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Co-designing resources for rehabilitation via telehealth for people with moderate to severe disability post stroke

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Abstract

Objectives The COVID-19 pandemic necessitated rapid transition to telehealth. Telehealth presents challenges for rehabilitation of stroke survivors with moderate-to-severe physical disability, which traditionally relies on physical interactions. The objective was to co-design resources to support delivery of rehabilitation via telehealth for this cohort.

Design Four-stage integrated knowledge translation co-design approach. Stage 1: Research team comprising researchers, clinicians and stroke survivors defined the research question and approach. Stage 2: Workshops and interviews were conducted with knowledge users (participants) to identify essential elements of the program. Stage 3: Resources developed by the research team. Stage 4: Resources reviewed by knowledge users and adapted.

Participants Twenty-one knowledge users (clinicians n = 11, stroke survivors n = 7, caregivers n = 3)

Results All stakeholders emphasised the complexities of telehealth rehabilitation for stroke and the need for individualised programs. Shared decision-making was identified as critical. Potential risks and benefits of telehealth were acknowledged and strategies to ameliorate risks and deliver effective rehabilitation were identified. Four freely available online resources were co-designed; three resources to support clinicians with shared decision-making and risk management and a decision-aid to support stroke survivors and caregivers throughout the process. Over six months, 1129 users have viewed the webpage; clinician resources were downloaded 374 times and the decision-aid was downloaded 570 times.

Conclusions The co-design process identified key elements for delivery of telehealth rehabilitation to stroke survivors with moderate-tosevere physical disability and led to development of resources to support development of an individualised telehealth rehabilitation plan. Future research should evaluate the effectiveness of these resources.

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Contribution of paper

- There is limited evidence to guide implementation of rehabilitation via telehealth for people with moderate-to-severe physical disability post stroke.
- Co-designed resources will assist clinicians, stroke survivors and caregivers to develop and implement safe, effective, individualised rehabilitation programs via telehealth.

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Introduction

There is strong evidence physical rehabilitation improves outcomes following stroke [1-3]. However, the COVID-19 pandemic disrupted stroke care [4,5]; access to rehabilitation was reduced [6,7] and telehealth replaced in-person appointments in many countries [8]. Telehealth involves the remote delivery of healthcare via technology that may occur synchronously or asynchronously [9]. Prior to the pandemic, delivery of stroke physical rehabilitation via telehealth was not generally part of routine clinical practice and until recently were not included in stroke guidelines [9]. While there are benefits of telehealth, there are many challenges, including the inability to conduct hands-on physical examinations or treatments [10–15]. Many components of stroke rehabilitation can be delivered by telehealth [16], however it is arguably more challenging to deliver physical rehabilitation to stroke survivors with moderate-to-severe physical disability as it relies on physical assistance from therapists and specialised equipment. Risks for stroke survivors and caregivers may also be greater. Evidence of the effectiveness of stroke rehabilitation via telehealth is limited [17–19]; many studies exclude people with cognitive impairment and none focus specifically on delivery of physical rehabilitation to people with moderate-to-severe physical disability post-stroke [17–19].

Despite limited evidence, telehealth provides access to rehabilitation when in-person therapy is restricted. Telehealth is novel for many clinicians and stroke survivors, particularly those with moderate-to-severe physical disability, therefore guidance to develop telehealth programs is required. Utilising a co-design approach this study aimed to identify and then develop the key resources needed to support delivery of telehealth rehabilitation (via videoconference or telephone) for people with moderate-to-severe physical disability following stroke. To ensure genuine partnership within the project the specific aims were defined through the co-design process. However, the broad aim was to co-design a program to support delivery of physical rehabilitation via telehealth to stroke survivors with moderate-to-severe physical disability.

Methods

Study design

Study design and decisions were informed by the research paradigm of pragmatism [20], driven by the rapidly evolving COVID-19 pandemic. Pragmatism requires researchers to recognise research as a process of inquiry occurring in everyday life contexts, to develop potential actions to respond to a defined problem and then take actions likely to address this problem [20]. The 'everyday life' context of the rapidly evolving global COVID-19 pandemic required timely development of potential actions (e.g., supports for delivery of physical rehabilitation via telehealth) which informed our research process and decisions. In keeping with the approach of pragmatism, the research team did not just examine what they would do at each stage of the project, they also examined why they decided on key actions and how this would inform the subsequent stage of the codesign process [20]. Funding was provided by the Melbourne Disability Institute, who advertised the study via social media. They did not play any role in study design, conduct or reporting.

An integrated knowledge translation (IKT) approach was used to engage knowledge users and researchers as partners throughout the process [21]. 'Knowledge users' are people who use knowledge generated by the research and include stroke survivors, caregivers, clinicians and researchers. The IKT approach involves active participation of knowledge users in all project phases, including the research team (Appendix 1, Table 1), and optimises engagement, uptake and usability of interventions [22,23]. Knowledge user involvement in research and intervention development is recommended by the International Stroke Recovery and Rehabilitation Roundtable [24]. The study followed four stages of a pre-defined framework to IKT, illustrated in Fig. 1, previously used by the research team [25,26].

Participants and recruitment

Participants contributed to Stages 2 and 4 and included stroke survivors, caregivers and clinicians. Participants were recruited by advertising via social media, organisations or



Fig. 1. Overview of the project framework. IKT = Integrated Knowledge Translation.

services providing support to stroke survivors or via registries of people interested in participating in research.

Purposive sampling identified participants with a diversity of relevant experience to ensure we addressed the broad research aim. Our screening questions enabled us to determine diversity in role (e.g. caregiver or person with stroke) level of disability, communication issues and rehabilitation/telerehabilitation experience for people with lived experience; and, profession, role, experience delivering rehabilitation to people with stroke, and experience with telehealth for healthcare workers (Appendix 1, Table 2). Screening questions identified supports required to optimise participation, such as familiarisation with videoconferencing technology prior to the workshop, individual interview (as an alternative to the workshop), additional time to process information and respond, or more frequent rest breaks.

Eight to ten stroke survivors or caregivers and eight to ten clinicians were sought for Stage 2; four to six stroke survivors or caregivers and four to six clinicians were sought for Stage 4. Sample size estimation was made by the research team, some of whom (CMS, ER, DH, EL, CE) had previous experience in conducting workshops co-designing interventions. This considered the need to ensure sufficient participants to capture a breadth of knowledge and experience while effectively conducting workshops online. All participants provided written informed consent.

Procedure

The IKT framework comprised four iterative stages, outlined in Fig. 1. Each stage involved facilitated workshops and interviews. During Stage 1 the research team (comprising researchers, clinicians and stroke survivors) defined the research questions and approach. In Stage 2 knowledge users identified essential elements of the program. In Stage 3, the research team developed resources. In Stage 4 knowledge users reviewed resources and provided feedback. The research team adapted resources to incorporate feedback.

Data collection

Demographic data of knowledge user informants were collected via questionnaire. Workshops and individual interviews occurred virtually via videoconference.

Two workshops were held in Stage 1 with the research team. In Stage 2, five workshops and six interviews were held with knowledge users. Stage 3 involved one workshop with the research team. Finally, one workshop with research team members and knowledge users was held in Stage 4. The facilitator (ER/CMcD) used a collaborative approach to stimulate discussion for each objective. Table 1 provides examples of seeding questions. Another member of the research team (CMcD/EB/CS) took notes and reviewed recordings. A 'car park' system was used to capture subjects raised beyond the scope of the individual workshop. Ideas and issues outside the workshop scope were formally documented. This allowed acknowledgement of everyone's input, and facilitated re-integration of ideas and issues into other workshops (where appropriate) while ensuring the focus of each workshop remained pertinent to its objectives.

Data collected from workshops/interviews included: 1) video recordings; 2) researcher notes summarizing content discussed and outcomes; 3) field notes written by workshop facilitators; and 4) participant feedback.

Data synthesis and analysis

Workshop and interview data were analysed using an iterative process; this involved synthesising data, reaching consensus on key decisions and modifying outcomes based

Table 1

Examples of seeding questions used by the facilitator in the workshops.

Stage 2 workshops with knowledge users:

- What are some of the barriers to participating in rehabilitation via telehealth?
 - o Consider:
 - Can you identify any risks that need to be managed?
 - Are there any decisions that need to be made prior to participating?
 - What are some of the benefits of participating in rehabilitation via telehealth?
- What would you need to participate in stroke rehabilitation via telehealth?
 - o Consider:
 - Resources or information
 - Before you begin rehabilitation
 - During the rehabilitation
 - Safety
- What are the important outcomes of a telehealth rehabilitation program for you?
- Stage 4 workshops with knowledge users:
- What do we need to change to make this program work better for you? o Consider:
 - Safety of the program
 - Your ability to use the information and resources
 - Your confidence and comfort

on feedback from knowledge users [27]. A research assistant who attended each workshop/interview reviewed the recording and synthesised the data into a written summary of the discussions and any key decisions arrived at by consensus. Each interview/workshop summary was reviewed by the facilitator for agreement and circulated to attendees who were asked to provide any amendments or further suggestions. This allowed the inclusion of any additional ideas that arose after workshop participation, recognising that issues such as fatigue and cognition may have impacted workshop participation. Notes on workshop/ interview procedures, facilitator reflections, and feedback provided via email by workshop/interview participants were recorded in field notes. This process was repeated at each of the four stages.

An additional process of data analysis was undertaken with data from stage 2 workshops/interviews. Summaries of workshops/interviews were systematically analysed by a research team member (CMcD) to identify all the essential program components raised by participants and verified by other team members (CS, ER). Four categories informed deductive coding of data: 'clinician considerations', 'stroke survivor considerations', 'carer considerations', and 'essential program components and resources for safety and effectiveness'. Repeated or similar suggestions were collated/collapsed and unique suggestions retained, to form a comprehensive set of essential program components. Data referring to eligibility criteria for telerehabilitation, risk assessment or specific resources were identified and abstracted to inform a first draft of these tools for the program.

To achieve rigour in aspects of the IKT process that involved qualitative inquiry (e.g., workshop/interview data collection and data synthesis and analysis) the following strategies were incorporated: an appropriate sample of participants in stage 2 and 4 workshops/interviews to produce a rich and thick data set, workshop/interview syntheses were verified by research team members, workshop/ interview syntheses underwent member checking by participants, and a deductive coding system (four key categories) was developed for stage 2 workshop/interview data analysis [28]. To highlight the rigorous approach employed in this study for data collection, synthesis and analysis, an excerpt of participant quotes, a workshop summary from stage 2, participant feedback on a workshop summary from stage 2, and field notes recorded immediately after a workshop from stage 2 are provided in Appendix 2.

Dissemination and evaluation

A dissemination plan was developed during Stage 1 and refined throughout the project. Evaluation of webpage usage and online resources were completed using Google Analytics.

Results

Participant characteristics

Twenty-one participants (clinicians n = 11, stroke survivors n = 7, caregivers n = 3) were recruited; 17 in Stage 2 (clinicians n = 8, stroke survivors n = 6, caregivers n = 3); nine in Stage 4 (clinicians n = 5, stroke survivors n = 4, caregivers n = 0). Some participants took part in both stages. Seven participants from Stage 2 provided additional feedback at Stage 4 by email or telephone. Demographic data is provided in Appendix 1, Tables 3 and 4. Nine clinicians were physiotherapists, eight worked predominantly with people with neurological disorders and seven had telehealth experience. Stroke survivors were a median age 44 years (IQR 40, 69), 50% female, and median time post stroke 7 years (IQR 4, 14). Four reported some difficulty with communication and five were confident with technology. One caregiver declined to provide demographic data. Of the two caregivers who provided data, one was female, both had provided care for over two years.

Stage 1 Outcomes: Research question, aims and approach defined

Stage 1 outcomes informed the study protocol submitted for ethics approval. The research team defined 'moderateto-severe' level of physical disability as 'requiring assistance from another person to attend daily needs, for example walking, toileting and dressing'. This was determined to be more meaningful to stroke survivors and caregivers than definitions based on clinical assessment tools. 'Telehealth' was defined as health care provided by a

Table 2

Research questions and aims defined in stage 1.

Research questions:

- What should clinicians, people with stroke and their carers consider before commencing physical rehabilitation via telehealth for people with moderate-to-severe levels of physical disability following stroke?
- 2. What are the essential components needed to deliver safe and effective physical rehabilitation via telehealth to people with moderate-to-severe physical disability post stroke?
- 3. What resources are needed for people with stroke, carers and clinicians to participate in a telehealth rehabilitation program?

Aims:

- 1. Create a framework for joint decision making around inclusion of telehealth in a person's model of care and for joint goal setting.
- 2. Create a risk assessment tool for clinicians providing physical rehabilitation via telehealth.
- Develop a guide to assist clinicians and people with stroke participate in a telehealth physical rehabilitation program. This will include collating existing resources and developing additional resources as required.

clinician via telephone or videoconferencing. Given the heterogenous and complex needs of this group, the research team agreed that rehabilitation via telehealth needed to be individually tailored. Joint decision making with clinicians, stroke survivors and caregivers and comprehensive risk assessment and management were critical. Aims and research questions are outlined in Table 2. The four-stage approach was agreed upon and consensus reached on key components of each stage, summarised in Appendix 1, Table 5. The plan for each workshop was refined as the study progressed in response to the ideas and needs of knowledge users.

Stage 2 Outcomes: Essential elements of rehabilitation via telehealth identified

Knowledge users emphasised the complexities of rehabilitation via telehealth for people with moderate-to-severe physical disability following stroke. They articulated that telehealth rehabilitation is not the same as in-person rehabilitation; ideally telehealth should supplement inperson therapy and only replace in-person therapy in exceptional circumstances. The critical role of the caregiver was emphasised. Essential elements included an individualised rehabilitation plan with person-centred goals. Active engagement of stroke survivors and caregivers in decision making and planning, early commencement of planning (e.g., during inpatient rehabilitation) and ensuring stroke survivors and caregivers understood what was involved in rehabilitation via telehealth were identified as critical to success.

Knowledge users discussed the importance of ensuring telehealth rehabilitation was delivered safely and effectively. Comprehensive assessment and systematic identification of potential risks to stroke survivors and caregivers followed by individual tailoring of strategies to reduce risk were recognised as essential. Knowledge users identified some risks require greater consideration when telehealth is the only mode of health care delivery, such as psychological wellbeing or skin integrity. Inclusion of strategies to ensure effective delivery of rehabilitation, including maximising motivation and monitoring progress were highlighted. All knowledge users acknowledged program costs and access to technological support and equipment as important logistical considerations.

Additional issues unique to specific groups were discussed. Stroke survivors highlighted the importance of psychological and emotional support. Caregivers emphasised they should not be expected to replace the therapist. Clinicians' concerns included ensuring they had skills to deliver rehabilitation via telehealth and identification of suitable outcome measures and intervention resources (e.g., access to a database of appropriate exercises). One issue frequently raised beyond the study scope, captured in the 'car park', was limited access to funding for ongoing rehabilitation in the chronic stages of recovery. Table 3 summarises key issues to be considered to deliver rehabilitation safely and effectively via telehealth.

Stage 3 Development of resources for telehealth rehabilitation

The research team reviewed Stage 2 outcomes, along with existing evidence and resources. The team determined resources to support shared decision-making and risk assessment required development, and that the shared decision-making process should be clinician led. Existing resources which supported delivery of rehabilitation via telehealth were integrated into these resources to avoid unnecessary duplication.

The research team reviewed existing shared decisionmaking models and selected two established models for consideration: Interprofessional Shared Decision-Making model (IP-SDM model) [29,30]; and the Ottawa Decision Support Framework (ODSF) [31,32]. These models have been applied in health care contexts where interdisciplinary communication is critical to patient care and patients or caregivers face difficult decisions [33–36]. The principles and theoretical components of these models were used to identify critical elements to shared decision-making in the context of stroke rehabilitation via telehealth. A key feature of the models is that all parties must have access to, understand and discuss evidenced-based information about treatment options, benefits, harms and costs, outcome probabilities, uncertainties and patient values and preferences. Elements of these two models were used to develop a shared decision-making tree accompanied by a guide to assist clinicians support stroke survivors and caregivers through the shared decision-making process. A decision-aid was developed to provide stroke survivors and caregivers with information about telehealth and rehabilitation to assist them participate in the process.

Based on the risks and management strategies identified in Stage 2, a comprehensive risk assessment guide was Table 3

Summary of the essential program components described by knowledge users.

Policies and procedures	Local policies and procedures to guide safe practice, decision making, risk minimisation and
Compiles collaboration	collaboration across corritors to address all reads of nearly with strates or deverse. Ontions for in person
Service conaboration	sessions in combination with telehealth sessions as indicated.
Holistic approach to rehabilitation	Consider all the needs of the individual: cognitive, communication, physical, emotional, psychological, social, cultural and language
	Consider capacity and capability of carer
Technology equipment and support	Technology devices including portable stands for hands-free use. May need more than one device.
	Technology support staff.
	Investment in infrastructure to ensure stable bandwidth and reliable connection.
Access and equity	Support for people unable to afford technology or equipment i.e. loan or hire system.
Risk assessment	Cognition, communication, physical function and impairments, medical history, medication, social
	supports, home environment and set up, falls history and balance, dizziness, continence, emotional and
	psychological wellbeing, footwear and clothing, gait aids, other orthoses and aids, equipment, caregiver
	ability and capacity for involvement, privacy, occupational health and safety considerations. Some risks
	may require additional consideration if all rehabilitation via telehealth.
Rehabilitation equipment, resources and	Prescribed and fitted necessary aids and rehabilitation equipment.
environment.	Necessary support people available to facilitate safe participation.
	Set up of home environment(s) for telehealth sessions.
	Database of exercises.
	Personal protective equipment as required.
Session plan	Individualised plan for every session (which aligns with overall person-centred goals and
	rehabilitation plan).
Monitoring / evaluation	Portable monitoring equipment to allow live/real-time feedback of physiological parameters.
	Mechanisms for monitoring safety during rehabilitation.
	Reliable and valid outcome measures.
	Plan to evaluate progress and ensure efficacy of therapy.
	Include plan for celebrating progress and encouragement.
Feedback pathway	Clear communication.
	Defined feedback pathways to ensure needs are met and to inform service development.

developed to assist clinicians systematically identify potential risks and create a tailored management plan. The guide included recommendations for devising an emergency management plan and flagged additional risks to consider where telehealth is the only delivery mode.

Stage 4 Outcomes: Feedback and adaptation of resources

The four resources were reviewed by knowledge users in Stage 4. In response to feedback, videos were created to introduce the resources to knowledge users. The decision-aid was modified to include checklists, icons used to reduce text and a second simplified decision-aid developed for people with aphasia. Resources were formatted so they could be printed in grayscale and information duplication was minimised. The importance of clinicians discussing the resources with stroke survivors and caregivers was highlighted. Some recommendations were beyond the scope of the project, such as making the resources interactive and translation into other languages, and will be considered for future development.

Dissemination

Resources were made publicly and freely available online (http://go.unimelb.edu.au/f96j) and shared via social media, stroke and government affiliated health services (e.g. Stroke Foundation Australia, Department of Health, Victoria) and professional networks (e.g. Australian Physiotherapy Association). Over the first six months (27/11/2020–27/5/2021) the webpage was viewed 1212 times by 1129 unique users. Clinician resources (shared decision-making tree, shared decision-making guide and risk assessment) were downloaded 374 times; the decision-aid was downloaded 570 times.

Discussion

A co-design process identified development of an individualised plan was critical to safe, effective and feasible rehabilitation via telehealth for people with moderate-to-severe physical disability following stroke. Further, the process identified the plan should be achieved via a shared decision-making process with comprehensive risk assessment and management. Resources were developed to assist clinicians, stroke survivors and caregivers to develop and deliver an individually tailored rehabilitation program via telehealth. These resources support immediate implementation of telehealth rehabilitation for stroke survivors.

Shared decision-making is useful where there is no 'right' decision. Current stroke guidelines emphasize the importance of shared decision-making [2], however most literature in this area is focused on medical management [37,38]. The shared decision-making tree and guide were

developed using established models to assist clinicians steer stroke survivors and caregivers through the shared decisionmaking process, supported by a decision-aid for stroke survivors and caregivers. Extensive input from stroke survivors and caregivers and inclusion of a speech pathologist on the research team optimised accessibility of the decision-aid for people with communication deficits including aphasia. The risk assessment tool provides a comprehensive assessment of risks alongside mitigation strategies and informs shared decision-making. Evaluation of these resources is required to determine whether they assist development of implementable telehealth rehabilitation programs.

The pandemic necessitated a rapid transition and substantial investment in telehealth [39]. However telehealth is likely to remain part of stroke rehabilitation as recognised in updated guidelines [2], either as a stand-alone treatment option or an adjunct to in-person care. Telehealth has potential to increase equity and access to services [40], particularly where access is limited including regional and rural areas[41]. People participating in rehabilitation delivered via telehealth report high degrees of satisfaction [11,42,43]. Research to evaluate efficacy and safety of rehabilitation via telehealth following stroke is required to support integration into healthcare delivery.

This study used a robust co-design methodology; knowledge users, including stroke survivors and clinicians, were part of the research team and participated in all phases of the project. By incorporating the expertise of knowledge users, specific needs of key stakeholder groups are addressed. This ensures resources are based on scientific principles of rehabilitation and feasible to utilize, increasing the likelihood of sustainable uptake. Two stroke survivors (KE, GM) were included in the research team to minimise individual burden, reduce risk of power imbalance and ensure they were equal partners [44]. They were supported via formal (e.g. scheduled meetings to discuss research processes) and informal contact, in addition to participation in meetings and communications with the whole research team. Co-designing resources using robust methodology is time and resource intensive, thus we made all resources freely and publicly available for utilisation. Resources will be adapted based on feedback to ensure they continue to meet the needs of all users.

Limited funding and access to ongoing rehabilitation during the chronic stage of recovery were raised as a major concern by knowledge users. Stroke survivors and caregivers reported privately funding ongoing rehabilitation and expressed concern that services were not accessible to all. This issue was deemed beyond scope of this project, which focused on substitution of existing rehabilitation services with telehealth. Nonetheless, equitable access to programs supporting long term recovery following stroke is an important issue that must be urgently addressed.

Limitations

This project was conducted rapidly due to urgency surrounding the pandemic and during a time of great change. Some of the research team were new to the concept of IKT and most had limited experience with telehealth. All research team members worked remotely and meetings were conducted via videoconferencing; however this enabled engagement of researchers and participants with a diversity of experiences and will increase applicability to different health systems.

This study utilised a rigorous co-design process to develop and disseminate resources in a limited time frame. Over half of the stroke survivors were under 60 years of age, all had access to equipment for videoconferencing and the majority indicated they were confident with technology; thus our sample may not be representative of the broader stroke population. Furthermore, our sample may be more likely to report confidence and more positive views on telehealth than some other people with stroke who are less familiar with technology. While most knowledge users only had experience of the Australian health system, some had experience from other developed countries. This increases translation internationally, although translation to developing countries remains limited. We were not able to fully achieve the third aim (identified in Stage 1), which included collating existing resources, due to insufficient time and funding. Additional resources identified will be included in future updates [45].

Evaluation of resources was limited to data on website usage and downloads. The feasibility and effectiveness of using the resources to support development and implementation of rehabilitation via telehealth must be evaluated, from the perspectives of service providers, stroke survivors and caregivers. Future research should explore adaptation to other groups, including people with mild disability post-stroke or other health conditions.

Conclusion

Using a co-design approach, we identified that development of an individualized program via a shared decisionmaking process with comprehensive risk assessment and management were critical to rehabilitation delivery via telehealth. Resources to support these processes were codesigned by stroke survivors, caregivers, clinicians and researchers and made available online. While resources were developed for people with moderate-to-severe disability, they may be adapted for other groups. Research to evaluate utilisation of resources to support implementation, safety and effectiveness of telehealth rehabilitation in this population is required.

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Conflict of interest

Nil.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.physio.2024. 02.006.

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