Original Research Article

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Development and assessment of feasibility of a 'NeuroCare' app for home care of neurosurgery patients

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ABSTRACT

Background: Patients undergoing neurosurgery may require long-term care at home after discharge from the hospital. Mobile apps may assist their caregivers in care provision. This study aimed to develop and assess the feasibility of a 'NeuroCare' App for neurosurgery patients.

Methods: The study was carried out at the neurosurgery department of a tertiary care institution. A mobile app was developed following a preliminary assessment of patients' post-surgery health problems and the caregivers' training needs. This bilingual app consisted of videos on oral care, back care, hand hygiene, Tracheostomy tube (TT) care, TT suction, TT change, RT feeding, etc. It was validated by 22 experts in nursing, public health, physiotherapy, and neurosurgery. The feasibility of the App was assessed on purposely selected 16 patients and their caregivers.

Results: The majority (81.3%) of experts were highly satisfied with the functions of the app such as its contents, voice clarity, video clarity, content sequence, and understanding, and 80% of the caregivers preferred using the app in Hindi language. All the caregivers responded that the videos were not time-consuming. 60% of the caregivers were highly satisfied with the functions of the 'Neuro-Care' app.

Conclusions: The 'NeuroCare' app was found to be feasible and may be a useful component for home care of postoperative neurosurgery patients.

Keywords: Caregivers, Mobile app, Neurosurgery patients

INTRODUCTION

Various vital functions such as body temperature, respiration, protective reflexes, etc. are regulated by the nervous system. Events like traumatic brain injury, spinal cord injury, aneurysm, etc. may adversely affect these functions. Post-operatively, these patients may remain bedridden or have altered activity levels leading to various complications. The dependency may be complete

or partial as per the severity of the impairment leading to a burden of care on family members. After initial neurosurgical management, the patients are discharged with appropriate instructions. A great proportion of these patients develop physical, cognitive, emotional impairments, and disabilities. Thus, they need care on a regular basis for months and sometimes for years together. The family caregivers are constantly challenged to solve the day-to-day problems of the patients. They

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have to make decisions as per the necessities of the patients. They often feel confused and handicapped because they are untrained in providing care and lack basic knowledge about it. Sometimes, because of the financial constraints, they are not able to afford the trained or paid caregivers. So, certain strategies are required for these vulnerable caregivers to reduce the burden and depression associated with caregiving. Oupra et al. have demonstrated that providing education and support to the family caregivers of survivors can reduce their strain and enhance their quality of life.

Cost-effective, multidisciplinary post-discharge rehabilitation strategies are required to address unmet needs and mitigate the rising burden of post-surgery long-term dependability.⁹

Following the COVID-19 pandemic, worldwide, there has been a significant increase in smartphone users, and the number is projected to reach over 950 million by 2025. 10 Smartphone-based healthcare apps aid patient education, self-management, and home care, garnering substantial attention in healthcare. Many studies have highlighted the encouraging potential of mobile apps for formal training in post-discharge rehabilitation, with a main focus on addressing physical disabilities, speech difficulties, and cognitive dysfunction. 11-14 Additionally, app-based rehabilitation is thought to embrace cost reduction, quality of life improvement, and reduction in caregiver burden. 15-17

Endorsement to this background, the current study elucidates the development and feasibility of a web-based mobile application compatible with IOS and smartphones to deliver educational interventions to caregivers who were involved in the care of post-operative neurosurgery patients after discharge from the hospital. The app includes guidance and training in providing tracheostomy tube (TT) suctioning, TT care, hygiene of the patients, tube feeding, etc. to their loved ones at home.

METHODS

The study was conducted in neurosurgery units of a tertiary care institution of Northern India. There are primarily six neurosurgery units. Among them, the three units from where the post-operated patients are discharged were the study settings. Ethical permission was sought from the Institutional Ethical Committee of our center. Informed written consent was obtained from each participant. Caregivers of patients with aneurysms and head injury with motor scores of 5 and 6 on the Glasgow Coma Scale (GCS), with the activity of daily living (ADL) <2 score, the caregivers who spent more than 1 hour with them for care and having smartphones were enrolled in the study. A pre-validated checklist was used to assess the problems of caregivers. The 'NeuroCare' app was developed after reviewing the relevant literature and taking into consideration the health problems of patients as well as the problems of the caregivers (detail has been given under results) A semi-structured questionnaire was used to assess the different parameters (clarity, content, etc.) of the mobile app. Another checklist was developed to assess the feasibility and usability of the app. Caregivers were asked to give suggestions to improve the app functions in view of the users.

Development of content of the mobile app

The following steps were taken into consideration to develop the content of the App:

The first step was the analysis of the practices regarding the discharge of the patients. It was observed that due to the high patients' influx, the stable patients after initial surgical management were discharged for long-term management at home or a nearby hospital for further care mainly home-based care which is usually given by their formal caregivers. A total of 50 patients and their caregivers were purposively enrolled to explore various post-neurosurgery problems and the caregiving needs being experienced by them. It was noticed that 64% of patients were on tracheostomy, 56% had a complaint of headache, 74% with motor weakness, 56% were catheterized, and 34% had constipation. Almost all the health care professionals agreed regarding the concept of the development of a Mobile app for the caregivers of patients for their ready reference to provide care at home. 80% verbalized the preferred app in the Hindi language.

A thorough review of the literature was done from different databases.

Creation of the mobile app for neurosurgery patients and their caregivers

Based on the above findings, the content of the mobile app was developed. The main specifications of the app were as follows:

Nomenclature of the mobile app

After thorough discussion with neurosurgery experts and caregivers, the app was named as 'NeuroCare' app. 'NeuroCare' means the care of neurosurgical patients by their caregivers at home.

App logo design

In the app, logo represents 'The brain and head of the neurosurgery patient are protected safely by the hands of the caregiver'. One hand of health care personnel is just put behind the brain of the patient to closely protect it. The head of the patient is securely placed in the circle which represents a 24x7 care provision (Figure 1).

Content of App

The content of the App included steps of hand hygiene, oral care, back care for prevention of bedsores, Ryle's tube feeding, TT change, TT suctioning, and communication with the patient on tracheostomy tube. First of all this content was developed in 'English' and validated by the experts in the field of neurosurgery, neuro nursing, and physiotherapy. After that, this app content was translated into Hindi which was validated by the experts who were well aware of both 'Hindi and English' languages. Table 1 presents the 'NeuroCare' app content.

Features of the 'NeuroCare' app: This 'NeuroCare' App was developed by the IT professionals for both iOS (iPhone/iPad) and Android platforms. Additionally, App files were created by the backend using Slim Framework (API Micro Framework) to share and retrieve data from "Neuro-care" to the database. Through this app's administrative interface, the administrator may keep an eye on users while they are logged in. Many reports about the caregivers usage of applications can be seen and exported from this panel.

The website www.neurocareapp.com serves as the interface for this web-based application. The website's main page includes an outline of the app that has been designed along with a number of navigational icons, including home page about the app, references,

acknowledgment and contact the researcher for any query (Figure 2) in two languages i.e. in English and Hindi. Patients also have opportunity to switch any time to English or Hindi language while using the app. In addition to this, this app also has Audio/Visual and bilingual content with nearly 95% of the content is in the videos format.



Figure 1: App logo.

Table 1: Content of "Neuro care" mobile app.

Main section	Subsection	Videos (available in Hindi and English)	Duration English	Duration Hindi
Taking care of patients at home	Hygiene related procedures	Hand hygiene	4:36min	4:29 min
		Back care	4:12 min	4:35 min
		Oral care	3:58min	4:02min
	Tracheostomy tube-related care	TT change at home	6:44 min	6:15 min
		TT suction at home	8:08min	7:29 min
		TT care at home	4:49min	4:27 min
		How to give chest physiotherapy?	1:13 min	1:16 min
		How to get sterile dressing?	1:11min	1:01 min
		How to get sterile water at home?	0:36 min	0:37min
		How to wear gloves?	1:01min	1:05 min
		How to get sterile articles at home	1:11min	1:04min
	Communication	A verbal icon was used by the patient	Command	
	with the patients	to communicate	based	
	Ryles tube feeding	How and What to give in Ryles tube feeding	6:07 min	5:57min

How to use the app

The app is very user friendly and secured by One Time Password (OTP). On the title page of the app there is option to select the language i.e. Hindi or English. On installation page the caregivers need to enter their mobile number.

Registration and page for sign-in

The caregivers utilizing services can register by using their one-time passwords shared on their registered mobile number to authenticate the process. Patients and their family caregivers' details are added as part of a necessary registration process after confirmation and verification. Details of the patient, details of the caregiver and relationship with the patient, address, mobile number, qualification, profession, salary from any source, and any prior caregiver teaching are required for the registration process (Figure 3).

Home page of the app

The homepage of the 'NeuroCare' app has a menu option on the main page of the application which contains patient details, caregiver's details, patient care procedures, communication with the patient, references, acknowledgment, emergency helpline number, and settings. Patient care procedures are divided into three categories i.e. Hygiene related procedures, TT carerelated procedures, and Ryle's tube feeding of patients at home. "Taking care of my patient at home": The caregivers are directed from this portion of the homepage to a page of caregiving procedure videos. After watching and understanding the care procedures, caregivers can improve the patient's home-based care and avoid complications.

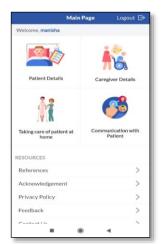




Figure 2: App main page in English and Hindi.



Figure 3: App login page.

In the feedback segment, the caregivers can post their opinions and responses by filling out an easy Performa or in the form of a written text on WhatsApp. They can also ask doubts and enquire about difficulties they came across while performing any care procedure on patients. The researcher can view the feedback of the app on a given Google form or WhatsApp message and they can contact caregivers to answer and solve their questions and difficulties.



Figure 4: Investigator explaining about 'NeuroCare' app features to caregivers.

Statistical analysis

Descriptive analysis was done using SPSS software version 22.0. Categorical variables like gender, health problems of patients, suggestions to improve app, the feasibility of app, etc. are expressed as percentages (%). Continuous variables like age, etc. are expressed as mean with standard deviation (SD).

RESULTS

Findings of the validation of 'Neuro Care' mobile app

The app was validated by 22 experts in neuro-nursing, neurosurgery, physiotherapy, and community medicine. The mean age of the experts was 37.5±6.19 years (range: 28 to 57yrs). 41% were male and females. 32% were doctors, 23% were nursing faculty and the majority (83%) of the experts were working. The mean years of experience of the experts was 12.15±5.2yrs

A majority (81.3%) of the experts were highly satisfied with the app functions like its contents, voice clarity, video clarity, content sequence, and understandability. All experts appreciated the app and suggested that it should be available on the Google Play Store. Five other experts suggested adding about DVT prophylaxis and range of motion exercises whereas eight other experts suggested adding about bed sore management and prevention at home in the app. Experts from neuro surgery suggested making the app available for all patients free of cost (Table 2).

Findings of the feasibility or usability of 'NeuroCare' mobile app

After completion of the initial app design, the feasibility of the App was assessed on 16 post-operative neurosurgery patients and their caregivers who were selected purposively. Fourteen caregivers were using Android and 4 were using iOS smartphones. At the time of discharge, the investigator installed the app on their phones via shared link and explained to them how to use the features of the app at home to provide care to their

patients. A telephonic follow-up was done to inquire about the app's features including videos and clear, acceptable language. 80% of caregivers used the Hindi language in their app. All participants responded that the app's language and video content was suitable, comprehensible, and clear. Everyone responded that videos were not time-consuming. 60% were highly satisfied with the app and the rest (40%) were satisfied with the app. None of the caregivers were dissatisfied with the app (Table 3).

Table 2: Experts' suggestions and comments to improve the mobile app.

Suggestions / Comments	N (%)		
Should be available on Google Play Store			
The exit option is not there in the app			
This app is an asset for patients.			
It's a good app	14 (64)		
Highly informative app providing clear and concise information			
There should be one-time log-in			
Good app, and easy to download. The content is easily understandable. Almost the whole of the content r/t care is covered. Even for laymen, it is quite beneficial.			
Synchronization of Audio and video			
Addition of content on pneumatic stocking and DVT prevention			
Need to add content on bedsore prevention and management at home			

Table 3: Feasibility or usability of 'NeuroCare' mobile app.

App feasibility parameters		(n=16)	%	Action taken
Internet connection	3G	4	25	
	4G	12	75	
App installed in their	Yes	16	100	
phone	No	-	-	
Any problem during	Yes	8	50	The problem was discussed with the technical team; a
installation	No	8	50	website was created in which both the links for Android
Installation problems after the rectification	Yes	-	-	as well as iOS phone was created. Participants were
	No	16	100	directed to open the website www.neurocareapp.com and click on the link and automatically app was installed on their smartphone. The participants were helped during this process of installation.

DISCUSSION

Due to more patient influx at tertiary care hospitals majority of patients after initial management are discharged for long-term care at home. The family caregivers need some formal training for the care of their loved ones at home. Currently, many smartphone medical apps might be helpful for neurosurgery patients, medical professionals, and different trainees. However, every app is designed for conferences, education, and learning about diseases, etc. None of the apps is made for the skill development of the caregivers in various nursing procedures. The NeuroCare app is designed as an educational intervention to improve health, and QOL, and decrease postoperative secondary complications.

Before the development of the App, the needs of stakeholders including the patients, and family caregivers, were assessed. This concept has been supported by other studies that before the development of any app we should assess the problems of the stakeholders who are going to use that app so that they can carry out the tasks of providing care at home skillfully. ^{19,20} It has been reported in previous studies that family caregivers have a heavy caregiving burden due to the difficult and complex tracheostomy care and that they need knowledge/skill training to carry out the process. ^{21,22} In certain earlier studies written study material was provided to caregivers at discharge regarding the home care of the patients. ²³⁻²⁶ However, the NeuroCare app is the first of its kind for the neurosurgery patient's home care.

Most of the caregivers were gratified with the quality of the app. Not a single caregiver had reported it as dissatisfactory. Many other studies have also shown patient and caregiver satisfaction with the health-related apps.²⁷ It was found that the app reduced health center visits for small queries and it was time-saving, cost-effective, and user-friendly.^{9,21-23}

It becomes essential to check the feasibility and validity of these apps to make them reliable for the general public and health care professionals too. 23-26 As internet facilities are accessible to all at nominal rates. World Health Organization (WHO) recommends that healthrelated app must be validated by health professionals before being available to the general public and there should be involvement of the healthcare professionals as well as patients and their caregivers to ensure the authenticity and validity of the app. 28,17,29-31 This app was validated for its contents, voice, video, and clarity by experts in the fields of neurosurgery, public health, community medicine, nursing, and physiotherapy. The authors conducted a study on developing skills in suctioning and TT change. It was found that the skills of the caregivers can improve if proper discharge training is given to them. It can help them to take care of their loved ones at home and reduce unnecessary hospital visits. 23,24

There were few limitations of the study. The cost effectiveness of the app was not evaluated. Apart from this, its usage with respect to the frequency of using by each individual caregivers were not checked.

CONCLUSION

The "NeuroCare" app was developed based on the health problems faced by post-operative neurosurgery patients after discharge, problems faced by their caregivers while providing care to their patients. The health professional's opinions regarding the care provision of the patients were also taken into consideration. The app was feasible for the caregivers to provide care to their patients at home.

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Institutional Ethics Committee

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