Development of strategies to support home-based exercise adherence after stroke: a Delphi consensus

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ABSTRACT

Objective To develop a set of strategies to enhance adherence to home-based exercises after stroke, and an overarching framework to classify these strategies.

Method We conducted a four-round Delphi consensus (two online surveys, followed by a focus group then a consensus round). The Delphi panel consisted of 13 experts from physiotherapy, occupational therapy, clinical psychology, behaviour science and community medicine. The experts were from India, Australia and UK.

Results In round 1, a 10-item survey using open-ended questions was emailed to panel members and 75 strategies were generated. Of these, 25 strategies were included in round 2 for further consideration. A total of 64 strategies were finally included in the subsequent rounds. In round 3, the strategies were categorised into nine domains—(1) patient education on stroke and recovery, (2) method of exercise prescription, (3) feedback and supervision, (4) cognitive remediation, (5) involvement of family members, (6) involvement of society, (7) promoting self-efficacy, (8) motivational strategies and (9) reminder strategies. The consensus from 12 experts (93%) led to the development of the framework in round 4.

Conclusion We developed a framework of comprehensive strategies to assist clinicians in supporting exercise adherence among stroke survivors. It provides practical methods that can be deployed in both research and clinical practices. Future studies should explore stakeholders’ experiences and the cost-effectiveness of implementing these strategies.

INTRODUCTION

Stroke is one of the leading causes of death and disability across the world. Rehabilitation is recommended to promote recovery, enhance independence and improve quality of life after a stroke. However, healthcare services and comprehensive stroke rehabilitation centres are often expensive and beyond people’s reach. Considering the limited access to hospital-based healthcare services after stroke, home-based rehabilitation is often preferred and sometimes the only option for stroke survivors living in low-resource settings. Home-based rehabilitation has been shown to have functional and cost benefits. Adherence to the home-based regimen is of utmost importance for any intervention to be beneficial. Improving adherence to exercise programmes after stroke has been shown to improve functional recovery.

Non-adherence to physical exercises is a common problem among stroke survivors. The level of adherence to prescribed home-based exercises among Indian stroke survivors was found to be only 28%. Barriers to exercise after stroke include factors at the individual, interpersonal, organisational and community levels. Modifiable factors include lack of knowledge about stroke, lack of supervision and motivation, and inadequate exercise prescription by healthcare providers. Other factors that impact adherence include pain, fear of falls and post-stroke fatigue. In addition, environmental factors such as cost, accessibility and transport are other barriers for people with chronic
stroke. Thus, developing effective strategies that reinforce adherence to home-based exercises is important. As stated by the WHO, ‘increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments.’ Therefore, improving adherence to post-stroke rehabilitation may enhance recovery and improve the quality of life among stroke survivors.

Exercise adherence can be improved through motivational interventions, behavioural change strategies, multimedia, follow-up sessions, feedback, cognitive-behavioural therapy, skill training, self-monitoring, goal setting, coping strategies and coaching. However, there is limited information on how to practically incorporate these into clinical practice. Therefore, developing strategies for promoting post-stroke exercise adherence is essential. Identifying barriers affecting adherence to exercise, and developing strategies that can be practically implemented by stroke survivors to modify those barriers, increases the potential for improving exercise adherence. Thus, we aimed to develop a set of strategies to facilitate adherence to home-based exercises after stroke and a comprehensive framework to classify these strategies.

METHODS
This study was a part of a doctoral thesis that was conducted in four phases. In the first phase, we measured the level of exercise adherence among community-living stroke survivors. In the second phase, we conducted qualitative interviews with stroke survivors to understand the factors affecting exercise adherence. Using the themes derived in the second phase, a Delphi study was conducted in the third phase to develop a framework of strategies to support adherence to the home exercise programme. The fourth phase involved testing the effectiveness of the developed framework of strategies in a pilot randomised controlled trial. The methods and findings of phases I, II and IV are published elsewhere. The current study (Delphi consensus) describes the process and findings of the third phase of the project.

Participant recruitment
Participants (experts) were recruited using purposive sampling. The criteria for selection were: (1) expertise in stroke/behavioural change/community health, (2) having more than 10 years of clinical experience, (3) published in peer-reviewed journals, (4) involvement in translational and collaborative health research, and (5) employed in academia, research or clinical practice.

We identified the experts through the collaborative network of the Centre for Comprehensive Stroke Rehabilitation and Research at the Manipal Academy of Higher Education. We aimed to recruit a majority of experts from India to ensure suggestions were context-specific to low-income and middle-income countries. We invited experts to participate in the study from different fields (physiotherapy, occupational therapy, neurology, clinical psychology, community medicine and behaviour science) to ensure that the strategies were comprehensive and covered multiple aspects of adherence.

Experts were invited via email. Those who agreed to participate gave their written consent and were included in the study. We conducted a four-round Delphi consensus; two online surveys, followed by a focus group to build a set of adherence strategies for home-based exercises based on survey results, then a final online consensus round. Each round took 2 months. Experts were sent two reminder emails and any non-respondents were excluded from that round. Except for the focus group, the experts were blinded to each other for all rounds, and responses were anonymous. The Delphi rounds were conducted between January 2018 and December 2018. The primary investigator, an experienced stroke physiotherapist (AM) collected and analysed the data. The focus group was conducted by another investigator (JMS) who has more than 15 years of experience in neurological rehabilitation and qualitative studies.

Data collection and analysis
Round 1
Our previous study explored factors influencing adherence to home-based exercises among stroke survivors through in-depth interviews. Using this information, we categorised the barriers reported by the stroke survivors into internal and external factors using the Intervention Mapping approach. We also performed a literature search in PubMed, Scopus, Web of Science and Cochrane using the search terms “physical exercises,” “adherence,” “compliance,” “behavior change,” and “health behavior.” We reviewed studies from the bibliographies of the relevant articles. We identified health behavioural change theories and existing strategies/interventions used for improving adherence to long-term therapies. Our review of the literature identified common principles for supporting adherence such as motivation, self-efficacy, social support, the role of family, online health support (mHealth) and behavioural change techniques. Our findings from the literature and our qualitative study were combined to form a 10-item survey using open-ended questions in SurveyMonkey software (https://www.surveymonkey.com/). The survey was then emailed to the expert panel (online supplemental file 1).

We merged the experts’ written responses to perform content analysis and coded the responses using ATLAS.ti V.8 software. The responses that were suggested by more than nine out of 13 (70%) experts were considered as ‘certain strategies’. Responses that were not common and suggested by less than nine experts were labelled ‘uncertain strategies’ for further consideration in round 2.

Round 2
The second survey, consisting of only the ‘uncertain strategies’, was emailed to the expert panel, and they
were asked to agree/disagree on the given strategies and provide reasons for their opinion. For an ‘uncertain strategy’ to become a ‘certain strategy’, it needed to have a majority agreement, that is, 6 out of 11 experts. This process resulted in a final set of 64 strategies.

**Round 3**

We then conducted a face-to-face focus group to collate the included strategies into broader categories. The expert panel was asked to categorize the list of strategies into a specific domain. They also suggested practical ways of implementing the suggested strategies such as: who should design it, the content, how it should be delivered and target stakeholders. Any experts who could not be present at the focus group were emailed the categories and asked to evaluate the draft framework.

**Round 4**

The framework of strategies was sent to all the experts for minor modifications and approval. The consensus from the experts led to the development of the final framework. Figure 1 shows the development of the framework.

**Patient and public involvement**

While this Delphi study was conducted among subject experts; opinions of patients and caregivers were used to develop the open-ended questions included in the first round of the Delphi process. Qualitative interviews were conducted among community-dwelling stroke survivors to explore their exercise behaviour and barriers to exercise adherence in the second phase of this project. The patients’ opinions highlighted that not only patient-related factors, but family, healthcare system and community-level factors played a role in exercise non-adherence. This information was used in the development of open-ended questions that were included in the first round of the Delphi process. Therefore, the patients’ perceptions and needs were incorporated in this study for designing adherence strategies and framework.

**RESULTS**

We invited 22 experts across India and abroad to participate in the Delphi survey. Thirteen consented
to participate in the study and responded to round 1 (figure 2). The final panel consisted of physiotherapists (n=7), clinical psychologists (n=3), occupational therapist (n=1), behaviour scientist (n=1) and epidemiologist (n=1). Three experts were from Australia, one from the UK, and the remaining experts were from India. Each panel member had more than 10 years of clinical experience and multiple publications (table 1).

Round 1
The open-ended survey and the summary of responses received in the first round are provided in online supplemental file 1. The content analysis of the responses received in round one yielded a total of 75 strategies. Of these, 50 strategies were suggested by more than nine experts (i.e., >70%) and were considered ‘certain’. The remaining 25 were considered ‘uncertain’ strategies (suggested by less than nine experts) and were included in the next round for further consideration.

Round 2
The response rate for round two was 85% (11 experts.) More than 60% of experts agreed on 14 out of 25 uncertain strategies and hence those were included. The remaining 11 strategies with less than 60% agreement were excluded. The percentage of agreement for each uncertain strategy is provided in online supplemental file 2. We included a total of 64 strategies (50+14) for the subsequent rounds.

Round 3
Six experts (three clinical psychologists, two physiotherapists and one epidemiologist) participated in the face-to-face focus group. The remaining seven experts responded
| Participants | Qualification | Area of work | Expertise | Country |
|--------------|---------------|--------------|-----------|---------|
| 1            | Epidemiologist | Research, Academic | Community and rural health Associated with the WHO, Indian Council of Medical Research and Global Burden of Disease Network | India |
| 2            | Occupational Therapist | Clinical | Stroke care and activities of daily living | Australia |
| 3            | Physiotherapist | Research, Academic | Stroke rehabilitation and physical activity. Associated with the World Stroke Organisation, Stroke Recovery and Rehabilitation Roundtable and Priority Research Centre for Stroke and Brain Injury | Australia |
| 4            | Physiotherapist | Research | Stroke and cardio-respiratory fitness. Associated with the World Stroke Organisation and Priority Research Centre for Stroke and Brain Injury | Australia |
| 5            | Physiotherapist | Clinical | Stroke rehabilitation | India |
| 6            | Physiotherapist | Research, Academic | Stroke rehabilitation | India |
| 7            | Physiotherapist | Research, Academic | Community Physiotherapy, and technology in rehabilitation | India |
| 8            | Physiotherapist | Research, Academic, Clinical | Physical activity epidemiology | India |
| 9            | Physiotherapist | Research, Academic, Clinical | Stroke rehabilitation | India |
| 10           | Behaviour scientist | Research | Behaviour change evidence and theories. Designing and evaluation of behaviour change interventions | UK |
| 11           | Clinical Psychologist | Research, Academic, Clinical | Cognitive rehabilitation, behavioural therapies | India |
| 12           | Clinical Psychologist | Research, Academic, Clinical | Cognitive rehabilitation, behavioural therapies | India |
| 13           | Clinical Psychologist | Research, Academic, Clinical | Cognitive rehabilitation, behavioural therapies | India |
via email and provided input to the framework. The final 64 strategies were grouped into nine domains (table 2).

Round 4
The final framework of strategies for improving home-based exercise adherence was agreed on by 12 (93% response rate) experts. The experts agreed that the exercise-related strategies should be designed and delivered by therapists having experience in stroke care such as an occupational therapist, physiotherapist, physiatrist or stroke nurse. They suggested that the strategies requiring behavioural techniques should be designed and supervised by a licensed clinical psychologist or behaviour therapist. In the following section, we have highlighted the key suggestions from the expert committee under each domain. The details of the framework are provided in online supplemental file 3.

Strategies for improving adherence to home-based exercises post stroke under each domain

Domain I: patient education on stroke and recovery
Experts agreed that the patient education should comprise of: (1) usual time course and speed of recovery, (2) the impact of practice and exercise on recovery, (3) adverse effects of rest and positive effects of activity, (4) the importance of secondary risk factor management, (5) managing complications (e.g., spasticity, pain, fatigue, contracture, depression), (6) complementary medicine (including traditional medicines and religious practices), (7) importance of adhering to the exercise programme, dosage of the exercise programme, (8) role of a caregiver, (9) recovery and return (interaction between severity and prognosis), (10) proper positioning techniques and (11) misconceptions about stroke recovery.

Methods recommended for delivering education included: written information, individual discussions, and phone calls that are individually tailored to each patient’s needs, as well as conducting group sessions wherein testimonials from recovered patients and their caregivers are presented.

Domain II: methods of exercise prescription
Exercises that are prescribed should be task-specific and individually tailored based on each person’s impairments, goals and context. These exercises should be reinforced using demonstration and practice. Exercise prescription should include personalised information or messages of personal encouragement.

Additional ways for prescribing exercises may include written or pictorial instructions, videos of exercises, voice-assisted programme or internet-based applications. Other ways that can support adherence are video recording of patients’ exercise performance, splitting the exercise into smaller steps for severe impairments and gradually increasing difficulty level. Gaming or gamification may also facilitate exercise adherence since it gives a sense of achievement and reinforces exercise behaviour.

Domain III: feedback and supervision
For regular feedback and supervision, maintaining an exercise log, everyday activity status or updates that are monitored by the medical team could be useful for supporting adherence.

Having therapists clear any doubt that patients might have about their exercise prescription, routinely ask patients about their progress and periodically ask patients to give feedback about the quality of their interaction with therapists will provide a sense of supervision and accountability, thus facilitating adherence.

There should be regular contact with the therapists (in person or via telehealth.) Therapists can use recorded audio/video clips, individual or group discussions for feedback and supervision. Therapists should use standardised assessments to measure clinical outcomes and provide feedback on progress.

Domain IV: cognitive remediation
The experts in behavioural science and cognitive rehabilitation agreed on prescribing tasks that are focused on functional recovery, planning the exercise centred on individual goals and understanding the patient’s motivation before the treatment session. Motivational interviewing or motivation enhancement therapy could be used to understand their baseline motivational level and establish intrinsic motivation for behavioural change. Providing positive feedback and reinforcement for small improvements engenders confidence in patients. Additionally, having a contingency plan for days when exercises could not be performed would prevent abrupt cessation of the exercise routine. Using behavioural activation (a treatment technique used in clinical psychology for managing depression) so that patients perform one enjoyable activity each day would keep them motivated to stick to their exercise schedule.

Domain V: involvement of the family members
Experts suggested that the family should be involved; however, the amount of assistance provided by the family needs to be balanced so as not to promote dependency. Assessing knowledge and understanding of the caregivers on post stroke exercises is crucial for them to reinforce patients’ adherence. Family can be involved by being the patient’s exercise partners, or by setting up exercise reminders, or by helping track the patient’s progress. Demonstrating and practising exercises with family can also enhance the self-efficacy and confidence of caregivers.

Managing the expressed emotions of the family members is important as it may hinder treatment and restrict the patient’s autonomy. Rotating family members in the supervision of the patient’s activities can help in reducing burnout and maintaining novelty in routine.

Domain VI: involvement of society/ community
Family and friends can interact with the patient on topics not concerning the illness (areas of interest to the patient
| Items | Domains | Strategies |
|-------|---------|------------|
| 1     | Patient education on stroke and recovery | Patient education about stroke and its treatment, Patient education on adherence, Caregiver education and involvement, Written instructions and pictures, Testimonials from recovered patients, Information on support agencies, Benefits of exercise, Psycho-education |
| 2     | Exercise prescription | Written instructions and pictures, Videos of exercises, Task-oriented training, Prioritising on a few tasks at a time, Meaningful and relevant exercises, Breaking down exercises into smaller steps, Individualised programme, Fun and engaging exercises, mHealth applications, Demonstrate and practice exercises |
| 3     | Feedback and supervision | mHealth applications, Activity log, Feedback from patients, Feedback on their progress, Exercise charts with video/audiorecording, Asking to tell approach, Clearing doubts by the medical team, Regular contact with therapists, Recording exercises for feedback, Regular monitoring, Understand previous exposure with exercises |
| 4     | Cognitive remediation | Educating on the benefits of exercise, Motivational interviewing, Cognitive–behavioural therapy techniques, Behavioural activation, Contingency charts, Involving group sessions, Meaningful tasks, Psycho-education |
| 5     | Involvement of family members | Exercise buddies, Emotional support, Assessing knowledge and understanding of the family on the importance of exercise, Rotate family members in care giving, Activity scheduling |
| 6     | Involvement of society | Involvement of friends, Involving group sessions, Modelling behaviour, Support and exercise groups, Social comparison |
| 7     | Promoting self-efficacy | Personal graph charts, Reduce the no of alternatives presented to the patient, Provide activities that can be done independently, Standardised assessment, Goal setting, Self-efficacy enhancement: using substitution and optimisation principles, Ongoing support, Methods of tracking exercises, Coaching methodology, Psycho-education |

Continued
such as work/politics/current affairs/sports.) Some strategies for involving society include having weekly phone/face-to-face interactions with colleagues, family, and friends, or joining/creating support groups or associations of families with stroke. Testimonials of recovered patients and their experiences with rehabilitation can be used for motivating other patients. Additional ways to include community are awareness programmes for healthy adults, local group exercise for people with stroke and peer support or exercise buddies.

Domain VII: promoting self-efficacy

Experts suggested using evidence-based behaviour change strategies (e.g., the Capacity Opportunity Motivation-Behaviour model,36 or Intervention Mapping approach25 and using rehabilitation principles of substitution and optimisation. Some suggested strategies to promote self-efficacy include:
► Collaborating with patients to devise the best monitoring strategy for them such as exercise practice sheets, paper, electronic diary or internet-based applications.
► Providing continual support after the termination of the formal therapy programme.
► Providing personal graph charts of success that can be generated weekly or monthly.
► Ensuring an adequate number of activities in which the patient can engage independently or with minimal supervision.
► Identifying anchors in the day (sleep times/meals/activities—exercise, recreation, social) and setting a general intention of sticking to their exercise programme or developing contingency ‘if/then’ plans.
► Discuss and explore potential barriers that would impede or hinder exercise sessions with patients.
► Overcome barriers using pie charts, pros versus cons analysis/identification of cognitive distortions/downward arrow techniques/developing a life brochure/movement or art-based therapeutic activities.
► Motivation interviewing to help to elicit patients’ intention to adhere to exercises and understand their motivation level.

Domain VIII: motivational strategies

Panel experts suggested that motivation can be facilitated by establishing positive feedback mechanisms at home with caregivers’ help to reward adherence. Motivational strategies can be implemented as follows:
► Showing functional improvements or devising individual graphs (every three sessions plus monthly).
► Having a display board/wall of fame where ‘patient of the month’ and photos of patients achieving good outcomes could be displayed in a rehabilitation centre or common mHealth application.
► Using productivity monitoring tools to keep them motivated.
► Maintaining a daily log for positive feelings or gratitude journal, and telephone follow-up where the medical team provides words of encouragement can promote adherence.
► Having video feedback at regular intervals, setting progressive but attainable targets, and involving patients in goal setting may motivate patients to continue exercising.
► Devising wrist bands of different colours (coded for level of recovery and mastery of tasks).
► Giving t-shirts or wrist bands of that colour and upgrading as they progress to encourage regular exercising.
► Competitions during group sessions among people with similar impairments and provide tokens or badges.
Intervention Mapping approach, which is underpinned by the Socio-Ecological Model. Our framework is constructed on the Socio-Ecological Model of behavioural change. Since there is limited access to healthcare facilities, higher cost of clinic-based rehabilitation, and lack of transport to hospital setup in low resource settings, home-based exercise adherence becomes crucial for recovery. The developed adherence strategies could be influential for the success of home-based rehabilitation in the long term.

The suggested strategies were categorised into nine domains, which were in line with the findings in existing systematic reviews. The included studies reported behaviour strategies and theories such as self-efficacy, motivational interventions, social-cognitive theory, activity-monitoring, feedback system, goal-setting, self-regulated exercises, for improving adherence. However, none of the studies had used Delphi approaches and provided broad concepts for enhancing exercise adherence without providing specific context, culture or techniques for delivering the interventions.

Adherence is affected by multiple factors such as age, self-efficacy, caregiver support, previous exercise behaviour, the severity of stroke and stages of stroke recovery. Therefore, the framework of strategies provides the opportunity to individualise the strategies based on each person’s impairments, recovery, the severity of stroke and available support system. The exercises can be tailored depending on the abilities and context of each person.

Adherence to poststroke rehabilitation is a dynamic process and changes with each stage of recovery, characterised by a higher adherence rate during the initial period of recovery, followed by a slow decrease in adherence rate and a stable phase where adherence does not change much. Some strategies such as enhancing self-efficacy, activity scheduling, regular feedback and monitoring can be initiated during the early phase while strategies such as interim progress tracking, personal graphs, involvement of peer group, gamification of exercises, providing rewards, and reminders can be started gradually to break the monotony of ongoing exercise programmes and encourage adherence. Therefore, implementing these adherence strategies early in rehabilitation can be beneficial for maintaining adherent behaviour in the long term. The results from a meta-analysis of mixed disease populations demonstrated that adherence is low when perceived disease severity is high among patients with serious illnesses. However, future studies are needed to establish the effects of stroke severity on exercise adherence.

The different sets of strategies within the framework can be deployed to improve exercise adherence after stroke. The framework is useful for stroke survivors, caregivers and healthcare providers as it offers adherence techniques at a personal, interpersonal and organisational level. It gives clear recommendations on each strategy’s content, different ways of delivering it, healthcare professionals who should design it, and one who might benefit from those strategies.

The strategies that were agreed on by more than 60% of experts were included while the remaining uncertain strategies were excluded. The excluded strategies were participating in social events, regular checks by neighbours or games/competition with family/caregivers. Such strategies may improve the social interaction but may not be feasible due to the caregiver’s burden after stroke, and family members may not find adequate time for such activities. Other uncertain strategies such as virtual reality, circuit training or award function were excluded due to the cost, training and equipment required. Strategies such as educating patients on the location and types of exercises can be tailored depending on the abilities and severity of stroke and available support system. The exercises can be adapted to individualise the strategies based on each person’s impairments, recovery, the severity of stroke and available support system. The exercises can be tailored depending on the abilities and context of each person.

DISCUSSION

We aimed to develop a comprehensive set of clinically applicable strategies for optimising adherence to home-based exercises after a stroke. In a Delphi method, experts from different fields co-construct knowledge and provide recommendations on a particular topic. In our study, we incorporated knowledge from experts in exercise science, behaviour science and experts experienced in community care to develop the set of strategies.

The 10-item open-ended survey, used in the first round, was based on our qualitative study that explored factors influencing adherence among stroke survivors using the Intervention Mapping approach, which is underpinned by the Socio-Ecological Model. Our framework is constructed on the Socio-Ecological Model of behavioural change. Since there is limited access to healthcare facilities, higher cost of clinic-based rehabilitation, and lack of transport to hospital setup in low resource settings, home-based exercise adherence becomes crucial for recovery. The developed adherence strategies could be influential for the success of home-based rehabilitation in the long term.

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The key strength of this study lies in the multidisciplinary nature of the expert panel that was recruited, which included specialists in stroke and exercise prescription, experts in behaviour and community experts having diverse experiences that contributed to developing a multi-faceted framework of strategies. Due to the pandemic that has compromised clinic-based rehabilitation worldwide, these strategies can be delivered in any healthcare setting, are easy to implement, affordable and offer a comprehensive set of strategies to facilitate exercise adherence. We have tested the framework of strategies in a recent randomised controlled trial and found it to be effective in improving adherence levels among people with stroke. Choosing the strategies from the framework can help in the pragmatic implementation in clinical practice or research trials. The framework is a useful guide for both clinicians and researchers to select appropriate strategies for enhancing exercise adherence.

We did not include stroke survivors and caregivers in the Delphi panel which we consider a limitation of this study. However, the perceptions of stroke survivors were explored to develop the questionnaire for the first round. The representation of experts from each speciality was unequal which could have influenced the decision-making process that differentiated certain vs uncertain strategies. Hence, some of the strategies deemed uncertain may have clinical relevance for supporting adherence. Moreover, as the open-ended questionnaire was developed from the literature review and opinions of stroke survivors in the previous study, the experts did not get a chance to develop the initial themes.

CONCLUSION

A set of strategies and a framework for enhancing adherence to home-based exercises after stroke has been developed and classified under nine domains: patient education on stroke and recovery, exercise prescription, feedback and supervision, cognitive remediation, the involvement of family members, the involvement of society, promoting self-efficacy, motivational strategies and reminder strategies. In countries where home-based exercises are the mainstay of rehabilitation, these strategies could reinforce self-management and facilitate adherence in the long term. Future studies should explore the experiences of stakeholders in implementing these strategies using qualitative methods. The set of strategies could be incorporated in a telerehabilitation model and cost analysis could be performed in the future.

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