up to three preferred dates for follow-up [Figure 4g and h]. The investigator at the other end confirms a follow-up date and time, which is sent as a text message to the registered numbers of the users.

"Feedback": This section assists the user to post their feedback in the form of a short video (25 s) or written text

for any queries or challenges they face while performing or following any care protocol on the patients [Figure 4i and j]. A few of the screenshots of the videos that demonstrate the intervention protocols for managing various post-stroke complications are shown in Figure 5. The investigator can view the feedbacks in the administration section of the app and may contact the users to answer and solve their queries.

Administrator module

The app is built with an administrator module, where the usage and utilization patterns of the users can be tracked, and reports can be generated, which can be utilized to improve the functioning of the app. The administrator can modify the video content when required, thereby customizing or improvising the content of the intervention according to the need. The administrator module is protected and strictly secured through a username and password to ensure privacy and confidentiality of the user information [Figure 6].
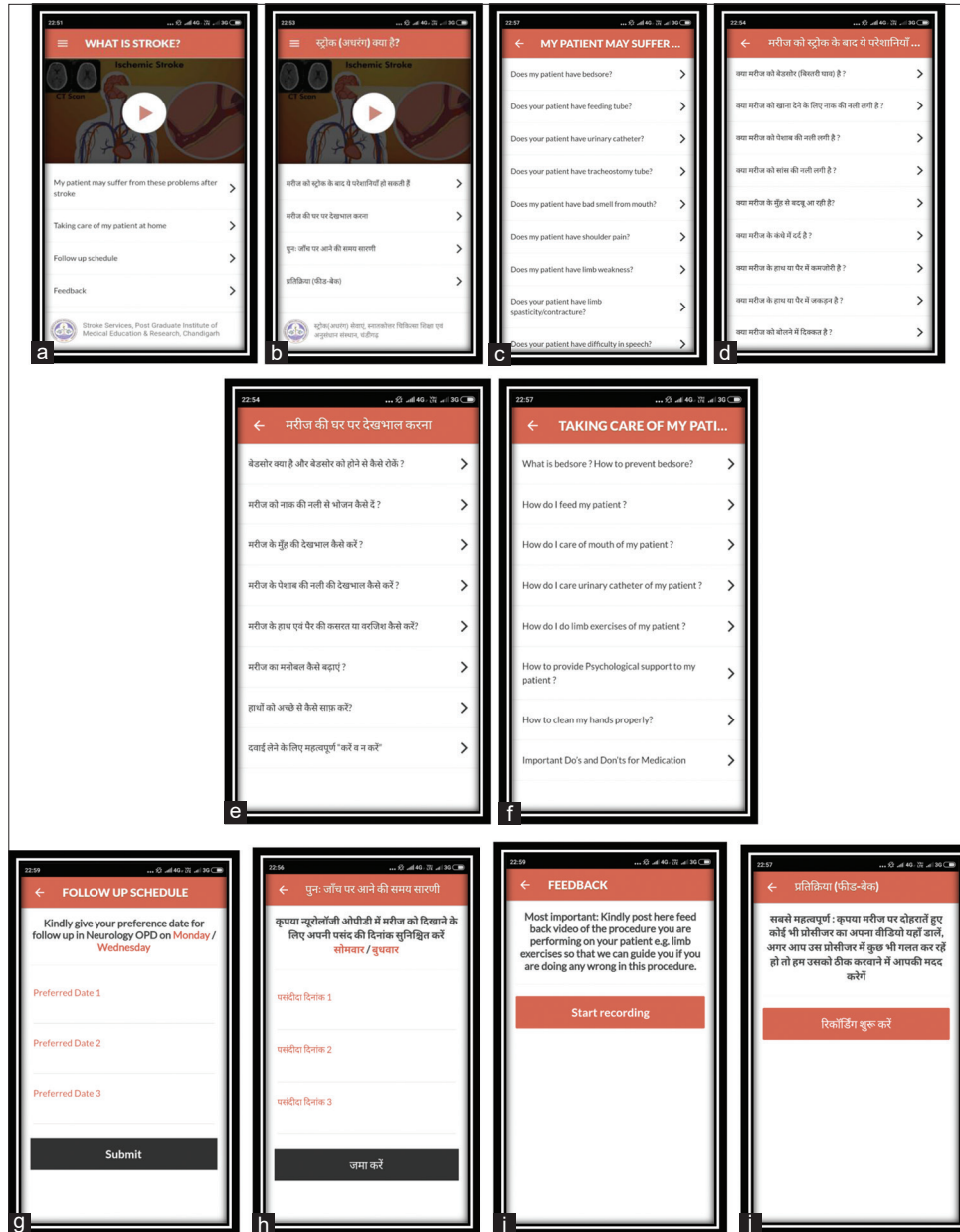
Figure 4: (a-j) Various sections of "Stroke Home Care" app.

## Pilot feasibility and validity study and final development of the app

After finalizing the preliminary App design, SHC App version 0.0.0 was developed. The App's feasibility was conducted through a pilot phase on 25 stroke patients and their respective caregiver dyad. A semi-structured questionnaire was used for data collection. All had 4G internet connections on their smartphone, and none faced any problems installing the App. These results indicate that the SHC app would be feasible for the second phase.

RESULTS

All participants responded that App and its contents, including videos and language, were clear, coherent, and appropriate. The majority (92%) of the participants preferred the Hindi language for App use. All respondents agreed that the App had enhanced stroke-related knowledge. All respondents found the video lengths (average 7 min for each video) appropriate and agreed that for proper care of the patient, it was necessary to include every aspect of the care protocol in the videos. Three-fourths (76%) of the respondents were highly satisfied with the App, and the rest

Figure 5: (a-d) Screenshots of the videos demonstrating intervention protocols.
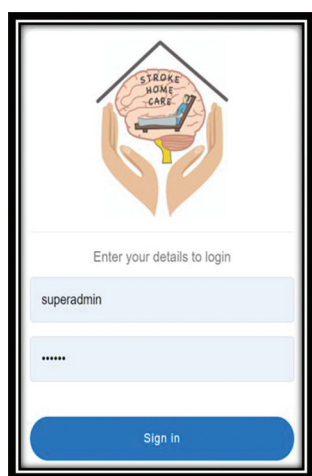
Figure 6: Administrative module protected by username and password.

(24%) were satisfied with the App experience. None of the caregivers were dissatisfied or highly dissatisfied.

Furthermore, the validity of the SHC App was also assessed. For this part, 20 experts in nursing, stroke neurology, physiotherapy, and psychology were requested to validate the SHC App's sequence of the care protocol videos, audio-video clarity, and comprehensibility of the contents. Sixteen experts responded, and most (81.3%) of the experts were highly satisfied with the app functions, and the remaining (18.7%) were satisfied.

After feasibility and validation proof, the final "SHC" app version 0.0.1 was developed, and a randomized controlled trial (RCT) has been planned to assess its efficacy in reducing post-stroke complications.

DISCUSSION

The SHC app has been designed and developed to assist caregivers in providing home-based post-stroke care to avert post-stroke complications. It has been observed in the recent past that mobile apps for healthcare are being introduced at an exponential rate. However, in the absence of regulatory guidelines, it seems difficult for a healthcare professional to put trust in those apps. Therefore, it is essential to perform preliminary feasibility and validity studies to develop a reliable and robust app.

Sureshkumar *et al.* developed an app named "Care for Stroke" for stroke survivors and their caregivers to assist in home-based management of post-stroke physical disability only in Southern India.[7,18,40,41] On the other hand, the SHC app provides interventional assistance in the home-based care of the most common post-stroke complications identified through the preliminary rehabilitation needs study, expert opinions, and extensive evidence search. "Care for Stroke" app investigators enrolled 50 stroke survivors in the assessment of the rehabilitation need study, and there was no follow-up performed. Whereas, to develop SHC app, 170 stroke survivors were enrolled as per inclusion-exclusion criteria and were followed up for up to 6 months to identify the rehabilitation needs and common post-stroke complications over the follow-up duration. Ensuring a significant duration of follow-up is crucial for capturing crucial details concerning exposure, time, and outcomes within an interventional study.[42] Consequently, studies lacking proper follow-up might not yield sufficient findings. The present study explored all three components during an up to 6 months (time) follow-up to record any post-stroke complications (outcome) in survivors due to stroke (exposure). The post-stroke complications identified in the present study were given a mnemonic "ABCDEF" (Aspiration pneumonia, Bedsore, CAUTI, DVT, and Frozen shoulder/Contractures). The rehabilitation for psychological support has been identified as a crucial factor in various studies;[43,44] therefore, we provided the feature of psychological support rehabilitation in the SHC app. In addition, bedridden stroke survivors (mRS 4 and 5) were recruited in the present study to assure the app's usability among those who would benefit the most by post-stroke rehabilitation interventions. On the contrary, mild to moderately disabled stroke patients who could even walk with minimal support were recruited in the previous study.[7]

Both the "Care for Stroke" and SHC apps contain audio-video content on stroke information. However, the focus areas of post-stroke intervention in both of the apps are extensively different. Post-stroke rehabilitation focus of the "Care for Stroke" App was chiefly on residual motor disability, and functional independence was targeted. This App contains extensive care protocols on the upper and lower limb exercises, functional skill training, the activities of daily living, and the use of assistive devices. In contrast, SHC App's focus area of post-stroke rehabilitation revolves around the common post-stroke complications in bedridden

patients and their home-based management by an untrained caregiver. Both of the Apps show promising utility for both stroke survivors and their caregivers. However, the "Care for stroke" App seems more patient-oriented, whereas SHC App is more caregiver-centered. "Care4Stroke" is another App that is focused on rehabilitation of post-stroke residual disability and targets and functional independence similar to the "Care for Stroke" App.[45]

SHC App is a comprehensive post-stroke care package chiefly composed of home-based interventions to manage post-stroke complications in addition to physical exercises and psychological support. It aspires to be an integral and prudent tool in post-stroke rehabilitation in the LMICs where post-stroke services could not reach the deprived communities.

Limitations

This app was tested for its feasibility in few users in Hindi and English languages only. In other parts of India or on an international level where stakeholders are not familiar with these languages (Hindi and English), the use of this app is not practical. Bedridden and severe disabled patients were mainly focused during development and feasibility of the app. Mobile patients may not get much advantage of this app.

CONCLUSION

A mobile app has been developed to facilitate home-based post-stroke rehabilitation for stroke survivors. This application equips caregivers to address post-stroke complications among survivors at home, employing validated succinct and comprehensive care modules, primarily presented as instructional videos. Consequently, the authors have designed a RCT to evaluate the app's efficacy. The researchers contend that integrating this application into standard post-stroke care could mitigate the obstacles to stroke rehabilitation access for a substantial patient population, consequently augmenting the potential for enhanced management and recuperation outcomes.

Acknowledgments

Ethical approval

The study is approved by the Institutional Review Board, number CTRI/2017/08/009267, dated 4th August 2017.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

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Nil.

Conflicts of interest

There are no conflicts of interest.

Use of artificial intelligence (AI)-assisted technology for manuscript preparation

The authors confirm that there was no use of artificial intelligence (AI)-assisted technology for assisting in the writing or editing of the manuscript and no images were manipulated using AI.

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